

Realising Disability Rights?
**Implementation of the UN Convention on
the Rights of Persons with Disabilities in
England - A Critical Analysis**

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One of the main tasks of the international human rights system in this field is to make societies aware of the contradiction between their self-professed values and their application (or rather their non-application or misapplication) in the context of disability.

Quinn and Degener (2002) 23

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Abstract

This thesis is about understandings, how those understandings shape the law and how the law helps to shape those understandings. Its first premise is that law is not neutral: it is formed and functions within a complex and dynamic socio-political context from which it is inseparable. From that premise, the thesis argues that partial understanding of the context in which the law has been formed may result in mis- or partial understandings, and thus mis- or partial application, of the law itself. The argument is made through political discourse analysis of the UN Convention on the Rights of Persons with Disabilities (CRPD) and implementation in England of Article 19, the right to live independently and be included in the community.

The CRPD is seen as emancipatory law, offering a re-description of the world and of disabled people's place in it, and requiring for its full implementation transformative paradigm change. Whether the Convention-drafters' hegemonic project succeeds will depend in part on the understandings already circulating in national settings. Turning to the United Kingdom, the thesis identifies resistance on the part of successive governments to international understandings of economic, social and cultural rights, and their consequent invisibility in domestic discourse, as potential barriers to realisation of the CRPD's emancipatory purpose.

The remainder of the thesis investigates the extent to which this misunderstanding currently affects implementation in England of CRPD Article 19. Independent living policy, legislation, decision-making and redress are examined for evidence of CRPD-compatible change. The thesis concludes that the exclusion of international economic, social and cultural rights standards from domestic discourse results in mis- and partial understandings, and thus in mis- or partial application, of Article 19. This in turn undermines implementation of the Convention as a whole, and frustrates its drafters' purpose in the English domestic sphere.

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INTRODUCTION

CHAPTER 1

UNDERSTANDINGS

Introduction

This thesis is about understandings, about how those understandings shape the law, and about how the law helps to shape those understandings. Its first premise is that law is not neutral: it is formed and functions within a complex and dynamic socio-political context from which it is inseparable.¹ As such, law may both reflect and influence social understandings, structures and identities. This premise is explored through political discourse analysis of the UN Convention on the Rights of Persons with Disabilities and its implementation in the UK.

The UN Convention on the Rights of Persons with Disabilities (the Convention/CRPD) was adopted by the UN General Assembly in 2006, came into force in 2008 and was ratified by the UK in 2009. This thesis will argue that it is an emancipatory human rights treaty. It presents a re-description of the world, where disabled people are no longer excluded recipients of welfare but active, valued and equal rights-holders; where impairment is no longer seen as an aberration to be ‘othered’, but as universal human variation to be accepted, respected and accommodated. Realisation of this new world requires deep reconstruction² of understandings, structures and identities – transformative ‘paradigm change’ from exclusion to inclusion and from

¹ See for instance O’Cinneide C, ‘Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and New Possibilities’ in Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009) 168

² Stein MA, ‘Disability Human Rights’ (2007) 95(1) *California Law Review* 75; Lawson A, Lawson A, ‘The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?’ (2006-2007) 34 *Syracuse Journal of International Law and Commerce* 563

welfare to rights.³ Part 1 of the thesis traces events leading to adoption of the Convention and examines its text. The indivisibility and interdependence of civil, cultural, economic, political and social rights is identified as a key element of the Convention's understandings, purpose and structure.

Realisation, however, will depend not only on the Convention's capacity to bring about a new agenda, but also on understandings already circulating in national settings. Part 2 of the thesis turns to the UK. Examination of the constructive dialogue with the UN Committee on Economic, Social and Cultural Rights reveals successive UK governments' strong resistance to any domestic recognition of these rights as rights, or to any enforcement of their more durable human rights dimensions. Instead, economic, social and cultural rights are re-articulated as welfare entitlements. The thesis explores the consequences of this re-articulation through examination of policy, law, administration and redress in England relating to CRPD Article 19, the right to live independently and be included in the community. It concludes that failure to fully grasp the full importance of economic, social and cultural rights in this context results in partial application of Article 19 and threatens realisation here of the Convention's re-description of the world.

Chapter 1 positions the thesis within the disciplines of law and disability studies. It introduces the key concepts on which the thesis is built, and the language used to discuss the development and implementation of the law. Elements of political discourse theory are explained, illustrated with examples relevant to the focus of the thesis. This theory provides both the 'viewpoint' and the language used to discuss development and implementation of the law in context. The place of law in that context, and its role as 'expressive' or

³ See Quinn, G & Degener, T, with Bruce, A, Burke, C, Castellino, J, Kenna, P, Kilkelly, U, Quinlivan, S, 'Human Rights and Disability: the current use and future potential of United Nations human rights instruments in the context of disability', United Nations, New York and Geneva, 2002 HR/PUB/02/1, Chapter 1; Lawson A, 'The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?' (2006-2007) 34 *Syracuse Journal of International Law and Commerce* 563; Stein MA and Lord JE, 'Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities' in Arnandóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

'emancipatory' are then considered. Santos' 'cartography of law' and 'interlegality' are introduced, before the structure and content of the thesis are outlined. The Chapter begins with some context on 'disability'.

Disability

Estimates of the number of disabled people in the world vary. According to the United Nations, around 650 million people live with impairment, about 10 per cent of the world's population.⁴ This figure is said to be increasing through population growth, medical advances and the ageing process,⁵ with forecasts of around 800 million by 2015.⁶ If the members of those people's families are included, almost a third of the world's population⁷ is directly affected by disability.⁸ More recent estimates are higher still, with more than a billion people⁹ estimated to live with some form of disability.¹⁰

Needless to say, these broad brush statistics, like any attempt to categorise human beings, conceal untold complexities.¹¹ Statistical results depend on design of research and questions,¹² including how the researchers define disability. This varies across cultures and systems,¹³ and, as Goodley explains, '[o]fficial definitions of disability reflect the organisational

⁴ United Nations Enable Factsheet on Persons with Disabilities, <http://www.un.org/disabilities/documents/toolaction/pwdfs.pdf> accessed 2.1.11.

⁵ World Health Organisation 'World Report on Disability' (2011) http://www.who.int/disabilities/world_report/2011/report/en/index.html accessed 5.7.11

⁶ Peters, S, Wolbers, K and Dimling, L, 'Reframing global education from a disability rights movement perspective', in Gabel, S and Danforth (eds) *Disability and the International Politics of Education* (Peter Lang 2008) 291-310, cited in Goodley D, *Disability Studies: an interdisciplinary introduction* (Sage 2010)

⁷ Around two billion people

⁸ UN Enable Factsheet, supra

⁹ About 15% of the world's population

¹⁰ World Health Organisation (2011)

¹¹ See United Nations *Disability Statistics Compendium* (Department of Economic and Social Affairs Statistical Office 1990) http://unstats.un.org/unsd/publication/seriesy/seriesy_4e.pdf last accessed 7.1.11

¹² See for instance the 1984 Office of Population, Censuses and Surveys (OPCS) question: 'Does your health problem/disability prevent you from going out as often or as far as you would like?' and compare to the alternative suggested by Oliver (1990): 'What is it about the local environment that makes it difficult for you to get about in your neighbourhood?'

¹³ http://unstats.un.org/unsd/publication/seriesy/seriesy_4e.pdf accessed 2.1.11;

<http://www.un.org/disabilities/default.asp?id=1515> accessed 5.1.11

requirements of governments, their institutions and key welfare professionals¹⁴ rather than the experience of those living with impairment.¹⁵ In a dominant culture which identifies difference as an individual, medical ‘problem’ to be fixed, figures may be influenced by multiplying labels for the diagnosis of ‘dis-ease’ such as autism, ADHD or ‘baby flat head syndrome’, ‘mixed anxiety depression’, or ‘temper dysregulation disorder’.¹⁶ They may reflect the (un)availability of ‘welfare’ resources,¹⁷ or the pragmatic political needs of a particular government.¹⁸ Furthermore, ‘disability’ is not a static event: human beings, in the course of their life, may fall into, or out of, whichever definition is being used from one day to the next.¹⁹ Statistics will therefore only ever be a rough guide to the incidence of impairment; they may, on closer scrutiny, tell us more about the motives, assumptions and cultures of the researchers.

By contrast, this thesis understands the differences of ‘impairment’ as part of universal human experience. We are each born with our individual combination of abilities, limitations and potential. During our life span, we acquire further abilities and further limitations; we develop and express our potential in different ways and in our diverse and dynamic social relationships. As Birkenbach *et al* explain, ‘disability is not a human attribute

¹⁴ Goodley D, *Disability Studies: An Interdisciplinary Introduction* (Sage 2010) 5; see also Stone D, *The Disabled State* (MacMillan 1984); Liachovitz C, *Disability as a Social Construct: legislative roots* (University of Pennsylvania Press 1988)

¹⁵ Though this may be just beginning to change: work is ongoing at the UN to improve the quality of disability statistics: ‘Assembly resolution 63/150 requests the Secretary-General to give higher priority to the concerns of, and issues related to, persons with disabilities, as well as their inclusion within the work programme of the United Nations system in order to ensure that the 2010 World Programme on Population and Housing Censuses is inclusive of the perspective of persons with disabilities.’ <http://www.un.org/disabilities/> accessed 5/1/11. See also the *International Classification of Functioning, Disability and Health* (ICF), which ‘attempts to bridge the medical and social models [of disability] by providing a biopsychosocial model’ (World Health Organisation 2001)

¹⁶ See e.g. American Psychiatric Association, ‘Diagnostic and Statistical Manual of Mental Disorders’, 5th ed (2010)

¹⁷ For instance, changes to eligibility for Disability Living Allowance, see M Oliver, *The Politics of Disablement* (Palgrave Macmillan 1990)

¹⁸ Such as the transfer of claimants from unemployment benefit to incapacity benefit by the Thatcher government in the early 1990s. See also some current (2012) media portrayal of disabled people as ‘benefit cheats’ etc. e.g. the Sun: ‘Human Right to Benefits’ <http://www.thesun.co.uk/sol/homepage/news/politics/4424527/Human-right-to-benefits.html> accessed 13.7.12

¹⁹ T Burkhardt, ‘The Dynamics of Being Disabled’, CASE paper 036 (Centre for Analysis of Social Exclusion 2000); T Burkhardt, ‘Being and Becoming: social exclusion and the onset of disability’ CASE Report 21 (Centre for Analysis of Social Exclusion 2003)

that demarks one portion of humanity from another; it is an infinitely various but universal feature of the human condition.²⁰

Of the 10% of global population identified as disabled by the UN, 80 per cent or more²¹ live in the world's poorest countries, overwhelmingly in rural areas.²² It may seem unsurprising, then, that statistics also show a strong correlation between disability and poverty, with 20 per cent of the world's poorest people living with impairment and being regarded as the most disadvantaged in their community.²³ This is not, however, simply a 'poor country' issue. Many people living with impairment in the wealthy countries of the world also experience a lower standard of living than their peers, with the multiple disadvantages summed up by the expression 'social exclusion'.²⁴ As the UN Committee on Economic, Social and Cultural Rights recognised in 1994, 'there is no country in the world in which a major policy and programme effort is not required'²⁵ to address these inequalities.

The exclusion of disabled people is not only economic. A substantial body of evidence relates to disabled people's wider marginalisation in societies.

²⁰ J.E.Birkenbach, S Charrerji, E M Badley, T B Ustun, 'Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps' (1999) 48 *Social Science & Medicine* 1173, 1182, cited in O'Connell C, 'Disability Discrimination' in Bamforth N, Malik M and O'Connell C, *Discrimination Law: Theory and Context*, 1st ed (Sweet & Maxwell 2008)

²¹ 80% according to the UN Development Programme (UN Enable Factsheet, supra); 88% according to Marks, D, *Disability: Controversial Debates and Psychological Perspectives*, London, Routledge, 1999, cited in Goodley (2010) supra

²² 90% according to Marks (1999) supra

²³ See also World Health Organisation *World Disability Report*, supra Chapter 2; and Beresford P 'Poverty and Disabled people: challenging dominant debates and policies' (1996) 11(4) *Disability & Society* 553

²⁴ See for instance O'Grady A, Pleasence P, Balmer NJ, Buck A and Genn H, 'Disability, social exclusion and the consequential experience of justiciable problems' (2004) 19(3) *Disability & Society* 259; Burchardt T 'Being and Becoming: Social exclusion and the onset of disability' CASE Report 21 (ESRC Research Centre for Analysis of Social Exclusion (CASE) 2003. M Howard, A Garnham, G Finnister, J Veit-Wilson *Poverty: the Facts* (CPAG 2001); B Hughes (2002) Bauman's Strangers: Impairment and the invalidation of disabled people in modern and post-modern cultures, in 17 *Disability and Society*, p 571 and p 580; Beresford P, Green D, Lister R and Woodard K, *Poverty First Hand: Poor people speak for themselves* (Child Poverty Action Group 1999). For international data see e.g. International Disability Rights Monitor, *IDRM International Disability Rights Compendium*, (Centre for International Rehabilitation 2003) and website of Disability Awareness in Action <http://daa.org.uk/> last accessed 30.8.12.

²⁵ UN Committee on Economic, Social and Cultural Rights, General Comment 5: Persons with Disabilities, 9/12/94; see also Disability Rights Commission 'Disability Briefing' (DRC 2006)

Typically, a recent International Disability Rights Monitor report on the Americas found that ‘many people with disabilities face involuntary institutionalisation in countries throughout the region resulting in some of the most blatant and abusive human rights violations’.²⁶ Although the experiences of most disabled people in the UK may be relatively acceptable by comparison, disability hate crime, including murder,²⁷ and incidents of systemic abuse in care homes²⁸ continue here too. ‘Do not resuscitate’ notices are used without consent; and people diagnosed with mental health issues continue to be detained and treated against their will.²⁹ Many, particularly older people, are placed in institutional care against their wishes;³⁰ and public debates around disability focus on assisted suicide, ‘mercy killing’ and avoidance of the ‘tragedy’ of impairment through pre-natal testing and abortion.

Disabled people have mobilised to challenge their oppression.³¹ They have turned traditional medical and moral understandings³² on their head by identifying disability as a social construct.³³ Rather than being sited in the individual, disability results from the failure of society to accommodate those

²⁶ International Disability Rights Monitor, *IDRM: Regional Report of the Americas*, (International Disability Network and the Centre for International Rehabilitation 2004). See also International Disability Rights Monitor, *IDRM: Regional Report of Asia*, (IDRM 2005); International Disability Rights Monitor, ‘The United Kingdom’ in *IDRM: Regional Report for Europe* (IDRM 2007); and Light R, ‘Review of Evidence contained on the DAA Human Rights Database’ (DAA 2003)

²⁷ Disability Now Hate Crime Dossier, <http://www.disabilitynow.org.uk/the-hate-crime-dossier> last accessed 12.10.11; Sherry M, *Disability Hate Crimes: does anyone really hate disabled people?* (Ashgate 2010)

²⁸ For instance, see Commission for Social Care and Healthcare Commission, *Joint Investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*, July 2006; and Winterbourne View: BBC Panorama ‘Undercover Care: the Abuse Exposed’ BBC1, 31 May 2011

²⁹ Mental Health Act 1983 ss2 & 3; Mental Health Act 2007

³⁰ Prime Minister’s Strategy Unit, ‘Improving the Life Chances of Disabled People’, January 2005; and Department of Health ‘Vision for Adult Social Care: Capable Communities and Active Citizens’, 16 November 2010, Gateway reference 14847

³¹ Campbell J and Oliver M, *Disability Politics: Understanding Our Past, Changing Our Future* (Routledge 1996); Barnes C, ‘A Legacy of Oppression’ in Barton L, Oliver M, *Disability Studies: Past Present and Future* (The Disability Press 1997); Charlton JI, *Nothing About Us Without Us: Disability Oppression and Empowerment* (University of California Press 2000). For summary see Goodley (2010) 2-10

³² A medical model sees disability as a problem sited in the individual to be cured and normalised; a moral model sees disability as punishment for moral lapse or sin

³³ see Liachowitz C, *Disability as a Social Construct: legislative roots* (University of Pennsylvania Press 1988)

'with impairments' who function differently.³⁴ They identify the 'negative social reaction to biological, cognitive, sensory or psychological difference'³⁵ as 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.'³⁶ This forceful challenge has given rise, *inter alia*, to a new academic discipline of disability studies. This discipline is international and trans-disciplinary in nature and breaks boundaries between cultures and disciplines.³⁷ Embracing a variety of perspectives, emerging from differing national contexts and histories,³⁸ it tries to analyse and re-align understandings of 'disability' to support the ambitions of disabled people and to contest their oppression.

One important aspect of this new discipline concerns ownership. Mainstream research into disability has overwhelmingly been carried out by people who define those with impairments as 'other'. As Linton observes, '[t]his contributes to the objectification of disabled people and contributes to their experience of alienation'.³⁹ Disability studies researchers have therefore

³⁴ Whilst this thesis refers broadly throughout to the 'social model of disability', neither the concept nor the content of such a model are undisputed among disability activists: see for instance Oliver M, 'The Individual and Social Models of Disability' (1990) Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians, 23 July 1990; Paul Abberley 'The Concept of Oppression and the Development of a Social Theory of Disability' 1997, Leeds Disability Archive; Corker M, 'Disability Discourse in a Postmodern World' in Shakespeare T (ed) *The Disability Reader* (Cassell 1998); Oliver M and Barnes C, 'Disability Politics and the Disability Movement in Britain: where did it all go wrong?' (2006) Leeds Disability Archive; Finkelstein V, 'The 'Social Model of Disability' and the Disability Movement' (2007) Leeds Disability Archive; Light R, 'Social Model or Unsociable Muddle?' (Disability Awareness in Action, undated). For further perspectives see discussion and references in Goodley (2010) supra.

³⁵ Sherry M, *(Post)Colonising disability* 4 (Summer) Wagadu, Journal of Transnational Women's and Gender Studies 10 cited in Goodley (2010) 8

³⁶ Thomas C, *Sociologies of Disability, 'Impairment' and Chronic Illness: Ideas in Disability Studies and Medical Sociology* (Palgrave 2007) 73

³⁷ Goodley (2010) 32, following Thomas C (2007)

³⁸ For discussion, see Goodley (2010) 11-21; see also, for instance, Hvinden B 'Nordic Disability Policies in a Changing Europe: Is There Still a Distinct Nordic Model?' (2004) 38(2) *Social Policy & Administration* 170

³⁹ Linton, S, 'Disability studies/not disability studies' (1998) 13(4) *Disability & Society*, 525. See also Hunt P, 'Settling Accounts with the Parasite People: a Critique of 'A Life Apart' by E. J. Miller and G. V. Gwynne' (1981); Oliver M, 're-Defining Disability: A Challenge to research' (1987) 5 *Research, Policy and Planning*; Barnes C and Mercer G (eds) *Doing Disability Research* (The Disability Press 1997); Rioux MH 'Disability: the place of judgement in a world of fact' (1997) 41(2) *Journal of Intellectual Disability Research* 102; Gibbs D 'Disabled People and the Research Community' Belfast 1999; Barnes C 'Emancipatory' Disability research: project or process?' Glasgow 2001; Beresford P, 'User Involvement in Research: connecting lives, experience and theory' (University of Warwick 2003); Clark M,

been at pains to develop research methods that not only do not contribute to that experience of alienation, but which positively contribute to the inclusion and well-being of all participants. The discipline thus subverts ‘the normative tendencies of academic disciplines, testing respected research encounters and challenging theoretical formations.’⁴⁰

This thesis positions itself within both the discipline of law and the discipline of disability studies. Whilst its focus is firmly on the law, its ethos is that of emancipation. It explores the capacity of law to be emancipatory:⁴¹ to reflect disabled people’s challenge to the status quo and to bring about change.⁴² To that end, the thesis is concerned both with the practical content and application of the law, and with the socio-legal and political concepts which underlie and surround it at international and national levels. To discuss all of these aspects, it is necessary to find a language that enables discussion and analysis of relevant ideas, assumptions and conceptions as well as their practical legal manifestations.⁴³

The conceptual model underlying the theory and practice of a subject is often described as a ‘paradigm’.⁴⁴ This language allows us to talk about different paradigms, conflicting paradigms, or a ‘paradigm shift’, meaning ‘a

Glasby J and Lester H, ‘Cases for Change: User Involvement in Mental Health Services and Research’ (2004) 22(2) *Research Policy and Planning*, 31; Glasby J and Beresford P ‘Who knows best? Evidence-based practice and the service user contribution’ (2006) 26 *Critical Social Policy* 268; Hodge N, ‘Evaluating Lifeworld as an emancipatory methodology’ (2008) 23(1) *Disability & Society* 29; Smith B and Sparkes AC, ‘Narrative and its potential contribution to disability studies’ (2008) 23(1) *Disability & Society* 17; Priestley M, Waddington L and Bessozi C, ‘Towards an agenda for disability research in Europe: learning from disabled people’s organisations’ (2010) 25(6) *Disability & Society* 731. It remains the case that a search on ‘disability’ on any of the major academic search engines will result in an overwhelming mass of medical information, where disabled people feature only as the objects of medical scrutiny.

⁴⁰ Goodley (2010) 32

⁴¹ Santos BS, *Toward a New Legal Common Sense*, 2nd ed (Butterworths 2002) chapter 9

⁴² Stein MA and Lord JE, ‘Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities’ in Arnandóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

⁴³ ‘Analytical jurisprudence should broaden its focus not only geographically, but also in respect of the range of concepts, conceptual frameworks, and discourses that it considers...’ Twining W ‘Have concepts, will travel: analytical jurisprudence in a global context’ (2005) 1(1) *International Journal of Law in Context* 5, abstract

⁴⁴ Oxford Compact English Dictionary 2000: paradigm: 1 a typical example, pattern or model of something; 2 a conceptual model underlying the theories and practice of a scientific subject...

fundamental change in approach or underlying assumptions'.⁴⁵ Indeed, talk of 'paradigm shift' is common in discussion of the UN Convention on the Rights of Persons with Disabilities which is the focus of this thesis.⁴⁶ However, this language takes us no further: it does not provide us with a technical language for analysing the processes by which a particular paradigm has come about, why it is the way it is, how it might interact with others, how it might develop or 'shift', or what the consequences might be. Nor does it allow us to pinpoint how such paradigms become sedimented in the structures and norms through which the dominant orders at any one time attempt to regulate our societies, or how they are translated through legal and administrative practice into the realities of people's lives. By contrast, the language of political discourse theory provides a sophisticated tool for just such analysis.

Political discourse theory⁴⁷

Laclau and Mouffe see the social sphere as an inescapable political space where everything has meaning. It is not possible to stand outside that space, to take a 'neutral' position. The social space is filled with discourses. For

⁴⁵ Ibid

⁴⁶ See for instance. UN High Commissioner for Human Rights Navi Pillay, Address to the Human Rights Council, 6.March 2009: The Convention 'requires us to move away from charity-based or medical-based approaches to disability to a new perspective stemming from and firmly grounded in human rights...The depth and implications of the paradigm shift of the Convention require nothing less than a thorough and dispassionate reflection on what is needed at the national level...'; see also Kayess, R & French, P, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities', (2008) 8 HRLR 1; Melish T, 'The UN Disability Convention' (2007) 34 Human Rights Brief 37. Quinn G and Arnardóttir OM, 'Introduction' in Arnardóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009) xvii. See also footnote 3 above.

⁴⁷ Key writings which have informed the political discourse content of this thesis include: Laclau E and Mouffe C, *Hegemony and Socialist Strategy* (Verso 1985); Laclau E, *New Reflections on the Revolution of our Time* (Verso 1990); Mouffe C, *The Return of the Political* (Verso 1993); Howarth D, Norval AJ and Stavrakakis Y(eds), *Discourse Theory and Political Analysis: identities, hegemonies and social change* (Manchester University Press 2000); Torfing J, *New Theories of Discourse: Laclau, Mouffe and Žižek* (Blackwell 1999); Critchley S and Marchart O (eds), *Laclau: a critical reader* (Routledge 2004); Howarth D, *Discourse* (Open University Press 2000). See also Laclau E, 'Philosophical Roots of Discourse Theory' (undated) Essex University Centre for Theoretical Studies, <http://www.essex.ac.uk/centres/TheoStud/onlinepapers.asp>, accessed 23/4/08

Laclau and Mouffe (and for this thesis), **discourses** are not only about language: they are ‘ ‘worlds’ of related objects and practices that form the identities of social actors’.⁴⁸ Although language is important in their constitution and (re-)articulation, discourses are primarily dynamic systems of social relations,⁴⁹ where meaning is constantly renegotiated.⁵⁰

Howarth and Stavrakakis offer the example of a forest standing in the path of a proposed motorway:⁵¹

[The forest] may simply represent an inconvenient obstacle impeding the rapid implementation of a new road system, or might be viewed as a site of special scientific interest for scientists and naturalists, or a symbol of the nation’s threatened natural heritage. Whatever the case, its meaning depends on the orders of discourse that constitute its identity and significance. In discourses of economic modernisation, trees may be understood as the disposable means for (or obstacles to) continued economic growth and prosperity, whereas in environmentalist discourses they might represent essential components of a viable ecosystem or objects of intrinsic value and beauty. Each of these discourses is a social and political construction that establishes a system of relations between different objects and practices, while providing (subject) positions with which social agents can identify. In our example these subject positions might be those of ‘developers’, ‘naturalists’, ‘environmentalists’ or ‘eco-warriors’. Moreover, a political project will attempt to weave together different strands of discourse in an effort to dominate or organise a field of meaning so as to fix the identities of objects and practices in a particular way.’

Three dynamic and interwoven components of a discourse come into view here: understandings, structures and identities. Understandings shape (and are shaped by) construction of the discourse. They compete to dominate the field of meaning, influencing relationships between objects and practices, and forming the identities of social actors. Discourses thus continually interact and change, borrowing or excluding elements from each other in their search for hegemony. Such **articulations**⁵² always involve the exercise of power.⁵³

⁴⁸ Howarth D, *Discourse* (Open University Press 2000) 101

⁴⁹ Ibid 102-3

⁵⁰ Torfing (1999) 85

⁵¹ Howarth D and Stavrakakis Y, ‘Introducing discourse theory and political analysis’ in Howarth D, Norval AJ and Stavrakakis Y, *Discourse Theory and Political Analysis: Identities, Hegemonies and Social Change* (Manchester University Press 2000) 2

⁵² ‘Articulation’ is defined as a ‘practice establishing relations among elements such that their identity is modified as a result of the articulatory practice’: Laclau E and Mouffe C (1985) supra 105, cited in Torfing (1999) 101

A successful **hegemonic** discourse is one that manages to redefine the terms of the political debate and set a new agenda.⁵⁴

Final resolution of these discursive articulations is impossible. Because there is no ultimate, non-negotiable centre to ground the process of renegotiation, the 'play of meaning' extends infinitely and is never exhausted.⁵⁵ This can be viewed empirically as a result of the infinite richness of reality, or theoretically.⁵⁶ Either way, the dynamic nature of this social space is infinite and inescapable.

Discourse theory investigates such processes: how actual social practices articulate and contest the discourses that constitute social reality.⁵⁷ But discourse theorists do not 'apply' theory to that reality; rather they use its insights to help to unravel and illuminate the events or actions that are the focus of their research. As Howarth explains, 'instead of applying a pre-existing theory on to a set of empirical objects, discourse theorists seek to *articulate* their concepts in each particular enactment of concrete research.'⁵⁸ (original emphasis).

Laclau describes his work as 'an attempt to construct a viewpoint from which to think politics'.⁵⁹ He also recognises that his propositions are only useful as steps to be discarded once one has climbed them.⁶⁰ It is in this spirit that

⁵³ 'Power' is used in this context in the Foucauldian sense: 'The exercise of power... is a total structure of actions brought to bear upon possible actions; it incites, it induces, it seduces, it makes life easier or more difficult; in the extreme it constrains or forbids absolutely; it is nevertheless always a way of acting upon an acting subject or acting subjects by virtue of their acting or being capable of action.' Foucault M, 'The Subject and Power' appended to Dreyfus HL and Rabinov P, *Michel Foucault: Beyond Structuralism and Hermeneutics* (University of Chicago Press 1982) 220, cited in Tremain S (ed) *Foucault and the Government of Disability* (University of Michigan Press 2005) 8

⁵⁴ Torfing (1999) 102

⁵⁵ *Ibid* 85-87

⁵⁶ According to Derrida, 'instead of being an inexhaustible field, as in the classical hypothesis, instead of being too large, there is something missing from it: a centre which arrests and grounds the play of substitutions.' Derrida J, *Writing and Difference* (Routledge & Kegan Paul 1987 [1967]) 289, cited in Torfing (1999) 86

⁵⁷ Howarth D and Stavrakakis Y (2000) 3

⁵⁸ *Ibid* 5

⁵⁹ Laclau E (1990) Preface xvi

⁶⁰ Following Wittgenstein: Wittgenstein L, *Tractatus Logico-Philosophicus* (1981) 189 cited in Laclau (1990) 5

political discourse theory is used as an analytical tool in this thesis: to provide a language in which to think about, describe, discuss and analyse the complex and dynamic nature of the law in its context. Here, Laclau's 'viewpoint' helps to explore how the law (as a social practice) reflects – or fails to reflect - changing discourses to influence 'the nexus between law, norms, and societal mores',⁶¹ particularly in the context of the UN Convention on the Rights of Persons with Disabilities, and its realisation in England.

For instance, consider '**disability**'. This word, in itself, is a negative: *dis-*ability. Its primary use has been within the particular discourse of 'normality' which has come to dominate modern capitalist society from the late 18th century.⁶² Within that discourse, 'disability' signifies a lack of ability, a failure of the individual to achieve 'normality' and so to function in or contribute to 'normal' society. Consequently, the '*dis-*abled' individual must be diagnosed, segregated, and treated in order to be 'made better' or 'normalised'. Until they become 'better' (if they do), such individuals are seen as 'other', as outside the scope of 'normal' society, as 'useless', a drain on resources, as less than human, as objects of charity.⁶³ 'Normality' discourse thus excludes disabled people not only physically through segregation but also in terms of identity. As Campbell describes, '[d]isability and disabled bodies are effectively positioned in the nether regions of "unthought"... the ongoing stability of ableism⁶⁴ ...depends on the capacity of that network to "shut away", to exteriorize, and *unthink* disability and its resemblance to the essential (ableist) human self'.⁶⁵ Such invisibility manifests itself in a multitude of ways, some of which will be touched on in this thesis.

⁶¹ Stein M and Lord JE, (2009) 31-35

⁶² See for instance Borsay A, *Disability and Social Policy in Britain since 1750: a History of Exclusion* (Palgrave Macmillan 2005); Tremain S, 'Foucault, Governmentality and Critical Disability Theory' in Tremain S (ed) *Foucault and the Government of Disability* (University of Michigan Press 2005); Barnes C, 'A Legacy of Oppression' (1997) 3-24

⁶³ See for instance Hughes B 'Bauman's Strangers: Impairment and the invalidation of disabled people in modern and post-modern cultures' (2002) 17(5) *Disability & Society* 571

⁶⁴ Campbell defines 'ableism' as 'a network of beliefs, processes, and practices [read 'discourse'] that produce a particular kind of self and body... that is projected as the perfect, as the species-typical, and, therefore, as essential and fully human.' Campbell FK, 'Legislating Disability' in Tremain S (2005) 127 footnote 2

⁶⁵ *Ibid* 109

Political discourse theory recognises this exclusion of identity as a typical and necessary function of a developing discourse. In the process of its drive for hegemony, a discourse will always attempt to accommodate the widest possible range of demands, views and attitudes. At the same time, it will exclude those that are incapable of inclusion, that directly negate its own meanings.

Such exclusion creates what Laclau and Mouffe call the **constitutive outside** of the discourse. The constitutive outside serves to strengthen the dominant discourse by defining its limits. For example, the discourse of 'normality' that forms the identity of the 'able' liberal subject relies on the exclusion of 'dis-abled' people's identity for the maintenance of its hegemony. As Campbell explains, '[i]n order for the notion of "ableness" to exist and to transmogrify into the sovereign subject of liberalism it must have a constitutive outside... disability is *always* present (despite its seeming absence) in the ableist talk of normalcy, normalization, and humanness.'⁶⁶ 'Disabled' and 'abled' identities are inextricably linked in the act of exclusion which at once renders disabled people invisible and confirms the hegemony of the 'able' liberal subject.

Thus, any discourse's

hegemonic articulation ultimately involves some element of force and repression. It involves the negation of identity in the double sense of the negation of alternative meanings and options and the negation of those people who identify themselves with these meanings and options.⁶⁷

This negation of identities has a double effect. Firstly, it shores up and strengthens the dominant discourse: 'I'm normal, you're not – I feel better about my normality now that I've excluded you'. Often, that process involves playing on people's fears:⁶⁸ impairment is seen as a personal 'tragedy', to be pitied; those who 'overcome' impairment as 'brave'.

⁶⁶ Ibid

⁶⁷ Torfing J (1999) 120

⁶⁸ 'The hegemonic force, which is responsible for the negation of individual or collective identity, will tend to construct the excluded identity as one of a series of threatening obstacles to the full realization of chosen meanings or options.' Torfing, *ibid*

Secondly, negation of identity may give rise to '**social antagonism**'. Here, people whose identities have been excluded respond to that exclusion. Responses can take various forms, from open confrontation to self-blame or resignation.⁶⁹ Many people internalise the *dis*-ability imposed on them by 'normality' discourse. Demos provides the following example:

When Tara was two she was sent to a special school and feels very strongly that the segregated education has had a lasting negative impact on her relationship with her family, her educational opportunities and, for many years after she left school, on the way she viewed herself. 'We were told that we must be as 'normal' as possible. The big shock was leaving school and finding I was on my own and having to communicate with non-disabled people. I had no idea what to say to them. So I spent the next ten years in the disability closet. People didn't ask about my impairment, and I worked so hard to pretend it didn't exist. It was like the elephant in the room that no one wants to talk about....'⁷⁰

A different response to negation of identity is open confrontation. Here, the excluded identity is reclaimed by those who identify with it, and is used to challenge dominant assumptions. One example is Gay Pride; another is the Disabled People's Movement.⁷¹ Disabled people began to mobilise as a political force in Britain from the late 1960s.⁷² One of the first outcomes of that mobilisation was a re-casting of the understanding of 'disability'. By distinguishing between impairment (individual functional limitation) and disability (caused by physical and social barriers), their social model of disability directly challenged the assumptions of 'normality' discourse - 'I'm disabled by society, not by my impairment.' The 'problem' is no longer the individual, but society: it is society, not the individual that needs to change. Social antagonisms can thus threaten a dominant discourse, as well as defining and strengthening it. As will be seen in the course of this thesis, the social model of disability has proved a very effective political tool.

⁶⁹ Torfing (1999); see also Table 6.1 in Goodley (2010) 86-7

⁷⁰ Miller P, Parker S and Gillinson S, 'Disablism: How to tackle the Last Prejudice' (Demos 2004)

⁷¹ See 'affirmation' model of disability, Goodley (2010) 12

⁷² Hunt P (ed) *Stigma: The Experience of Disability* (Geoffrey Chapman 1966) Leeds Disability Archive; Campbell J and Oliver M, *Disability Politics: Understanding Our Past, Changing Our Future* (Routledge 1996); Campbell J, "Growing Pains": Disability Politics The Journey Explained and Described' in Barton L and Oliver M (eds) *Disability Studies: Past, Present and Future* (The Disability Press 1997)

The re-casting of 'disability' by the Disabled People's Movement also serves to illustrate Laclau and Mouffe's explanation of what happens within a discourse.

[S]ocial practices systematically form the identities of subjects and objects by articulating together a series of contingent signifying elements available in a discursive field.⁷³

Identities emerge as the social practice articulates or re-articulates those elements.⁷⁴ The Disabled People's Movement has re-articulated 'disability' from negative to positive, from individual problem to social construct, thus creating a new 'disabled' identity which is opposite to the understanding of 'dis-ability' in 'normal' discourse. And it is a new identity which 'disabled' people can – and do - embrace:

It was when Tara 'woke up' to the social model of disability that things changed... 'I had a sudden realisation that everything that's happened was because of how people look at impairment – as different, less, unacceptable.... Suddenly you can be the person you always thought you were but never could be.' Now Tara is a campaigner rallying other disabled people to realise that the problem isn't with them but with the society that holds them back.⁷⁵

As Howarth describes, 'social antagonisms occur because social agents are unable to attain fully their identity... when 'the presence of "Other" prevents me from being totally myself.'⁷⁶

'Disability', in its social model/social construct sense, has been one of the key concepts that bind the Disabled People's Movement as it has grown in strength and power. In discourse theory terms, it can be described as a '**nodal point**' – a point of reference that binds together a system of meanings.⁷⁷ From its early focus on physical impairment, the Disabled

⁷³ Howarth and Stavrakakis (2000) 7

⁷⁴ See for instance the quote from Joshua Malinga in Chapter 2.4 below: 'I went to Winnipeg to attend the Rehabilitation International [RI] Conference... When I left I was very passive, but when I returned I was very radical... At that time, we began to recognize that disability was about human rights, about social change, about organizing ourselves. We did not want to emphasize welfare but organization.' Charlton J (2000) 12

⁷⁵ Miller *et al* (2004) 22

⁷⁶ Howarth and Stavrakakis (2000) 10, citing Laclau and Mouffe (1985) 125

⁷⁷ Howarth and Stavrakakis (2000) 8; 'The practice of articulation... consists in the construction of nodal points which partially fix meaning', Laclau and Mouffe (1985) 113, quoted in Howarth and Stavrakakis (2000) 22 note 37

People's Movement has grown to encompass people with illness, mental health issues, learning disabilities, and, more recently, older people and 'carers'. It has spawned an international academic discipline of disability studies, and built political networks across the world. Although disability activists and academics have continued to develop a variety of perspectives,⁷⁸ the understanding of 'disability' as social construct has been fundamental to the identification of such diverse people and practices with the Disabled People's Movement and its new 'disability' discourse.

According to Laclau, nodal points, in order to enable the possibility of such hegemonic success, must be **empty signifiers**.⁷⁹ We have seen '*dis-ability*' as a negative, helping to strengthen 'normality' discourse by its exclusion; and we have seen the re-articulation of 'disability' through the social model as social antagonism, reclaimed as positive identity by the Disabled People's Movement to challenge the 'ablist' discourse of normality. Both meanings rely on a dichotomy between 'disabled' and 'non-disabled'/'normal'. But that dichotomy is not always clear. Tregaskis points out that we all have many different identities. She identifies herself as researcher, consultant, member of staff, friend, woman, white person, body, disabled person, oppressor and activist.⁸⁰ This view illustrates Laclau's '**subject positions**', whereby any one individual may have a number of different subject positions: identities acquired 'by a whole series of unconscious practices, rituals, customs and beliefs, with which they come to identify.'⁸¹ Tremain, from a Foucauldian perspective, also contests the political effectiveness of the dichotomy. She sees the social model of disability as a 'paradigmatic example of [Foucault's concept of] juridical power'.⁸² In this view, impairment as a category emerged

⁷⁸ Goodley (2010) 10-21

⁷⁹ Drawing on the linguistic theory of Saussure, discourse theory differentiates between the 'signifier' and the 'signified'. 'Signifier': The sound-image (or expression) that signifies a certain signified. 'Signified': The concept (or content) that is expressed by a certain signifier. Torfing(1999) 87 and Glossary 305. See also Laclau E, 'Philosophical Roots of Discourse Theory' (undated) Essex University Centre for Theoretical Studies, <http://www.essex.ac.uk/centres/TheoStud/onlinepapers.asp>, accessed 23/4/08

⁸⁰ Tregaskis C, *Constructions of Disability: researching the interface between disabled and non-disabled people* (Routledge 2004)

⁸¹ Howarth and Stavrakakis (2000) 13

⁸² Tremain S, 'Foucault, Governmentality and Critical Disability Theory' in Tremain S (ed) *Foucault and the Government of Disability* (University of Michigan Press 2005); see also

(and still persists) in order to legitimise the governmental (or medical) practices that generated it in the first place. If the identity of the subject of the social model – the ‘person with impairments’ - is actually formed by the very political arrangements that the social model is designed to contest, then the social model will in fact confirm and extend those arrangements, shoring up, rather than challenging, ‘normality’ discourse. Campbell goes further still. She holds that ‘as a signifier, *disability* may be understood in terms of *catachresis*. That is, there is no literal referent for this concept. As soon as we discursively interrogate “disability”, its meaning loses fixity, generality, and ultimately collapses.’⁸³ (original emphasis). This view may well be shared by those around the world who have ever tried to define disability for legal purposes,⁸⁴ including the drafters of the CRPD.⁸⁵ However, it is the very ‘emptiness’ of this signifier as its nodal point that enables the Disabled People’s Movement discourse to embrace the elements of history and understanding that have come with its expansion: from survivors of psychiatry, from people with learning disabilities, from academia, from international politics and more. It is the ability to take in and incorporate such new discursive elements that has enabled it to grow and to flourish.

Laclau and Mouffe theorise this ability of discourses to take in or to exclude discursive elements as **relations of equivalence and difference**.⁸⁶ Relations of equivalence come to the fore when people weaken their internal differences to come together to oppose a particular discursive system. Torfing offers the example of the British Conservative and Labour Parties working together to defeat Nazism during World War II. This process of ‘equivalence’ applies not only to those who (temporarily) come together to

Tremain S, ‘On the Subject of Impairment’ in Corker M and Shakespeare T (eds) *Disability/Postmodernity: embodying disability theory* (Continuum 2002)

⁸³ Campbell FK, ‘Legislating Disability’ in Tremain (2005) *supra*, 127 note 1; ‘catachresis’ = the incorrect use of a word, Oxford Compact English Dictionary, 2nd ed, Oxford, 2000

⁸⁴ See, for instance, discussion of this issue in the context of the CRPD in Chapter 3 below; and see Office for Disability Issues ‘Review of Disability Estimates and Definitions’ In-house Report 128 (ODI 2004); Disability Rights Commission, ‘Consultation on definition of disability in anti-discrimination law’ (DRC 2006); Disability Awareness in Action, ‘Definitions of Disability – a Briefing Paper’ (DAA 2005)

⁸⁵ See Chapter 3 below

⁸⁶ Laclau and Mouffe (1985) 129-130; Howarth and Stavrakakis (2000) 11-12; Torfing (1999) 125-126

oppose, but also to 'the enemy' – the collection of 'evil forces' they are opposing - thus producing 'a political frontier between two opposed camps'.⁸⁷ Where relations of equivalence are uppermost, as they were at the beginning of the Disabled People's Movement, the political space will tend to simplify: 'if you're not with us, you're against us'. Polarisation of the disabled/non-disabled dichotomy is emphasised, and construction of the 'other' or constitutive outside is strengthened. Conversely, where relations of difference are uppermost, there is room for proliferation of differences and for stable compromises. The Disabled People's Movement has grown in size and influence by incorporating a variety of different elements. During negotiation of the CRPD, disabled people's organisations from a wide range of cultures and histories came together in the International Disability Caucus to work jointly and collaboratively with governments and the UN. Here, confrontation is weakened, to include that which has previously been excluded. But, as explained above, there can be no final resolution. Neither set of relations will dominate completely: which predominates at any one time depends on the political struggles for hegemony.

So we have the picture of a social world consisting of ever-changing and dynamic discourses, forming and attempting to expand themselves by incorporating some discursive elements and excluding others. We see the identities of individuals being formed by those discourses, and responding to their inclusion or exclusion. And we see those excluded 'others' constantly challenging and seeking to undermine the discourse(s) from which they have been excluded. There is no possible 'final' resolution of these dynamic tensions; but that does not prevent us from wishing, and working, for such resolution through promotion of the hegemony of those discourses with which we identify.

Hegemony 'involves the expansion of a particular discourse of norms, values, views and perceptions through persuasive re-descriptions of the

⁸⁷ Howarth & Stavrakakis (2000) 11; one of the effects of this will be discussed in Chapter 2 below

world'.⁸⁸ Those re-descriptions are articulated not in a vacuum, but through **hegemonic practice**: by 'political agents attempting to bring about a moral, intellectual and political leadership'.⁸⁹ Where such agents come together in a **hegemonic project**, such as the drafting of an international Convention, the outcome may be a **hegemonic formation**, such as the CRPD, which captures and sediments the various elements of the discourse they are seeking to promote. Here, the word 'hegemonic' means hegemonic in intent, rather than hegemonic in effect: whether the project succeeds in producing 'hegemony' is another question.⁹⁰

Chapters 2 to 4 of this thesis trace the re-articulation of disability and human rights discursive elements to form a new disability/human rights discourse; and the encapsulation of that discourse into a new international legal order. To what extent, if any, this new legal order can succeed in promoting the hegemony of the new discourse in England is the question underlying the remainder of the thesis.

However hard we try to consolidate and strengthen the discourses with which we identify, they are always subject not only to social antagonism, but also to chance: events beyond our control may bring about their structural **dislocation**. For instance, the traumatic events of the Second World War can be seen as destabilising earlier discourses by going beyond their understandings. Before 1939, international human rights agreements such as the earlier Geneva Conventions⁹¹ had focused primarily on relations between States. At that time, the possibility of mass extermination of its own citizens by a modern State was beyond belief. The events of World War II shattered those assumptions, along with many structures, individual lives and identities.⁹² But such dislocation also provides the opportunity for a new

⁸⁸ Torfing (1999) 302

⁸⁹ Ibid

⁹⁰ Torfing (1999) 293

⁹¹ First Geneva Convention for the Amelioration of the Condition of the Wounded and Sick in Armed Forces in the Field, 1864; Second Geneva Convention for the Amelioration of the Condition of Wounded, Sick and Shipwrecked Members of Armed Forces at Sea, 1906; Third Geneva Convention Relative to the Treatment of Prisoners of War, 1929

⁹² Howarth and Stavrakakis (2000) 15

ideology⁹³ to emerge to fill the space; earlier discursive elements are rearticulated to construct a new ‘myth’.⁹⁴

Modern international human rights law and ideology, often portrayed as a collective response to the dislocation of the Second World War,⁹⁵ can be seen as such a ‘myth’, drawing on and rearticulating elements of earlier rights discourses,⁹⁶ whilst also blending them with new components,⁹⁷ to produce a renewed vision of a world of ‘freedom, justice and peace’ (empty signifiers/nodal points) to which the ‘common man’ aspires.⁹⁸ As with any ‘myth’, this vision is unattainable at present; it represents an ideal society⁹⁹ which is specifically contrasted with the dislocatory events which have preceded it,¹⁰⁰ and is further constituted by the threat of social breakdown¹⁰¹ should this discourse not prevail. In direct response to the events of the time, the emphasis is on peace between nations and on protecting individuals from the abuse of State power.

Similarly, in describing the later pluralisation of the human rights framework, Mégret¹⁰² suggests three possible explanations for the appearance of ‘group-specific’ international human rights treaties such as the CRPD: 1) that they are a political and pragmatic response to the failure of ‘mainstream’ human

⁹³ ‘The construction of particular discursive forms within a totalising horizon with universalist pretensions’: Torfing (1999) 114

⁹⁴ ‘Myth is defined as a principle of reading of a given situation. The condition of emergence of myth is structural dislocation, and the function of myth is to suture the dislocated space by means of constructing a new space of representation.’ Torfing (1999) 303

⁹⁵ See generally Alston P, Goodman R, Steiner H, *International Human Rights in Context: Law, Politics, Morals*, 3rd ed (Oxford University Press 2007) chapter 2; Harris D, O’Boyle, Bates E and Buckley C, *Law of the European Convention on Human Rights*, 2nd ed (Oxford University Press 2009) chapter 1

⁹⁶ Such as the Magna Carta 1215, the writings of Enlightenment philosophers such as John Locke or Thomas Paine, the American Declaration of Independence 4 July 1776 or the Déclaration des Droits de l’Homme et du Citoyen 1789

⁹⁷ Such as the ‘four freedoms’ proclaimed by President Franklin D Roosevelt on 6 January 1941 <http://www.americanrhetoric.com/speeches/fdrthefourfreedoms.htm> 30.8.12

⁹⁸ Universal Declaration of Human Rights 1948 Preamble para 2

⁹⁹ A ‘totalising horizon with universalist pretensions’: Torfing (1999) 114

¹⁰⁰ Preamble para 2: ‘Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind....’

¹⁰¹ Preamble para 3: ‘Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law.’

¹⁰² Mégret F, ‘The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?’ (2008) 30(2) Human Rights Quarterly 493

rights - a 'wake-up call'; 2) that something is missing in the 'mainstream' framework that requires it to be adapted for the specific context; or 3) that '[s]pecific instruments are needed not only to adapt the existing language of rights, but because there is a dimension of the experiences of specific groups that is inherent to them and which almost requires the creation of new rights'.¹⁰³ In each explanation, there is a '**lack**' which has been identified in the human rights framework, a space to be filled by a new ideology, or myth. In the case of disability, this 'lack' has been filled by the disability/human rights myth captured in the CRPD text.

Howarth and Stavrakakis explain that

[f]rom their emergence until their dissolution, myths can function as a surface of inscription for a variety of social demands and dislocations. However, when a myth has proved to be successful in neutralising social dislocations and incorporating a great number of social demands, then we can say that the myth has been transformed into **imaginary**. A collective social imaginary is defined by Laclau as 'a horizon' or 'absolute limit which structures a field of intelligibility'. He gives examples such as the Christian Millenium, the Enlightenment and positivism's conception of progress as evidence of these social phenomena.¹⁰⁴ (emphasis added)

Here the myth has been so successful in embracing different elements and events that it comes to represent a 'default' system of meanings that underlies and structures our society. If the myth of disability rights succeeds in becoming imaginary, the CRPD will be redundant: the rights of disabled people will be so much taken for granted that we will no longer need to ask the questions.

¹⁰³ Ibid 495

¹⁰⁴ Howarth and Stavrakakis (2000) 15-16, citing Laclau (1990) 64

Law

Emancipatory law

One method of articulating and regulating systems of social relations is law. The sedimentation of ideas and practices in legal text, the interpretation and implementation of those legal texts through legal and administrative systems, is one collection of social practices through which a political discourse may seek to dominate the field of meaning. For Santos, law plays a key role in these dynamics. He describes forms of law as ‘revolving doors through which different forms of power and knowledge circulate’.¹⁰⁵ In general, law helps to reinforce the power of dominant discourse and to contain and regulate social order.¹⁰⁶ But dominant social orders are always under pressure from those whose identities have been denied in the process of their formation. When influenced by those pressures, law can also play a part in bringing about and in consolidating change. Stein and Lord speak of ‘expressive’ law: ‘the process whereby law can influence behaviour by altering broader social perceptions and conventions.’ For them, ‘law carries with it a symbolic social meaning, and so influences the nexus between law, norms and societal mores’.¹⁰⁷ Santos also highlights the law’s emancipatory function:

[w]hile regulation guarantees order in society as it exists in a given moment and place, emancipation is the aspiration for a good order in a good society in the future... the success of emancipatory struggles resides in their capacity to transform themselves into a new form of regulation, whereby good order becomes order.¹⁰⁸

The CRPD can be seen as an example of ‘expressive’ or ‘emancipatory’ law, born of the hegemonic negotiation project which encapsulated the new disability/human rights discourse into a new legal order. According to Stein and Lord,

¹⁰⁵ Santos (2002) 417

¹⁰⁶ Ibid

¹⁰⁷ Stein and Lord (2009) 31-35. Some also speak of ‘reflexive law’, for example Teubner G, ‘Juridification: Concepts, Aspects, Limits, Solutions’ in Teubner G (ed) *Juridification of Social Spheres: A Comparative Analysis in the Areas of Labour, Corporate, Antitrust and Social Welfare Law* (de Gruyter 1987) 3–48, discussed in Hepple B, ‘Enforcing Equality Law: Two Steps Forward and Two Steps Backwards for Reflexive Regulation’ (2011) 40(4) *Industrial Law Journal* 315

¹⁰⁸ Santos (2002) 2-3

[a]n expressive law analysis of the CRPD indicates that the treaty has the potential to legislate a belief change regarding persons with disabilities... These notions create the point of departure for understanding the Convention itself as a process through which actor identities and interests may be shaped and reconstituted.¹⁰⁹

The implication is that reshaping those identities and interests will lead towards the 'good' (or at least a 'better') society - a fundamentally emancipatory aim. Both Santos and Stein and Lord describe what political discourse theory might call hegemonic practice: an attempt by political agents to bring about - in this case through law - 'the expansion of a particular discourse of norms, values, views and perceptions'¹¹⁰ - or paradigm change.

Although Santos does not identify himself as a political discourse theorist, his ideas have many parallels with those of Laclau and his followers. Capitalist societies, Santos says, are made up of constellations of political power, law and knowledge (discourses) which are characterised by ideological suppression of all forms of political power, law and knowledge except domination, State law, and science (negation of alternative discourse/identity; creation of constitutive outside). These dominant constellations (discourses) thus create their own forms of 'common sense' (myth), which, once they become embedded in the social, political and cultural *habitus* of people and of social scientists (hegemonic), guide social practice, create comforting order, and produce reassuring labels (empty signifiers/nodal points).¹¹¹ Both viewpoints thus see societies as comprising dynamic and competing discourses or constellations, which include or exclude elements in their search for hegemony, which organise systems of social relations, and which form the identities, and guide the actions, of social actors.

Similarly, Santos describes the tension between regulation - 'the set of norms, institutions and practices that guarantee the stability of

¹⁰⁹ Stein & Lord (2009) 32

¹¹⁰ Torfing (1999) 302

¹¹¹ Santos (2002) Chapter 1

expectations’¹¹² (dominant discourse) – and emancipation – ‘the set of oppositional aspirations and practices that aim to increase the discrepancy between experiences and expectations by calling into question the status quo’¹¹³ (social antagonism). For Santos as for Laclau and Mouffe, ‘the idioms of regulation [dominant discourse] and emancipation [social antagonism] are inextricably linked together’.¹¹⁴ Neither regulation nor emancipation will ever be complete or everlasting. There will always be social struggles between regulatory powers, laws and knowledges (dominant discourse) on the one hand, and emancipatory powers, laws and knowledges (social antagonism) on the other. There can be no final resolution.

Discussion of law in this thesis is aided by two of Santos’ analytical tools: his ‘cartography of law’ and his concept of ‘interlegality’. In the first, Santos holds that ‘the relations laws entertain with social reality are very similar to those between maps and spatial reality’,¹¹⁵ prompting the metaphorical application of such cartographical mechanisms as scale and projection to the analysis of legal text.

The cartography of law: scale and projection

Scale ‘is the ratio of distance on the map to the corresponding distance on the ground’.¹¹⁶ Scale determines the reach of the map, and the amount of detail it contains. This aspect of Santos’ cartographic metaphor identifies international law as small-scale law. Just as a map of the world shows no more than a broad overview of continents, oceans and mountain ranges, so international law is drafted in general terms to cover all eventualities and legal contexts. It provides an overall framework rather than detailed instructions for implementation. National law, on the other hand, like a national road-map, can be seen as larger-scale law containing a higher degree of detail, but still suitable for generalising within national boundaries. It may in turn require more detailed secondary legislation that, like a walker’s

¹¹² Santos (2002) 2


¹¹³ Ibid

¹¹⁴ Ibid 417

¹¹⁵ Ibid 420

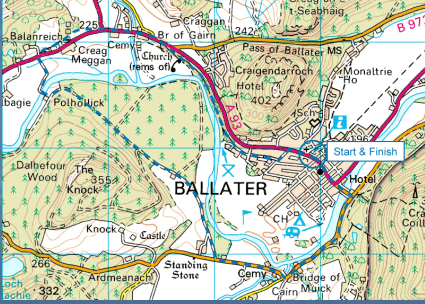
¹¹⁶ Monmonier M, *Maps Distortion and Meaning* (Association of American Geographers 1981) cited by Santos (2002) 422

2½ - inch to the mile map, sets out, for instance, the precise calculations of eligibility for social security entitlement.



Inherent dignity of the human person
Equal and inalienable rights

(3) in determining a claimant's total benefit income in his second benefit week for the purpose of calculating the amount of any transitional addition to which he would have been entitled, no account shall be taken of any payment referred to in paragraph (1)(j) of regulation 9 of the Transitional Regulations (total benefit income) which is made in respect of that week to compensate for the loss of entitlement to income support.



By this analysis, the CRPD is small-scale law. Its purpose is universal and its reach global, the rights it sets out, and the obligations it imposes, intended to apply across all cultures and legal systems. At the same time, its drafting raises interesting issues of scale which are discussed further in Chapter 3.

The English 'community care' legislation discussed in Chapter 7, on the other hand, encompasses both law of national scale¹¹⁷ and larger scale regulations and guidance detailing the duties of local authorities towards each individual;¹¹⁸ while each local authority, in turn, has its own local interpretations, policies and systems.

¹¹⁷ Such as the National Health Service Act 1977, which requires the Secretary of State to 'continue the promotion in England and Wales of a comprehensive health service': National Health Service Act 1977, s1(1)

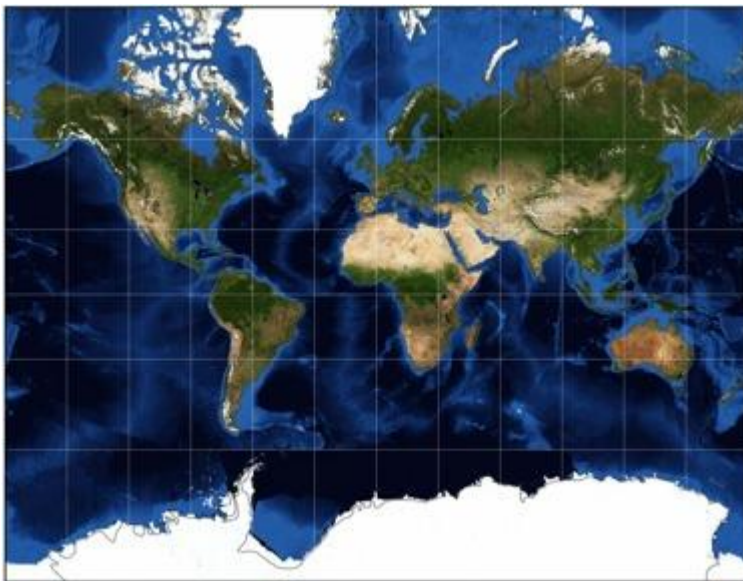
¹¹⁸ 'Where a local authority has assessed a person under section 47 of the National Health Service and Community Care Act 1990 (assessment) and have decided that accommodation should be provided pursuant to section 21 of the National Assistance Act 1948 (provision of residential accommodation) the local authority shall, subject to paragraph 3 of these Directions, make arrangements for accommodation pursuant to section 21 for that person at the place of his choice within England and Wales (in these Directions called 'preferred accommodation') if he has indicated that he wishes to be accommodated in preferred accommodation.' National Assistance Act 1948 (Choice of Accommodation) Directions 1992, para 2

Projection is the technique used by map-makers to represent the curved surface of the earth on a flat plane.¹¹⁹

The earth is roughly spherical in shape, and three dimensional. Maps, however, are flat and only two dimensional. There is a variety of ways in which the 3-D earth can be translated onto the 2-D map, but the process of doing so (map projection) needs to be consistent and thorough if the map is to be credible and 'accurate'.¹²⁰

Cartographers have developed different types of projection. Some preserve angles rather than areas; some preserve distances at the expense of angles; other, hybrid, projections distort angles, distances and areas, but preserve the familiarity of shapes. Each time, increasing the accuracy of one feature will increase the distortion of another.

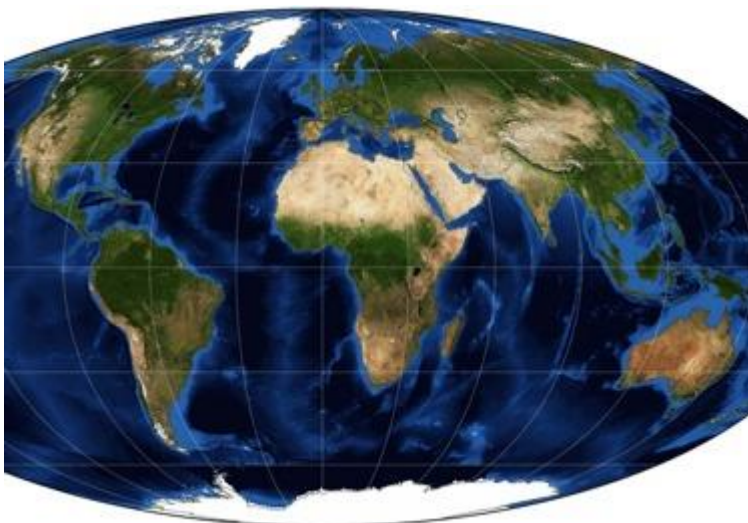
'Take a look at the following map of the world, made using the well known Mercator projection.



¹¹⁹ Santos (2002) 423

¹²⁰ British Cartographic Society <http://www.cartography.org.uk/default.asp?contentID=748>
accessed 1.11.09

Compare it with the following map made with a Mollweide projection. Look at the relative sizes of Africa and Greenland in both maps.



Africa is 14 times the size of Greenland. The Mollweide projection accurately represents areas, whereas the Mercator projection exaggerates the areas as you get closer to the pole. However, the Mollweide projection shears the shapes near to the poles.¹²¹

Transferring this concept to the creation of law, Santos defines projection as 'the procedure by which the legal order defines the limits of its operation, and organizes the legal space inside them.'¹²² How projection decisions are applied by the cartographer will be determined by technical factors. It will also vary according to the purpose of the map, its cultural context and the ideology of the cartographer. It will inevitably involve some distortion of reality.¹²³ And because choices need to be made, that distortion will never be neutral. Similarly, the drafters of a new legal order must choose how to transfer the political social reality that is the subject of their project into a legal instrument that is technically sound and practical. How that is done will vary according to the purpose of the legal instrument, the discursive elements to

¹²¹ Map Toaster, 'What is Projection?' <www.maptoaster.com/.../datum-projection.htm> accessed 9.11.09

¹²² Santos (2002) 430

¹²³ Santos tells Jorge Luis Borges' story of the emperor who ordered the production of an exact map of his empire: it turned out to be not very practical, as it was the same size as the empire....

be included, and the hegemonic intent of the drafters. It will inevitably involve some distortion of the social reality, and that distortion will never be neutral.

The cartographers of the CRPD included a range of social actors: UN organisations, governments, national human rights organisations, and disabled people, each bringing with them their various histories and perspectives, but joined in a common hegemonic project. There were many ways the text could potentially have been written, but none that would reflect the whole of social reality without distortion. The drafters drew on earlier models of human rights convention,¹²⁴ and on equality law.¹²⁵ They made full use of the reintegration of civil, cultural, economic, political and social rights. And they attempted to ensure that their project would continue through innovative implementation and monitoring procedures. It will be seen in Chapters 3 and 4 that, from their central ideological perspective, the particular projections that this group of actors chose for translating their rounded and multi-dimensional social reality into the flat and two-dimensional text of this legally binding international human rights treaty are unique, taking forward understandings of both disability and human rights.

Interlegality

Santos' second contribution is his concept of 'interlegality'. Santos divides capitalist societies into six clusters of social relations (or discourses – see Table 1 below). They are: the household, the work-place, the market, the community, civil society (or the citizen-place) and the world as global. Each of these clusters has a legal dimension. For instance, the legal dimension of the household relates to all of the informal rules and dispute settlement mechanisms that constitute social relations within the household; the market-place also has rules of its own, such as private contract law or informal bargaining; national State law belongs to the citizen-place, and international law to the global world arena.

¹²⁴ Such as CEDAW and the Convention on the Rights of the Child

¹²⁵ For such concepts as equality of opportunity and reasonable accommodation

Table 1

Structural place	Legal dimension	Epistemological form
Household	Domestic law	Familial culture
Work-place	Production law	Technology, training, corporate culture
Market-place	Exchange law	Consumerism, mass culture
Community-place	Community law	Local knowledge, community culture, tradition
Citizen-place	Territorial (State) law	Nationalism, civic culture
World-place	Systemic law	Universal progress, global culture

*From Santos Toward a New Legal Common Sense*¹²⁶

Whilst each of these legal dimensions is active within its own social context, they also interact with each other. For instance, State family law may intervene in the household, so that informal household systems are required to adapt. Conversely, informal household law may in practice sometimes limit what State law is able to achieve. State law may itself have been influenced

¹²⁶ Santos (2002) 371

by international law, such as the UN Convention on the Rights of the Child, and household law by legal dimensions of the community. It is the 'dynamic interplay' within and between these legal dimensions – their 'contingency and creativity', the ebb and flow of their respective discursive power - that produces what Santos calls legal constellations, or 'interlegality'.¹²⁷ In this sense, interlegality can be seen as the legal dimension of political discourse, and law as a 'revolving door through which different forms of power and knowledge circulate.'¹²⁸

It will be seen in Chapter 3 that the CRPD encompasses multiple legal dimensions, drawing on international, national and local legal precedents, and demanding new legal relations between state and society, between state and individual, between individual and community.¹²⁹ The creativity thus produced acts as an engine for change, complete with 'transmission belt'¹³⁰ to drive domestic implementation. Conversely, Chapter 5 eavesdrops on the 'constructive dialogue' between the UN Committee on Economic, Social and Cultural Rights and the UK. Here, the interplay between international legal understandings and national ones is less creative, leading to impasse and mutual frustration.

¹²⁷ Santos (2002) 437; see also the concept of 'reflexive law', Teubner G (1987) and Hepple (2011) *supra*.

¹²⁸ Santos (2002) 417

¹²⁹ Mégret, F 'The Disabilities Convention' (2008) *supra*, and see Chapter 3 above

¹³⁰ Quinn G, 'Added value of the UN Convention on the Rights of Persons with Disabilities' (2008) presentation to Seminar of the European Coalition for Community Living, Drammen, Norway; printed in Newsletter of the European Coalition for Community Living, December 2008/January 2009, 2

The thesis

Structure

The theoretical ideas outlined above provide a viewpoint and language to discuss and analyse the complex and dynamic thesis material. The core material, however, is practical international, national and local law. The thesis falls into two parts. Part 1 focusses on the CRPD, while Part 2 examines the UK's understandings of economic, social and cultural rights, and the impact of those (mis)understandings on implementation in England of Article 19.

Part 1: The UN Convention on the Rights of Persons with Disabilities

Chapter 2 describes events leading to adoption of the CRPD. It traces construction of a disability/human rights myth which sets a new agenda at the UN, leading to a hegemonic project to embed that myth in a new international human rights treaty. **Chapter 3** analyses the text of the Convention.¹³¹ The central understandings captured in the Convention's title, purpose and principles project the rights themselves, melding together civil, cultural, economic, political and social rights, highlighting angles of the human rights framework in new ways and challenging basic human rights assumptions. The CRPD myth embedded in the Convention presents a re-description of the world, demanding its 'deep reconstruction' to reposition disabled people from excluded recipients of welfare to full and equal rights-holders. **Chapter 4** examines the Convention's implementation and monitoring provisions designed to ensure that the hegemonic project continues to expand; and looks more closely at Article 19, the right to live independently and be included in the community. This 'hybrid' right is identified as fundamental towards the Convention's goal of paradigm change,¹³² and the economic,

¹³¹ In the light of its context, object and purpose, its preamble and travaux préparatoires, and the circumstances of its conclusion. Vienna Convention on the Law of Treaties 1969, Articles 31 and 32

¹³² Chair of the Ad Hoc Committee, Daily Summary, 7th session, 19th January 2006, afternoon session

social and cultural rights it incorporates as essential to Convention realisation.

Part 2: Implementation in England

Chapter 5 examines the constructive dialogue between the UK and the UN Committee on Economic, Social and Cultural Rights. This reveals the failure of successive UK governments to acknowledge the durable nature of such rights, re-articulating them instead as welfare entitlements to be implemented through the ‘specific laws, policies, and practices’ of the welfare state. The Chapter concludes from this evidence that the UK has not yet made the transformation in understanding from ‘welfare’ to ‘rights’ that the CRPD demands.

The question then arises as to how the disability/human rights myth will fare in a domestic context where economic, social and cultural rights are rendered invisible. This question is explored through examination of the ‘specific laws, policies and practices’ in England relating to Article 19, the right to live independently and be included in the community.

Chapter 6 traces *understandings* of independent living in domestic policy. It finds a discourse in transition from paternalistic to ‘person-centred’ provision, relying on principles of autonomy and participation which fit well with the emancipatory message of the Convention. However, that policy is couched not in the language of rights but of welfare. The economic, social and cultural rights necessary for its realisation remain invisible, leaving understandings of independent living and the services essential for its realisation without protection from unfettered re-articulation to suit differing political agendas, or from dislocation by global economic instability.

Systems are explored through legislation. **Chapter 7** compares two attempts at mapping the legal space: a ‘neutral’ review of existing adult social care legislation, and a rights-based Independent Living Bill. Whilst Article 19 rights to individual autonomy and choice are likely to be strongly supported in

the forthcoming Social Care Reform Bill, the economic, social and cultural rights required for their exercise appear set to remain invisible, leaving the domestic legal map essentially unchanged.

Discourses form and are formed not only through understandings and systems of social relations, but also through the *identities* of individuals. **Chapter 8** examines administrative decision-making relating to independent living services in England. It explores the potential for administrative power relationships and systems in this setting to oppress or to emancipate. It finds that despite some areas of progress, the decision-making process continues to negate and oppress many of those it purports to serve.

Chapter 9 investigates the capacity of administrative redress systems to counter such mis- and partial understandings, and to influence policy, law and administration towards a more CRPD-compatible, emancipatory discourse. The power of internal complaints procedures to influence wider policy, law or administration in this way is found to be negligible. In the courts, incipient development of rights to dignity and participation have been countered by a high bar to engagement, with the result that case law reflects rather than alters dominant exclusionary understandings. The role of the Ombudsman provides more positive possibilities, but is not without its challenges. Redress systems generally engage a complex and labyrinthine system of power relations which may intensify rather than countering oppression.

Part 2 concludes that the UK's failure to acknowledge economic, social and cultural rights results in mis- and partial understandings, and thus in mis- or partial application, of Article 19 in policy, law and practice. This in turn results in failure to fully implement the Convention as a whole, leading to frustration of its drafters' hegemonic project in the English domestic sphere.

Chapter 10 draws the thesis to its conclusion. It finds that the UK's reluctance to acknowledge economic, social and cultural rights as rights goes to the heart of CRPD implementation, calling into question its Article 4(1)

undertaking to 'ensure and promote the full realisation of all human rights and fundamental freedoms for all disabled people'. The thesis recommends explicit incorporation of economic, social and cultural rights into domestic law, policy, culture and administration, alongside acknowledgement that independent living law, policy and practice are rooted in the indivisibility and interdependence of rights without which the terms of Article 19, and thus of the Convention as a whole, will not be realised.

Method

This thesis is grounded in the writer's experience as a practitioner in independent legal advice, including work in and with organisations of disabled people at local and national levels. That experience nurtured both a deep and long standing engagement in the field of disability rights and an interest in the capacity of administrative and human rights law to bring about emancipatory change. In the world of political discourse theory, everything has meaning: it is not possible to take a 'neutral' position. Although no ultimate resolution is possible, actors continue to work for the promotion of those discourses with which they identify. In that sense, this thesis – like the law it explores - is not neutral: it seeks to apply sound academic research methods to encourage new, emancipatory understandings.

The research is a case study engaging a variety of qualitative research methods, including elements of observation, 'real-time' documentary research and classical legal doctrinal analysis. The thesis reflects on developments to April 2012. Subsequent events, including publication in July 2012 of a White Paper and Draft Bill relating to adult social care, are noted in a Postscript.

Chapters 2 to 4

Research for this thesis was conducted part-time over a period of seven years. When it began in early 2005, the first working draft of the CRPD had just been produced in New York. The researcher therefore had the benefit of following, through online reports and commentaries, conferences and personal discussions, the negotiation, adoption and ratification of the CRPD.

This lends to the research the advantage of real-time observation of developments. However, because those developments are so recent and ongoing, the body of academic work relating to the CRPD remains relatively small, though growing.¹³³ The writer has therefore had to rely disproportionately, particularly in the initial stages of the research, on ‘grey’ materials and non-academic resources.

Chapter 5

Research for Chapter 5 included detailed analysis of past constructive dialogue documents from 1992 as well as personal observation of the 2009 meeting between the UK and the UN Committee. Absence from the UN Treaty Body database of official Summary Records of the first session of that meeting has necessitated strong reliance on the writer’s notes taken on the day. These notes have been checked against the record published by the International Service for Human Rights,¹³⁴ who were also present; and are consistent with history of the constructive dialogue and with the UN Committee’s 2009 concluding observations.¹³⁵

Chapters 6 to 9

The developments in domestic independent living policy, law, administration and redress described in Chapters 6 to 9 have also been unfolding during the period of the research. The Life Chances Report was produced in 2005, leading to the ‘transformation’ of service provision launched by the New Labour government in 2008. This ‘transformation’ was overtaken by events,

¹³³ See for example on-going work at the Centre for Disability Policy and Law, National University of Ireland, Galway; The Center on Human Policy, Law and Disability Studies, Syracuse University, USA; the Nordic Network on Disability Research (NNDR); and the Graduate Program in Critical Disability Studies, York University, Canada. Recent landmark publications include Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009) and Rioux MH, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011)

¹³⁴ International Service for Human Rights, Treaty Body Monitor <http://www.ishr.ch/treaty-body-monitor/cescr#42> accessed 16.9.11

¹³⁵ See UN Committee on Economic, Social and Cultural Rights, <http://www2.ohchr.org/english/bodies/cescr/index.htm>. See also Bates E, ‘The United Kingdom and the International Covenant on Economic, Social and Cultural Rights’ in McCorquodale R and Baderin M (eds) *Economic, Social and Cultural Rights in Action* (Oxford University Press 2007)

including the global economic crisis and election of the Coalition government. Similarly, review of social care legislation took place in 2011, and the courts' potential role in stemming the effects of public funding cuts is only now becoming apparent. Again, the body of academic work addressing these issues is as yet relatively small: the writer has relied strongly on documentary and web-based research and observation.

The original intention for Chapters 8 and 9 of the thesis was to initiate an empirical user-led research project to recount the impact of administrative justice on participants' experiences of independent living. An unsuccessful funding bid, however, necessitated reliance on existing literature. Analysis of this 'second-hand' literature has been complemented, wherever possible, by resources produced by disabled people and decision-makers in relation to their first-hand experience.

PART 1

The UN Convention on the Rights of Persons with Disabilities

CHAPTER 2

INTERNATIONAL DISABILITY RIGHTS

Introduction

Chapter 1 has discussed the meanings of some concepts central to this research, and has introduced the theoretical tools used in the thesis to assist in discussion and analysis of the law relating to those concepts. In Chapters 3 to 9 that law is examined, first at international level and then through its translation into domestic policy, law and administration in England. First, however, we look at where the international law has come from.

Howarth and Stavrakakis explain that ‘a political project will attempt to weave together different strands of discourse in an effort to dominate or organise a field of meaning so as to fix the identities of objects and practices in a particular way’.¹ The myth captured in the UN Convention on the Rights of Persons with Disabilities came about through the partial convergence of various discursive strands, each with their attendant social practices, some relating to international human rights law, others to the experience of disability.² To understand that myth, and the ‘disability/human rights’ discourse which is central to it and to this thesis, it is necessary to understand some of the preceding and concurrent ‘worlds’ which have been contested or partially absorbed and re-articulated in the process of its construction.

This chapter explores some of those ‘worlds’. It examines the individualisation and pluralisation of the international human rights

¹ Howarth and Stavrakakis (2000) 2; and see Chapter 1 above

² A further contextual paradigm has been development of the Millennium Development Goals, from which the issue of disability has, until very recently, been conspicuous by its absence. (‘Realizing the Millennium Development Goals for Persons with Disabilities through the Implementation of the World Programme of Action concerning Disabled Persons and the Convention on the Rights of Persons with Disabilities’, Report of the Secretary General to 64th Session UN General Assembly, A/64/180, July 2009, para 4). International development is, however, beyond the scope of this thesis.

framework; developing understandings of equality; and renewed recognition of the interdependence of civil, cultural, economic, political and social rights. The experience of *dis*-ability drives the growing influence of the disabled people's movement, with its resistance to oppression, its reinterpretation of 'disability', its insistence on inclusion and participation, on 'rights' rather than 'welfare'. The partial convergence of all of these elements gives rise to a new discourse of 'disability/human rights', which in turn leads to a hegemonic project: the negotiation of 'a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities'.³ This project attempts to sediment a new myth – a re-description of the world and of the place of disabled people in it - into a new legal order: the UN Convention on the Rights of Persons with Disabilities.

International Human Rights

The modern framework

Modern international human rights discourse did not come out of the blue. As we have seen in Chapter 1, it can be identified in political discourse terms as attempting to fill a 'lack' brought about by the 'dislocation' of the Second World War.⁴ The United Nations' primary purpose was 'to save succeeding generations from the scourge of war'⁵ by promoting the conditions of stability

³ GA Res 56/168 of 19 December 2001

⁴ Rights discourses were already in existence well before the 20th century – see Chapter 1 footnote 96 above. The incipient international structures that followed the First World War, such as the League of Nations and the International Labour Organisation had already introduced an international network of states which could be incorporated into the new, more powerful, structures of the United Nations, and into the concept of International treaties. The post-war myth of international human rights re-articulated and built on these earlier discourses to produce a renewed vision of the world.

⁵ Charter of the United Nations 1945 (UN Charter) Preamble para 1. Article 1 of the 1945 Charter of the United Nations sets out its purposes:

1. To maintain international peace and security...
2. To develop friendly relations among nations based on respect for the principle of equal rights and self-determination of peoples...
3. To achieve international co-operation in solving international problems of an economic, social, cultural or humanitarian character, and in promoting and encouraging respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language or religion; and

and well-being necessary for peaceful and friendly relations among nations.⁶ The promotion of such stability and well-being required a holistic range of action: promoting higher standards of living, full employment, and conditions of economic and social development; finding solutions to international economic, social, and health problems; and universal respect for, and observance of, human rights and fundamental freedoms for all without distinction as to race, sex, language or religion.⁷ The Preamble to the 1948 Universal Declaration of Human Rights elaborates this vision further, conjuring a world of freedom, justice and peace, where human beings enjoy freedom of speech and belief and freedom from fear and want; where the inherent dignity, equality and inalienable rights of all members of the human family are recognised; where nations collaborate to promote social and economic progress; and where a common understanding of rights and freedoms comes about through education and progressive implementation.⁸ As with any myth, this new world is unattainable at present: this is expressive law, which seeks to influence behaviour to bring about a world to which the 'common man' aspires.

The human rights and fundamental freedoms which are to be respected, without discrimination, in this new world include civil rights to life, liberty and security,⁹ to a fair trial,¹⁰ to freedom of movement,¹¹ of expression¹² and assembly.¹³ They include protection from slavery,¹⁴ from torture,¹⁵ and from arbitrary arrest or detention,¹⁶ from interference with private and family life,¹⁷

4. To be a centre for harmonizing the actions of nations in the attainment of these common ends.

⁶ UN Charter Article 55

⁷ *ibid*

⁸ As described in Chapter 1, this myth is further constituted by contrast with the dislocatory events which have preceded it, and by the threat of social breakdown should the new myth not prevail.

⁹ UDHR Article 3

¹⁰ UDHR Articles 10, & 11

¹¹ UDHR Articles 13, 14 & 15

¹² UDHR Article 19

¹³ UDHR Article 20

¹⁴ UDHR Article 4

¹⁵ UDHR Article 5

¹⁶ UDHR Article 9

¹⁷ UDHR Article 12

and from deprivation of property.¹⁸ They include political rights to take part in government, to access public services, and to vote in elections.¹⁹ And they include the right to realisation ‘through national effort and international co-operation and in accordance with the organization and resources of each State’, of economic and social rights to social security,²⁰ to work,²¹ to rest,²² to education,²³ and to an adequate standard of living, including food, clothing, housing and medical care and necessary social services.²⁴ Everyone also has the right ‘freely to participate in the cultural life of the community’,²⁵ as well as ‘duties to the community in which alone the free and full development of his personality is possible’.²⁶ In line with the UN Charter, the Universal Declaration of Human Rights sets out a holistic range of rights – civil, cultural, economic, political and social - whose protection is required in order to help bring about the world envisioned by its drafters.

To become, and remain, hegemonic, and to increase that hegemony to the point where it becomes imaginary,²⁷ a myth must seek to incorporate new discursive elements, and to negotiate social antagonism and dislocation. Since its inception, antagonism to the modern human rights discourse has arisen from many quarters;²⁸ the myth continues to be understood in a multitude of ways.²⁹ ‘Human rights’ can thus be seen as an empty signifier, acting as nodal point for a variety of interpretations. Since the 1940s,

¹⁸ UDHR Article 17(2)

¹⁹ UDHR Article 21

²⁰ UDHR Article 22

²¹ UDHR Article 23

²² UDHR Article 24

²³ UDHR Article 26

²⁴ UDHR Article 25

²⁵ UDHR Article 27

²⁶ UDHR Article 29

²⁷ See Chapter 1 above

²⁸ See for instance Campbell T, Ewing KD and Tomkins A (eds) *Sceptical Essays on Human Rights* (Oxford University Press 2001); ; Santos BS, ‘Toward a Multicultural Conception of Human Rights’ in Hernandez-Truyol B (ed) *Moral Imperialism: A Critical Anthology*, (York University Press 2002); Kennedy D, *The Dark Sides of Virtue: reassessing international humanitarianism* (Princeton University Press 2004); Dembour M-B, ‘Critiques’ in Moeckli D, Shah S and Sivakumaran S, *International Human Rights Law* (Oxford University Press 2010); An-Naim AA, *Human Rights in Cross-Cultural Perspectives: A Quest for Consensus* (University of Pennsylvania Press 1995)

²⁹ Pillay N, ‘Human rights in United Nations action: norms, institutions and leadership’ (2009) 1 EHRLR 1

international human rights discourse has succeeded in broadening from its post-war mission to protect people against the abuse of State power, to reflect increasing dominance of the discourse of liberal individualism and the unsatisfied demands of a variety of social groups. It has seen the interpretation and re-interpretation of its core value of equality³⁰ and the near-fracturing and subsequent reclaiming of its holistic character through the tensions and resolutions of the Cold War. These re-articulations are considered next.

Individualisation

In the context of the post-war growth of Western liberal capitalism and its attendant individualism, the focus of the international human rights agenda has moved on. Whilst the prohibition of State interference with individual rights remains, a growing emphasis has developed on restoring power and value to the individual.³¹ Human rights jurisprudence has imposed on States not only a 'negative' duty not to interfere with an individual's rights, but also 'positive' duties to protect and fulfil those rights.³² These must not only be respected by the State, but also protected from interference by others and fulfilled through positive action, to allow for 'the development, without outside interference, of the personality of each individual in his relations with other human beings'.³³ As Conor Gearty puts it, 'our dignity... demands that we each of us be given the chance to do the best we can, to thrive, to flourish, to do something with ourselves'.³⁴

In thus focusing on the individual, human rights jurisprudence has constructed an abstract view of what it is – at least in the context of human rights discourse - to be human.³⁵ This view is underpinned by values of dignity, autonomy, equality and solidarity, and broadly coincides with the

³⁰ See for instance the 'five generations' of equality law outlined in Hepple B, 'The new Single Equality Act in Britain' (2010) 5 Equal Rights Review 11

³¹ Fredman S, *Human Rights Transformed* (Oxford University Press 2008)

³² Mowbray AR, *The Development of Positive Obligations Under the European Convention on Human Rights by the European Court of Human Rights* (Hart 2004)

³³ *Botta v Italy* (1998) 26 EHRR 241

³⁴ Gearty C, *Can Human Rights Survive?* (Cambridge University Press 2006) 50

³⁵ Mégret F, 'The Disabilities Convention: Towards a Holistic Concept of Rights' (2008) 12(261) International Journal of Human Rights 3

liberal 'subject' as described by writers such as John Stuart Mill.³⁶ This autonomous human 'subject' has freedom to live his life how he chooses, and to exercise his rights, limited only exceptionally by the State (or his own conscience) for the common good or to protect the rights of others. In theory, this 'subject' functions autonomously within a society designed to enable his wellbeing, not least through its protection and promotion of his human rights and fundamental freedoms.³⁷

Once this abstract view of the subject is established, it becomes clear that the actual experience of some people within real societies makes it harder – if not impossible - for them to achieve such an 'ideal' existence. For the international human rights myth to flourish, those 'unsatisfied demands' must be incorporated into its discourse. In response to social and political pressures,³⁸ the human rights framework has come to recognise, and attempt to mitigate, the disadvantage of successive groups of people; to articulate these additional 'unfixed' elements into the human rights discourse, and to sediment them in international human rights treaties such as CERD, CEDAW or the UNCRC. In doing so, the human rights discourse itself has been modified,³⁹ giving rise to what has been described as the 'pluralisation' of human rights.⁴⁰

Pluralisation

Frédéric Mégret defines pluralisation as the 'phenomenon whereby human rights, as law and ideology, has increasingly recognised the needs of specific groups or categories of humanity as worthy of specific human rights

³⁶ Mill JS, *On Liberty* (1859): 'Over himself, over his own body and mind, the individual is sovereign'

³⁷ For alternative perspectives see for instance Donnelly J, *Universal Human Rights in Theory and Practice (Cornell paperbacks)* 2nd ed, (Cornell University Press 2002) chapter 5; An-Naim AA, *Human Rights in Cross-cultural Perspectives: A Quest for Consensus* (University of Pennsylvania Press 1995); Baderin M, *International Human Rights and Islamic Law* (Oxford University Press 2005)

³⁸ Such as the civil rights movement of the 1960s or feminism from the 1970s

³⁹ Laclau and Mouffe (1985) 105, cited in Torfing (1999) 101

⁴⁰ Mégret F, 'The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?' (2008) 30(2) *Human Rights Quarterly* 493

protection'.⁴¹ As noted in Chapter 1, he suggests three possible explanations for this phenomenon,⁴² each of which exhibits a 'lack' in the human rights framework. Mégret argues that human rights discourse (not least by failing to raise the question) has been 'intensely ambiguous' about how pluralisation 'at least potentially and implicitly challenges the idea that human rights are about promoting equal rights for all'. Pluralisation suggests that 'human rights may *also* be about delving deeply into issues of identity, survival and dignity of particular groups' (original emphasis).⁴³

This analysis taps into two important and inter-related concepts, elements of which have been re-articulated and re-formulated in disability/human rights discourse to become essential elements of the CRPD myth. Firstly, it questions the formal approach to equality that underlies international human rights law. Secondly, it suggests a need to delve deeper into identity, survival and dignity, to seek to understand and put in place the conditions required to transform the experience of oppression into inclusion and the equal, and actual, exercise of autonomy.

Equality

The idea that human rights are equally inherent in all human beings, and should therefore be realised equally, has played a fundamental role in modern international human rights discourse from the start;⁴⁴ it is reflected, *inter alia*, in the ubiquitous requirement for rights to be realised without discrimination.⁴⁵ However, as Mégret identifies, there is a tension between

⁴¹ Ibid 494

⁴² 1) A political and pragmatic response to the failure of 'mainstream' human rights - a 'wake-up call'; 2) that something is missing in the 'mainstream' framework that requires it to be adapted for the specific context; or 3) that '[s]pecific instruments are needed not only to adapt the existing language of rights, but because there is a dimension of the experiences of specific groups that is inherent to them and which almost requires the creation of new rights'. Mégret F, 'The Disabilities Convention' (2008) 495

⁴³ Mégret (2008) *supra* 496; see also Otto D 'Everything is Dangerous: Some Post-structural Tools for Rethinking the Universal Knowledge Claims of Human Rights Law' (1999) 1 Australian Journal of Human Rights 22

⁴⁴ For instance, see Universal Declaration of Human Rights Article 1: All human beings are born free and equal in dignity and rights. See also standard human rights treaty phrasing: Everyone has the right to.../ No one shall be subjected to...

⁴⁵ See for example International Covenant on Civil and Political Rights Article 2(1); International Covenant on Economic, Social and Cultural Rights Article 2(2); European Convention on Human Rights Article 14. Also International Convention on the Elimination of

the traditional formal understanding of equality which underlies the universality of the modern human rights framework and the experiences of those groups who express their 'unsatisfied demands'. Equality law has attempted to address that tension.

Traditional liberal discourse features freedom from discrimination as a basic civil liberty,⁴⁶ designed to enable the autonomous subject to make choices and to act freely in society without encountering irrational, discriminatory barriers. Despite some disagreement about the philosophical justifications for interfering with individual freedom,⁴⁷ most liberal capitalist societies have, since the 1960s, accepted the need for some degree of domestic legal regulation in this field.⁴⁸ Early non-discrimination law was based on the traditional formal view, requiring identical treatment of men and women, or of people with different racial backgrounds. Disability discrimination law introduced an element of asymmetry for the first time, applying only to disabled people;⁴⁹ and imported the concept of 'reasonable accommodation'⁵⁰ requiring a limited degree of positive action to remove individual disadvantage.

These innovations allow disabled people to be treated differently from others, to the extent that it is 'reasonable' to do so.⁵¹ They move discrimination law from a 'formal' to a more 'substantive' concept of equality, to taking a fuller

All forms of Racial Discrimination 1966 (CERD) and Convention on the Elimination of All Forms of Discrimination against Women 1979 (CEDAW)

⁴⁶ See Bamforth N, Malik M and O'Connell C, *Discrimination Law: Theory and Context*, 1st ed (Sweet & Maxwell 2008); Fenwick H, *Civil Liberties and Human Rights* (Routledge-Cavendish 2010)

⁴⁷ According to Bamforth *et al*, '[w]ithin the liberal justification of discrimination [law] there are differences between those approaches that use a procedural form of liberalism and equality as a formal treatment of "like with like"; and those that base liberalism on deeper values such as autonomy, dignity or respect... For procedural liberals... discrimination law and policy can be justified because of their contribution to the goal of state neutrality. For perfectionist liberals [those calling on 'deeper values'] ...they are justified because they allow the state to secure valuable goods such as autonomy for individuals.' Even this level of 'interference' with the freedoms of others goes too far for some.

⁴⁸ Beginning with the Americans with Disabilities Act 1990; and see Lindqvist B, 'UN Standard Rules on Disability Pave the Way for Human Rights' (2004) 14(3) INTERRIGHTS Bulletin 95

⁴⁹ For instance, the provisions of the UK Disability Discrimination Act 1995 might only be called upon by individuals who met the definition of disability set out in section 1.

⁵⁰ Or 'adjustment'

⁵¹ See for example *Archibald v Fife Council* [2004] IRLR 651; [2004] ICR 954 (HL) para 68

and more flexible approach which allows for human difference. Some argue, however, that it may also reinforce stereotypes, and so entrench disadvantage.⁵² Furthermore, enforcement remains in the hands of individuals, after the (allegedly) discriminatory event, and there are many reasons why individuals may not take such action,⁵³ rendering the law less effective.

A further development, described by Hepple as 'transformative equality', attempts to bypass these issues by addressing structural disadvantage. This imposes duties on public sector organisations to proactively assess the impact of their actions on particular disadvantaged groups. Under this model, positive action to remove discriminatory barriers and to promote equality of outcome is seen as necessary, legitimate and desirable.⁵⁴ Although the language is different,⁵⁵ a growing congruence can be identified between this systemic understanding of equality and the human rights agenda's focus on positive action to protect the dignity and autonomy of each individual.⁵⁶

Some take these arguments further again. Stein⁵⁷ argues that '[a]s human beings, each of us has strengths and weaknesses, abilities and limitations.'

⁵² Amardóttir OM, 'A Future of Substantive and Multidimensional Equality?', presentation to The Human Rights of Persons with Disabilities – from Social Policy to Equal Rights Conference, Reykjavik, 27 September 2007; also Stein MA, 'Disability Human Rights' (2007) 95(1) *California Law Review* 75, Part 2C. See also Quinn (2002) chapter 13; Horejes T and Lauderdale P 'Disablism Reflected in Law and Policy: The Social Construction and Perpetuation of Prejudice' (2007) 3(3) *The Review of Disability Studies: an International Journal* 13 www.rds.hawaii.edu accessed 20/9/07

⁵³ Genn, H, *Paths to Justice: What People Do About Going to Law* (Hart 1999); Pleasance *et al*, *Causes of Action: Civil Law and Social Justice*, 2nd ed, (Legal Services Commission 2006); Hurstfield *et al*, 'Monitoring the Disability Discrimination Act 1995 (DDA): phase 3' (Disability Rights Commission 2004); and Chapter 8 below

⁵⁴ See for example Disability Discrimination Act 1995 Part 5A, and associated Regulations. For further discussion see O'Conneide C, 'Disability Discrimination' n Bamforth N, Malik M and O'Conneide C, *Discrimination Law: Theory and Context*, 1st ed (Sweet & Maxwell 2008)

⁵⁵ Before the CRPD, there is no mention in human rights jurisprudence of reasonable accommodation/adjustment. Instead, the emphasis is on human dignity and personal fulfilment.

⁵⁶ This congruence can be traced in the domestic case law discussed in Chapter 9 below. See also Disability Rights Commission Legal Bulletin issue 11/April 2007, 61 and issue 12 Legacy Edition 2007; also Fletcher A and O'Brien N, 'Disability Rights Commission: From Civil Rights to Social Rights' (2008) 35(4) *Journal of Law and Society* 520

⁵⁷ Building on the human right to development and the 'capabilities approach' advanced by Amartya Sen and Martha Nussbaum: see Stein MA, 'Disability Human Rights' (2007) 95(1)

He espouses a human rights framework that 'esteems potential over extant function', recognising the value of every individual for his or her own end, and assessing the efficacy of human rights protection in light of external factors that impact on individual development. This view, sometimes described as 'multidimensional disadvantage equality',⁵⁸ or equality of worth, again focuses on the inherent dignity and rights of each individual but now judges human rights protection in terms of its success in relieving the external factors which impinge on that individual's fulfilment.⁵⁹ This is a far cry from the traditional liberal understanding of formal equality, requiring action to be taken in relation to those external factors. Stein suggests that 'ensuring equality in any really meaningful sense requires not only the assertion of negative rights, but also a deep reconstruction of our world if we are to value and include every individual's participation'.⁶⁰

The 'exogenous factors', or 'multidimensional disadvantages', that impinge on an individual's development bring us back to the holistic vision of the drafters of the Universal Declaration of Human Rights. For them, economic, social and cultural rights are as important as civil and political rights in bringing about realisation of 'the inherent dignity and... equal and inalienable rights of all members of the human family'.⁶¹ However, the interdependence of rights has not always had a smooth trajectory.

Economic, Social and Cultural Rights

With the onset of the Cold War, the holistic human rights formation was fractured, with East and West falling broadly into two camps. In the West, immediate implementation and enforcement of civil and political rights took priority, whilst socio-economic rights were seen as inconsistent with the free

California Law Review 75; also Burchardt T, 'Capabilities and Disability: the capabilities framework and the social model of disability' (2004) 19(7) *Disability & Society* 735

⁵⁸ Arnadóttir (2009) Chapter 3

⁵⁹ See also O'Conneide C, 'The Right to Equality: A Substantive Legal Norm or Vacuous Rhetoric?' (2008) 1 HRR 81, 99: 'Philosophical debates about the meaning of equality may illuminate discussion but it is ultimately the interplay of legal, social and political factors against the historical background context that will drive forward change in how equality rights are interpreted and understood.'

⁶⁰ Stein M, 'Disability Human Rights' draft version 2006/07, 48

⁶¹ Universal Declaration of Human Rights 1948, Preamble para 1

market ideology underlying capitalist/Western progress.⁶² Eastern European states, by contrast, tended to focus on economic, social and cultural rights, and 'expressed reluctance and often outright animosity' towards proposals for international human rights monitoring devices.⁶³ This conflict resulted in an International Bill of Rights consisting of two separate treaties: the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).⁶⁴ The holistic human rights discourse was thus partially dislocated by Cold War antagonisms that were more powerful than itself.

The dichotomy reflected in the texts of the two Covenants also affected their ensuing development: the two 'sets' of rights were treated unequally in terms of institutions, procedures or the development of norms.⁶⁵ Although the Preambles to both Covenants recognise that

the ideal of free human beings enjoying freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his economic, social and cultural rights, as well as his civil and political rights,⁶⁶

in practice the obligations of States Parties under each Covenant are very different. Notably, whereas each State Party to the ICCPR undertakes 'to respect and to ensure to all individuals within its territory and subject to its jurisdiction' the civil and political rights set out in that Covenant,⁶⁷ a State ratifying the ICESCR undertakes merely to 'take steps... to the maximum of its available resources, with a view to achieving progressively the full realization of the rights...'.⁶⁸

⁶² See for instance Hayek FA, *Law, Legislation and Liberty: a new statement of the liberal principles of justice and political economy*, vol 2: The Mirage of Social Justice (Routledge & Kegan Paul 1976)

⁶³ Rosas A and Helgesen J, 'Introduction' in Rosas A and Helgesen J (eds) *Human Rights in a Changing East-West Perspective* (1990), cited in Hunt P (1996)

⁶⁴ Alston P, 'Economic, Social and Cultural Rights' in Henkin L and Hargrove JL (eds) *Human Rights: an Agenda for the Next century* (1994) cited in Hunt P(1996). Both treaties were adopted by the UN General Assembly in 1966 and came into force in 1976.

⁶⁵ Hunt P(1996) 1

⁶⁶ ICESCR Preamble para 3, mirrored in ICCPR Preamble para 3

⁶⁷ ICCPR Art 2(2)

⁶⁸ Article 2(1).

Monitoring systems also developed unequally. States Parties to the ICCPR have been reporting to the Human Rights Committee since 1976 ‘on the measures they have adopted which give effect to the rights’.⁶⁹ That Committee also has power to consider inter-State complaints,⁷⁰ and complaints from individuals claiming violation of their rights by a State Party to the Covenant’s Optional Protocol.⁷¹ By contrast, no such monitoring committee was established by the ICESCR. It was 1987 before the present Committee came into being, with a brief to ‘emulate, as far as practicable, the approach followed by the Human Rights Committee’.⁷² This Covenant requires States to report ‘in stages’ on their progress in implementing the rights,⁷³ indicating, if appropriate, ‘factors and difficulties affecting the degree of fulfilment of obligations’.⁷⁴ There is no provision for State-to-State complaints equivalent to Article 41 ICCPR, and (until recently)⁷⁵ no Optional Protocol allowing for individual complaints. It will be seen in Chapter 5, however, that since 1987, the ESCR Committee has worked to clarify the norms contained in the Covenant,⁷⁶ to expand the information base relevant to its work,⁷⁷ and to design an effective system for monitoring States’ performance.⁷⁸

Despite these tensions and inconsistencies between the two International Covenants, the overwhelming majority of UN Member States has ratified both

⁶⁹ ICCPR Article 40(1)

⁷⁰ Article 41

⁷¹ Optional Protocol to the International Covenant on Civil and Political Rights, adopted 1966, in force 1976, ratified by 100 States as at 1.1.08; the UK has neither signed nor ratified this Protocol

⁷² Alston (1994)

⁷³ ICESCR Art 17(1)

⁷⁴ ICESCR Art 17(2)

⁷⁵ An Optional Protocol to the ICESCR allowing for individual and group complaints was first discussed in 1990, and was adopted by the General Assembly in December 2008. The Protocol was opened for ratification in September 2009; it requires 10 ratifications to come into force.

⁷⁶ Alston, P, ‘The Committee on Economic, Social and Cultural Rights’ in Eide, A, Krause, C, Rosas, A (eds) *Economic, Social and Cultural Rights: a textbook*, Martinus Nijhoff, Dordrecht, 1995; see also the Committee’s 20 General Comments available on <http://www2.ohchr.org/english/bodies/cescr/comments.htm>

⁷⁷ Since 1998, UN Special Rapporteurs have been appointed in relation to economic, social and cultural rights, with four currently mandated by the Human Rights Council to report on rights to housing, education, food and health. Information is also collected from UN Specialised Agencies, national human rights institutions and NGOs

⁷⁸ Based on that set out in the ICCPR and developed by the Human Rights Committee. Alston (1995) 489

treaties.⁷⁹ Since the end of the Cold War, re-evaluation of the inter-relationship between the two sets of rights has resulted in a renewed recognition of their indivisibility,⁸⁰ which by the beginning of the new century had again become an article of faith at the UN. Human rights discourse has seized the opportunity to restore some of the stability of the post-war myth by reclaiming its holistic nature.

We have seen how modern international human rights law and ideology have come about, in response to the dislocations of the Second World War, by re-articulating elements from earlier human rights discourses; and how, despite antagonisms and dislocations, they have since extended their reach, taking on board or reclaiming, as circumstances allow or demand, the individualism of Western liberal capitalism, the 'unsatisfied demands' of disadvantaged groups, substantive understandings of equality and the indivisibility and interdependence of civil, cultural, economic, political and social rights. This behaviour is typical of a discourse seeking to maintain and increase its hegemony.⁸¹ Given these developments, one might suppose that disabled people's human rights would be sufficiently protected. However, here as elsewhere, disabled people were invisible.⁸²

Despite its ostensible embrace of 'all members of the human family', the only mention of disability in the Universal Declaration of Human Rights is found in

⁷⁹ ICCPR: 167 parties, ICESCR: 160 parties, as of 8 February 2013. The USA has not ratified the ICESCR; China has not ratified the ICCPR.

⁸⁰ Hunt P (1996) 1. See also the Vienna Declaration and Plan of Action 1993: '[a]ll human rights are universal, indivisible and interdependent and interrelated. The international community must treat human rights globally in a fair and equal manner, on the same footing, and with the same emphasis.' As UN Secretary General from 1997, Kofi Annan introduced reforms to ensure that all human rights became a cross-cutting issue to be extended across the world organisation. As Human Rights Commissioner, Mary Robinson gave priority to this integration, becoming known for her 'mantra' of treating all human rights equally. The 50th anniversary of the Universal Declaration of Human Rights in 1998 provided a further opportunity to reaffirm the principle of interdependence and indivisibility. See also Hunt P, 'Taking Economic, Social and Cultural Rights Seriously' (2006) Human Rights Law Resource Centre 2006 Human Rights Dinner, Melbourne, Australia, 29 April 2006

⁸¹ Hegemony: 'The achievement of a moral, intellectual and political leadership through the expansion of a discourse... It involves the expansion of a particular discourse of norms, values, views and perceptions through persuasive redescriptions of the world.' Torfing (1999) 302

⁸² Quinn and Degener (2002) Chapter 1, para 1.3

Article 25,⁸³ where disability is identified with 'lack of livelihood' and disabled people as deserving to be supported by the State or other providers of 'security'. The Declaration thus reflects the dominant discourse of the time, which identified disabled people, if at all, as recipients of welfare rather than as holders of rights. Elsewhere, the Declaration fails to include disability in its list of prohibited grounds for discrimination,⁸⁴ a pattern followed by subsequent treaties until 1989.⁸⁵ It was not until disabled people themselves began to mobilise at international level that this exclusion was challenged.

Disability

International mobilisation

Building on pockets of earlier protest,⁸⁶ the political mobilisation of disabled people began in earnest in the 1960s.⁸⁷ One important catalyst for their mobilisation at international level was a conference organised by Rehabilitation International, which took place in Winnipeg, Canada in 1981. Rachel Hurst takes up the story:

There was an international organisation called Rehabilitation International which was mostly made up of rehabilitation professionals of one sort or another. There were one or two leading disabled people who were involved with RI, notably Ben Lindquist... and those few... were trying to get RI to listen to the voice of disabled people. He was being singularly unsuccessful, which is not surprising. And in 1980 RI had one of their world congresses in Winnipeg in Canada... [B]ecause of things that people like Ben had been saying, they invited some

⁸³ This despite the fact that President Roosevelt was a wheelchair user. UDHR Article 25: 'Everyone has the right to a standard of living adequate for the health and well-being of himself and family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.'

⁸⁴ UDHR Article 2

⁸⁵ UN Convention on the Rights of the Child 1989, Articles 2(1) & 23

⁸⁶ For example internationally from the World Federation of the Deaf and the International Federation of the Blind: Hurst, R, 'The International Disability Rights Movement', seminar to Centre for Disability Studies, University of Leeds, 11 October 2000; in the UK from organisations such as the British Deaf Association or the National League of the Blind: Campbell J, 'Growing Pains' Disability Politics The Journey Explained, and described' in Barton L and Oliver M (eds) *Disability Studies: Past, Present and Future* (The Disability Press 1997) 78-90; both documents available from Leeds Disability Archive <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>

⁸⁷ See Chapter 5 below for early developments in the UK and USA

disabled people from all over the world... 2[00] to 300 disabled people were invited. The rest of the conference was 3000 non disabled people, heavily professional... [Disabled activists from England and US] were invited but there was also and this was much more important really, for the international movement, there were disabled people who came from the developing countries... And when they met the disabled movement in Winnipeg, which was very small but it was strong, very strong, arranged a barbecue for the first evening of the RI conference.... Everybody met, drank a lot and discovered for the first time this shared commonality of oppression and it was a very, very emotional time but it was one of those times when history was really made and as a result of that barbecue they decided to go to the council of RI and demand that they had the substantial voice in the decisions that were being made. And so the next day they did. They marched into RI and the big plenary session they went up and said we demand that we are the people you are talking about, we must have a substantial voice in what you're saying and the council said to them sorry we've got structures, we are going to stick to our structures, we know best, go away. So they did, they actually, all two hundred of them... walked out of the conference and they never went back and they held their own conference in the hotel and they had workshops and they... had a tremendous time really analysing where they were all coming from, what barriers for their inclusion really were and how they could overcome them. And by the end of the week they had made a major decision. One that they had to set up an international body of disabled people, which was going to only look at the establishment of rights and equalisation of opportunities for disabled people. This is very important. It was not about getting services... It was purely and simply as an organisation which reflected the voice of disabled people and supported rights and equalisation of opportunities. Each of the disabled people were [sic] told to go home and set up their own national organisations. Vic and Stephen came back and set up the British Council of Organisations for Disabled People. Joshua went back and set up the National Council of Disabled People of Zimbabwe. Others went back to their countries and there were forty. And then in 1981 in Singapore they met again and Disabled Peoples' International was founded.... It does not provide services, it is cross impairment, it has national assemblies now in 120 countries...⁸⁸

That experience radicalised many of those involved. As Joshua Malinga from Zimbabwe reports,

I went to Winnipeg to attend the Rehabilitation International [RI] Conference... When I left I was very passive, but when I returned I was very radical... At that time, we began to recognize that disability was

⁸⁸ Hurst R, 'The International Disability Rights Movement', seminar to Centre for Disability Studies, University of Leeds, 11 October 2000, available on <http://www.leeds.ac.uk/disability-studies/archiveuk/Hurst/Disability%20Rights.pdf> last accessed 18.8.2009

about human rights, about social change, about organizing ourselves. We did not want to emphasize welfare but organization.⁸⁹

Hurst describes the RI conference as the first discovery of 'this shared commonality of oppression'. The concept of oppression brings a new element to the conflict, challenging the individualism of liberal discourse. As Young describes, '[f]or contemporary emancipatory social movements... oppression is a central category of political discourse. Entering the political discourse in which oppression is a central category involves adopting a general mode of analyzing and evaluating social structures and practices which is incommensurate with the language of liberal individualism...'.⁹⁰ For Young,

a theory of justice should attend to factors other than individual rights and the distribution of resources: for example, the social structure and institutional context; issues of decision-making power and procedures; division of labour and culture.⁹¹

All of these aspects feature strongly in disabled activists' discourse.

As we have seen in Chapter 1, the social model of disability on which the Disabled People's Movement is predicated demands transformation not of the individual but of social structures and institutions to accommodate the differences of impairment. Joshua Malinga talks of 'social change'. As Hurst reports elsewhere, disabled people realised 'that what they needed wasn't special privileges, wasn't special services but was actually to change society itself'.⁹²

Similarly, the demand not only to be heard, but to be actively involved in decision-making, to share power, comes strongly from Hurst's account: 'we are the people you are talking about, we must have a substantial voice in what you're saying'. This message has been captured in the Movement's mantra of 'Nothing about us without us', which shaped and permeated the

⁸⁹ Charlton JI, *Nothing About Us Without Us: disability oppression and empowerment* (University of California Press 2000) 12

⁹⁰ Young IM, *Justice and the Politics of Difference* (Princeton University Press 1990) cited in Bamforth *et al* (2008) 225

⁹¹ Bamforth *et al* (2008) 224

⁹² Hurst (2000)

CRPD negotiations, and, as we shall see in Chapters 3 and 4, the text of the Convention.

But individual rights and the distribution of resources matter too. A third essential ingredient of this contestation of liberal understandings of 'normality' is the demand for 'rights' in place of 'welfare'. Welfare is seen as compensation for exclusion; rights as the inherent, inalienable and equal birth right of all human beings. Where people have been treated as outside humanity, assumed not to have a role to play in society, not 'subjects' as understood in liberal philosophy, not capable of exercising their autonomy or participating on an equal basis with others, then recognition of and respect for their rights takes on a particular and fundamental significance. As Bengt Lindqvist was still insisting in 2000:

Disability is a human rights issue! I repeat: disability is a human rights issue. Those of us who happen to have a disability are fed up of being treated by society and our fellow citizens as if we did not exist or as if we were aliens from outer space. We are human beings with equal value, claiming equal rights...⁹³

Disability at the UN

Such deeply rooted exclusion not only from society, but also from human rights protection, began to change in response to the growth and activities of the disabled peoples' movement. The earliest disability-related UN provisions date from the 1970s,⁹⁴ and reflect the individual/medical model of disability discourse prevalent at the time. 1981 was designated UN International Year of Disabled People, followed by a ten-year World Programme of Action concerning Disabled People,⁹⁵ aiming at 'equality' and 'full participation' in social life and development.⁹⁶ Disabled Peoples'

⁹³ Speech by Bengt Lindqvist, Special Rapporteur on Disability of the United Nations Commission for Social Development, at the Nineteenth Congress of Rehabilitation International, Rio de Janeiro, 25 – 30 August 2000

⁹⁴ Declaration on the Rights of Mentally Retarded Persons 1971; Declaration on the Rights of Disabled Persons 1975. Both instruments reflect the individual/medical model of disability dominant at the time.

⁹⁵ Coordinated by the Centre for Social Development and Humanitarian Affairs

⁹⁶ See General Assembly resolution A/RES/36/77, 8 Dec 1981; A/RES/37/52, 3 Dec 1982
<http://www.un.org/documents/ga/res/36/a36r077.htm>;
<http://www.un.org/documents/ga/res/37/a37r052.htm>

International applied for observer status to the UN and had ‘a quite substantial impact’ on the writing of the World Programme of Action.⁹⁷

Special Rapporteur Leandro Despouy confirms that

it was at the urging of the non-governmental organizations concerned that the admissibility of this question [of disability as human rights issue] was recognized and the problem of disability could be considered by bodies responsible for the protection of human rights from the standpoint of and in connection with violations.⁹⁸

Disabled Peoples’ International argued for a convention on the rights of disabled people, but its time had not come, and they became involved in writing of the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (the Standard Rules).⁹⁹ Nevertheless, Quinn et al note that it is at this period that ‘an irreversible shift from the “caring” to the “rights” model’ can be identified.¹⁰⁰

Disability was beginning to be understood as a function of the relationship between disabled people and their environment, produced by their encounter with cultural, physical or social barriers;¹⁰¹ and disabled people’s expertise was beginning to be recognised.¹⁰² Moreover, the World Programme of Action served also to broaden the concept of human rights to recognise explicitly the right of every human being to equal opportunity.¹⁰³ The

⁹⁷ Hurst (2000); Despouy L, ‘Human Rights and Disabled Persons’, Human Rights Studies Series, number 6 (UN Centre for Human Rights, 1993) para 91
www.un.org/esa/socdev/enable/dispapersdes1.htm

⁹⁸ Despouy (1993)

⁹⁹ Hurst (2000). Half way through the World Programme Decade, a global meeting of experts convened to review its implementation. They recommended that the rights of disabled people should be recognised in an International Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, to be ratified by States by the end of the Decade. A draft outline convention was prepared by Italy and presented to the General Assembly in 1987, and further presentations were made by Sweden in 1989, but no consensus could be reached. The majority felt that existing human rights documents were sufficient to guarantee disabled people’s rights. In 1990, the Economic and Social Council agreed instead to concentrate on the elaboration of the non-binding Standard Rules

¹⁰⁰ Quinn and Degener (2002) 30

¹⁰¹ Despouy (1993) para 91

¹⁰² For Despouy, ‘[p]ossibly one of the most striking aspects [of the World Programme] is the realization of the joint responsibility of governments, the community and disabled persons themselves for achieving [its] aims.... one of the most notable features of the Decade has been the leading role played by non-governmental organizations headed by disabled people, and the acknowledgement of their status as experts in their own affairs.’

¹⁰³ Despouy (1003) para 12

disability/human rights discourse was gathering momentum, beginning to influence human rights discourse and to spawn activity around the world.¹⁰⁴

The 1993 Vienna Declaration sedimented this progress:

all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities... The place of disabled persons is everywhere. Persons with disabilities should be guaranteed equal opportunity through the elimination of all socially determined barriers, be they physical, financial, social or psychological, which exclude or restrict full participation in society.¹⁰⁵

The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (the Standard Rules) were adopted by the General Assembly in 1993.¹⁰⁶ Although not mandatory, the Rules 'imply a strong moral and political commitment on behalf of States to take action'.¹⁰⁷ They set out preconditions for equal participation, such as medical care and support services; target areas for equal participation, such as accessibility, education, employment, income maintenance, family life, culture and recreation; and implementation measures such as legislation, economic policies, training and research. They require a national focal point of coordination and input from organisations of disabled people. The Rules are promoted and monitored by a United Nations Special Rapporteur, working alongside a panel of experts appointed by the major international organisations of disabled people.¹⁰⁸ In addition to its consultative role, this

¹⁰⁴ The International Year and the World Programme of Action influenced, and tuned into, many and various developments. For instance, the 1981 African Charter on Human and Peoples' Rights, stipulates: "[t]he aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs." The Sub-Commission on Prevention of Discrimination and Protection of Minorities highlighted in 1983 the relationship between human rights violations and disability. In the same year, the International Labour Organisation adopted Convention 159 and Recommendation 168, appealing for renewed efforts to ensure that disabled persons are ensured equal access to training and employment. This was also the year that Disabled Peoples' International acquired special consultative status at the UN. Waves were also felt at regional level. In 1986, the Council of the European Communities adopted a Recommendation on the employment of disabled people based on the principle that disabled people have the right to equal opportunity in training and employment.

¹⁰⁵ Vienna Declaration and Programme of Action 1993, A/CONF.157/23, section II B 6

¹⁰⁶ General Assembly Resolution A/RES/48/96 of 20 December 1993

¹⁰⁷ General Assembly Resolution A/RES/48/96 para 14

¹⁰⁸ The six international disability organisations represented on the panel of experts are: Disabled Peoples' International, Inclusion International, Rehabilitation International, World Blind Union, World Federation of the Deaf and World Network of Users and Survivors of

panel actively participates in monitoring activities and provides access to a world-wide network of national and local disabled people's organisations.¹⁰⁹

The Standard Rules are thus an important precursor to the CRPD. They accept the social model differentiation between individual impairment and social discrimination,¹¹⁰ recognising the need to address 'both the individual needs... and the shortcomings of society'.¹¹¹ They acknowledge the influence of disabled people's organisations in bringing about 'a deepening knowledge and extension of understanding concerning disability issues and the terminology used'.¹¹² They recognise disabled people's expertise in relation to their identity, survival and dignity, and make use of that expertise in development, promotion and monitoring. Although they focus primarily on access and discrimination, the Rules help to cement what may be seen as a 'half-way' point reached by the 1990s in the journey towards a full 'disability/human rights' discourse.

Looking back in 2004 on his nine-year stint as Special Rapporteur, Bengt Lindqvist observed that

the Standard Rules have been widely used by disability NGOs [non-governmental organisations] and by governments... The panel of experts is an effective link between the UN monitoring activities and the NGOs in the field... This unique cooperation between the NGOs and the UN has proved to be very useful for both the UN and the organisations concerned.¹¹³

Psychiatry; Lindqvist B, 'UN Standard Rules on Disability Pave the Way for Human Rights' (2004) 14(3) INTERIGHTS Bulletin 95 note 3

¹⁰⁹ Lindqvist (2004); see also Charlton (1998) 136

¹¹⁰ Para 18

¹¹¹ Para 21

¹¹² Para 19

¹¹³ Lindqvist identifies three main areas of impact for State governments: legislation, structures for cooperation between government and disability organisations, and evaluation of laws, programmes and services. A majority of the new disability laws introduced in over 40 countries have been inspired by the Standard Rules; more than 100 countries have reorganised national coordinating structures which include disabled people; and the Rules have been used as an evaluative instrument¹¹³ Lindqvist (2004)

However, '[p]erhaps the most important effect of the introduction of the Standard Rules ten years ago has been to pave the way for the new paradigm of disability as a human rights issue'.¹¹⁴

We can trace in these developments the growing influence of disabled people themselves. So far, they have succeeded in initiating admissibility of the question of disability as a human rights issue; they have taken part in shaping the World Programme of Action, and in drafting, promoting and monitoring the Standard Rules. In the process, they are gaining experience of international human rights systems and themselves earning acknowledgement of, and respect for, their expertise. Mégret suggests a need for the human rights framework to delve deeper into issues of identity, survival and dignity of those whose rights it seeks to protect. Disabled people are beginning to supply that expertise.

Disability/human rights discourse

Understandings

We saw in Chapter 1 that discourses are 'worlds' of related objects and practices that form the identities of social actors; that they continually interact and change, borrowing or excluding elements from each other in their search for hegemony. This chapter has so far explored some of the elements of international human rights and disability worlds which have contributed to a new discourse of 'disability/human rights.' New discourses come about through hegemonic practices of articulation:¹¹⁵ in this case through the struggles of disabled people to contest their oppression and their invisibility in the world of international human rights. In the process, some basic

¹¹⁴ Lindqvist (2004). The work of the Special Rapporteur and his panel of experts was also influential in encouraging States to introduce anti-discrimination legislation, much of it based on the Standard Rules or on the influential Americans with Disabilities Act (ADA) of 1990.

¹¹⁵ 'the term 'hegemonic practices' refers to attempts to dis- and re-articulate social elements in and through antagonistic struggles in order to become hegemonic. Whether such attempts succeed in constructing a hegemony is not important in this regard.' Torfing (1999) 293

assumptions of human rights discourse relating to autonomy and equality are challenged.

Hill has set out seven conditions for the exercise of autonomy:

- (1) [individuals] have the psychological capacities for rational decision-making which are associated with autonomy;
- (2) they actually use these capacities when they face important choice situations;
- (3) they have the rights of autonomy... i.e., a right to make morally and legally permissible decisions about matters deeply affecting their own lives free from threats and manipulation from others;
- (4) other people actually respect this right as well as their other rights;
- (5) they are able and disposed to have distinctly human values;
- (6) others respect this capacity by not presuming that they value only good experiences for themselves and by not counting their comfort as more important than their declared values; and, finally,
- (7) they have ample opportunities to make use of these conditions in living a life over which they have a high degree of control¹¹⁶

This liberal definition of autonomy makes a number of assumptions. It assumes rationality, and that rationality is desirable; it assumes 'ample opportunities' to exercise capacity, without manipulation; it assumes respect for that capacity from others; and it assumes a high degree of control.

We have seen in Chapter 1 how the modern capitalist discourse of 'normality' has excluded disabled people as less than human, both physically through segregation and institutionalisation, and in terms of identity. As a result, for many people living with impairments, the exercise of self-determination without manipulation, with respect for their decision-making and the consequent degree of control over their life is beyond the realms of possibility. As disability advocate Marca Bristo describes,

[f]undamentally, most of the problems experienced by people with disabilities stem from the perception that they are not fully human. All too often people with disabilities have been excluded from the human franchise. Frequently, they are simply left out in the planning and implementation of programs in the areas of housing, healthcare, employment and education. Many are subjected to horrific and

¹¹⁶ Hill TE, *Autonomy and Self-Respect* (Cambridge University Press 1991) cited in Bamforth *et al* (2008) 201

degrading treatment, warehoused and forgotten in institutions designed to remove them from society.¹¹⁷

This reality equates to Young's definition of oppression; and it identifies the autonomous liberal subject at the heart of the modern human rights framework as a fundamentally 'ableist' ideal.¹¹⁸ Even where human rights discourse allows for some positive obligations on the part of the State, as O'Conneide points out, these are 'treated as useful but limited tools, only applicable where necessary to remove obstacles which prevent self-sufficient individuals from freely exercising their personal autonomy'.¹¹⁹

For people treated in the ways described by Marca Bristo to exercise their autonomy on an equal basis as full members of humanity requires more than the limited positive obligations of human rights law. It requires reversal of the exclusionary understandings and practices of modern 'normality' discourse; it requires emancipation from oppression and active inclusion in, and transformation of, the planning and implementation of social programmes and structures; it requires respect for the exercise of individual decision-making and autonomy; and it requires the opportunity to participate and to live a life over which one has a high degree of control. As Charlton identifies, '[t]he principles, demands and goals of the DRM [Disability Rights Movement] cannot be accommodated by the present world system'.¹²⁰ They seek fundamental transformation – a re-description of the world.¹²¹

Human rights understandings of equality are similarly challenged. The traditional formal understanding which underlies the universality of human rights discourse is found to be inadequate to encompass those 'whose direct

¹¹⁷ International Disability Rights Monitor <http://www.idrmnet.org> last accessed 20.6.10; IDRM Disability Rights Compendium (Center for International Rehabilitation 2003) 1

¹¹⁸ Campbell FK, 'Legislating Disability' in Tremain S, *Foucault and the Government of Disability* (The University of Michigan Press, 2005)

¹¹⁹ O'Conneide C, 'Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and New Possibilities' in Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

¹²⁰ Charlton (1998)

¹²¹ See also 'Disability Human Rights Paradigm' in Stein MA, 'Disability Human Rights' (2007) 95(1) California Law Review 75, 93

claims to human rights are based on irreducible experiences that require a tailoring of the general rights regime', and to which the principal human rights instruments have so far been 'insufficiently sensitive'.¹²² As Mégret identifies, 'a concept of human rights that presupposes that all individuals are equal because they are all fundamentally alike can become oblivious to the fact that persons with disabilities, for example, are *not autonomous in the same way* as persons without disabilities.'¹²³ (emphasis added). Instead, Stein's re-articulation of the concept of equality 'repositions disability as a universal and inclusive concept ... [It] embraces disability as a universal human variation, rather than as an aberration'.¹²⁴ Against the liberal concept of formal equality, which separates, categorises and compares, Stein's approach allows for all human beings, regardless of 'abilities and limitations' to be included in the human family. It repositions disabled people in the world as equal rights-holders. Again, this view of equality requires 'a deep reconstruction of our world'.¹²⁵ Such fundamental challenge to core human rights understandings of autonomy and equality reveals a basic 'lack' in the international human rights framework which the new disability/human rights discourse seeks to fill. Human rights discourse functions as a 'surface of inscription' for a re-description of the world and of the place of disabled people in it, for a shift in understanding from exclusion to inclusion, and from welfare to rights.

Two further components assist with this process. Firstly, the openness of human rights discourse to pluralisation through incorporation of the unsatisfied demands of successive groups of people. Precedents have been set by CERD, CEDAW and the CRC, and the way has been paved by the Standard Rules. Secondly, economic, social and cultural rights have been reclaimed from their Cold War wilderness. The timing of this renewal of the principle of interdependence and indivisibility of the two 'sets' of rights has significant consequences for disabled people. As Leandro Despouy pointed

¹²² Mégret (2008a) 515-516

¹²³ Ibid

¹²⁴ Ibid, Conclusion. See also Burchardt T, 'Capabilities and Disability: the capabilities framework and the social model of disability' (2004) 19(7) Disability & Society 735

¹²⁵ Stein (2007) draft 48

out in 1993, '[d]isability is perhaps the area in which the importance of recognizing the indivisibility and interdependence of human rights...is most evident and sharp'.¹²⁶ More recently, Quinn and Bruce argue that

[s]et against the backdrop of using rights to restore power to people, economic, social and cultural rights have an enabling function – they provide a bridge whereby persons with disabilities can take their place as valued and often highly productive citizens.... they enable people to take charge of their own lives. It is in this sense that economic, social and cultural rights enhance freedom.¹²⁷

Socio-economic rights can be seen as a kind of 'reasonable accommodation' by society to enable the exercise of all human rights by individuals:¹²⁸ they address the 'multi-dimensional disadvantage', or 'exogenous factors' that impinge on an individual's development. It will be seen in Chapter 3 that the integration of economic, social and cultural rights in the Convention text drives realisation of all of the Convention rights.

Disabled people also bring key elements to the new discourse. They bring their experience and their expertise: their understanding of oppression, their history of mobilisation and resistance, their reclaimed identity, with its concomitant social model of disability; and their demand for inclusion, participation, and rights. It is their leading contribution that allows human rights discourse to 'delve deeply into issues of identity, survival and dignity',¹²⁹ enabling re-articulation of liberal understandings of autonomy and equality; and their expertise which enables international human rights

¹²⁶ Despouy (1993) para 31

¹²⁷ Quinn G and Bruce A, 'Toward Free and Inclusive Societies for People with Disabilities: Reflections on the Liberating Role of Economic, Social and Cultural Rights' (undated) Disability Law and Policy Research Unit, Faculty of Law, National University of Ireland, Galway. Quinn & Bruce, 'Toward Free and Inclusive Societies for people with Disabilities', 5 <http://www.nuigalway.ie/law/Common%20Files/Disability%20Research%20Unit/GQ/Quinn%20and%20Bruce%20Disability%20Paper.pdf>

¹²⁸ See for example Fredman S, 'Disability Equality: a Challenge to the Existing Anti-discrimination Paradigm?' in Lawson A, Gooding C, *Disability Rights in Europe* (Hart 2005); Fletcher A and O'Brien N, 'Disability Rights Commission: From Civil Rights to Social Rights', (2008) 35(4) *Journal of Law and Society* 520-50; Ziv N, 'The Social Rights of People with Disabilities: reconciling care and justice' in Barak-Erez D and Gross AM, *Exploring Social Rights: between theory and practice* (Hart 2011); Ellis K, 'Disability rights in practice: the relationship between human rights and social rights in contemporary social care' (2005) 7 *Disability & Society* 691

¹²⁹ Mégret (2008a) 496

discourse to act as a surface of inscription for the unsatisfied demands of this new antagonism, and thus to preserve and expand its own hegemony.

A successful hegemonic discourse is one that manages to redefine the terms of the political debate and set a new agenda. By this definition, the disability/human rights discourse has arrived. Disabled people are no longer invisible on the human rights stage, no longer excluded from the international human rights agenda. They are acknowledged as rights-holders, and their experiences and contributions are recognised and valued.

But at this stage, this new agenda is not yet fully embedded in international human rights law. As noted above, calls for a legally binding treaty were unsuccessful in the 1980s and 90s. The international activities of disabled people, however, continued to gather pace. A millennium World Summit on Disability in Beijing attended by leading international disabled people's NGOs produced the *Beijing Declaration on the Rights of People with Disabilities in the New Century*, committing these organisations to 'strive for a legally binding international convention'. The impetus of this drive was further accelerated by high profile adoption elsewhere at the UN of the Millennium Development Goals, which aim to halve world poverty by 2015. Despite disabled people being significantly over-represented amongst the world's so-called 'poorest of the poor',¹³⁰ they receive no mention in the Millennium Development Goals.¹³¹ This persistent invisibility proved an additional spur to the arguments of those working for a Convention.¹³²

¹³⁰ World Health Organisation, *Global Programming Note 2006-2007: Call for Resource Mobilisation and Engagement Opportunities*, 2006

¹³¹ 'While persons with disabilities make up ten per cent of the world's population, disability is associated with twenty per cent of global poverty according to the World Bank's findings. Currently, there are no references to persons with disabilities either in the MDGs themselves or in the accompanying body of guidelines and policies, programmes and conferences that are part of the on-going MDG efforts. In addition, the new revisions of the MDGs currently in process do not include persons with disabilities.'

<http://www.un.org/disabilities/default.asp?id=1470> 21.12.10

¹³² Pinto PC, 'Monitoring Human Rights: a Holistic Approach' in Rioux MH, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011)

At the same time, the UN High Commissioner on Human Rights commissioned a study on the human rights dimensions of disability 'to examine what might be done to strengthen both the protection and the monitoring of the human rights of persons with disability'.¹³³ Following its in-depth analysis of the moral authority for a human rights approach to disability, the Quinn Report¹³⁴ concluded that '[t]he unreserved endorsement of a human rights perspective on disability has naturally put pressure on the human rights system to respond positively and appropriately';¹³⁵ it supported the development of a thematic convention.¹³⁶ In December 2001, the UN General Assembly accepted that efforts so far by national and international bodies 'ha[d] not been sufficient to promote full and effective participation and opportunities for persons with disabilities in economic, social, cultural and political life.' It adopted a resolution establishing an Ad Hoc Committee to consider proposals for a 'comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination...'.¹³⁷ The UN had finally recognised the need to incorporate disabled people's 'unsatisfied demands' fully into the human rights framework, and into binding international human rights law.

The hegemonic project

The scene is thus set in 2001 for a new hegemonic project: the coming together at international level of a variety of agents - States delegations, UN officials, national human rights institutions and disabled people's organisations - in a joint attempt to capture the various elements of the new disability/human rights discourse they are seeking to promote.¹³⁸ By embedding their new 'vision of how state, economy and civil society should be organised'¹³⁹ in a new international treaty, they will attempt to create a

¹³³ Quinn and Degener (2002) Foreword

¹³⁴ Quinn and Degener (2002)

¹³⁵ Ibid 46, para 2.9

¹³⁶ Ibid Chapter 13

¹³⁷ General Assembly Resolution 56/168 of 19 December 2001

¹³⁸ Torfing (1999) 302

¹³⁹ Ibid

new legal order aimed at transforming their vision into 'a new form of regulation, whereby good order becomes order'.¹⁴⁰ This hegemonic formation¹⁴¹ will seek to 'influence behaviour by altering broader social perceptions and conventions', carrying with it 'a symbolic social meaning' which 'influences the nexus between law, norms and societal mores'.¹⁴² It will sediment a myth, which, it hopes, will in due course become imaginary.¹⁴³ This project, like the discourse it seeks to sediment, demands a new approach: a comprehensive, holistic, multi-faceted approach combining social development, human rights and non-discrimination, and involving disabled people and their organisations in consultation and drafting.¹⁴⁴ It produces a new hegemonic practice of participatory law-making.

We have traced above the role of disabled people in raising the question of disability as a human rights issue, in shaping the World Programme of Action and in drafting, promoting and monitoring the Standard Rules. Their resulting experience of international human rights systems, and others' acknowledgement of, and respect for, their expertise, is carried forward into the drafting of the Convention.¹⁴⁵ We have also seen that a key demand of the disabled people's movement has been not only to be heard, but to be

¹⁴⁰ Santos (2002) 2-3

¹⁴¹ See Chapter 1 above

¹⁴² Stein and Lord (2009) and see Chapter 1

¹⁴³ See Chapter 1 above

¹⁴⁴ The preliminary findings of the Quinn report, including a strong recommendation for a thematic convention (Chapter 13) were presented to the UN in January 2002. That meeting also agreed on a 'multi-faceted approach' to disability, highlighting 'the need to continue and reinforce social development efforts in the field of disability and to integrate more effectively the United Nations work in that domain with reinforced attention to the matter from a human rights perspective'. The importance of the involvement of disability NGOs in the consultation and drafting process was highlighted. This holistic emphasis grew in confidence as the work of the Ad Hoc Committee progressed. In 2004, the General Assembly reaffirmed 'the universality, indivisibility and interdependence of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination'¹⁴⁴ and was '[c]onvinced of the contribution that a convention can make...' (original emphasis)¹⁴⁴ In 2005, the General Assembly was 'encouraged by the increased support of the international community for such a convention'.

¹⁴⁵ Responses to a survey carried out for the Quinn report 'reveal the extent to which the disability NGOs have themselves made the transition to the rights-based perspective on disability. Many of the NGOs... stated that they saw themselves primarily as human rights NGOs. Many of them use United Nations human rights doctrine in their work. Some of them already have some experience of engagement with the United Nations human rights treaty system and generally had positive things to say about this experience..... These findings are highly positive. They show how the shift to the human rights perspective is being mirrored in the self-understandings of the disability NGOs, who are willing and interested in engaging with the United Nations human rights machinery...'. Quinn and Degener (2002) Chapter 10

actively involved in decision-making, to share power – a demand summed up in the motto ‘Nothing about us without us’. This, too, is carried forward into the Convention drafting.

Throughout the drafting process, disabled people played an unprecedented part in proceedings. The first meeting of the Ad Hoc Committee¹⁴⁶ made three crucial decisions which shaped the remainder of the negotiations and their outcome. Firstly, it agreed to allow accredited representatives of NGOs without consultative status to attend and to participate in public meetings.¹⁴⁷ This was later extended to informal consultations and closed meetings, and included substantive representation in the Working Group which produced the first draft text of the Convention.¹⁴⁸ In order to promote equal NGO representation from the poorest and richest countries, a UN Voluntary Fund on Disability was set up to support travel and accommodation for disabled people and their assistants. Large numbers of disabled people’s organisations from around the world took advantage of this opportunity, with estimates of up to 800 by the Final Session.¹⁴⁹ They organised themselves into an International Disability Caucus to develop a position on controversial points and to adopt spokespersons on different issues.¹⁵⁰

In a further move, States were formally encouraged to incorporate disabled people into their official delegations to the negotiations, and to consult with

¹⁴⁶ attended by representatives of States, the UN and NGOs with consultative status at the UN

¹⁴⁷ The Secretary-General, *Note by the secretary-General on the Comprehensive and Integral International Convention to promote and Protect the Rights and Dignity of Persons with Disabilities*, para 10, submitted following the conclusion of the deliberations of the Ad Hoc Committee, UN Doc A/57/357 (Aug. 27 2002); see Lawson, A, *The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?* (2006-2007) 34 *Syracuse Journal of International Law & Commerce* 563, 588

¹⁴⁸ The Working Group which drew up the first draft text comprised representatives from 27 governments (designated by regional groups), 12 NGOs, and one national human rights institution.

¹⁴⁹ Lawson (2006-2007) 588; Don McKay, Chair of the Ad Hoc Committee gives a more conservative estimate of over 400 representatives pre-registered at some of the later meetings: McKay D, ‘The United Nations Convention on the Rights of Persons with Disabilities’ (2006-2007) 34 *Syracuse Journal of International Law and Commerce* 323, 328

¹⁵⁰ Member of UK delegation to the CRPD negotiating Committee, ‘Convention on the Rights of Persons with Disabilities’ (2007) presentation to the Centre of Applied Disability Studies, University of Sheffield, 18 April 2007; Lawson (2006-2007) 26. Original in author’s possession.

disabled people at home in preparing their negotiating positions.¹⁵¹ Almost all States obliged, bringing disabled people either as heads of delegation or as official advisers. As Melish describes, 'these experts contributed an unusual degree of substantive expertise, sensitivity, receptiveness, creativity and commitment to the drafting committee'.¹⁵² The Chair described the negotiation process as 'genuine dialogue, genuine interaction, and willingness to hear, comment upon, and accommodate other opinions' by 'a very unique group of delegates indeed'.¹⁵³

UN staff had to work hard to overcome access issues to accommodate the delegates.¹⁵⁴ The sheer number of disabled people taking part in the proceedings, combined with inaccessibility of the UN building and its information systems, significantly affected practical aspects of the drafting process. Instead of the standard method of drafting articles of the treaty in small groups of State representatives, full article-by-article debate took place in the only accessible large conference room, with the full participation of all Member State delegations, national human rights institutions and hundreds of civil society and disabled people's organisations representatives. At each session, formal considerations were followed by input from NGOs and State governments, followed by general informal discussions. As Melish describes, '[t]his process required a level of transparency, cooperation, self-restraint and consensus unmatched in human rights treaty drafting, and allowed civil society to monitor, participate in, and influence all decision-making discussions'.¹⁵⁵

It also served to educate. One UN Secretariat representative acknowledged later in the negotiations that

[disabled people's] involvement was especially crucial in the early stages of the process, as there was limited disability expertise among

¹⁵¹ See for example GA Res A/RES/57/229 para 13

¹⁵² Melish T, 'The UN Disability Convention: Historic Process, Strong Prospects, and Why the U.S. Should Ratify' (2007) 14 Human Rights Brief 37, 43

¹⁵³ <http://v1.dpi.org/lang-en/resources/details.php?page=310> accessed 25.10.10

¹⁵⁴ McKay (2006-2007) 330

¹⁵⁵ Melish (2006-2007) 44; French P, 'Human Rights Indicators for People with Disability – a resource for disability activists and policy makers' (Queensland Advocacy Incorporated 2007)

government representatives. Now, many government delegations include persons with disabilities, including representatives of Disabled Peoples' Organizations, and the expertise has spread among the Committee members.¹⁵⁶

As one State delegate remarked, 'if in your country disabled children do not attend school at all, how can your government reach a view on the relative merits of mainstream or specialist education?'¹⁵⁷ The negotiating process introduced people from many countries in the world to emancipatory models of disability – and of decision-making - for the first time.¹⁵⁸

The Convention thus represents

an historic break from a state-centric model of treaty negotiation, in which instruments are negotiated behind closed doors, away from the very people they are intended to benefit. It moves instead toward a participatory approach that takes the views and lived experience of the affected as the principle point of departure¹⁵⁹

reflecting the relations of difference uppermost in this discursive setting. This participatory ethos is reflected not only in the text of the CRPD, but also in the emphasis placed there on the ongoing participation of disabled people and their organisations in policy and programme development, and in implementation and monitoring at domestic and international levels.¹⁶⁰ It is an approach built into the text and requirements of the Convention itself.¹⁶¹

Where relations of difference are uppermost, there is room for proliferation of differences and for stable compromises.¹⁶² Just as development of the disability/human rights discourse has entailed the partial congruence and re-articulation of a variety of elements of disability and international human rights understandings, modifying both, so this hegemonic social practice of

¹⁵⁶ Mona Paré, UN Department of Economic and Social Affairs, 'Towards a Convention on the Rights of Persons with Disabilities', paper delivered at the Gulf Seminar on the Convention on the Rights of Persons with Disabilities, Doha, Qatar (June 18, 2006), quoted in Lawson (2006-2007) 617

¹⁵⁷ Member of UK delegation (2007)

¹⁵⁸ Ibid

¹⁵⁹ Melish (2007) 37

¹⁶⁰ French (2007)

¹⁶¹ See Chapters 3 and 4 below; see also Stein MA and Lord JE, 'Jacobus tenBroek, Participatory Justice, and the UN Convention on the Rights of Persons with Disabilities' (2007) 13 *Tex.J.on C.L.& C.R.* 167

¹⁶² See Chapter 1 above

drafting a treaty brings together the different players into a new and unique process which reflects those elements and further modifies and develops the identities of those individuals. The experience that disabled people and their organisations bring to the table educates and enriches States' understandings. In turn, 'the shift to the human rights perspective is being mirrored in the self-understandings of the disability NGOs' ¹⁶³ as they strengthen their cooperation and co-ordination and their familiarity with the international human rights system, resulting in increased capacity and confidence to help take implementation forward.¹⁶⁴ Relations of difference enable stable compromise and discursive expansion.

The Chair of the drafting Committee comments that the result of this unique drafting process was

an extraordinarily far-reaching convention... When I first became involved in the process I would not have seen States being able to reach out as far as they have on the issues in the Convention. The credit for that undoubtedly goes to colleagues from civil society who have been so actively engaged in the process in such large numbers. They have constantly cajoled, urged, entreated, pressured, argued and very very effectively persuaded governments to keep shifting the boundaries of the envelope in so far as the Convention is concerned.¹⁶⁵

Indeed, according to Lawson,

given the importance of the role played by disability NGOs in its development, it would not be inaccurate to regard the CRPD as having been largely written by disabled people.¹⁶⁶

Relations of difference enable stable compromise: the CRPD was also the fastest drafted UN convention, taking a mere four years to complete.

¹⁶³ Quinn and Degener (2002) Chapter 10

¹⁶⁴ Disabled Peoples International

<http://v1.dpi.org/files/uploads/INDIA%20WORKSHOP%20-%20CRPD.PDF>

¹⁶⁵ Don McKay, Chair of Ad Hoc Committee, Press conference on the adoption of the Convention on the Rights of Persons with Disabilities, UN Headquarters, New York, 6 December 2006, cited in Lawson A, *Disability and Equality Law in Britain: the role of reasonable adjustment* (Hart 2008) 26

¹⁶⁶ Lawson (2008) 618; see also Lawson A, 'The UN Draft International Convention on the Rights of Persons with Disabilities: Purpose, Progress and Potential' (2006) Presentation delivered at London School of Economics, 9 March 2006

Conclusion

This chapter has traced the articulation and re-articulation of a number of discursive elements relating to international human rights and disability as they have come together to form a new disability/human rights discourse. The individualisation and pluralisation of the human rights agenda, developing understandings of equality and the fracturing and subsequent reintegration of the holistic human rights framework have converged with international mobilisation of the disabled people's movement with its resistance to oppression, and its challenge to exclusion from human rights protection. At international level, the new discourse has succeeded in redefining the terms of the political debate and in setting a new agenda. That agenda re-articulates liberal 'ableist' understandings of 'normality', autonomy and equality through the experience of *dis*-ability to produce a re-description of the world and of the place of disabled people in it. Disabled people are re-positioned from exclusion to inclusion, from welfare to rights.

The new discourse is the subject of a hegemonic project aimed at laying down its vision of a new accessible and inclusive world into international human rights law. The practice thus engendered reflects the nature of the new discourse in its holistic and participatory approach that takes the views and lived experience of disabled people as its principle point of departure. The relations of difference come to the fore as disabled activists work alongside UN human rights organisations, governments, national human rights institutions and human rights NGOs to bring about a new hegemonic formation, or legal order: a 'comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination.'¹⁶⁷

Chapter 3 examines the outcome of that hegemonic practice - the UN Convention on the Rights of Persons with Disabilities. Concepts of scale and

¹⁶⁷ GA Res 56/168 of 19 December 2001

projection drawn from Santos' 'cartography of law'¹⁶⁸ provide analytical tools for examination of the core principles and the rights as set out in the Convention text.

¹⁶⁸ Santos (2002) Chapter 8

CHAPTER 3

The UN Convention on the Rights of Persons with Disabilities

Introduction

We have seen law as a social practice, as a method of articulating and regulating systems of social relations, and as Santos' 'revolving doors through which different forms of power and knowledge circulate.'¹ Chapter 2 has described the growing disability/human discourse that has succeeded in setting a new agenda at the UN. Encapsulation of that discourse's re-description of the world into a new legal order entails the creation of a 'revolving door' through which its power and knowledge can circulate, to establish new understandings, systems of social relations and identities around the world that reflect and promote its particular norms, values, views and perceptions. Ultimate success would result in expansion of the disability/human rights discourse from myth to imaginary: its re-description of the world and of the place of disabled people in it would become a 'default' system of meanings that underlie and structure our societies. As we saw in Chapter 2, the realisation of this new vision would require fundamental revision of dominant assumptions, structures and practices: 'a deep reconstruction of our world'.²

Sedimentation of rounded and multi-dimensional social reality into the flat and two-dimensional text of a legally binding international human rights

¹ Santos (2002) 417

² Stein (2007) 2006 draft 48

treaty, however, will inevitably distort that reality.³ The drafters must choose the scale and operational limits of their legal order, and must organise the legal space within. Their choices will reflect not only the technical challenges of their project, but also the purposes, identities and ideologies of the actors.

With the help of Santos' 'cartography of law', this Chapter explores the text of the UN Convention on the Rights of Persons with Disabilities: how it captures, lays down and projects the various elements of the disability/human rights myth into a coherent international treaty. In line with the Vienna Convention on the Law of Treaties,⁴ the Convention text is interpreted in its context, including its preamble, and in the light of its object and purpose, its travaux préparatoires and the circumstances of its conclusion.

A skilled cartographer will choose projection techniques that serve the purpose of the map. Those techniques will help to clarify the terrain, to orient the map-user, and to guide them to their destination. Similarly, in drafting the Convention, negotiators must find a way to set out the rights in ways which express the central 'myth' and serve this expressive legal order's hegemonic aims. Their drafting techniques must clarify the disability/human rights terrain, and must orient and guide its various users to reach that ultimate destination where the new vision becomes imaginary. Which techniques might be chosen, and how might they be applied?

First and foremost, the CRPD is a human rights convention. The raw material from which it must be fashioned is the existing international human rights framework: the Convention's remit excludes the creation of new rights.⁵ Unusually, though, it is also a social development convention. Economic, social and cultural rights are as available to the drafters as civil and political

³ See Chapter 1 above for discussion of Santos' cartography of law

⁴ Vienna Convention on the Law of Treaties 1969 Articles 31 and 32

⁵ See Stein and Lord (2009) 30, note 111; French (2007) 15-16; Quinn G, 'Added value of the UN Convention on the Rights of Persons with Disabilities' (2008) presentation to Seminar of the European Coalition for Community Living, Drammen, Norway; printed in Newsletter of the European Coalition for Community Living, December 2008/January 2009, 2. The UK was one of the parties that were adamant during the negotiations that no new rights should be created: Dr Richard Light, OBE speech to Making Rights a Reality Conference, 2008.

rights. One projection, then, concerns the interpretation and reformulation of all of those rights together into an integral and comprehensive Convention text. A third element of this holistic endeavour is equality. The drafters must decide whether and how they will make use of the various understandings and legal interpretations of equality outlined in Chapter 2.

A further projection concerns realisation of the rights. Despite their established implementation and monitoring systems, existing treaties have failed to protect the rights of disabled people.⁶ The onus is on this Convention to bring about real change in societies and in the lives of individuals. The projection techniques chosen here will help to determine the success or otherwise of this new legal order and of the discourse it reflects and promotes.

Last but not least, for disabled people's 'unsatisfied demands' to be incorporated into 'ablist' human rights discourse, this Convention must delve deeper into issues of identity, survival and dignity of those whose rights it seeks to protect. The map must be shaped throughout by disabled people's experience and expertise.

Maps have centres: 'a fixed point, a physical or symbolic space in a privileged position, around which the diversity, the direction and the meaning of other spaces are organized.'⁷ The ideological 'centre', or 'myth', of the Convention is the disability/human rights discourse described in chapter 2. Its vision shapes and colours every aspect of the Convention text. Its most direct expression can be found in the Convention's title and in its purpose and principles as set out in Articles 1 to 9. These are considered first. Maps also have boundaries: the ambit of the Convention is discussed next. Thirdly, the Chapter turns to the rights themselves, as set out in Articles 10 to 30.

⁶ Quinn and Degener (2002); Louise Arbour, Arbour L, Statement to General Assembly Ad Hoc Committee, 7th session, New York 27 January 2006; International Disability Rights Monitor Reports etc.

⁷ Santos (2002) 423. Santos gives the example of the religious sites at the centre of medieval maps: Jerusalem in European maps, Mecca in Arab maps.

Realisation of the Convention's purpose, however, requires more: that this 'revolving door' enable the power and knowledge of disability/human rights discourse to circulate around the world. The Convention's implementation and monitoring provisions as set out in Articles 31 to 50 seek to ensure continuation of the hegemonic project. These are considered in **Chapter 4**.

Exploration of the CRPD text⁸ reveals a treaty which not only speaks forcefully to the re-positioning of people with impairments, but also, as Mégret remarks, 'provides a unique opportunity to rethink how we conceive of the human rights of all'.⁹

The Centre

Title and purpose

In 2001,¹⁰ the UN General Assembly instructed the Ad Hoc Committee to consider proposals for 'a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities'.¹¹ Inclusion of 'integral' in the instruction signals that this convention will have equal status with other core human rights treaties.¹²

⁸ For further commentary see for instance Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009); Hendriks A 'UN Convention on the Rights of Persons with Disabilities' (2007) 14(3) *European Journal of Health Law*, 273; Collingbourne T, 'The Disability Rights Convention: first human rights treaty of the 21st century' (2007) Summer BIHR Brief 14; McKay D 'The Convention on the Rights of Persons with Disabilities: A Benchmark for Action' (2007) 56(1) *International Rehabilitation Review*, 1; Schultze M, 'Understanding the UN Convention on the Rights of Persons with Disabilities: a handbook on the human rights of persons with disabilities' (Handicap International 2009); United Nations, 'From Exclusion to Equality', UN Handbook for Parliamentarians, no 14, (2007)

⁹ Mégret (2008b) 17

¹⁰ General Assembly Resolution A/RES/56/168 of 19 December 2001. The sponsors of Resolution 56/168: 'Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities' were Bolivia, Chile, Columbia, Congo, Costa Rica, Cuba, Democratic Republic of the Congo, Dominican Republic, Ecuador, El Salvador, Guatemala, Jamaica, Mexico, Morocco, Nicaragua, Panama, Philippines, Sierra Leone, South Africa and Uruguay. From French (2007) 18 note

¹¹ Ibid. This remained the working title throughout most of the negotiations, although shorter titles were being put forward from the start: 'Convention on the Rights of Persons with Disabilities' was supported by several members of the Working Group in January 2004. Daily Summary related to Draft Articles 1 and 2,

<http://www.un.org/esa/socdev/enable/rights/wgsuma2.htm>

The word 'comprehensive' encapsulates the Assembly's further instruction to the negotiating committee to base the convention on 'the holistic approach in the work done in the fields of social development, human rights and non-discrimination'.¹³

Initial consultations produced objectives ranging from the eradication of poverty, through multiple discrimination, access, de-institutionalisation, protection from abuse and the guarantee of personal dignity.¹⁴ The Working Group set up to draft an initial working text discussed the right to be different, accessible environments, survival, realisation of potential, and the importance of international cooperation and development.¹⁵ The 'holistic approach' characteristic of disability/human rights discourse was clear from the start.

Later discussion about shortening the working title was linked to consideration of a purpose clause. The CRPD's original working text includes as its Article 1:¹⁶

PURPOSE

The purpose of this Convention shall be to ensure the full, effective and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities.

¹² Kayess R and French P, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 Human Rights Law Review 1, 20; though placing the negotiations in New York rather than Geneva, with secretariat support from ECOSOC rather than the OHCHR somewhat negates that message.

¹³ GA Res A/RES/56/168

¹⁴ Compilation of Proposals for a Comprehensive and Integral Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities, Ad Hoc Committee 3rd session, New York, 16-27 June 2003 (A/AC.265/2003/CRP.13 and [Add.1](#)) http://www.un.org/esa/socdev/enable/rights/a_ac265_2003_crp13.htm; Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 'Views submitted by Governments, intergovernmental organizations and United Nations bodies concerning a comprehensive and integral international convention on the protection and promotion of the rights and dignity of persons with disabilities', note by the Secretary-General, A/AC.265/2003/4+A/AC.265/2003/4/Corr.1 (2003)

¹⁵ Daily Summary related to Draft Articles 1 & 2, January 5, 2004

<http://www.un.org/esa/socdev/enable/rights/wgsuma2.htm>

¹⁶ As presented to the Ad Hoc Committee at its third session: Report of the Working Group to the Ad Hoc Committee, 3rd session, A/AC.265/2004/WG/1

<http://www.un.org/esa/socdev/enable/rights/ahcwgreport.htm> The working group consisted of 27 States and 12 disability NGOs, with the South African Human Rights Commission representing national human rights institutions.

An alternative version 'that the Ad Hoc Committee may wish to consider' ran:

The purpose of this Convention shall be to protect and promote the rights of persons with disabilities.

In line with its individualisation agenda,¹⁷ international human rights jurisprudence has developed three levels of obligation in the realisation of human rights: a duty to respect, a duty to protect, and a duty to fulfil.¹⁸ The duty to respect prohibits a State from interfering with an individual's right. This relatively straightforward duty is generally associated with classic civil and political rights, though it may also apply in a socio-economic context.¹⁹ The duty to protect requires a State to prevent an individual's right being infringed by others. Here the duty becomes more complex: it involves the State taking action against one individual to protect the rights of another. However, as Fredman concludes, 'it is possible to formulate and apply a positive duty to protect without incurring insurmountable problems of indeterminacy'.²⁰

The duty to fulfil, on the other hand, is more contentious. Firstly, it requires the State to take positive action which may (or may not) involve the expenditure of significant resources.²¹ In liberal democracies, the expenditure of such resources is particularly controversial in relation to socio-economic rights, where it becomes entangled in debates between neo-liberal 'free-marketeers'²² and those who support varying levels of redistribution of society's 'goods'.²³ Secondly, it may be difficult to determine how and when

¹⁷ See Chapter 2 above

¹⁸ Apparently originating in Shue H, *Basic Rights: Subsistence, Affluence, and US Foreign Policy* (Princeton University Press 1980) 52; see also Hunt (1998) 31-34; Fredman (2008) 69. Sometimes a fourth 'duty to promote' is added in between protection and fulfilment.

¹⁹ Such as enforced eviction by the State: Hunt (1998) 32

²⁰ Fredman (2008) 76

²¹ Contrary to some assumptions, this applies to rights across the board – civil, cultural, economic, political and social. For instance, to guarantee the right to a fair trial it is necessary to invest in a civil and criminal justice system, including courts, representation and more; to guarantee the right to life involves provision of police and security services, a host of health and safety measures; and so on. See for example Statement by Louise Arbour, UN High Commissioner for Human Rights, to General Assembly Ad Hoc Committee, 7th session, New York 27 January 2006, 4 para 2; Hunt (1998) 34.

²² Such as Hayek

²³ Such as Rawls or Dworkin

a right has actually been fulfilled.²⁴ However, as Hunt points out, ‘when legislators wish to impose the tertiary obligation to fulfil, they can reduce the indeterminacy by precise, detailed drafting’.²⁵ The negotiators of the CRPD exercised this option to the full.

The consolidated ‘Chairman’s text’²⁶ retains the long title, and includes a revised purpose clause as Article 1:

The purpose of this Convention is to promote, protect and *fulfil* the full and equal enjoyment of all human rights and fundamental freedoms of persons with disabilities.²⁷ (emphasis added)

At the same time, the Chair questioned

‘whether we need this Article *at all*... it is not the practice in other treaties to have a “purpose” provision...’. (original emphasis)²⁸

The International Disability Caucus and others, however, argued for the clause, in the interests of the clarity and accessibility of the Convention.²⁹ The inclusion of a purpose clause serves to re-emphasise both the overall objective of the Convention, and the binding nature of its obligations.

At the same time, the International Disability Caucus

proposed replacing “fulfil” with “ensure.” It noted that governments must themselves refrain from interfering with the rights of persons with disabilities, prevent third parties from doing so, and take proactive measures to protect those rights, and that the language of the article

²⁴ Fredman goes back to basic principles in her discussion of this question. ‘Positive duties’, she says, ‘aim to secure to all the ability to exercise their rights. This requires the removal of constraints, as well as provision of resources or the facilitation of activities which ensure that all are substantively equal in the ability to participate fully as citizens in society.’ Fredman (2008) 77 ff. Other work on this question includes the development of indicators and benchmarks: see for example Hunt, P, Novak, M, Osmani, S, ‘Human Rights and Poverty Reduction Strategies: a discussion paper’ <http://www.fao.org/righttofood/kc/downloads/vl/docs/AH177.doc>, accessed 4.9.09. For an overview, see Malhotra R and Fasel N, *Qualitative Human Rights Indicators – A Survey of Initiatives* (2005) Background Paper developed for a seminar conducted by the Institute for Human Rights Abo Akademi University, which may be accessed at www.abo.fi/instut/imr. (from French (2007))

²⁵ Hunt (1998) 34

²⁶ Produced prior to the 7th negotiating session; see Covering Letter from the Chair, October 7th, 2005

²⁷ Article 1, para 1. Chairman’s Text, October 7th 2005

²⁸ Ibid 3

²⁹ Chairman’s Text as amended by the International Disability Caucus, January 2006, 7

must reflect this. It argued that “ensure” and perhaps “respect” might be useful to reflect this intention.³⁰

Santos describes how, during the Cold War, Western media showed the Soviet Union on a world map designed, through projection techniques, to exaggerate the size of the Soviet Union, and thereby to dramatize the Soviet threat. In the CRPD, the use of the word ‘fulfil’ in the purpose clause would enlarge the obligations of States, taking the Convention beyond the instructions of the General Assembly, and beyond the desires of those governments concerned to avoid potential resource implications.³¹ The replacement of ‘fulfil’ by ‘ensure’ subtly changes the projection of the Convention to reduce the size of that threat. The final version reads:

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Principles³²

Dignity

The concept of human dignity is a powerful one. It features in the preamble to the United Nations Charter,³³ and in the Universal Declaration of Human Rights,³⁴ and has played an important role in the individualisation and pluralisation of the human rights agenda. The concept of dignity is also a complex one, operating at different levels³⁵ and entailing both subjective and objective elements,³⁶ its legal protection includes both negative and positive

³⁰ Summary record, 7th session 30th Jan 2006

³¹ Costa Rica, for instance, ‘favored the Chair’s text but without “fulfil,” as it believed the guarantee of “fulfilment” was beyond the scope of a legal text.’ Summary record, 7th session, 30 January 2006

³² For further discussion of the principles of dignity, equality and participation in disability and human rights law, see Rioux M, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011); see also Batmanghelidjh C, ‘The gateless wall: a discourse on participation’ in Griffiths S (ed) *The Politics of Aspiration* (Social Market Foundation 2007)

³³ Para 2

³⁴ Preamble para 5, Article 1: ‘All human beings are born equal in dignity and rights...’

³⁵ ‘Human dignity can operate on three levels: the dignity attaching to the whole human species; the dignity of groups within the human species; and the dignity of human individuals. The legal implications of each kind of dignity are slightly different.’ Feldman D, ‘Human Dignity as a Legal Value’ Part I [1999] Public Law 682, 684

³⁶ ‘In relation to the subjective aspect of dignity, the law of human rights will typically be concerned to prevent treatment which damages a person’s self-respect and physical or

duties.³⁷ In negotiation, after ‘much discussion’ within its ranks, the International Disability Caucus recommended to the committee that dignity be included in the general principles under Article 3 (general principles) rather than in the purpose. The Caucus stressed ‘the inherent nature of dignity in every person and the need to avoid implying that the dignity of persons with disabilities requires promotion. For this reason it suggested referring to “respect for dignity.”’³⁸ Indeed, as the Chair summarised, ‘many delegations pointed out the need to approach the topic of dignity with caution...’ The balance of views supported removing ‘dignity’ from the title and including it in the purpose clause.³⁹

At the 7th (pen-ultimate) session, the title of the CRPD was shortened to ‘International Convention on the Rights of Persons with Disabilities’. Respect for the inherent dignity of disabled people is reiterated in the final text as a fundamental requirement not only in the Convention’s purpose, but also in its Preamble,⁴⁰ in individual articles,⁴¹ and as the first of its general principles, as set out in Article 3.⁴²

Three further principles in particular spring from the page in Article 3: autonomy, inclusion and participation.

moral integrity. With regard to the objective aspect, the law will usually have to go further, imposing positive duties on people to act in ways which optimise the conditions for social respect and dignity.’ Feldman [1999] 686-7

³⁷ See for instance Feldman D, ‘Human Dignity as a Legal Value’ Part II [2000] Public Law 61; Basser LA, ‘Human Dignity’ in Rioux M, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011); McCrudden C ‘Human Dignity and Judicial Interpretation of Human Rights’ (2008) 19(4) *European Journal of International Law* 655

³⁸ Summary record, 7th session, 30 January 2006; there was also discussion about whether or not to include the word ‘inherent’

³⁹ Summary record, 7th session, 30 January 2006

⁴⁰ Preamble (a) *Recalling* the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth ...; (h) *Recognizing also* that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person;...

⁴¹ For instance Article 8: awareness raising, para 1(a): ‘... to foster respect for the rights and dignity of persons with disabilities;’ Article 24: education, para 1(a) ‘The full development of human potential and sense of dignity and self-worth...’

⁴² Article 3(a) ‘Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons’

Autonomy

The first reads:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.

This restatement of such standard human rights principles might be seen as routine, but for disabled people's history of exclusion by the 'ablist' discourse of normality, and their previous invisibility in human rights and development discourse. As seen in Chapter 2, for people with impairments to exercise their autonomy requires reversal of that exclusion, respect for individual decision-making and the opportunity to live a life over which one has a high degree of control. In that context, the demand for respect for the attributes set out in Article 3(a) contests the outright denial of such attributes to disabled people by the understandings, structures and practices of 'normality'.⁴³

Inclusion and participation

Emancipation from oppression also requires active inclusion in social programmes and structures, and the opportunity to participate in the wider world.⁴⁴ Article 3(c) sets out the principle of 'full and effective participation and inclusion in society'. A key component of such inclusion is

- 3(d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.

This principle directly challenges the exclusionary force of 'normality' discourse, and repositions disabled people in the world. As such it is central to the 'expressive' purpose of the Convention as it seeks to transform cultural understandings of disability and associated ideas of 'normalcy' and 'impairment'.⁴⁵ People with impairments are no longer to be 'othered' on account of their differences, understood as less than human or (mis)treated accordingly. Instead, they are to be respected and accepted as full members of a diverse humanity.

⁴³ See chapter 2 above

⁴⁴ See for example Jones M, 'Inclusion, Social Inclusion and Participation' in Rioux *et al* (2011)

⁴⁵ See also Jackie Leach Scully, 'Reframing Disability in the UN Convention', presentation at NNDR Conference, Reykjavik, May 2011

Participation must be ‘full and effective’. This principle is reiterated throughout the Convention,⁴⁶ not least through the requirement that disabled people must be closely consulted and actively involved in the development of all legislation, policies and other decision-making processes that concern them, and in monitoring and implementation.⁴⁷ ‘Nothing about us without us’ is sedimented here and, as seen in Chapter 4 below, in the Convention’s implementation provisions.

Equality

Article 3 also includes a range of principles relating to equality, including non-discrimination,⁴⁸ equality of opportunity,⁴⁹ and gender equality.⁵⁰ Along with human rights and social development, non-discrimination forms one of the three ‘cross-cutting themes’⁵¹ of the Convention, as directed by the General Assembly. In designing the Convention map, the drafters had choices as to whether and how they made use of the various understandings of equality outlined in Chapter 2.

Quinn describes the negotiation process:

The first option was to draft a bald non-discrimination text. Such a text... could have been short... with a general prohibition against discrimination... [and] could have been adopted fairly rapidly as most States respond favourably to the non-discrimination ideal.... However, such a text would have lacked the specificity needed in complex areas like education to be a real driver of change. The second option was to follow the model of the Convention on the Rights of the Child (CRC) which takes great care to tailor the general human rights (both sets) to the particular situation of children.... However, virtually no State had an appetite for this approach... The end result is a curious hybrid between a simple non-discrimination approach and an approach that applies an informed understanding of non-discrimination to tailor a wide variety of substantive rights to the realities of persons with disabilities (again, including both sets of rights).⁵²

⁴⁶ Including for example Article 8 awareness-raising, Article 9 accessibility, and Article 19 living independently and being included in the community

⁴⁷ Article 4(3)

⁴⁸ Article 3(b)

⁴⁹ Article 3(e)

⁵⁰ Article 3(g); see also Rioux MH and Riddle CA, ‘Values in Disability Policy and Law: Equality’ in Rioux *et al* (2011)

⁵¹ Quinn G and Arnardóttir OM, ‘Introduction’ in Quinn and Arnardóttir (2009) xviii

⁵² *Ibid* xix

Many different but interlinked and fundamental changes to the ways in which people and societies function are required to bring about a world where all disabled people are fully recognised as being part of humanity, as having equal worth, with equal rights to live, to make choices, to participate in and to contribute to the world around them. Like any physical terrain, this social terrain is complex and multi-dimensional; the drafters must find ways to express in the map all the various aspects of equality required to bring about such changes. On a map, gradients and dimensions are shown by contours and by colouring. In the Convention, too, different 'levels' of equality can be traced, and they colour the text in different ways.

Disability discrimination as defined in Article 2 comprises

...any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.⁵³

As Lawson notes, this is an extremely broad definition.⁵⁴ It aims to reflect all elements of the disability/human rights discourse and to encompass all elements of the disability experience.

Non-discrimination provisions imposing primary duties to respect and protect disabled people's rights permeate the text.⁵⁵ General principles of non-discrimination⁵⁶ and equality of opportunity⁵⁷ are shored up by Article 5, where 'all persons are equal before and under the law'.⁵⁸ Obligations to ensure the 'full and equal enjoyment' of the rights⁵⁹ 'on an equal basis with

⁵³ This definition follows the definition of 'racial discrimination' in CERD Art 1

⁵⁴ Lawson A, *Disability and Equality Law in Britain* (Hart 2008) 30

⁵⁵ As the preamble recognises: (h) ... discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person

⁵⁶ Article 3(b)

⁵⁷ Article 3(e) – not 'equality of outcome'

⁵⁸ Article 5(1)

⁵⁹ See for example Article 1: purpose, Article 4: General obligations, Article 6: Women with disabilities, etc

others'⁶⁰ pepper the text. There must be equality, too, *between* disabled people. The text is expressly inclusive of *all* disabled people,⁶¹ on recognising their diversity,⁶² specifically 'including those who require more intensive support',⁶³ echoing Article 3(d).

A further contour is added by the concept of **multiple discrimination**.⁶⁴ States must 'guarantee to disabled people legal protection against discrimination on *all* grounds.'⁶⁵ (emphasis added). There is particular recognition of the greater risks faced by disabled women and girls,⁶⁶ and added protection for disabled children.⁶⁷ However, there are limits to this multiple discrimination contour. During early discussions, the rights of a number of vulnerable groups were raised, including ethnic minorities and older persons.⁶⁸ There are some passing references to age or older people

⁶⁰ This phrase recurs 18 times in the main body of the text - though, as Richard Light points out, this can be read in more than one way: 'If Member States are quite so anxious about ensuring that disabled people do not enjoy greater human rights protection than non-disabled people, I would ask that a generic paragraph be included as a 'General Principle' within Article 3 rather than indiscriminately scatter this mantra throughout the Convention.' Light R, 'Review of the Chair's Draft Text Prepared Subsequent to the Sixth Session of the UN Ad Hoc Committee' 17

⁶¹ See for instance Article 1 Purpose; Article 4 General obligations; Article 17 Protecting the integrity of the person; Article 19 Living independently and being included in the community, etc.; see also International Disability Alliance, 'Position Paper on the Convention on the Rights of Persons with Disabilities (CRPD) and Other Instruments' (IDA 2008)

⁶² Preamble (i); Article 3 General principles;

⁶³ Preamble (j) As Thailand said in the Working Group discussions, disabled people ' "who cannot express their own self-determination" are still entitled to live in dignity', Working Group Discussions, Volume 3/1, January 5, 2004, 2

⁶⁴ The Preamble expresses concern 'about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.' Preamble (p). This was foreshadowed by the 1975 Declaration on the Rights of Disabled Persons, whose rights 'shall be granted to all disabled persons without any exception whatsoever and without distinction or discrimination on the basis of race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation applying either to the disabled person himself or herself or to his or her family' - an impressive early recognition of both multiple discrimination and discrimination by association.

⁶⁵ Article 5(2); In line with the earliest discussions of the Ad Hoc Committee: Compilation of proposals for a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities, Specific Proposals, 2003

⁶⁶ Equality between men and women is a general principle (Article 3(g)); women with disabilities have an Article of their own (Article 6), and gender equality is mainstreamed throughout the Convention text including Article 8, awareness-raising; Article 16, freedom from exploitation, violence and abuse; Article 17, Protecting the integrity of the person; Article 28: Adequate standard of living and social protection. See also Preamble (q)

⁶⁷ Article 53(h), Article 7 etc.

⁶⁸ See, for instance, Seminar of Quito, June 2003

in the final text⁶⁹ but no specific reference to race or ethnicity outside the preamble.

For the central purpose of the Convention to be realised, the ‘various barriers’ which hinder disabled people’s full participation in society must be addressed. As noted in chapter 2, national disability discrimination law has developed the concept of ‘**reasonable accommodation**’ for this purpose.⁷⁰ In the CRPD, this concept makes its first appearance at international treaty level, thus extending its reach to all States Parties to the Convention. Failure to take all appropriate steps to ensure that reasonable accommodation is provided⁷¹ constitutes discrimination under the Convention.⁷² This provision, however, raises the equality contour only so far, focusing as it does on each individual case and allowing for a defence of ‘undue burden’.⁷³ Nevertheless, it helps to add a more substantive equality contour, which requires some positive action to remove barriers and change environments.

⁶⁹ Article 8(1)(b), Article 28(2)(b) and (e); see also Townsend P, ‘Policies for the aged in the 21st century: more “structured dependency” or the realisation of human rights?’ (2006) 26 *Ageing & Society*, 161

⁷⁰ In countries with such law in place, those with anti-discrimination duties are required to adjust their arrangements so as to remove disadvantage to the individual. 45 out of 193 UN Member States currently have some form of disability discrimination law. See Lindqvist (2004); Lawson (2008)

⁷¹ Article 5(3)

⁷² Article 2, para 3 The duty to make reasonable accommodation is also specified in relation to particular rights: in relation to access to justice (Article 13(1)); liberty and security of the person (Article 14(2)); education (Article 24(2)(c) & (5)); and employment (Article 27(1)(i)). For Kayess and French, ‘[t]he incorporation of a State obligation to ensure that reasonable accommodations are made... is perhaps the most fundamental instrumental element of the convention.’ Kayess and French (2008) 1, 12. It certainly adds a new concept to international human rights law, and seeks to ensure its practical exercise in a far wider geographical and cultural context than heretofore. However, on its own, it seems unlikely to bring about the fundamental emancipatory shift required for full realisation of the Convention rights.

⁷³ ‘... Necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’ Article 2, para 4. As Lawson identifies, ‘[t]he emphasis is on the barriers which operate in a particular case and thus on the need to respond to the specific circumstances of the individual disabled person in question’: it is unlikely to encompass the more generalised type of public equality duty required under the UK Disability Discrimination Act. The duty is further narrowed by the defence of ‘disproportionate or undue burden’, the interpretation of which may vary according to the resources of the duty-bearer. Lawson (2008) 31. As Kayess and French anticipate, this formulation of ‘reasonable accommodation’ ‘is more likely to produce results for persons who require marginal changes to the prevailing social environment.’ Furthermore, as they observe, ‘the terminology ‘undue burden’ is most unfortunate in that it activates precisely the construction of persons with disability as ‘burdens’ on the community that the CRPD otherwise attempts to overcome.’ Kayess and French (2008) 12

Other Convention provisions take this process further. Despite the replacement of 'fulfil' with the less threatening 'ensure' in the purpose clause, the drafters of the Convention show no compunction in imposing **positive duties** on ratifying States. Article 5(4) provides express permission to take '[s]pecific measures...necessary to accelerate or achieve de facto equality of persons with disabilities': such measures 'shall not be considered discrimination under the terms of the present Convention'.⁷⁴

Full realisation of **substantive equality** for those who exercise their autonomy in different ways, however, requires more than measures generally designed to remove obstacles from self-sufficient individuals.⁷⁵ Reversal of their oppression requires social and structural change. States must therefore take a broad sweep of proactive measures to bring about that change. Some are practical measures that directly impact on the ability of individuals to function, such as technological research⁷⁶ and training of those who provide personal assistance and services.⁷⁷ Others aim at wider social change. Article 8 seeks to remove attitudinal barriers, requiring States to raise awareness and foster respect for the rights and dignity of disabled people;⁷⁸ to 'combat stereotypes, prejudices and harmful practices... in all areas of life';⁷⁹ and to 'promote awareness of the capabilities and contributions' of disabled people.⁸⁰ The obligation to ensure access to the physical environment, to transportation, to information and communications, and to other public facilities and services is set out in Article 9, and throughout the text.⁸¹ Less tangible structural barriers must be removed through the

⁷⁴ This presumably refers to relatively short-term positive measures to compensate for historic inequality. Unlike the parallel provision in CEDAW, this is not confirmed in the Article text, leaving interpretation open. Article 4(1) of CEDAW says: 'Adoption by States Parties of temporary special measures aimed at accelerating *de facto* equality between men and women shall not be considered discrimination as defined in the present Convention, but shall in no way entail as a consequence the maintenance of unequal or separate standards; these measures shall be discontinued when the objectives of equality of opportunity and treatment have been achieved.'

⁷⁵ O'Conneide (2009)

⁷⁶ Article 4(f) & (g)

⁷⁷ Article 4(i)

⁷⁸ Article 8(1)(a)

⁷⁹ Article 8(1)(b)

⁸⁰ Article 8(1)(c)

⁸¹ General principle under Article 3(f); e.g. Article 4(h), Article 13(1), Article 20, Article 21 etc...

abolition of discriminatory laws, regulations, customs and practices;⁸² acts or practices that are inconsistent with the Convention must be avoided.⁸³ The protection and promotion of Convention rights must be taken into account in all policies and programmes.⁸⁴

The central purpose and principles of the Convention thus encapsulate the different elements of disability/human rights discourse so as to reverse oppression and to bring about transformation of the world. This is expressive, emancipatory law, with hegemonic intent. Human rights values of dignity, autonomy and participation are shaped to contest the denial of identity brought about by 'normality' discourse, and to demand respect and inclusion. Inclusion requires not only non-discrimination and its contours, but also 'a deep reconstruction'⁸⁵ of the technical, attitudinal, physical and structural environment. The direction and meaning of the rest of the Convention radiate from this central vision. The drafters make thorough and imaginative use of 'precise, detailed drafting' to that end,⁸⁶ not only in relation to these central provisions but also, as will be seen below, in the way that the rights themselves are formulated, and in the steps States must take to implement them.

Boundaries

Legal regulation (like a map) requires boundaries and definitions. To make sense of the map, we need to know the extent and depth of its reach. How far does the Convention's power to regulate seep into society? What is the scope of that power, and who are the duty-holders? As importantly, given the fundamentally inclusive nature of the Convention's core principles, whose rights are being reaffirmed by this Convention on the Rights of Persons with

⁸² Article 4(1)(b)

⁸³ Article 4(1)(d)

⁸⁴ Article 4(1)(c)

⁸⁵ Stein (2007) draft 48

⁸⁶ Hunt (1996)

Disabilities? Whose rights (if any) are being excluded from protection? What are the limits of the operation of this legal order?

As with any international human rights treaty, the primary duty-holder under the CRPD is the State.⁸⁷ But the obligations that States shoulder when they ratify this Convention extend beyond the public into the private sphere. This aspect springs from the earliest discussions of the Ad Hoc Committee,⁸⁸ and can be traced in different ways within the Convention text. States must take measures to ensure that private entities as well as public take accessibility into account.⁸⁹ They must promote the employment of disabled people in the private sector.⁹⁰ They must eliminate disability discrimination by 'any person, organisation or private enterprise'.⁹¹ Their awareness-raising measures must range 'throughout society'.⁹² The reach of the Convention thus permeates not just public functions, but all of civil society.⁹³

Moreover, Convention duties do not stop at the individual's front door. Disabled people are to be protected from 'all forms of exploitation, violence and abuse, both within and outside the home';⁹⁴ many services will be provided in a domiciliary setting.⁹⁵ And such responsibilities are not only laid at the door of the State. Individuals too have moral duties, albeit not legally binding under the Convention, to other individuals and to the community to which they belong, 'to strive for the promotion and observance of the rights recognized in the International Bill of Human Rights'.⁹⁶ The Convention's

⁸⁷ See for instance Article 4, general obligations

⁸⁸ See for example seminar of Quito: option 1 (b) eliminate all forms of discrimination against persons with disabilities in public and private spheres...; Compilation of proposals for a Comprehensive and Integral Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities, A/AC.265/CRP.13, Add.1 & Add. 2 (2003)

⁸⁹ Article 9(2)(b)

⁹⁰ Article 27(1)(h)

⁹¹ Article 4(e)

⁹² Article 8(1)(a)

⁹³ An interesting development here is the recent establishment of a regional monitoring body under the aegis of the League of Arab States, entirely funded by the private sector, 'indicating the growing awareness of and interest and involvement in the rights of persons with disabilities on the part of sectors that were never involved previously.' Hissa Al-Thani (2009) *infra*

⁹⁴ Article 9(1)

⁹⁵ Such as Article 23(2); Article 4(1)(i)

⁹⁶ Preamble (w)

power to regulate leaves no stone unturned; it links all of Santos' structural places.

And whose rights does this all-pervading legal order seek to protect?

The drafters of previous international human rights conventions have not been faced with such complex considerations surrounding the definition of the human beings whose rights they protect.⁹⁷ As discussed in chapter 1, agreeing a definition of an empty signifier such as 'disability' is notoriously difficult, if not impossible. Furthermore, the negotiators of the Convention were drawn from a wide range of cultural backgrounds and understandings of disability, making consensus even harder to achieve.⁹⁸ Negotiation on this issue was left to the end of the drafting, with many people, including the Chair,⁹⁹ suggesting that there should be no definition in the Convention, as defining might unintentionally exclude people. Others, perhaps recalling some courts' exclusive application of national definitions,¹⁰⁰ argued that the only qualifying hurdle should be that one is 'human'.¹⁰¹ The International Disability Caucus agreed that there should be no definition of 'disability', but argued that it was necessary to define who is protected: '[i]f we do not have such a definition, States may define what they find best and may exclude

⁹⁷ CERD Art 1 defines 'racial discrimination'; CEDAW Art 1 defines 'discrimination against women'; CRC Art 1 defines 'child' quite simply as 'every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier.'

⁹⁸ One member of the UK delegation, for instance, describes how 'different UN member states approached the drafting process from starting points that varied enormously, both in respect of their existing legislation and in respect of their existing attitudes to disabled people.' Member of UK delegation to the CRPD negotiating Committee, 'Convention on the Rights of Persons with Disabilities' (2007) presentation to the Centre of Applied Disability Studies, University of Sheffield, 18 April 2007 para 15

⁹⁹ Chair's Text, Covering Letter from the Chair (Don MacKay), October 7th 2005, 3: 'Views are divided as to whether it is necessary to define "Disability" and "Persons with disabilities". I tend to think that we don't, as this will be very difficult, and there is a risk that we will unintentionally exclude someone.' This position was supported by the EU and the UK among others.

¹⁰⁰ See for instance the US Supreme Court's decisions under the ADA90. Also judgement of the European Court of Justice on the meaning of the term 'disability' in the EU Directive 2000/78 in *Chacón Navas v Eurest Colectividades* (C-13/05) [2006] E.C.R. I-6467: discussion in Burca G de, 'The European Union in the Negotiation of the UN Disability Convention', (2010) 35(2) *European Law Review* 174,190

¹⁰¹ Light R, 'Review of the Chair's Draft Text Prepared Subsequent to the Sixth Session of the UN Ad Hoc Committee: A Report for Disabled People and Non-Governmental Organisations in the UK', 16

disability groups which should be covered and protected by this Convention.¹⁰²

A definition of 'persons with disabilities' was eventually agreed at the final session.¹⁰³ It is found in Article 1, alongside the purpose, making it impossible for States to derogate from the definition without also derogating from the overall purpose of the Convention.¹⁰⁴ The definition reads:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

The definition reflects a social model of disability: it is the interaction with barriers that hinders equal participation.¹⁰⁵ It is designed to be open and inclusive, to minimise the risk of exclusion. As Grainne de Burca explains, '[t]he aim was to satisfy those who wanted to retain flexibility and the possibility of dynamic evolution, as well as those who sought above all to prevent governments or courts resiling from commitments by adopting excessively narrow or exclusionary interpretation'.¹⁰⁶ The openness of the definition is further supported by recognition in the preamble that 'disability is an evolving concept...'.¹⁰⁷

In line with the holistic and inclusive nature of the purpose and principles at the Convention's core, these negotiations betray an unwillingness to define the limits of this legal order at all, albeit tempered by recognition that not to do so may lead to undesired consequences.

¹⁰² Chairman's text as amended, *supra*, 8

¹⁰³ In the working text, February 2006: annex II to Ad hoc committee report of 7th session, there is no definition in Article 1, or mention of 'evolving concept' in the preamble. These decisions were made at the final session in August 2006. The EU agreed with the Chair: <http://www.un.org/esa/socdev/enable/rights/ahc7eu.htm>

¹⁰⁴ Quinn and Arnadóttir (2009)

¹⁰⁵ Though in fact this model is not consistently applied in the body of the Convention text: for instance Art 25, right to health (b) requires provision of healthcare needed 'because of their disabilities' rather than 'because of their impairments'; Art 23, respect for home and family (4) states that 'no child shall be separated from parents on the basis of disability...' rather than 'on the basis of impairment'.

¹⁰⁶ Burca G de (2010) 191

¹⁰⁷ Para (o)

The boundaries of this legal order are thus pervasive, open and flexible. The Convention's power to regulate seeps far into society, through public and private sectors, and into the home. Duty-holders range from States through organisations to individuals. These boundaries – or lack of them – answer to Mégret's identified 'lack' in the international human rights framework: the failure to understand that exclusion, oppression, discrimination or violence may stem not only from the State, but also from social structures, prejudices, the community or the family.¹⁰⁸ Furthermore, the 'disabled/non-disabled' dichotomy almost becomes blurred at the edges. The rights being protected here are potentially those of all of us.¹⁰⁹

From this transformative centre, and within these open and flexible boundaries, how is the legal space organised to project the rights which are the treaty's raw material? How do the drafters choose to distort and fashion that material, emphasising some aspects above others, drawing continents larger or smaller, reshaping their picture of the world to expose and inscribe the disability/human rights terrain? Specific rights are projected through Articles 10 to 30.

Projecting the rights

The Convention was never intended to create 'new' rights, or to give disabled people rights that others do not have.¹¹⁰ Rather, it reaffirms and reformulates existing rights, moulding them to reflect the experience of disability.¹¹¹ The negotiators of the Convention had at their disposal the full range of civil, cultural, economic, political and social rights, as set out in the International Bill of Rights, as well as their various international, regional and national interpretations. Choices had to be made as to how this raw material should

¹⁰⁸ Mégret (2008a)

¹⁰⁹ Stein (2007)

¹¹⁰ Member of the UK delegation (2007) para 32

¹¹¹ Quinn G and Arnardóttir OM, 'Introduction' in Arnardóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009) xix

be fashioned into an international human rights treaty capable of delivering its particular purpose. The resulting projections, as Mégret concludes, have ‘a significant impact on the formulation of human rights... because disability forces human rights to re-examine some core assumptions about what the needs of human beings are, and how they relate to society and the state’.¹¹²

Reshaping the rights

Some existing rights needed little elaboration from the drafters. The right to life,¹¹³ for instance, is plainly stated, with the simple addition that disabled people’s right to life must be protected on an equal basis with others – not so simple when one remembers that that protection has not always been,¹¹⁴ and is often still not,¹¹⁵ forthcoming.¹¹⁶ The right to life is supplemented by a duty to protect disabled people in situations of risk, such as armed conflict, humanitarian emergencies and natural disasters¹¹⁷ - a duty drawn from

¹¹² Mégret (2008b) 3

¹¹³ Article 10

¹¹⁴ See Nazi Aktion T4 programme: <http://www.britannica.com/EBchecked/topic/714411/T4-Program>, accessed 7.1.10; Crow L, ‘Resistance: which way the future?’ Film installation <http://www.manchestersfinest.com/arts/film-reviews/resistance-liz-crow/> accessed 31.8.12; The Stanley Burton Centre for Holocaust and Genocide Studies, <http://www2.le.ac.uk/centres/stanley-burton-centre> accessed 31.8.12; United States Holocaust Museum website, http://www.ushmm.org/research/library/bibliography/?lang=en&content=people_with_disabilities#05-web_resources accessed 7.1.10; Caplan AL (ed) *When Medicine Went Mad: Bioethics and the Holocaust* (Humana Press 1992); Wagoner RG, ‘Speaking for the “Unfit”: A Commentary on Disability, the Holocaust and the Modern Eugenics Movement’ (Wagoner & Associates Inc, undated) <http://weradaexperts.com/kruppel.pdf> accessed 14.6.10

¹¹⁵ See for example Disability Now Hate Crime Dossier <http://www.disabilitynow.org.uk/the-hate-crime-dossier?searchterm=hate+crime+dossier> accessed 3.6.10; Sherry M, *Disability Hate Crimes: Does Anyone Really Hate Disabled People?* (Ashgate 2010); ‘David Askew collapsed and died after decade of attacks’, Times Online, 11 March 2010

¹¹⁶ As the UK-based Disability LIB Alliance points out: ‘Disability is different to other equality agendas in that the issue of the right to exist looms large. Whereas these arguments have largely been won in the other diversity areas the concept that disabled people’s lives are of equal value is still not widely accepted. There are numerous examples of this including: when a parent kills a disabled child it is presented in the press as a ‘mercy killing’; it is not uncommon to terminate a pregnancy because a child has a cleft palate, a club foot or fused toes...’ Disability LIB Alliance ‘Thriving or Surviving: Challenges and Opportunities for Disabled People’s Organisations in the 21st Century’, (Scope 2008) 4 footnote 4. See also <http://www.notdeadyetuk.org> accessed 17.6.10. However, the Convention stops short of addressing bioethical issues around prenatal testing or end-of-life issues such as euthanasia and assisted dying. As Kayess & French remark, this may come to be regarded as the Convention’s greatest failing. Kayess and French (2008) 29

¹¹⁷ Article 11: Situations of risk and humanitarian emergencies

international humanitarian law, and an extra reminder that disabled people may suffer disproportionately in such circumstances.¹¹⁸

Freedom from torture or cruel, inhuman or degrading treatment or punishment¹¹⁹ is simply drafted, with the addition that '[i]n particular, no one shall be subjected without his or her free consent to medical or scientific experimentation', recalling, *inter alia*, the experience of people with learning disabilities in that context.¹²⁰ That right is then supplemented by a duty to protect disabled people from all forms of exploitation, violence and abuse, both inside and outside the home,¹²¹ depredations frequently visited on those living with impairment.¹²² Furthermore, the 'existence of a disability [impairment] shall in no case justify a deprivation of liberty'¹²³ – recalling the widespread involuntary institutionalisation of disabled and older people and those with mental health issues.¹²⁴

¹¹⁸ See for example 'Uganda: Disabled people abandoned in refugee camps: Local leaders in Northern Uganda have complained that elderly and disabled people, as well as orphans, have been abandoned by relatives in recently closed refugee camps in the war-torn region... <http://allafrica.com/stories/200911130128.html>, from www.daa.org.uk, Our Rights newsletter, Issue 19, 9 December 2009, accessed 7.1.10; see also IDRM, *Disability and Early Tsunami Relief Efforts in India, Indonesia and Thailand*, 2005 <http://www.idrmnet.org/reports.cfm> accessed 7.1.10; or reports of the New Orleans flood in 2005. For articles on disability and displacement, see Forced Migration Review 35 - Disability and Displacement, accessed 26.6.10; Hemingway L and Priestley M, 'Natural hazards, human vulnerability and disabling societies: a disaster for disabled people?' (2006) 2(3) Review of Disability Studies 57
Priestley M and Hemingway L, 'Disabled People and Disaster Recovery: a tale of two cities?' (2006) 5(3/4) Journal of Social Work in Disability and Rehabilitation 23

¹¹⁹ Article 15

¹²⁰ This Article is identical to Article 7 ICCPR, perhaps drafted in response to Nazi experiments during WWII. see also Diesfeld, K, 'International Ethical Safeguards: genetics and people with learning disabilities, (1999) *Disability & Society*, 14(1) 21-36

¹²¹ Article 16 Freedom from exploitation, violence and abuse

¹²² See e.g. Disability Now, The Hate Crime Dossier, <http://www.disabilitynow.org.uk/the-hate-crime-dossier> accessed 7.1.10; Commission for Social Care and Healthcare Commission, 'Joint Investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust', July 2006; Healthcare Commission 'Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust' January 2007; Joint Committee on Human Rights, 'A Life Like Any Other? Human Rights of Adults with Learning Disabilities'. Seventh Report of Session 2007-08, HL Paper 40 HC 73, 6 March 2008; BBC Panorama 'Undercover Care: the Abuse Exposed' BBC1, Winterbourne View, Tues May 31 2011; Equality and Human Rights Commission, 'Hidden in Plain Sight: Inquiry into Disability-Related Harassment' (EHRC 2011); Equality and Human Rights Commission 'Close to Home: an Inquiry into Older People and Human Rights in Home Care' (EHRC 2011)

¹²³ Article 14 Liberty and security of the person

¹²⁴ 'Many are... warehoused and forgotten in institutions designed to remove them from society' International Disability Rights Monitor, *IDRM International Disability Rights Compendium* (Centre for International Rehabilitation 2003)1; Morris J, *Independent Lives:*

Of key importance is the right of disabled people to recognition everywhere as persons before the law.¹²⁵ Again, this seems simple enough, but for the different ways that the law treats those who are deemed not to have legal capacity. Here too, this is – sometimes literally - a vital issue for disabled people, and another area in which others make fundamental decisions on their behalf.¹²⁶ Having required States to recognise that disabled people ‘enjoy legal capacity on an equal basis with others in all aspects of life’,¹²⁷ Article 12 proceeds to specify the measures to be taken, where necessary, to support disabled people in exercising that capacity.¹²⁸ Once such support is in place, if required, the person should have equal property rights, control of their own financial affairs,¹²⁹ and equal access to justice.¹³⁰ Disabled people’s physical and mental integrity must be respected;¹³¹ they must be free to choose their nationality and residence,¹³² and to vote.¹³³

Respect for home and family life¹³⁴ focuses strongly on the right to marry and have a family, to retain fertility and to ‘freely and responsibly’ make decisions about child-bearing – rights taken for granted by non-disabled people, but frequently, even routinely, denied to many disabled people.¹³⁵ No child¹³⁶

Community Care and Disabled People (Macmillan 1993); Prime Minister’s Strategy Unit, ‘Improving the Life Chances of Disabled People’, January 2005; Department of Health ‘Vision for Adult Social Care: Capable Communities and Active Citizens’, 16 November 2010

¹²⁵ Article 12(1)

¹²⁶ See for example *R (on the application of Burke) v General Medical Council* [2005] EWCA Civ 1003; [2005] All ER (D) 445 (Jul)

¹²⁷ Article 12(2)

¹²⁸ Article 12(3) Those measures must respect the rights, will and preferences of the person, be free of conflict of interest and undue influence, proportional and tailored to the person’s circumstances, apply for the shortest time possible and be subject to regular review by a competent, impartial and independent authority (Article 12(4)) in order to respect and protect the person’s autonomy

¹²⁹ Article 12(5)

¹³⁰ Article 13

¹³¹ Article 17; Kayess and French (2008) argue that the final text fails to regulate ‘one of the most critical areas of human rights violation of persons with disability – the use of coercive State power for the purpose of ‘treatment’’. But see also Minkowitz T, ‘The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from Non-consensual Psychiatric Interventions’ (2006-2007) 34 *Syracuse Journal of International Law and Commerce* 405

¹³² Article 18 Liberty of movement and nationality

¹³³ Article 29

¹³⁴ Article 23

¹³⁵ See for instance *Violence Against Women: Forced Sterilization Of Women With Disabilities Is A Reality In Europe*, European Disability Forum, 9 November 2009, http://www.edf-feph.org/Page_Generale.asp?DocID=13855&thebloc=23097 accessed 7.1.10

shall 'be separated from its parents on the basis of a disability [impairment] of either the child or one or both of the parents'.¹³⁷ In sum, disabled people must be free to exercise the standard freedoms of the 'able' liberal subject in a democratic, capitalist society.

These basic civil and political rights take on a new dimension when subjected to the disability experience. The framing of the rights emphasises that, for disabled people more than most, life-threatening violence and abuse may occur on a daily basis; being in a family¹³⁸ or managing one's own affairs may seem beyond the realms of possibility. In reshaping existing rights to contest that experience, the drafters draw out particular angles under new headings. For instance, respect for personal integrity and protection from exploitation, violence and abuse feature as separate Articles, emphasising their importance in the disability context. In the process, the text comes close to creating 'new' rights.¹³⁹

Economic, social and cultural rights undergo similar distortions. The right to health is supplemented by rights to habilitation and rehabilitation,¹⁴⁰ to privacy of health records,¹⁴¹ and to personal mobility.¹⁴² The right to work requires reasonable accommodation in the workplace and affirmative action programmes to promote employment in the private sector. As befits the Convention's social development remit, and the impoverished circumstances of millions of disabled people around the world,¹⁴³ States must take a range

¹³⁶ Here, children have specific protection: they must be registered immediately after birth, with rights to a name, nationality, and, as far as possible, the right to know and be cared for by their parents. (Article 18(2)) To prevent the 'concealment, abandonment, neglect and segregation of children with disabilities', support must be given early to disabled children and their families (Article 23(3)). 'Mortality for children with disabilities may be as high as 80 per cent in countries where under-five mortality, as a whole, has fallen to below 20 per cent. In some cases, it seems as if disabled children are being "weeded out".' Department for International Development, United Kingdom, quoted in United Nations, 'From Exclusion to Equality', UN Handbook for Parliamentarians, no 14 (2007) 3

¹³⁷ Article 23(4)

¹³⁸ Whether as parent or child

¹³⁹ Mégret (2008a) 497

¹⁴⁰ Article 26

¹⁴¹ Article 22(2)

¹⁴² Article 20

¹⁴³ According to the UN, 80% of disabled people live in poorer countries ('Realizing the Millennium Goals...', report of the Secretary General to 64th Session UN General Assembly, A/64/180, July 2009, para 4); 20% of the world's poorest people have a disability, and tend

of steps to safeguard and promote the equal right to an adequate standard of living, including access to appropriate and affordable services to meet disabled people's impairment-related needs, and their inclusion in poverty reduction programmes.¹⁴⁴ Disabled people must 'have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society',¹⁴⁵ with support for 'their specific cultural and linguistic identity, including sign languages and deaf culture'.¹⁴⁶

The right to education strongly reflects the disability projection. Many disabled people's negative experience of their own treatment in childhood, including segregation from family and community, institutionalisation, medicalisation and denial of education, continues to inform their identities, capacities and actions as adults, producing a strong driving force for change.¹⁴⁷ Moreover, education is a crucial element in achieving the overarching principle of respect for disabled children's evolving capacities and their right to preserve their identities'.¹⁴⁸ Education merits one of the

to be regarded in their own communities as the most disadvantaged (World Bank, quoted in United Nations, 'From Exclusion to Equality', UN Handbook for Parliamentarians, no 14 (2007) 3; and see Chapter 1 above

¹⁴⁴ Article 28. See 'Realizing the Millennium Goals...', report of the Secretary General to 64th Session UN General Assembly, A/64/180, July 2009, para 4; Pleasence P and Balmer N, 'Mental health and the experience of housing problems involving rights' (2007) 2(1) People, Place and Policy Online, 4

¹⁴⁵ Article 30(2)

¹⁴⁶ Article 30(4)

¹⁴⁷ See, for instance, Tara's story in Chapter 1 above; Reiser R, 'Internalized Oppression: How it seems to me' in Rieser R and Mason M (eds) *Disability Equality in Education* (ILEA 1990)

¹⁴⁸ Article 3(h). How best to achieve this outcome remains a contentious issue: alongside those who fight for inclusion in mainstream provision, there are also those who strongly favour separate education. The World Blind Union, for instance, considers that 'UNESCO's promotion of inclusive education has harmed blind children enormously. Blind children find themselves mainstreamed in a class without support, with teachers who can't read Braille and lack the ability to communicate effectively with blind children.' The World Federation of the Deaf is concerned that '[i]n developing countries... some deaf schools are being closed in the name of inclusive education, resulting in high illiteracy among deaf children.' Others recognise that '[w]hat is more complicated is striking the balance between special versus inclusive education... The fundamental principle at the core of this article is the issue of choice. The article should not allow for reliance on special schools as excuse for States to not make general schools accessible.' European Disability Forum, Daily Summary, 3 August 2005

longest articles in the Convention text, providing detailed instructions on how it is to be realised.¹⁴⁹

The interdependence of civil, cultural, economic, political and social rights is now widely accepted – at least in theory - within international human rights discourse; the way that they are mapped out in this Convention, in the context of disabled people’s profound experiences of exclusion, reaffirms that interdependence.¹⁵⁰ The ‘universality, invisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination’ is reaffirmed in the Preamble.¹⁵¹ Economic and social rights not only appear as rights in themselves: they are incorporated into articles dealing with civil and political rights, and vice versa, leading to inseparable fusing of the traditional dichotomy. Such ‘hybrid’ rights include, for instance, the right to health which prohibits discriminatory denial of healthcare,¹⁵² echoing the right to life; the right to work includes protection from slavery, forced or compulsory labour.¹⁵³ Conversely, appropriate support services must be provided to victims of exploitation, violence or abuse;¹⁵⁴ accessible family planning education and services must be available to allow informed reproduction choices.¹⁵⁵ As Mégret identifies, the drafters ‘ride roughshod’ over the traditional international human rights dichotomy between the two ‘sets’ of rights.¹⁵⁶ It will be seen in Chapter 4 below that Article 19, the right to live independently and be included in the community which stands at the centre of Convention realisation, exemplifies this fusion. Here again, as Stein and Lord note, ‘several articles appear at first blush to reflect newly

¹⁴⁹ Article 24

¹⁵⁰ ‘I have not separated Civil and Political rights from Economic, Social and Cultural rights, as there were strong views that this should not be done...’ Covering Letter from the Chair of the Ad Hoc Committee, October 7th 2005, 2

¹⁵¹ Preamble para (c)

¹⁵² Article 25(f)

¹⁵³ Article 27(2)

¹⁵⁴ Article 16(2) & (4)

¹⁵⁵ Article 23(1)(b)

¹⁵⁶ Mégret identifies the following dichotomies as having been over-ridden: negative/positive rights, civil and political/economic, social and cultural rights, public/private sphere, state/individual, state/society, individual/community, domestic/international, immediate obligation/progressive realisation, absolute/relative, vertical/horizontal, individual rights/state obligation, law adoption/policy implementation, remedy/prevention.

created rights, but in fact were included for the purpose of clarifying the means through which other CRPD rights are realized'.¹⁵⁷

As discussed in Chapter 2 above, economic, social and cultural rights have an enabling function, allowing people to take charge of their own lives, to exercise their autonomy and to participate in and contribute to society. Disability is a context in which that function is particularly 'sharp'.¹⁵⁸ These rights are thus inextricably bound up with the exercise and realisation of all Convention rights; they are a key element in the repositioning of disabled people from welfare to rights in the new world of the disability/human rights discourse, and on the Convention map.

However, the two 'sets' of rights remain unequal in their application: whilst civil and political rights are to be implemented immediately, economic, social and cultural rights may be subjected to 'progressive realisation'.¹⁵⁹ How to address this dichotomy engendered much discussion during negotiation. Whilst a requirement for immediate implementation of all economic, social and cultural rights was generally accepted as unrealistic, delegates were concerned that such flexibility should not apply to non-discrimination in their application. Others argued that the aspects of economic, social and cultural rights accepted in international law as requiring immediate application go well beyond non-discrimination:¹⁶⁰ these aspects should also be given immediate effect. The problem was finally resolved in Article 4(2).¹⁶¹ The Chairman's 2005 draft of this section allows for progressive realisation of economic, social and cultural rights except where this 'would result in discrimination on the basis of disability.'¹⁶² Following negotiation, this exception was rephrased, allowing for broader interpretation:

With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available

¹⁵⁷ Stein and Lord (2009) 30; such as mobility, habilitation and rehabilitation

¹⁵⁸ Despouy (1993)

¹⁵⁹ See Chapter 2 above.

¹⁶⁰ NHRIs, Daily Summary, 31 January 2006; for discussion of immediate application of economic, social and cultural rights see Chapter 5 below

¹⁶¹ See Daily Summary, Seventh Session, 30/31 January 2006

<http://www.un.org/esa/socdev/enable/rights/ahc7sum31jan.htm>

¹⁶² Chairman's text, October 2005, Article 4(2)

resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realisation of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.¹⁶³

The Convention's central re-description of the world thus projects the rights themselves in ways that fundamentally alter the traditional rights perspective. It melds the rights together, it highlights angles of the human rights framework in new ways, and it challenges basic human rights assumptions. The drafting techniques have another dimension that stretches the international human rights framework, not only focusing the rights themselves, but also driving their practical realisation. The CRPD has been described above as small-scale, 'systemic'¹⁶⁴ law: its function as an international treaty is to provide a broad, universal framework. These cartographers, however, have engaged in larger-scale drafting. 'The tertiary obligation to fulfil' is not far from their minds:¹⁶⁵ they map in not just the continents, but also some particular roads to be followed.

Enlarging the scale

The detail and nature of those roads vary from one right or duty to another. The objective of Article 8, for instance, is to bring about the sea-change in attitudes necessary to achieve the Convention's purpose. Earlier international human rights treaties have addressed parallel aims, but none has provided such specific direction to States as to how they should bring about the desired outcome. CEDAW and CERD maintain their small-scale, overarching style.¹⁶⁶ The CRPD, on the other hand, not only sets out in broad

¹⁶³ See 2009 discussion between UN Committee on Economic, Social and Cultural Rights and UK delegation in Chapter 5 below

¹⁶⁴ Santos (2002), see Chapter 1 above

¹⁶⁵ Hunt (1999) 34: 'when legislators wish to impose the tertiary obligation to fulfil, they can reduce the indeterminacy by precise, detailed drafting.'

¹⁶⁶ CERD addresses such culture change in its Article 7: 'States Parties undertake to adopt immediate and effective measures, particularly in the fields of teaching, education, culture and information, with a view to combating prejudices which lead to racial discrimination and to promoting understanding tolerance and friendship among nations and racial or ethnical groups...'. CEDAW Article 5 requires States 'to modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the supremacy of either of the sexes or on stereotyped roles for men and women', and to ensure

terms what States should do, but also goes into detailed directions about the means to be used: including running public awareness campaigns,¹⁶⁷ fostering respect in the education system¹⁶⁸ and in the media,¹⁶⁹ and promoting disability awareness training.¹⁷⁰ The Article thus strays from its small-scale remit into larger-scale territory in an effort to promote the actual realisation in practice – the fulfilment - of its objective.

Other duties are equally specific. To achieve accessibility, States must identify and eliminate obstacles in, *inter alia*:

- (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
- (b) Information, communications and other services, including electronic services and emergency services.¹⁷¹

They must provide minimum access standards and guidelines; training for stakeholders; and easy-read and Braille signage, guides and interpreters. They must promote support to ensure disabled people's access to information and technology.¹⁷² This list includes items which are commonly viewed as 'reasonable accommodations' in the individual context; here they are demanded of the State.

The road to freedom of expression¹⁷³ requires information to be made available in accessible formats, alternative communication methods to be used in official interactions, and private service providers and the mass media to be encouraged to do the same. Even this traditional 'negative' civil right – a freedom from State interference - entails very specific (and socio-economic) positive actions on the part of the State.

that family education includes a proper understanding of the roles of men and women in the upbringing of children.'

¹⁶⁷ Article 8(2)(a)(i),(ii)&(iii)

¹⁶⁸ Article 8(2)(b)

¹⁶⁹ Article 8(2)(c)

¹⁷⁰ Article 8(2)(d)

¹⁷¹ Article 9(1)(a) & (b)

¹⁷² Article 9(2)

¹⁷³ Article 21

The right to education makes full use of this technique. As well as a long list of measures to ensure a fully inclusive education system at all levels,¹⁷⁴ ‘appropriate measures’ to be taken by States include:

- (a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
- (b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
- (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximise academic and social development.¹⁷⁵

The disability/human rights projection of the rights themselves and these forays into larger-scale drafting combine to give a clearer picture than usual of the nature and contours of this terrain, and the routes through it to the intended destination.

Conclusion

Sedimentation of a discourse into a new international legal order entails the creation of a ‘revolving door’ through which its particular forms of knowledge and power can circulate, to establish new understandings, systems of social relations and actor identities around the world. Like cartographers, the Convention drafters must convert their rounded and multi-dimensional social reality into the flat and two-dimensional text of a legally binding international human rights treaty. They must define their central ideological perspective and the limits of their legal order. They must apply projection techniques that are technically sound, whilst serving the purpose of their hegemonic project. They must set out the terrain so as to guide the Convention’s travellers towards the ultimate destination where the disability/human rights myth becomes imaginary.

¹⁷⁴ Article 24(2)(a) – (e)

¹⁷⁵ Article 24(3)

This Chapter has examined the Convention text as it lays down its central purpose and principles, its boundaries and its projection of the rights themselves. It has found a purpose clause designed to re-emphasise the overall objective of the Convention and the binding nature of its obligations; principles of respect for dignity, autonomy, inclusion, participation and equality which aim to re-position disabled people from 'other' to integral part of human diversity and humanity; and broad, inclusive and flexible boundaries which blur the dichotomy between 'disabled' and 'non-disabled' to apply the Convention's terms potentially to all of us. Civil, cultural, economic, political and social rights are melded together to reshape all rights in the light of disabled people's experience, and to provide clear roads to the intended destination. Traditional dichotomies are brushed aside,¹⁷⁶ relations of difference prevail, and dynamics of interlegality abound.

Like any myth, the vision of the CRPD drafters is unattainable at present: it represents an ideal society. As Lawson comments,

[a] reading of the terms of the CRPD might well lead one to the view that it heralds a "new era". If implemented fully it would impact on all aspects of the lives of millions of disabled people and, indeed, on their very existence. Further, its impact would not be confined to disabled people, but would extend to all. It may, of course, directly benefit any member of the human race because those who are currently not disabled may become so at any moment. In addition, its provisions require the reshaping of societies in a way required by no other human rights treaty. The realization of human rights for disabled people requires fundamental changes to be made to building and product design, to modes of transport, of communication and of information and service provision, as well as to the attitudes and expectations of the general population and of political leaders.¹⁷⁷

This re-description of the world has been mapped, but it is not yet reality; it awaits a fundamental transformation which has yet to take place. Existing treaties, with their implementation provisions, have failed to bring about that transformation.¹⁷⁸ The onus is on the drafters of this Convention to succeed where earlier treaties have failed – to ensure that their new legal order does

¹⁷⁶ Mégret (2008b)

¹⁷⁷ Lawson (2006-2007) 618-9

¹⁷⁸ Quinn and Degener (2002), Louise Arbour (2006), IDRM Reports etc

enable disability/human rights discourse to circulate, and to establish new understandings, systems of social relations and actor identities around the world. Again, the drafters apply a number of innovative techniques to put in place the necessary conditions for expansion of their project's hegemony. These include the Convention's implementation and monitoring provisions, which are examined next. To make concrete the enquiry into the Convention's goal of paradigm change, **Chapter 4** also examines further the Article 19 right to live independently and be included in the community.

Chapter 4

Implementation

Introduction

Chapter 3 has highlighted the Convention map's central purpose and principles, and its flexible boundaries. It has explored the techniques used to project civil, cultural, economic, political and social rights through the experience of disability, and to give a clearer picture than usual of the nature and contours of the terrain and the routes through it to the intended destination. But roads are of no use unless they are travelled; maps just decorative until they are used; and international treaties of symbolic value only unless and until they are effectively implemented. The Convention's realisation provisions are designed to ensure that the hegemonic project from which this map has emerged does not end with adoption of the Convention, but continues to build its power and influence to transform understandings, practices and identities around the world – to transform the myth into imaginary.

This Chapter examines the implementation and monitoring provisions designed to take the hegemonic project forward. It also examines in more depth a right which is fundamental to realisation of the Convention project: the right to live independently and be included in the community set out in Article 19. Although some Convention drafters were concerned that Article 19 should not be seen as endorsing disabled people's independent living movement, it is argued here that the concept of independent living as understood by that movement is so deeply ingrained that it is impossible to extract it from the Convention myth. Section 2 below provides a brief overview of the history, philosophy and practice of independent living before examining the text of Article 19. As a 'hybrid' right included to clarify the

means through which other Convention rights are realised, implementation of Article 19 is chosen as ‘barometer’ for success or otherwise of the Convention drafters’ hegemonic project in Part 2 of the thesis.

Implementation and monitoring

The ‘projection techniques’ used to try to ensure realisation of the CRPD’s vision are at once practical and imaginative. They include the standard UN systems, but, as one might expect of these ‘cartographers’, systems are shaped, augmented and coloured to emphasise their focus and their direction; and they are deepened to engage players across the board and at all levels, not least disabled people themselves. They thus encourage the continued development of relations of difference and of constellations of interlegality,¹ and set in train a series of implementation mechanisms designed to ensure that the hegemonic project that has succeeded in embedding the disability/human rights myth into international law continues to flourish. These mechanisms are set out in Articles 30 to 50.

Like other international human rights treaties, the CRPD establishes a **monitoring committee**.² When nominating their candidates, States Parties ‘are invited to give due consideration’ to Article 4(3).³ This is the ‘nothing about us without us’ provision which requires States to ‘closely consult with and actively involve’ disabled people and their organisations when implementing the Convention. As well as reflecting ‘equitable distribution’

¹ See Chapter 1 above

² Article 34. Consisting initially of twelve members elected by the States Parties, increasing to eighteen once eighty States have ratified: Article 34(2) Once elected, members serve a term of four years, and are eligible for re-election once: Article 34(7). The Committee reports every two years to the General Assembly and to the Economic and Social Council. The initial Committee was elected in November 2008 and held its first session in February 2009. One of its first actions was to ensure that disabled people had access to its meetings, including provision of information in accessible formats, interpreters and personal and technological assistance. As at August 2012, the Committee has held seven reporting sessions, published rules of procedure and guidance on monitoring, and held ‘days of discussion’ on equal recognition before the law (2009) and accessibility (2010): for updates see <http://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx> last accessed 1.9.12

³ Article 34(3)

along geographical, cultural, gender and legal system lines, 'consideration shall be given' to participation on this Committee of 'experts with disabilities'.⁴ The CRPD is thus the first international human rights treaty to specifically call on States Parties to nominate experts coming from the target group.⁵ The Committee, once established, has the standard job of monitoring States Parties' implementation progress through a 'constructive dialogue' based on their periodic reports.⁶ Here too, States are 'invited to consider' preparing their reports with 'due consideration' to consultation with and involvement of disabled people as required under Article 4(3). Where a State has ratified the Convention's **Optional Protocol**, the Committee has competence to consider complaints from individuals or groups in that State who claim to be victims of violations of their Convention rights.⁷

This part of the monitoring procedure ties the Convention securely into the established UN human rights monitoring framework. The reporting system produces a national/international 'dialogue' with potential to influence discursive dynamics, and to strengthen the disability rights 'myth'. But under this Convention, States will also talk to each other on a regular basis, and to civil society, in a **Conference of States Parties**, a forum with no equivalent in other international human rights treaties.⁸ Under Article 40, a Conference

⁴ Article 34(4)

⁵ 'CRPD: An Overview of the Conference of States Parties and Committee of Experts', adapted from an article co-authored by Shatha Rau Barriga, RI; and Kirsten Young (formerly of the Landmine Survivors Network) in *Rehabilitation International Review*, December 2007. Although other UN Monitoring Committees may, in practice, appoint, for instance, women to the CEDAW Committee, there is no provision within the text of CEDAW which requires them to consider doing so.

⁶ Article 35(1) and (2). An initial 'comprehensive' report must be submitted by each State within two years of ratification, and subsequent reports at least every four years.

⁷ Optional Protocol to the Convention on the Rights of Persons with Disabilities, Article 1

⁸ Burca reports that 'Article 40 was strongly advocated by the Latin American and Caribbean grouping of States, as well as by NGOs. The model which the NGOs had for a strong biennial conference was apparently inspired by a similar provision in the Ottawa Landmines Convention, in which the annual conference plays a particularly substantive role because there is no independent monitoring provision provided for in that Treaty. The CRPD, on the other hand, has... an international monitoring mechanism with an optional individual complaints procedure, as well as significant provisions on national monitoring. The provision in Art. 40 providing for a biennial meeting of the parties is therefore additional to these, and therefore serves a slightly different function from that under the Ottawa Convention.' Burca (2010) 187-188. See also Liebowitz T, Minkowitz T, Trommel S and Barriga SH, 'How the Conference of States Parties Can Serve as an Essential Forum for CRPD Implementation' (2008) 57(1) *Rehabilitation International Review* 8; Barriga SR and Young K, 'CRPD: An

of States Parties must be convened by the UN Secretary-General every two years⁹ to consider 'any matter with regard to the implementation' of the Convention.¹⁰ Delegates to the Conference attend formal sessions and take part in interactive discussions. Less formal sessions are organised jointly with NGOs; and side events address specific issues.¹¹ As the final press release from the first conference in 2009 proclaimed: Delegates, Civil Society Representatives Take Part in Interactive Dialogue. This 'interactive dialogue' has now become an annual rather than a biennial event.¹²

A further dynamic is created by the engagement of **Regional Integration Organisations**. Both the Convention and its Optional Protocol are open not only for ratification by States, but also to 'formal confirmation' by 'regional integration organisations'.¹³ The EU was an active participant in the drafting negotiations,¹⁴ and acceded to the CRPD in 2010.¹⁵ It may vote in the meeting of States Parties, with a number of votes equal to the number of its member States that are party to the Convention, except where an individual

Overview of the Conference of States Parties and Committee of Experts' (2007) 56(4)
Rehabilitation International Review

⁹ Or on the decision of the Conference of States Parties: Article 40(2)

¹⁰ Article 40(1). Burca describes this element of the realisation framework as one of the 'experimentalist features' of the Convention: '[t]he idea of revisability, of a built-in opportunity for regular review and reconsideration of all aspects of the substance and functioning of a regulatory system, is central to the model of experimentalist governance.' Burca (2010) 187; see also Liebowitz *et al* (2007)

¹¹ For instance, at the second Conference in September 2009, an informal session was held on disability and poverty, 'with special reference to the current economic crisis'. (<http://www.un.org/disabilities/default.asp?id=1479> accessed 13/1/10). The Conference of States Parties thus provides a forum for the early consideration of such potential dislocatory events as the economic downturn.

¹² CRPD Article 42(2) requires the Secretary-General of the UN to convene a Conference of States Parties 'biennially or upon the decision of the Conference of States Parties'. The first Conference decided to make the event an annual one.

¹³ Optional Protocol Article 11; CRPD Article 42. These are organisations 'constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by [the] Convention.'¹³ Optional Protocol Article 12; CRPD Article 44

¹⁴ The EU's initial approach to the drafting of the Convention was 'somewhat ambivalent': it was concerned that a treaty might 'end up reinforcing a segregationist tendency in law and policy for people with disabilities'. However, 'once it became clear that there was to be a Disability Convention, the Commission perceived an opportunity for the European Union to become party for the first time, as a recognised international organisation, to an international human rights Treaty. At this point, the Commission switched tactics to make a strong argument for a binding instrument', albeit advocating for an 'anti-discrimination' rather than a 'substantive rights' approach, seeking to promote its own internal model of disability discrimination at the international level. Burca (2010) 179-80.

¹⁵ The EU acceded to the CRPD on 23 December 2010.

<http://www.un.org/disabilities/countries.asp?navid=12&pid=166> accessed 7.1.11

member State votes in its own right. The presence of regional organisations as Parties to the Convention brings new perspectives to the discussion, including their history and experience as a regional body, their institutional, legal and political relationships with their Member States, and, in the case of the EU, its established role in the international development field.¹⁶

More practical **international cooperation** is also required. This Convention came about in part because of the absence of disability from the Millennium Development Goals.¹⁷ One of the CRPD's aims is to ensure that such invisibility is not repeated. Ratifying States undertake to recognise the importance of international cooperation for realising the purpose and objectives of the Convention.¹⁸ The measures to be taken¹⁹ include ensuring the accessibility of international development programmes;²⁰ capacity-building;²¹ cooperation in research and its accessible dissemination;²² and providing technical and economic assistance.²³ In 2007, Special Rapporteur Hissa Al-Thani reported²⁴ that, despite strong political will, lack of resources and expertise was 'commonly cited' as an obstacle to achieving the Convention's objectives. She concluded that international and interregional cooperation in policy and practice is one of the most effective ways to hasten implementation.

¹⁶ See Ferri D, 'The Implication of the UNCRPD for EU Law' (2011) presentation to ERA (Academy of European Law) Seminar on the UN Convention on the Rights of Persons with Disabilities, Madrid, 15-16 December 2011

¹⁷ See Chapter 2 above. 'Realizing the Millennium Development Goals for Persons with Disabilities through the Implementation of the World Programme of Action concerning Disabled Persons and the Convention on the Rights of Persons with Disabilities', Report of the Secretary General to 64th Session UN General Assembly, A/64/180, July 2009, para 4; Kayess and French (2008) 17

¹⁸ Article 32(1)

¹⁹ 'As appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities', Article 32(1)

²⁰ Article 32(1)(a)

²¹ Article 32(1)(b)

²² Article 32(1)(c)

²³ Article 32(1)(d)

²⁴ Economic and Social Council, 'Monitoring of the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities', 16 November 2006, E/CN.5/2007/4, Hissa Al-Thani, Special Rapporteur, para 45

It should not be forgotten that the **Standard Rules** on the Equalisation of Opportunities for Persons with Disabilities,²⁵ with their Special Rapporteur and panel of experts, have not gone away. In her capacity as Special Rapporteur, Hissa Al-Thani attended the Ad Hoc Committee sessions and contributed to the Convention's drafting.²⁶ Al-Thani speaks of 'the symbiotic relationship' between the Standard Rules and the Convention:²⁷ CRPD articles mirror the Rules in content and substance, and the Rules 'serve as a detailed checklist on what needs to be done and how it should be approached'.²⁸ The role of **Special Rapporteur** has since been extended to cover not only promotion and monitoring of the Standard Rules, but also promotion and advocacy of the Convention.²⁹

The Disabled People's Movement's mantra of '**nothing about us without us**' not only served as a rallying call during the drafting negotiations,³⁰ but was also applied there in very practical and effective ways.³¹ That mantra also colours the Convention's realisation provisions.³² It insists on disabled people's continuing involvement:

- in Monitoring Committee nominations and on the Committee itself;
- in participation at Committee meetings, and in preparation of States' reports;

²⁵ see chapter 2 above

²⁶ Economic and Social Council, 'Monitoring of the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities', 16 November 2006, E/CN.5/2007/4, Hissa Al-Thani, Special Rapporteur, para 3

²⁷ Ibid, para 11

²⁸ Ibid, para 13. One such contribution is the Global Survey on Government Actions, which has resulted in the 'most comprehensive body of research into disability', yielding information on progress in 114 countries. Economic and Social Council, 'Monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities', 17 November 2008, E/CN.5/2009/6, para 31(c)

²⁹ Ibid para 29

³⁰ See chapter 2 above

³¹ See chapter 2 above

³² See for instance Office of the High Commission for Human Rights 'Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors' Professional training series no 17 (United Nations, 2010); Disability Rights Promotion International, 'Opportunities, Methodologies and training resources for Disability Rights Monitoring' (DRPI 2003); International Disability Rights Monitor, *IDRM International Disability Rights Compendium*, (Centre for International Rehabilitation 2003) International Disability Rights Monitor, *IDRM: Regional Report of the Americas*, (International Disability Network and the Centre for International Rehabilitation 2004) International Disability Rights Monitor, *IDRM: Regional Report of Asia*, (IDRM 2005) International Disability Rights Monitor, 'The United Kingdom' in *IDRM: Regional Report for Europe* (IDRM 2007)

- through potential complaint under the Optional Protocol;
- in the activities and discussions of the Conference of States Parties;
- through regional integration organisations; and
- in international development measures to realise the purpose of the Convention.

The right to form disabled people's organisations at international, national, regional and local levels can be found in Article 29(b)(i). Disabled people's organisations have not been slow to take up the challenge.³³

However, as Philip Alston remarks, international activities 'might be a useful catalyst, but what ultimately matters is what is done, perhaps in conjunction with those measures, at the national level.'³⁴ Here, too, the CRPD's realisation provisions point the way.

Perhaps the innovation with the most potential for driving real implementation is the Convention's provision for **national implementation and monitoring**.³⁵ Ratifying States 'shall designate one or more focal points within government for matters relating to implementation' of the Convention, with 'due consideration' to establishing 'a coordination mechanism within government to facilitate related action in different sectors and at different levels'.³⁶ Independent bodies, too, must be established to 'promote, protect and monitor' implementation of the Convention, 'in line with the principles relating to the status and functioning' of such institutions.³⁷ And relevant research data must be collected, disaggregated and accessibly

³³ As well as the Conference activities described above, they have published guidance and developed training, organised national, regional and international seminars, run advocacy campaigns and implementation projects, and more: 'Status of the Convention on the Rights of Persons with Disabilities and the Optional protocol thereto', General Assembly, 7 July 2009, A/64/128. Monitoring projects established prior to the Convention also continue: see Disability Rights Promotion International, <http://www.yorku.ca/drpi>; International Disability Rights Monitor <http://www.idrmnet.org>.; and Pinto PC, 'Monitoring Human Rights: a Holistic Approach' in Rioux MH, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011)

³⁴ Alston P, 'The Committee on Economic, Social and Cultural Rights' in Eide A, Krause C and Rosas A, *Economic, Social and Cultural Rights: A Textbook* (Brill 2001)

³⁵ Article 33

³⁶ Article 33(1)

³⁷ Article 33(2). The Paris Principles: <http://www2.ohchr.org/english/law/parisprinciples.htm>.

disseminated³⁸ to support this implementation assessment process. At national level, the requirement is for implementation focused and integrated into and throughout government, complemented by strong independent statutory promotion and monitoring mechanisms.

Here too, '[c]ivil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully' in that monitoring process.³⁹ As seen in Chapter 3 above, they must also be consulted and actively involved when governments develop and implement relevant legislation and policy, and in other decision-making processes that concern them.⁴⁰

As Quinn explains, this Convention is

interesting and unique and distinctive. Most international Conventions say: we have the obligations, in the pure ether, now go do it. The gap has always been – where is the transmission belt between international law and the domestic matrix for change? This Convention actually goes the extra step and requires that matrix to be in place.⁴¹

Just as the cartographers have shaped the rights to map out the disability/rights terrain more clearly than usual, and to orient the duty-bearer more specifically on the routes to be taken, so also projection of the Convention's implementation provisions strengthens and deepens the implementation process. All of the players involved in the drafting process will continue to meet at the Conference of States Parties, through their regional integration organisations and through international cooperation and development networks. The promotion and monitoring systems established through the Standard Rules continue and are strengthened, as are domestic networks within and outside government. Governments are engaged in dialogue with the UN Monitoring Committee, and with each other and their regional organisations at the Conference of States Parties. Disabled people

³⁸ Article 31

³⁹ Article 33(3)

⁴⁰ Article 4(3)

⁴¹ Quinn G, 'Added value of the UN Convention on the Rights of Persons with Disabilities' (2008) presentation to Seminar of the European Coalition for Community Living, Drammen, Norway; printed in Newsletter of the European Coalition for Community Living, December 2008/January 2009, 2

and their organisations are active and involved at every level around the world. The 'transmission belt' is not only between international and national spheres: all of Santos' structural places, with their legal dimensions, are engaged, offering countless opportunities for the continuation of dynamic interlegal interplay. Legal and political relations of difference leave room for a proliferation of differences and for stable compromises, allowing disability/human rights discourse to serve as surface of inscription for a variety of social demands and dislocations. The scene is set for continuation of the hegemonic project that has produced the Convention to translate its 'particular discourse of norms, values, views and perceptions'⁴² into 'imaginary'⁴³ and into the reality of the lives and identities of all concerned.

In addition to these implementation and monitoring provisions, there are several Articles particularly central to the Convention's goal of paradigm change. For example, the Article 12 requirement for States to recognise disabled people as persons before the law, enjoying legal capacity on an equal basis with others in all aspects of life is a pre-requisite for the exercise of other Convention rights;⁴⁴ and implementation of Articles 8 (awareness-raising) and 9 (accessibility) are essential to bring about the structural and attitudinal change necessary for substantive realisation of equality, autonomy and participation.⁴⁵ Also pre-requisite is Article 19, the right to live independently and be included in the community. As we have seen in Chapter 3, while Article 19 appears to create a 'new' right, in fact it was included for the purpose of clarifying the means through which other CRPD rights are realised.⁴⁶ For this reason, it is chosen in Part 2 as 'barometer' of hegemonic expansion of the disability/human rights discourse in England. In preparation, this section looks more closely at disabled people's independent living discourse, and at the terms of Article 19.

⁴² Torfing (1999) 302

⁴³ The 'default' system of meanings that underlie and structure our society: see Chapter 1 above

⁴⁴ See Chapter 3 above, and for example United Nations, 'From Exclusion to Equality', UN Handbook for Parliamentarians, no 14, (2007) 89. At the time of writing, the UNCRPD Committee is working on the legal, theoretical and practical aspects of Article 12: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> 2/4/12

⁴⁵ See Chapter 3 above

⁴⁶ Stein and Lord (2009) 30

Independent living

Although the Convention drafters' remit prohibited the creation of 'new' rights, several articles appear 'at first blush'⁴⁷ to do so. Article 19, the right to live independently and be included in the community, is one such article. Included to clarify the means through which other Convention rights are realised, it stands at the centre of Convention implementation. It both encapsulates core elements of disabled people's social-antagonistic discourse, directly challenging traditional assumptions of dependency and exclusion, and embodies the Convention's fusion of civil, cultural, economic, political and social rights. Progress in realisation of Article 19 will therefore serve as an important barometer of progress in implementing the Convention as a whole. Understandings of independent living, with their related systems and subject positions, will help to provide evidence of the progress – or otherwise – of disability/human rights discourse as it enters the national arena.

There is a substantial body of literature on independent living written by disabled people, which flows directly from their experience and which constitutes the authoritative perspective, or combinations of perspectives, on its meaning. The following section aims only to give sufficient flavour of that meaning for a reader unfamiliar with the concept of independent living to understand its importance to realisation of the Convention's purpose, and to follow the arguments made in Part 2 of the thesis.⁴⁸

Following a brief outline of the history, philosophy and practice of independent living, this section focuses on its sedimentation in Article 19 of the Convention. The negotiation and text of the Article are examined before we turn to the UK in Part 2 of the thesis.

⁴⁷ Ibid

⁴⁸ It is hoped that the reader will then feel moved to explore the literature for themselves to gain a deeper understanding. The Leeds Disability Archive at <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html> offers a useful starting point.

History

The international mobilisation of disabled people,⁴⁹ which has had such a formative influence on international human rights law,⁵⁰ sprang from earlier politicisation at national and local levels.⁵¹ In England, in 1966, Paul Hunt recognised that disability challenges accepted social values in fundamental ways:

disabilities like ours, which often prohibit any attempt at normal living in society, almost force one to consider the basic issues, not only of coping with a special handicap [*sic*], but of life itself... the most acute questions arise and the most radical 'answers' are called for.⁵²

As disabled people came together across impairment boundaries to discuss those acute questions, some radical answers began to unfold.⁵³ The 'social model' of disability⁵⁴ 'was, and remains, the British disabled people's movement's "big idea".⁵⁵

In the United States, one of the early manifestations of disability activism was the spread of Centres for Independent Living (CILs). The first CIL was set up in 1968 by a small group of disabled students from the University of Berkeley, California, known as the 'rolling quads'. As students, despite being accommodated in hospital quarters, they had got used to being part of the mainstream community. When they graduated, rather than accepting the prospect of future dependency, 'they got together and decided to think up ways of actually changing the society that they lived in.'⁵⁶ One result was an organisation that operated on three basic premises: it was led by disabled people, covered all impairments, and had as its objective social change. As Rachel Hurst comments, '[t]hose were quite, well very radical ideas...'.⁵⁷ By

⁴⁹ Hurst (2000) and see Chapter 2 above

⁵⁰ See Chapters 2 and 3 above

⁵¹ See Charlton (2000) Chapter 8; Campbell (1997); Barnes and Mercer (2006) Chapter 3

⁵² Hunt P, 'A Critical Condition' in Hunt P (ed) *Stigma: The Experience of Disability* (Geoffrey Chapman 1966), Leeds Disability Archive

⁵³ Campbell J and Oliver M, *Disability Politics: Understanding Our Past, Changing Our Future* (Routledge 1996); Barton L and Oliver M (eds) *Disability Studies: Past, Present and Future* (The Disability Press 1997)

⁵⁴ See Chapter 1 above

⁵⁵ Goodley (2010) 12; see also Chapter 1 above and Chapter 6 below

⁵⁶ Hurst (2000)

⁵⁷ *Ibid*

1971, just three years later, there were 144 such Centres across the USA, and their model has since spread around the world.

CILs signalled a clear break from the dominant understanding of disabled people as passive individual recipients of charitable services. The CIL was an organisation **of** disabled people with a radical political agenda: far from being passive, these disabled people were active, in control and demanding change. The philosophy of independent living, which developed from these beginnings, became a cornerstone of the US Disability Rights Movement (DRM);⁵⁸ its principles, together with the social model of disability, continue to underpin disability politics, and disabled people's organisations (DPOs), worldwide. Alongside the social construct understanding of disability, 'independent living' acts as a nodal point in disabled people's discourse.⁵⁹ Its emptiness as a signifier enables it to embrace a wide range of histories, viewpoints and aspirations.⁶⁰

Philosophy

Independent living has been described as 'the emancipatory philosophy and practice which empowers disabled people and enables them to exert influence, choice and control in every aspect of their life'.⁶¹ It stands in direct contrast to the 'welfare' model, which sees people as passive recipients of compensation for their exclusion from society.⁶² As Ed Roberts, one of the Berkeley group, explains, '[w]hen people with disabilities come to the conclusion that they have the right to be in the community, to have a say in how that community treats them, they are beginning to develop a consciousness about taking control of their lives and resisting all attempts to give others that control'.⁶³ There is a strong element of antagonistic

⁵⁸ Charlton (2000) 132

⁵⁹ See for instance John Evans' oral evidence to the JCHR inquiry into the implementation of the right of disabled people to independent living, 28 June 2011: disabled people have three main ideas: the social model of disability, independent living, and human rights.

⁶⁰ Though see Part 2 of the thesis for its openness to re-articulation and dislocation

⁶¹ Hasler F 'Philosophy of Independent Living' (Independent Living Institute 2003)

www.independentliving.org/docs6/hasler2003.html accessed 14.4.09.

⁶² Quinn and Degener (2002) 14-19

⁶³ Ed Roberts, quoted in Charlton (2000) 1

resistance to the experience of exclusion and enforced dependency:⁶⁴ this political discourse is not only about autonomy, it is about **anti-dependence**.

A second, related, key element is **control**. Charlton writes that '[t]he DRM's demand for control is the essential theme that runs through all its work, regardless of political-economic or cultural differences. Control has universal appeal for DRM activists because the needs of people with disabilities and the potential for meeting these needs are everywhere conditioned by a dependency born of powerlessness, poverty, degradation, and institutionalisation. This dependency, saturated with paternalism, begins with the onset of disability and continues until death.'⁶⁵ Individual empowerment and self-determination are not only seen as essential in themselves, they are central to a wider resistance to these conditions.

As Hasler explains, 'independent living is more than an individual aim. It encompasses a **change in social relations**.'⁶⁶ Independent living brings disabled people together to work collectively, and with their allies,⁶⁷ for a future where they will all enjoy the day-to-day choices and freedoms that others take for granted. As we have seen, achieving these goals involves a 'deep reconstruction'⁶⁸ of the world, which in turn requires ways of thinking that are incommensurate with the 'ableist', exclusionary language of liberal individualism.⁶⁹ It requires inclusive, collective action to bring about 'respect for difference and acceptance of persons with disabilities as part of human diversity and humanity'.⁷⁰

Moreover, that action must be **holistic**. Independent living means different things for different people. The barriers that they face will vary according to their individual and social circumstances and the choices they make.

⁶⁴ See for example Gabel S and Peters S 'Presage of a Paradigm Shift? Beyond the social model of disability toward resistance theories of disability' (2004) 19(6) *Disability & Society* 585

⁶⁵ Charlton (2000) 3

⁶⁶ Hasler (2003)

⁶⁷ 'Non-disabled professionals, experts, supporters who are 'prepared to share power, share resources and challenge exclusion' Hasler (2003)

⁶⁸ Stein MA, 'Disability Human Rights' (2007) 95(1) *California Law Review* 75

⁶⁹ Young IM, *Justice and the Politics of Difference* (Princeton University Press 1990)

⁷⁰ CRPD Article 3(d)

Independent living is an issue that spans all age groups and stretches right across all areas of social and economic life – through employment, housing, transport, education, health and social care, financial provision and more. As Young recognises, it is necessary to address all aspects of exclusion⁷¹ to overturn the structures and practices of oppression, or to address the ‘multidimensional disadvantages’ of inequality.⁷²

It will be apparent from this brief description that these discursive elements of the philosophy of independent living – *anti*-dependence, control, change in social relations and holistic structural transformation – are not only central to the understandings of the Disabled People’s Movement, but, through them, also central to the CRPD myth⁷³ and to its interpretation. As John Evans commented to the Joint Committee on Human Rights, the whole Convention is about independent living.⁷⁴

We may also see that this political philosophy aims to work through all of the dynamic and interwoven components of hegemonic discourse construction described in Chapter 1: through understandings, systems and identities. The growing social antagonistic construction of new understandings of disabled people’s place in the world forms the basis of the organisational design and ethos of the CIL, of identities of individual disabled people through their consciousness and empowerment.⁷⁵ It seeks to establish new

⁷¹ ‘Being able to grow up alongside non-disabled siblings, going to the neighbourhood school is a dream for many disabled young people today. But it is a dream that can become reality through the principles of independent living. Being able to use the same bus or get the same job as their friends is a dream for many disabled people today. Independent living says that this dream can be turned into real life, through collective action.’ Hasler (2003)

⁷² See Arnadóttir OM, ‘A Future of Multidimensional Disadvantage Equality?’ in Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff Publishers 2009)

⁷³ See Chapter 2 above

⁷⁴ John Evans, disability rights advocate and founding member of Project 81 in oral evidence to the Joint Committee on Human Rights inquiry into the implementation of the right of disabled people to independent living, 28 June 2011

⁷⁵ See Tara, Chapter 1; also for instance Zarb G, ‘Independent Living and the Road to Inclusion’ in Barnes C and Mercer G (eds) *Disability Policy and Practice: Applying the Social Model* (The Disability Press 2004)

systems of social relations through wider attitudinal and structural change.⁷⁶
The agenda is pursued through hegemonic practice.

Practice

As well as founding this empowering, inclusive and holistic philosophy of resistance and emancipation - including a new form of organisation through which to live and deliver that philosophy - the independent living movement has developed practical approaches to try to bring about the kinds of social change it seeks.

One of the first CILs in England⁷⁷ drew up a list of seven 'basic needs' of independent living. They are:

Information – to know what your options are

Peer Support – encouragement and guidance from other disabled people

Housing – a suitable place to live

Equipment – technical aids, to reduce unnecessary dependence on others

Personal Assistance – human help with everyday tasks

Transport – to get where you need to be

Access to the Environment – to go where everyone else does.⁷⁸

This list is not exhaustive – as noted above, 'basic needs' will vary from one person and circumstance to the next – but they constitute a minimum as identified, and generally agreed, by disabled people's organisations.⁷⁹ They are also reflected in Article 19 (and other Articles) of the CRPD.

The organisations *of* disabled people that deliver independent living support generally focus on these areas, campaigning on and providing information and help with housing, equipment, transport and access.⁸⁰ Many focus strongly on personal assistance: lack of such assistance is closely linked to

⁷⁶ See for example Barnes C, 'Independent Living, Politics and Implications for the 21st Century' in Alonso JVC (ed) *El Movimiento de Vida Independiente* (Luis Vives 2003)

⁷⁷ Derbyshire CIL, run by Ken and Mary Davis

⁷⁸ As quoted in Hasler (2003)

⁷⁹ See for example the National Centre for Independent Living (NCIL)

⁸⁰ See for instance NCIL, and members of the DIAL (Disability Information and Advice Line) network; Disability LIB 'Thriving or Surviving: Challenges and Opportunities for Disabled People's Organisations in the 21st Century' (Scope 2008); for further discussion, see Barnes and Mercer (2006) chapters 3 and 5

being forced to live in institutional care.⁸¹ Financial provision is also seen as essential to combat poverty and secure independence.⁸² Beyond these holistic services, however, the defining quality of a CIL is peer support: encouragement and guidance from other disabled people. There are many reasons for this. One is the high level of specialist expertise and local knowledge that these organisations have developed. Others are the personal expertise of those who work in the organisation, drawn from their own experiences of disability; and the overall accessibility of the organisation and its services. But it goes further even than this.

Realisation of independent living requires a change in power relations at both individual and collective levels. We have seen that individual responses to negation of identity, such as that experienced by many disabled people, range from open confrontation to self-blame or resignation; and that people frequently internalise the *dis*-ability imposed on them by 'normality' discourse. Escape from that response – to become 'the person you always thought you were but never could be'⁸³ – is both pre-requisite for and consequence of independent living. The power relationship between individual and CIL is one that recognises and shares that experience: it is one of respect, equality and empowerment as against disrespect, discipline and oppression.⁸⁴

⁸¹ Many CILs & DIALs in the UK have been contracted to provide support to recipients of direct payments/individual budgets who employ their own personal assistants. The European Network on Independent Living also focuses on personal assistance as a key component of independent living (www.enil.eu), as do other CILs around the world, for instance the Institute of Independent Living (www.independentliving.org) based in Sweden

⁸² 'The effect of increased income on other outcomes, through take-up of disability welfare benefits, is marked; in particular in reducing social exclusion' Benson/Waterhouse Consultancy with DIAL Waltham Forest, 'Hidden Benefits: the value of DIAL advice work' (DIAL UK 2003). 92% of respondents to this research report positive outcomes relating to practical (income, services, transport, access), health, quality of life and personal issues.

⁸³ See Tara Chapter 1

⁸⁴ 'I feel like I have a friend who will look after me and fight for my rights'; 'For the first time in a long time I felt someone was listening to my needs, which makes me feel very happy': respondents to Benson/Waterhouse Consultancy (2003) 20; Barnes C and Mercer G (2006) chapter 7; Lord Chancellor's Department and Law Centres Federation 'Legal and Advice Services: a Pathway Out of Social Exclusion' (LCD 2001); Gee A and Holdsworth M (ed) 'Regeneration and Renewal: a good practice guide for London advice agencies' (London Advice Services Alliance 2002); see also Peter Beresford video on the benefits of working with ULOs on Social Care Institute for Excellence, 'A Commissioner's Guide to Developing and Sustaining User-led Organisations' SCIE Guide 36

<http://www.scie.org.uk/publications/guides/guide36/> last accessed 16.9.12

This organisational model also captures and puts into practice the holistic, inclusive and collective nature of independent living philosophy, working together 'from below' to bring about change not only in the lives of individuals but also in the wider community.⁸⁵ The importance of organisations **of** disabled people in bringing about change has been clear from the history related so far in this thesis. That history demonstrates that not only individual identities but also systems and practices, including law, may be influenced as this hegemonic practice articulates and re-articulates its discourse.

Elements of disabled people's independent living discourse are reflected in many settings, including the UK government policy discussed in Chapter 6 below. And they are reflected throughout the Convention. Accessibility is a general principle under Article 3. Article 9 requires the elimination of obstacles to access to the environment, including transport, schools, housing, workplaces and communications - a requirement echoed throughout the Convention. Mobility aids and other assistive devices and technologies must be researched, promoted and made available.⁸⁶ Professionals and staff working with disabled people are to be trained so as to better provide the personal assistance and services guaranteed by the Convention.⁸⁷ The freedom of disabled people to form and join their own organisations is to be actively promoted and encouraged;⁸⁸ and those organisations are to be involved at all levels of the implementation process.⁸⁹

The Article that most clearly encapsulates the concept of independent living itself is Article 19: the right to live independently and participate in the community, which is considered next.

⁸⁵ Disability LIB Alliance (2008); NCIL 'Independently' Newsletter; Disability Rights UK website <http://www.disabilityrightsuk.org/> last accessed 1.9.12

⁸⁶ Article 4(f), (g) & (h); Article 20, personal mobility; Article 26, habilitation and rehabilitation

⁸⁷ Article 4(i)

⁸⁸ Article 29(b)(ii)

⁸⁹ Article 29(b)(ii)

Article 19

Under Article 19 Living independently and being included in the community:

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance, necessary to support living in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Quinn reports that the insertion of Article 19 was ‘rightly challenged by Governmental representatives, who said that there was no precedent for it elsewhere’.⁹⁰ This is indeed one of several CRPD Articles that initially appear to create ‘new’ rights, a power explicitly beyond the remit of the drafters.⁹¹ ‘But, of course,’ Quinn continues,

the argument that won at the end of the day was that this is because one assumes a capacity for freedom and choice. Whereas, in the disability context, we must go the extra mile to ensure people have the highest level of attainment to functioning, in order to enjoy the blessings of freedom.⁹²

The Chair of the negotiating committee identified

three views expressed on this matter of rights: (1) there is no right created in this Article, (2) the elements of the chapeau as a whole are a

⁹⁰ Quinn (2008) 6

⁹¹ Others are Article 20, personal mobility and Article 26, habilitation and rehabilitation

⁹² Quinn (2008) 6

right, and thus the word “right” should be in the chapeau, and (3) that the right is only in relation to 19(a).⁹³

The fact that this debate took place at all exemplifies the failure of others to see or address the human consequences of the exclusion, segregation and objectification of disabled people. As we have seen, independent living, when understood in the sense developed by disabled people, directly challenges those deep-seated attitudes and practices. It demands visibility, the right to have rights and to exercise them on an equal basis, and in community, with others. In so doing it pushes traditional liberal human rights understandings of autonomy and equality to encompass the experience of disability, and of those who may not exercise their autonomy in the same way as others. As such, Article 19 is arguably one of the most important rights set out in the Convention, a key feature of the terrain: without the actual choice, control and freedom it requires, the exercise of all other rights is compromised.

During drafting, some negotiators were keen to stress that Article 19 should not be seen as endorsing the independent living movement, the term ‘to live independently’ being preferable to ‘independent living’ for that reason.⁹⁴ Early in the negotiations, some expressed concern that the words ‘living independently’ did not reflect the cultural norm in many countries, and that the words might be misconstrued as meaning that disabled people should be separated from their families,⁹⁵ or as applying only to those capable of living in the community without support, thus negating the purpose of the Article.⁹⁶ However, retaining the concept was important to many delegations,⁹⁷ and by the 7th (pen-ultimate) session the Chair felt that consensus had been reached for using the term ‘living independently’ with the understanding that it was intended to reinforce the concept of ‘community living’.⁹⁸

⁹³ Daily Summary 7th session, 20 January 2006 morning session.

⁹⁴ For instance Thailand, Daily Summary, Third session, January 8 2004

⁹⁵ For example footnote 51 to Working Group text of draft Article15; Ontario Human Rights Commission, Comments, proposals and amendments, Third Session, 5

⁹⁶ Israel Position Paper for the 7th Ad Hoc Committee - First week 12 January 2006

<http://www.un.org/esa/socdev/enable/rights/ahc7israel.htm>

⁹⁷ Chair’s summary, 7th session, Jan 20th 2006

⁹⁸ The Chair, Daily Summary 7th session, 19 January 2006 afternoon session

'Independent living' has been identified above as a nodal point in disabled people's discourse, where it serves as surface of inscription for anti-dependence, control, change in social relations and holistic structural transformation. All of these discursive elements figured strongly in negotiation of Article 19 and are integrated throughout the Convention. Given the influence of disabled people through the participatory drafting process, this is not surprising. However keen the drafters to distance themselves from the independent living movement itself,⁹⁹ the concept of independent living as understood by that movement is so deeply ingrained that it is impossible to extract it from the Convention myth.

In the process of these discussions, there was wide agreement that autonomy and personal choice were at the heart of the article.¹⁰⁰ In Chapter 2, we touched on some of the assumptions made in liberal understandings of autonomy, and how disability/human rights discourse challenges those assumptions with its re-description of the world, and its re-positioning of those who are not autonomous in the same way as the 'able liberal subject'. In Article 19, we find encapsulation of that central challenge. The Article is also about inclusion. Anti-dependence and non-institutionalisation featured strongly throughout the negotiations. For instance, the World Network of Users and Survivors of Psychiatry explain that 'the issue here is the perception by others that PWD [persons with disabilities] need to be segregated from society, where a person without a disability makes the decision for/about the PWD, and the need for a shift away from this paradigm. Here the institution becomes a prison. So autonomy is the central issue in institutionalization.'¹⁰¹ Changing those perceptions, and the knowledge, power systems and identities they have established, is central to the hegemonic project. As the Chair of the negotiating committee confirmed,

⁹⁹ One manifestation of this tension can be seen in the discussions surrounding translation and interpretation of Article 19 in countries across Europe. See Jolly D, 'Personal Assistance and Independent Living: Article 19 of the UN Convention on the Rights of Persons with Disabilities' (undated) Paper for European Network on Independent Living, available on Leeds Disability Archive

¹⁰⁰ See for instance contributions from Thailand, New Zealand, Germany, Ireland, Rehabilitation International, and World Network of Users and Survivors of Psychiatry (WNUSP), Daily Summary, Third session, January 8 2004

¹⁰¹ WNUSP Daily Summary Third session, January 9, 2004, morning session

'Article 19 is fundamental towards the [Convention's] goal of a paradigm shift'.¹⁰²

In its final form, the head of the Article reaffirms disabled people's rights to inclusion, autonomy and participation, echoing the core CRPD principles set out in Article 3¹⁰³ and supported in preamble paragraphs (n):

(n) *Recognizing* the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,

and (m):

(m) *Recognizing* the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty.

Typically for this Convention,¹⁰⁴ Article 19 then goes on to enlarge the scale by mapping in some of the measures States should take to facilitate enjoyment by disabled people of this right. Article 19(a) goes straight to the heart of the matter, overturning enforced dependency and institutionalisation to grant choice of their living arrangements to disabled people themselves. This provision builds on ICCPR Article 12(1), CERD Article 5(d)(i) and CEDAW Article 15(4), all of which set out a right to freedom to choose one's residence.¹⁰⁵

Implementation of Article 19(b) offers the person the social support they need to function autonomously in their chosen home and to have access to their community, particularly to prevent isolation and segregation. During negotiation, some expressed concern that this text did not recognise the right

¹⁰² Daily Summary 7th session, 19 January 2006 afternoon session

¹⁰³ Article 3(a), respect for dignity, autonomy, choice and independence; Article 3(c), full and effective participation and inclusion in society; Article 3(d), respect for difference and acceptance of disabled people as part of human diversity

¹⁰⁴ See Chapter 3 above

¹⁰⁵ See Article 19 Background Documents, References, 7th Session

of the person to control these supports and services.¹⁰⁶ By contrast, the UK, on behalf of the EU, argued in favour of deleting this provision altogether,¹⁰⁷ despite its foundation in the Standard Rules.¹⁰⁸

Article 19(c) seeks to ensure that, once in that community, general facilities and services are available without discrimination, so as to enable the person to benefit and to contribute on an equal basis with others.

If we compare these provisions with the ‘seven needs’ of independent living, above, we find just two out of the seven here: housing, and personal assistance. The original Working Group text included an additional requirement that ‘(d) persons with disabilities have access to information about available support services’.¹⁰⁹ This provision was later subsumed into States’ general obligations under Article 4.¹¹⁰ As noted above, the remaining ‘needs’ for equipment, transport, access to the environment and peer support are similarly found elsewhere in the Convention.

Whilst Article 19 rights to inclusion, autonomy and participation, including the right to choose one’s residence, fall squarely into the civil and political category, access to the housing options, support services and community facilities essential for their realisation belong in the economic, social and cultural domain. Article 19 thus demonstrates the CRPD’s inseparable fusion of the two ‘sets’ of rights discussed in Chapter 3 above. Here, the interdependence and indivisibility of rights becomes particularly ‘sharp’. As Serbia and Montenegro recognised early in negotiations, ‘one of the

¹⁰⁶ IDC written proposal in advance of Seventh Session, and Daily Summary 7th Session, 20 January 2006: the IDC ‘supported Brazil’s position that “assistive technologies” and “peer support” be included, noting that such supports should be delivered in a manner that respects autonomy, individuality and dignity.’

¹⁰⁷ See Daily Summary, 6th Session, 1 August 2005, morning session, and Comments, proposals and amendments, 6th session, European Union

¹⁰⁸ Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1994, ‘Rule 4 Support services: States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights...’

¹⁰⁹ Working Group text 2004, draft Article 15 independent living (in earlier versions of the text)

¹¹⁰ Article 4(h): To provide accessible information to persons with disabilities about... other forms of assistance, support services and facilities.

preconditions to exercise the freedom of choice of where to live would be the necessary support.¹¹¹ Far from fulfilling a ‘welfare’ role in compensating disabled people for their *exclusion*, economic, social and cultural rights here take on the ‘enabling’ function vital to their *inclusion*.¹¹² They are thus key to repositioning disabled people as full, equal and active subjects in the new, accessible and welcoming world: once all of the provisions of this Article are realised, ‘the place of disabled people is everywhere’,¹¹³ and the hegemonic project is on its way.

However, as we have seen, whereas civil and political rights are to be implemented immediately, economic, social and cultural rights may be subject to ‘progressive realisation’. Whilst there was general acceptance among the Convention drafters that this was the case,¹¹⁴ how to address this dichotomy in the context of Article 19 engendered much discussion. One proposal¹¹⁵ that was accepted was to soften the head of the article by replacing ‘take... measures to *enable*’ disabled people to live independently with ‘take... measures to *facilitate*’ them to do so (emphases added). As with the replacement of ‘fulfil’ with ‘ensure’ in the Convention’s purpose clause,¹¹⁶ this change subtly alters the projection of the Article, reducing the imperative of socio-economic duties set out in subparagraphs (a), (b) and (c) to allow for progressive realisation. The EU suggested taking this alteration further by amending the end of the Chapeau to read ‘including *measures aimed at ensuring that...*’ rather than directly imposing a duty on States to ‘*ensure that...*’.¹¹⁷ This proposal was not agreed. Further discussion ranged around whether or not to include the words ‘to the maximum of available resources’

¹¹¹ Daily Summary, Third session, January 9, morning session

¹¹² See Chapter 2 above

¹¹³ Vienna Declaration and Programme of Action 1993, section II B 6

¹¹⁴ Chair, Daily Summary 6th Session, 1 August 2006, morning session

¹¹⁵ Supported by the EU, Thailand, Costa Rica and Republic of Korea. The Chair expressed concern that ‘facilitate’ was ‘not linguistically correct’. Daily Summary 6th Session, 1 August 2006, morning session.

¹¹⁶ See Chapter 3 above

¹¹⁷ Daily Summary, 6th Session, 1 August 2005, morning session, and Comments, proposals and amendments, 6th session, European Union.

in Article 19. Although various alternatives were suggested,¹¹⁸ it was eventually decided to reflect this issue generically in Article 4(2).¹¹⁹

Nevertheless, it remains the case that key elements of Article 19 are economic, social and cultural rights, and therefore subject to progressive realisation. As Serbia and Montenegro commented during negotiations, '[t]his is complicated by the centrality of freedom of choice in the article, which has more immediate implementation implications.'¹²⁰ As we have seen above, those implications relate not only to realisation of Article 19, but also to the other Convention rights that depend on realisation of Article 19 for their implementation. How the economic, social and cultural rights set out in Article 19 are implemented will therefore have a determinative effect not only on disabled people's experience – or otherwise – of living independently and being included in the community but also on their opportunity – or otherwise – to exercise all Convention rights. From a political discourse perspective, how these economic, social and cultural rights are understood, how systems of social relations are established to reflect that understanding, and how, in practice, they impact on the lives and identities of disabled people will determine whether – or not – the hegemonic project succeeds in repositioning disabled people in the world and thus in translating the Convention myth into imaginary. For these reasons, Article 19 is chosen in Part 2 of the thesis as 'barometer' for progress – or otherwise – of the hegemonic project in England.

Article 19 is emancipatory law *par excellence*. It is designed to contest oppression by bringing about 'a new political relationship'¹²¹ between the experiences and expectations of both disabled and 'non-disabled' people. It seeks to stabilise those expectations on a new and more demanding and inclusive level through a new form of regulation 'whereby its good order

¹¹⁸ Such as 'make every possible effort', Republic of Korea; 'to the maximum extent possible', Thailand. Daily Summary, 6th Session, 1 August 2005, morning session

¹¹⁹ See Chapter 3 above

¹²⁰ Daily Summary, 7th Session, 20 January 2006, morning session

¹²¹ Santos (2002), see Chapter 2 above

becomes order.¹²² Similarly, it is expressive law: 'a process through which actor identities and interests may be shaped and reconstituted.'¹²³ But at this stage, the Article's emancipatory, expressive potential has yet to be fulfilled.

Once the right to live independently and be included in the community, with its accompanying histories and understandings, is embedded in international law, its realisation becomes a requirement in widely differing political and cultural settings around the world.¹²⁴ Such realisation will depend on the manner of its reception into those national settings: acceptance of the myth and its transformation into imaginary will succeed or fail accordingly.¹²⁵ All manner of social antagonisms, dislocations and re-articulations await it along the way. Furthermore, we have identified 'independent living' as a nodal point in disabled people's discourse. Such nodal points are effective precisely because of their emptiness as a signifier, which allows the discourse to take in and incorporate new discursive elements with which a range of actors can identify.¹²⁶ Whilst this may assist in absorbing social antagonism and neutralising dislocations, it may equally lead to partial or mis-interpretations; to re- or mis-appropriation by other, more powerful, discourses; and to application in contexts far removed from the principles and practices from which it grew.¹²⁷ It may even become a new expression of old and unchanged oppression.¹²⁸ Whether or not Article 19 achieves its emancipatory potential will depend on many factors, not least the ability of disabled people and their supporters to retain ownership of its meaning, its interpretation and its application.¹²⁹

¹²² Santos (2002) 2-3, see Chapter 1

¹²³ Stein and Lord (2009) 31-35, see Chapter 1 above

¹²⁴ See for instance Parker C and Clements L 'The UN Convention on the Rights of Persons with Disabilities: a new right to independent living?' (2008) 4 European Human Rights Law Review 508

¹²⁵ See also Philip Alston (2001)

¹²⁶ See Chapter 1 above

¹²⁷ Quinn (2009) 6

¹²⁸ Hodgkins SL, 'Discoursing Disability: the Personal and Political Positioning of Disabled People in Talk and Textwork' PhD Thesis, University of Northampton, September 2008, Chapter 8, 277

¹²⁹ Collingbourne T, 'The UN Convention on the Rights of Persons with Disabilities and the Right to Independent Living', Paper for the European Network on Independent Living, July 2009

Conclusion

This thesis began by introducing the 'viewpoint' of political discourse theory. From that viewpoint, the social world is seen as consisting of ever-changing and dynamic discourses. As they compete for hegemony, such discourses incorporate or exclude discursive elements, establish systems of social relations and form the identities of social actors. Chapter 2 described the formation of one such discourse: a new international disability/human rights discourse which succeeded in setting a new agenda at the UN. This discourse presents a re-description of the world and of the place of disabled people in it. Here, the world is accessible and welcoming; impairment is no longer seen as an aberration to be 'othered', but as universal human variation to be accepted, respected and accommodated; and disabled people are no longer excluded recipients of welfare, but are included as active, valued and equal rights-holders. The new discourse succeeds in initiating a participatory hegemonic project aimed at sedimenting this vision into international human rights law.

Law is understood here as one method of articulating and regulating systems of social relations. The CRPD drafting project can thus be seen as one method by which the international disability/human rights discourse may seek to dominate the field of meaning, by creating a new legal order through which its particular combination of norms, values, views and perceptions can circulate within national societies around the world. Chapter 3 has examined that 'revolving door': the new hegemonic formation which is the UN Convention on the Rights of Persons with Disabilities. It has examined the Convention text, in line with the Vienna Convention on the Law of Treaties, in its context, including its Preamble, and in the light of its object and purpose, its travaux préparatoires and the circumstances of its conclusion. Metaphors of scale and projection drawn from Santos' 'cartography of law' have served to highlight the Convention's central purpose and principles, its flexible boundaries, its projection of all human rights through the experience of disability.

This Chapter has examined the dynamic implementation systems the Convention puts in place to try to ensure that the hegemonic project continues to expand. If that project succeeds, the disability/human rights myth encapsulated in the Convention will come to represent a 'default' system of meanings that underlies and structures our societies. The myth of disability rights will become imaginary, and 'good order' will become order.

This Chapter has also looked in more depth at one right which is fundamental to that transformation. Article 19, the right to live independently and be included in the community, has been identified as encapsulating core elements of disability/human rights discourse, and as clarifying the means through which other Conventions rights are realised. As a 'hybrid' right, Article 19 exemplifies the Convention's fusion between the two 'sets' of rights: realisation of its socio-economic provisions is a pre-requisite for exercise of its civil and political rights to autonomy and participation. How these socio-economic provisions are implemented will therefore have a determinative effect not only on realisation of Article 19, but also on exercise of all Convention rights and on success or otherwise of the hegemonic project. For that reason, implementation of the economic, social and cultural rights set out in Article 19 has been chosen as a 'barometer' of that success in Part 2 of the thesis.

By 2007, the myth has arrived and has been mapped. The new disability/human rights agenda is now entrenched in international human rights law. As Quinn comments, '[w]hatever happens now, there is no going back. Disability has moved to the core of the UN human rights agenda in theory'.¹³⁰ The 'startling instrument'¹³¹ that is the CRPD was the fastest-drafted international human rights convention;¹³² it achieved the greatest

¹³⁰ Quinn (2009) 256

¹³¹ Lawson (2006-2007) 619

¹³² United Nations, 'From Exclusion to Equality', UN Handbook for Parliamentarians, no 14, (2007) 1; see also UN High Commissioner for Human Rights 'Annual Report of the Nations High Commissioner for Human Rights... Thematic Study... on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities' A/HRC/0/48, 26 January 2010 para 5

number of signatories on its opening day,¹³³ and came into force just over one year later.¹³⁴ Despite this enthusiastic international reception, there is no guarantee that it will succeed, where its predecessors failed, in bringing about the 'deep reconstruction' of meanings, systems and identities it aims to achieve. All myths are constantly at risk of being undermined in their turn by social antagonisms or by dislocatory events beyond their control. As Charlton identifies,

[t]here are... two sides to the 'permanence' of disability oppression. On one side is the capacity of oppressive structures and institutions to reproduce themselves through the myriad power relationships in everyday life. On the other side is the inevitability that oppression will generate its opposites – resistance, empowerment, and, from these, potentially, liberation and freedom.¹³⁵

Whether or not this myth survives, and whether it achieves its ultimate emancipatory goal to become 'imaginary' will depend on the power of the disability/human rights discourse in all its forms to continue to incorporate and accommodate those antagonisms into its own project, to produce a 'new practice of disability politics'¹³⁶ and thus to build its hegemony.

Supporters of this transformation argue for 'persuasion', 'socialisation' and education as means to achieve the Convention's objectives. Quinn argues that

we should view the Convention less as a means for coercing States and more as a powerful tool for enabling its revolutionary insights to percolate into the political process (by 'persuasion' and 'socialisation') and hence transform the political process to the point that justice and rights for persons with disabilities is seen as the primary departure point and not as an annoying distraction.¹³⁷

¹³³ 81 signatories 30 March 2007 <http://www.un.org/disabilities>. As at 1.9.12 there were 153 signatories to the Convention, and 90 signatories to the Optional Protocol; 119 ratifications and accessions to Convention, and 72 ratifications and accessions to the Protocol.

<http://www.un.org/disabilities/countries.asp?navid=12&pid=166> accessed 1.9.12

¹³⁴ The Convention came into force with its Optional Protocol on 3 May 2008

¹³⁵ Charlton (1998) 153

¹³⁶ Quinn G, 'Resisting the Temptation of Elegance': Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in Arandóttir and Quinn (2009) 256

¹³⁷ Ibid 256: 'The dynamics of this process will call for the emergence of new political entrepreneurial skill on the part of civil society with respect to the multiple layers of actors at the international level and especially with respect to Governments and national institutions. It calls on civil society groups to come forward not merely with considered judgments about what is wrong but also with even more considered blueprints for change.'

By 'persuasion', Quinn refers to the potential for internalisation and 'ownership' of the Convention's values by States. 'Socialisation' entails actors within States adopting those beliefs and behavioural patterns, thereby becoming socialised to align policy with Convention values and bring about meaningful change.¹³⁸ In political discourse terms, this may be seen as the establishment of national systems of social relations and the provision of subject positions with which social actors identify. As will be demonstrated in Part 2 below, ownership, internalisation and socialisation of the Convention beliefs and values are vital not only to political change, but also to legal and administrative change.

Stein and Lord argue that

the CRPD should be regarded as an educative tool insofar as it can serve to teach mainstream society about the life circumstances of persons with disabilities by providing information regarding their relative position. Its potential may be fully realized provided the provisions in the Convention supporting its use as an educational tool are fully implemented by both State and non-State actors. In this respect, the CRPD's narrative regarding the unnecessary and amenable nature of the historical exclusion of persons with disabilities across societies can serve a vital function beyond the particular implementation of its substantive obligations in law and policy.¹³⁹

But law and policy are vital too. Law is one method of articulating and regulating systems of social relations. The disability/human rights myth has been set down in a new international legal order. States Parties are the primary duty-holders under that legal order. They deliver their international law obligations through domestic policy, law and administration. How they do so will be shaped by the constellations of power and knowledge that already circulate in their national arenas. Those domestic discourses, too, will influence the shaping of social practices and the identities of social actors. The extent to which domestic policy, law and administration reflect the intentions of the Convention's drafters will depend not only on the power of the emancipatory disability/human rights myth, but also on its reception in domestic settings. As Philip Alston remarks, 'what ultimately matters is what

¹³⁸ Ibid 219

¹³⁹ Stein and Lord (2009) 32-34

is done, perhaps in conjunction with [international] measures, at the national level'.¹⁴⁰

Part 2 of the thesis turns to the UK. **Chapter 5** stays in the international arena to explore broader domestic understandings of human rights as evidenced in successive UK governments' dialogue with the UN Committee on Economic, Social and Cultural Rights. **Chapters 6 to 9** delve into the intricacies of independent living in England, examining understandings through policy, systems through legislation, and identities through decision-making and redress. **Chapter 10** draws the thesis to a close with conclusions and recommendations.

¹⁴⁰ Alston (2001)

PART 2

Implementation in England

Chapter 5

The United Kingdom and economic, social and cultural rights

Introduction

Part 1 of this thesis described the disability/human rights myth, the sedimentation of that myth in the UN Convention on the Rights of Persons with Disabilities, and its implementation provisions designed to ensure that the hegemonic project continues to expand to translate the myth into imaginary. Whether, or to what extent, that project succeeds will depend not only on the power of the myth itself and of its legal order, but also on the antagonisms and dislocations it meets in the domestic sphere. **Part 2** of the thesis turns to the UK. **This Chapter** examines UK understandings of economic, social and cultural rights as evidenced in the international arena. The following chapters focus on the implementation of those rights in England, taking Article 19, the right to live independently and be included in the community, as case study.

The UK is often seen as one of the most neo-liberal States in Western Europe.¹ According to McFarlane, its society has for centuries² existed

¹ O'Cinneide C, 'Socio-economic Entitlements and the UK Rights Framework' (2005) Irish Human Rights Commission Conference on Economic, Social and Cultural Rights: Model of Enforcement, Dublin, 9/10 December 2005, 1

² 'England was as 'capitalist' in 1250 as it was in 1550 or 1750': McFarlane A, *The Origins of English Individualism* (Blackwell 1978) 195-96

within a capitalist discourse³ springing from a long-ingrained and idiosyncratic kind of individualism peculiar to England.⁴ This kind of individualism, with its particular understandings of liberty and equality,⁵ helped to form the philosophies of the Enlightenment⁶ and the classical free-market economics of Adam Smith.⁷ Although it has a long history of civil liberties,⁸ has played an active role in developing the modern international human rights framework,⁹ and is party to all of the main international human rights treaties,¹⁰ it was not until 2000 that the UK introduced human rights protection into its domestic law.¹¹ The European Convention on Human Rights (ECHR) 'brought home' through the Human Rights Act 1998 focuses overwhelmingly on civil and political rights.¹²

Even this limited introduction of human rights into domestic law met with some fierce political resistance.¹³ Despite campaigns¹⁴ to counter such

³ With a developed market, mobility of labour, private ownership and commoditisation of land, with individual geographical and social mobility, rational accounting and widespread pursuit of profit: McFarlane (1978). See also Adam Smith's 'nation of shop-keepers': Smith A, *An Inquiry into the Nature and Causes of the Wealth Of Nations* (1776)

⁴ In his view, this explains 'why England should have been precocious in its economic and social development in the eighteenth and nineteenth centuries, for it had been different [to its neighbours] for a very long period.' McFarlane (1978) 201

⁵ Ibid 197

⁶ In England, the liberal utilitarianism developed by Bentham and J.S.Mill reflects this history, emphasising values of secular individualism and rational self-interest and legitimating policies favouring the majority at the expense of the few; see Berlin I, *The Age of Enlightenment* (Mentor 1956)

⁷ Founded on free market competition and the rational 'economic' man. McFarlane (1978) 199

⁸ Magna Carta 1215, Bill of Rights 1688 etc. See for instance Fenwick H, *Civil Liberties and Human Rights* (Routledge-Cavendish 2010)

⁹ For example in drafting the European Convention on Human Rights 1950; leading development of the World Millennium Goals 2000 and more. See UK Report to first UN Universal Periodic Review, 2008

¹⁰ UK Fifth Report to UN Committee on Economic, Social and Cultural Rights, 16-24; see also 2004 review of UK human rights commitments: Department for Constitutional Affairs, 'Interdepartmental Review of International Human Rights Instruments' (2004)

¹¹ Human Rights Act 1998

¹² The right to education (Protocol 1, Article 2) is more concerned with the freedom of parents to choose the education of their child than on the right to education of the child. It will be seen in Chapter 9 that since 2000, domestic courts have occasionally interpreted ECHR jurisprudence to support some socio-economic entitlements. See also O'Cinneide C, 'Socio-economic Entitlements and the UK Rights Framework' (2005) Irish Human Rights Commission Conference on Economic, Social and Cultural Rights: Model of Enforcement, Dublin, 9/10 December 2005

¹³ Human Rights Insight Project, Ministry of Justice Research Series 1/08, January 2008 <http://www.justice.gov.uk/publications/research100108.htm> accessed 10.3.08

¹⁴ British Institute for Human Rights 'Something for Everyone: the impact of the Human Rights Act and the need for a Human Rights Commission' (BIHR 2002); Ministry of Justice,

resistance, the 'human rights culture' it was designed to encourage¹⁵ has been slow to materialise;¹⁶ antagonistic discourse persists;¹⁷ and, at the time of writing, the fate of the Human Rights Act itself still hangs in the balance.¹⁸ As Shami Chakrabarti comments, '[n]o modern Bill of Rights can have had such a testing infancy.'¹⁹ Meanwhile, economic, social and cultural rights enjoy no constitutional protection in UK law, and remain invisible in domestic human rights discourse.²⁰

'Making sense of human rights: a short introduction' (2006); Ministry of Justice, 'Human Rights: Common Values, Common Sense' (undated); Ministry of Justice, 'Review of the Implementation of the Human Rights Act' (2006); Lord Falconer of Thoroton, 'Human Rights and Common Sense', Harry Street lecture, Manchester University, 9 February 2007; Department of Constitutional Affairs, 'Human Rights Fact 'n' Fiction' (undated); Ministry of Justice, 'Human Rights Insight Report' Ministry of Justice Research Series 1/08 (January 2008); Liberty, 'The Human Rights Act – what's not to love?' <http://liberty-human-rights.org.uk/whatsnottolove/index.htm> accessed 10.3.08; Liberty, 'The Human Rights Act: Exploding the Myths' (Liberty 2006); Human Rights Lawyers' Association, 'Human Rights – Home to Stay' (HRLA 2008); Ghose K, 'This human rights hysteria threatens every one of us' (The Guardian, Wednesday August 22 2007)

¹⁵ Mike O'Brien MP, Parliamentary Under-Secretary of State for the Home Department, HC Deb col 1322, 21 October 1998; Lord Irvine of Lairg, Lord Chancellor; Joint Committee on Human Rights, 'Implementation of the Human Rights Act', Second Special Report session 2000-2001, Minutes of Evidence, 19 March 2001, HL 66-ii/HC 332-ii, para 38; Gordon R, 'The Impact of the HRA on English Public Law – a practitioner's view' (2005) British Institute of International and Comparative Law, London 2005

¹⁶ Audit Commission, 'Human Rights: Improving Public Service Delivery' (Audit Commission 2003); Butler F, 'Improving Public Services: Using a Human Rights Approach' (Institute for Public Policy Research 2005); Matthews L, Sceats S, Hosali S and Candler J, 'The Human Rights Act – Changing Lives' 2nd ed (British Institute of Human Rights 2008)

¹⁷ See for instance Ghose (The Guardian 2007) supra; Straw J, 'The Future of British Human Rights Legislation' (2007) Mackenzie Stuart Lecture, University of Cambridge Faculty of Law, 25 October 2007; Straw J, 'Human Rights Act 10 years on' (2008) Speech to the British Institute of Human Rights Conference, London 21 October 2008; Straw J, Speech to mark the 10th anniversary of the Human Rights Act at the Annual Human Rights Law Conference, London, 21 October 2008; see also Maiman R 'We've Had To Raise Our Game': Liberty's Litigation Strategy Under the Human Rights Act 1998' in Halliday S and Schmidt P (eds) *Human Rights Brought Home: Socio-Legal Perspectives on Human Rights in the National Context* (Hart 2004); Clements L and Morris R 'The Millennium Blip: The Human Rights Act 1998 and Local Government' in Halliday and Schmidt (2004)

¹⁸ 'Human rights cave-in: Cameron pledged to scrap Act... now Clegg champions it under ANOTHER coalition compromise' *The Daily Mail*, 20 May 2010. <http://www.dailymail.co.uk/news/article-1279544/Nick-Clegg-champions-Human-Rights-Act-David-Cameron-pledged-scrap.html#ixzz0wya6yTMz> accessed 20.5.10. For update on the Coalition government-appointed Bill of Rights Commission, see Postscript below.

¹⁹ Preface to Liberty, *Common Sense: Reflections on the Human Rights Act* (Liberty 2010)

²⁰ See below and Chapters 6 to 9 for more detailed discussion; see also Van Beuren G 'Including the Excluded: the Case for an Economic, Social and Cultural Human Rights Act' [2002] Public Law 456; Ewing KD 'Social Rights and Constitutional Law' [1999] Spring, Public Law 104; O'Cinneide C, 'Socio-economic Entitlements and the UK Rights Framework' (2005) Irish Human Rights Commission Conference on Economic, Social and Cultural Rights: Model of Enforcement, Dublin, 9/10 December 2005

The UK also has a long history of excluding disabled people.²¹ In response to political pressure, however, disabled people's rights have recently acquired some legal protection. The Disability Discrimination Act was passed in 1995²² and developed incrementally to include not only duties not to discriminate and to make reasonable adjustments in employment, education and housing, but also a positive public sector duty to promote disability equality.²³ Its provisions have now been incorporated into the Equality Act 2010.²⁴

The Human Rights Act 1998 and the Equality Act 2010, with their related case law,²⁵ make up the key legal dimensions of disability equality and human rights discourse in the UK.²⁶ For government, they constitute evidence that the UK 'has become a world leader in disability rights', with 'robust anti-discrimination and human rights legislation' already in place.²⁷

However, one important ingredient is missing. As Quinn *et al* reiterate, 'in the context of disability... the removal of barriers through civil rights and non-

²¹ See discussion in Chapter 6 below. Also Borsay A, *Disability and Social Policy in Britain since 1750* (Palgrave Macmillan 2005); Oliver M, *The Politics of Disablement* (Palgrave Macmillan 1990); Barnes C, *Disabled People in Britain and Discrimination: a Case for Anti-Discrimination Legislation* (Hurst 1991)

²² The first of its kind in Europe, enacted following many years of campaigning by disabled people. See Barnes (1991) Appendix to Chapter 10; Doyle B, 'Enabling Legislation or Dissembling Law? The Disability Discrimination Act 1995' (1997) 60(1) *Modern Law Review* 64

²³ Disability Discrimination Act 1995, as amended by Disability Discrimination Act 2005, Part 5, ss49A – 49F; for discussion see O'Conneide C, 'Disability Discrimination' in Bamforth N, Malik M and O'Conneide C, *Discrimination Law: Theory and Context*, 1st ed (Sweet & Maxwell 2008); Doyle, B, *Disability Discrimination: law and practice*, 6th ed, (Jordans 2008)

²⁴ With some differences: see Wadham *et al*, *Blackstone's Guide to the Equality Act 2010* (Oxford University Press 2010); Government Equalities Office and Equality and Diversity Forum 'Equality Act 2010: What do I need to know? Disability Quick Start Guide' (2010); Ashtiany S, 'The Equality Act 2010: Main Concepts' (2010) 5 *Equal Rights Review* 25; Jefferson M, 'Discrimination Law to Equality Law' (2010) Association of Law Teachers conference, April 2010; Hepple B, *Equality: the new legal framework* (Hart 2011)

²⁵ Including Disability Discrimination Act case law; see also Bindman G, 'Interaction between equality and human rights principles' (2007) *Disability Rights Commission Legal Bulletin* 12 Legacy Edition 78

²⁶ The Equality Act 2010 is law for Great Britain rather than for the UK, having effect in England, Scotland and Wales. (Almost all of) the Act does not apply in Northern Ireland, as equal opportunities and discrimination are areas of legislative responsibility transferred to the Northern Ireland Assembly under the Northern Ireland Act 1998, Schedule 2: Wadham *et al* (2010) para 1.1. See also Daw R 'The Impact of the Human Rights Act on Disabled People' (Disability Rights Commission 2004)

²⁷ Explanatory Memorandum to Command Paper containing text of the Convention laid before Parliament in preparation for ratification, 3 March 2009 paras 11 and 12

discrimination law is clearly not enough.’²⁸ Chapters 2 to 4 above have described the important role played by economic, social and cultural rights in disability/human rights discourse, in the CRPD text and in Article 19: that role is not one of welfare provision as compensation for *exclusion*, but is one of enabling *inclusion*, the exercise of autonomy and full subject hood without which all Convention rights are compromised. One reflection of this understanding is the formulation of Article 4(2) which, whilst allowing for some ‘progressive realisation’ of socio-economic rights, requires immediate application not only of non-discrimination in their application but also of more substantive obligations established in international law.²⁹ These rights are thus central to the hegemonic expansion of the disability/human rights myth which seeks to re-position disabled people in the world as rights-holders: they provide a ‘bridge’ whereby disabled people can take their place as valued and productive citizens.³⁰

This Chapter explores successive UK governments’ understandings of economic, social and cultural rights through their dialogue with the UN Committee on Economic, Social and Cultural Rights. It traces some of the dynamics as national understandings meet international discourse, and the legal dimensions of Santos’ citizen-place and world-place set up constellations of interlegality which will influence the understandings, systems and identities of those tasked with implementing Article 19 in England.

²⁸ Quinn and Degener (2002) 19; see also Stein MA and Stein PJS, ‘Beyond Disability Civil Rights’ (2006-2007) 58 Hastings Law Journal 1203

²⁹ ‘Those obligations contained in the... Convention that are immediately applicable according to international law.’ Article 4(2), and see discussions in Chapter 3 above and the constructive dialogue below.

³⁰ Quinn and Bruce (undated)

<http://www.nuigalway.ie/law/Common%20Files/Disability%20Research%20Unit/GQ/Quinn%20and%20Bruce%20Disability%20Paper.pdf> accessed 4.3.08

The constructive dialogue 1992 – 2009

Support for the principle of interdependence and indivisibility of rights features strongly in the UK's international self-presentation. The UK has been a party to the International Covenant on Economic, Social and Cultural Rights (ICESCR/the Covenant) since it came into force in 1976. In the international arena '[t]he UK Government believes that social and economic rights are as important as civil and political rights'.³¹ However, evidence closer to home suggests otherwise. There have been no moves to ratify, let alone incorporate, the European Convention on Human Rights' companion, the revised European Social Charter.³² Furthermore, the UK's acceptance of the European Union Lisbon Treaty in 2007 was conditional on agreement of a Protocol relating to application of the appended EU Charter on Fundamental Rights. This Protocol specifically emphasises 'for the avoidance of doubt' that nothing in Title IV of the Charter - which sets out, *inter alia*, socio-economic rights to work, social security, and health - 'creates justiciable rights applicable to ... the United Kingdom'.³³ Although, in practice, the Charter does apply to UK law insofar as it gives effect to EU law,³⁴ there remains an element of ambiguity – not to say downright contradiction - in the UK's overall position.

We saw in Chapter 2 above that the UN Committee on Economic, Social and Cultural Rights (the Committee) has established a system to consider

³¹ United Kingdom of Great Britain and Northern Ireland, Report to Universal Periodic Review, 1st session, 7-18 April 2008, A/HRC/WG.6/1/GBR/2, 2008, para 3 <http://daccess-dds-y.un.org/doc/UNDOC/GEN/G08/112/65/PDF/G0811265.pdf?OpenElement> accessed 28/5/08

³² Although the UK ratified the original Charter in 1962, it has signed but not ratified the revised Charter of 1996, and has not chosen to accept the Charter's Optional Protocol which grants rights of collective petition.

³³ Protocol 'On the Application of the Charter of Fundamental Rights of the European Union to Poland and to the United Kingdom', C306/156, 17.12.2007, Article 1: 1. The Charter does not extend the ability of the Court of Justice of the European Union, or any court or tribunal of ... the United Kingdom, to find that the laws, regulations or administrative provisions, practices or action of ... the United Kingdom are inconsistent with the fundamental rights, freedoms and principles that it reaffirms. 2. In particular, and for the avoidance of doubt, nothing in Title IV of the Charter creates justiciable rights applicable to ... the United Kingdom, except in so far as ... the United Kingdom has provided for such rights in its national law.'

³⁴ See *NS and others v Secretary of State for the Home Department* (C-411-10) ECJ

periodic reports by States Parties to monitor their progress in implementing the Covenant. In that process, a ‘conversation’ develops between State and Committee, known as a ‘constructive dialogue’, where the State Party is required to justify its actions or omissions. During their dialogue, disagreements have developed between the Committee and the UK on a number of key issues, necessitating successive UK governments to articulate their positions clearly and succinctly in response to the Committee’s questioning. Examination of that dialogue may thus provide some clarification of the UK’s apparently ambiguous understandings of its international obligation to implement economic, social and cultural rights.

Consistent reporting to the Committee did not begin until 1992, when the UK submitted its Core Document. This explains that:

the United Kingdom does not have a Bill of Rights or written constitution... Under the United Kingdom’s constitutional arrangements the possession of rights and freedoms is an inherent part of being a member of our society. Rights, therefore, are not conferred by the Government; they already exist unless Parliament decides that the needs of society are such that they should be restricted in some specific way... [Accordingly,] [t]reaties and conventions are not incorporated directly into domestic law.... and Courts in the UK interpret only those laws made by Parliament.³⁵

The Covenant itself does not require States Parties to formally incorporate its terms into their domestic law, or to accord it any specific kind of status there. It is, after all, small-scale law designed to apply across all cultures and legal systems. Article 2 adopts a broad and flexible approach, requiring implementation ‘by all appropriate means’, allowing for differences in national legal systems,³⁶ including the ‘dualist’ system adopted by the UK.³⁷ It does,

³⁵ United Kingdom Core Document, HRI/CORE/1/Add.5 (1992), para 133

³⁶ Article 2(1); see also UN Committee on Economic, Social and Cultural Rights General Comment 3, ‘The Nature of States Parties Obligations (Art. 2, par.1)’ 14/12/90, para 3 and General Comment 9, ‘The Domestic Application of the Covenant’ 03/12/98, para 1

³⁷ Some States have incorporated economic, social and cultural rights into their constitution: examples include India, South Africa and Canada. Here, national judicial systems will be called upon to determine relevant cases under the Constitution. Others, such as Norway, have incorporated the Covenant directly into domestic law. Yet other States, including the UK and New Zealand, whilst being party to the ICESCR, remain unconvinced of the justiciability of economic and social rights, and make no provision for determination of those rights as such within their domestic legal system.

however, suggest that 'appropriate means' will include 'particularly the adoption of legislative measures.'³⁸ In the words of the Committee,

the Covenant norms must be recognized in appropriate ways within the domestic legal order, appropriate means of redress, or remedies, must be available to any aggrieved individual or group, and appropriate means of ensuring governmental accountability must be put in place.³⁹

In 1994, the Committee asked the UK to 'cite specific laws that had been changed to enable the UK to comply with its Covenant obligations'. It was given a 'sample list' of recent legislation described as 'generally in line' with the principles and objectives of the Covenant. Though guided by the Covenant, the government was unable to cite any specific measures that had been taken as a result.

The UK's 1996 report is the first to cover Article 2 of the Covenant. Here the government sets out its stall in relation to implementation:

[r]ights corresponding to those enumerated in human rights conventions [*sic*] are provided for within the United Kingdom by the common law and supplemented by legislation.⁴⁰

Furthermore, it continues, the 'greater part' of the provisions of the Covenant do not purport to establish norms which lend themselves to translation into legislation or justiciable issues, but are statements of principle and objectives.⁴¹

Here we begin to see the UK government's failure to comprehend the idea of economic, social and cultural rights as 'rights'. We saw in Chapter 2 above how the holistic human rights formation was fractured in the aftermath of the Second World War, with socio-economic rights being understood in the capitalist West as being inconsistent with free market ideology. In the UK in 1996, after 17 years of Conservative government influenced by Hayek's principles of justice and economy,⁴² this discourse remains powerful.⁴³

³⁸ Article 2(1)

³⁹ General Comment 9

⁴⁰ United Kingdom Third Report to UN Committee on Economic, Social and Cultural Rights, E/1994/104/Add.11, 17 June 1996, para 8

⁴¹ *Ibid* para 9

⁴² Hayek (1982) and see discussion below

However, by the time this UK report comes up for discussion before the Committee in December 1997, major political changes have taken place in the UK with the landslide election of a New Labour government. Might these domestic changes be reflected in the ‘constructive dialogue’?

It seems not. At their 1997 meeting, New Labour plans to incorporate the European Convention on Human Rights (ECHR) into UK law are lauded by the UN Committee. Why not give the Covenant similar treatment? Committee members⁴⁴ suggest ‘that the UK [does] not regard the Covenant as having the effect of law, but only a guideline’: the UK is reminded of its full obligation as a Party to the Covenant to translate its international norms into binding legal obligations. But, as the UK delegates explain, ‘the British preference is for hard law on specific issues’; Covenant ‘principles’ are given effect by a large body of existing law dealing with many social, economic, and, less frequently, cultural, issues.

Far from domestic political change bringing about a rapprochement in the understandings of the Committee and the UK government, this dialogue reveals a growing distance between their respective positions. The Committee is becoming more confident in its monitoring role. It has worked to clarify the nature of States Parties’ obligations,⁴⁵ and the norms it expects to be translated into binding domestic law.⁴⁶ The UK, on the other hand, rejects interpretation of the small-scale Covenant rights as justiciable norms, interpreting them instead as ‘principles’ to be given effect through large-scale, ‘specific’ domestic legislation. This polarisation is reinforced by the UK delegation’s statement that ‘the general term “human rights” as applied by the Committee, is not one frequently in use in the UK...’⁴⁷ Not only does the

⁴³ But see JUSTICE and 13 other NGOs, ‘Poverty Undermines Rights in the UK’ Joint submission to the United Nations Committee on Economic, Social and Cultural Rights, October 1997

⁴⁴ Mr Sadi

⁴⁵ General Comment 3

⁴⁶ By the time of this dialogue (17th session, 1997), the Committee had produced 7 General Comments: Reporting by States Parties (1), international technical assistance (2), the nature of States Parties’ obligations (3), the right to adequate housing (4), persons with disabilities (5), the economic, social and cultural rights of older persons (6) and forced evictions (7).

⁴⁷ Committee on Economic, Social and Cultural Rights, Seventeenth Session, Summary record of the 36th meeting, E/C.12/1997/SR.36, 27 November 1997, para 47

UK not accept the Committee's interpretation of Covenant rights as justiciable norms, it rejects the whole discourse of economic, social and cultural rights as 'human rights'.

The UK's Fourth Periodic Report contains just one paragraph on implementation:

2.01 The United Kingdom gives effect to its obligations under the Covenant on Economic, Social and Cultural Rights by means of specific laws, policies and practices which implement the various rights set out in the Covenant.

This prompts a request from the Committee to 'explain further the meaning of paragraph 2.01... in particular with regard to the "effects" the UK intends to give to its "obligations" under the Covenant...'⁴⁸ to which the UK replies:

A.1 The Convention [*sic*] is not directly applied as law within the territories to which these reports apply. The United Kingdom gives effect to the various articles of the Convention by specific laws, policies and practices of the appropriate authorities in those territories. These are described in the paragraphs of the reports relating to those articles.⁴⁹

At their meeting in 2002, the Committee launches straight into the issue of incorporation. The UK delegation, however, stands its ground: the Covenant rights are not justiciable, and it is not appropriate for British judges to interpret them. Furthermore, '[s]ome aspects of the Covenant... [are] not entirely unequivocal.' This last comment brings a swift rejoinder. By now the Committee has produced a total of 15 General Comments designed to clarify interpretation of the Covenant,⁵⁰ including one on its domestic application.⁵¹ From the Committee's view, some Covenant rights are 'completely unambiguous' and any further ambiguities are covered by those General Comments. Maybe the UK will review its position in the light of the General

⁴⁸ List of Issues 2002

⁴⁹ Reply to List of Issues, 2002. See also JUSTICE and other NGOs, 'Joint NGO Report to the United Nations Committee on Economic Social and Cultural Rights: response to the UK Government's Fourth Report under the International Covenant on Economic, Social and Cultural Rights' April 2002, section 1: Background: Socio-economic rights in the UK legal system.

⁵⁰ Concluding observations of the Committee on Economic, Social and Cultural Rights: United Kingdom of Great Britain and Northern Ireland, E/C.12/1/Add.79, 17 May 2002, para 24

⁵¹ General Comment 9

Comments? But 'no' says the UK delegate: Covenant rights are justiciable under specific domestic legislation rather than under the Covenant as a whole. The UK has fulfilled its obligations and 'will not accept any charge of having evaded them'.⁵² The Committee, for its part, 'strongly recommends' that the UK 're-examine the matter'.⁵³

Far from re-examining the matter, the UK in its Fifth Report of 2007 confirms categorically that:

The ICESCR has not been and is not expected to be incorporated into domestic law. This means that the rights contained in the Covenant are not directly enforceable by domestic courts.⁵⁴

Furthermore,

the Government is not convinced that it can incorporate the rights contained in the ICESCR in a meaningful way within the British legal system.⁵⁵

Reasons given are that

- some of the rights are not clearly defined;
- budgets are limited: a court decision requiring 'greater progress' in one area, e.g. health, would imply a reduction in another, e.g. education;
- differing political views⁵⁶ mean that it would be inappropriate for the courts to determine government economic policy;
- individuals in the UK already have ways to challenge government policy through their MP or complaints procedures,⁵⁷ and
- not all human rights require identical approaches: UK policy has been to take legislative action within the scope of each right, e.g. Education Act etc.⁵⁸

⁵² Committee on Economic, Social and Cultural Rights, Twenty-eighth session, Summary Record of the 12th Meeting, 6 May 2002 para 36

⁵³ Concluding Observations 2002

⁵⁴ United Kingdom Fifth Report to UN Committee on Economic, Social and Cultural Rights E/C.12/GBR/5, July 2007, para 51

⁵⁵ Fifth Report, para 74

⁵⁶ Examples given are 'targeted interventionist policies' contrasted with deregulation and 'individual economic initiative'

⁵⁷ There is no mention here of judicial review or administrative redress - see Chapter 9 below

⁵⁸ Fifth Report, paras 74-5

In other words, the terms of the Covenant are too vague; politicians, not courts, should determine the allocation of limited resources; and individuals have political and administrative, rather than legal, routes to redress. It seems that this dialogue has reached deadlock.⁵⁹

Up to this point, the 'constructive dialogue' between the UK and the Committee has been conducted outside the realm of domestic human rights discourse.⁶⁰ Within that highly politicised domestic discourse, economic, social and cultural rights have remained invisible. Between 2007 and 2009, however, there appear to be some cracks in that invisibility.

Alongside the increased influence of the European Convention on UK legal discourse following introduction of the Human Rights Act, the UK's membership of the European Union⁶¹ has required it to accept a superior European legal order which takes precedence, in areas of EU competence, over the domestic legal order.⁶² Such precedence has been a contributory factor⁶³ underlying increased use of international law in UK domestic courts.⁶⁴ This broader outlook on the part of the judges has also

⁵⁹ See also British Institute of Human Rights 'BIHR Response to the UK Government's draft 5th periodic report under the ICESCR to the UN Committee on Economic, Social and Cultural Rights' (BIHR 2007)

⁶⁰ Apart from the few UK lawyers specialising in this area of international human rights law. Human rights NGOs focused overwhelmingly on civil and political rights. Documents were not available on government websites. When the writer requested a copy of the UK Fourth Report from the Foreign and Commonwealth Office (FCO) in 2002, she received a phone call asking for her credentials and why the Report was required. The Fifth Report was the first to be made readily accessible online, after responsibility was transferred from the FCO to the Department of Constitutional Affairs (now Ministry of Justice)

⁶¹ European Communities Act 1972

⁶² Particularly since the UK signed up to the EU Social Chapter in 1997, many of those areas of competence relate to socio-economic matters. See below for discussion of the EU Charter of Fundamental Rights 2000 and UK Protocol

⁶³ Together with the Human Rights Act requirement for courts to 'take into account' ECHR jurisprudence: HRA s2

⁶⁴ As Higgins remarked in 2000, '[c]ulture is not static, and the last decade has been marked by an extraordinary opening up of the English courts to the appropriate application of international law.' (Higgins R, 'Dualism in the Face of a Changing Legal Culture' in Andenas M and Fairgrieve D (eds) *Judicial Review in International Perspective*, Liber Amicorum in Honour of Lord Slynn of Hadley, vol II (Kluwer Law International 2000)). Questions about the status of international organisations (*Tin Council*, *Greenpeace*) or about the limits of national and EU competence (*International Transport Workers' Federation and Another v Viking Line ABP and Another*, Case C-438/05 (2007) Times, 14 December 2007) have demanded judges' attention to non-domestic law. NGOs have also played a legitimate role in influencing that process: Carter P, 'Polemics & Persuasion – the Use of International Law by NGOs' (2006) presentation to British Institute of International and Comparative Law lecture

encompassed increasing attention to – even application of - international human rights law.⁶⁵

Devolution, too, has produced tensions that challenge the status quo.⁶⁶ Since 1999, Scotland, Wales and Northern Ireland have each taken forward their own understandings of human rights issues, particularly in the realms of the economic, social and cultural rights that make up the majority of their devolved competence.⁶⁷

At Westminster, the Joint Parliamentary Committee on Human Rights (JCHR) was set up in 2000 to coincide with the introduction of the Human Rights Act. It has consistently interpreted its brief⁶⁸ as being wider than just the Human Rights Act. In 2007, three existing Equality Commissions⁶⁹ were subsumed into a new Equality and Human Rights Commission (EHRC)⁷⁰, the first independent statutory body to be tasked with the promotion and monitoring of human rights across England, Scotland and Wales. Together with its Northern Ireland and Scottish equivalents, the EHRC is accredited⁷¹ to monitor not only domestic human rights implementation but also the UK's international human rights commitments. As a result of these developments, and despite some strong antagonisms, elements of European and

Series International Law in the Domestic Courts, 8 May 2006: 'NGOs play a legitimate role in enhancing the effect of international law and in doing so change its nature by increasing its reception in municipal courts.'

⁶⁵ For further discussion of this phenomenon, see also Lord Bingham's maiden speech in the House of Lords HL Deb 3 July 1996 col 1465; McCrudden C, 'A Common Law of Human Rights?: Transnational Judicial Conversations on Constitutional Rights' (2000) 20(4) Oxford Journal of Legal Studies 499; Bingham T, *Widening Horizons: the influence of comparative law and international law on domestic law*, The Hamlyn Lectures 61st series (Cambridge University Press 2010)

⁶⁶ See, for instance, the dialogue surrounding a proposed Northern Ireland Bill of Rights, 2008, below

⁶⁷ Such as tuition fees, residential care funding (Community Care and Health (Scotland) Act 2002), proposed Northern Ireland Bill of Rights, etc.

⁶⁸ To consider 'matters relating to human rights in the United Kingdom'

⁶⁹ Equal Opportunities Commission, Race Equality Commission and Disability Rights Commission

⁷⁰ See for instance British Institute for Human Rights 'Something for Everyone: the impact of the Human Rights Act and the need for a Human Rights Commission' (BIHR 2002); Klug F, 'Establishment of the Commission for Equality and Human Rights: implications for the public sector' (2004) Westminster Explained 36: An assessment of the impact of the HRA, 7 December 2004; O'Cinneide C, 'The Commission for Equality and Human Rights: A New Institution for New and Uncertain Times' (2007) 36(2) Industrial Law Journal 141

⁷¹ in line with the international Paris principles; see Equality and Human Rights Commission 'EHRC's role in relation to UN Human Rights Treaties' (EHRC 2010)

international human rights discourses have begun to infiltrate the domestic sphere; traditional understandings of sovereignty and duality have been increasingly challenged.

These developments served to ensure that the UN Economic, Social and Cultural Rights Committee's 2002 recommendation to 're-examine the matter' of incorporation received more than usual attention. A JCHR inquiry into those conclusions⁷² found that: 'the case for incorporating guarantees of the Covenant rights in UK law... merits further attention'.⁷³ Economic, social and cultural rights 'should not be regarded as the poor cousins of the civil and political rights incorporated into UK law by the Human Rights Act'.⁷⁴ Later, discussion of a potential British Bill of Rights⁷⁵ prompted a further JCHR report.⁷⁶ Here we find analysis by the JCHR of the New Labour government's 'evolving position'⁷⁷ on incorporation of socio-economic rights: from outright opposition, through apparent acceptance that 'a constitution or Bill of Rights can "accord importance" to economic and social rights',⁷⁸ to contemplation of 'the possibility of including provisions about social and economic rights in the form of "deliberative and interpretive principles"'.⁷⁹ The JCHR itself suggests an approach which imposes a duty on government to achieve progressive realisation of the relevant rights, within available resources, and to report to Parliament on the progress made; whilst ensuring

⁷² Joint Committee on Human Rights, 'The International Covenant on Economic, Social and Cultural Rights', Twenty-first Report of Session 2003-04, HL Paper 183, HC 1188, para 1

⁷³ Ibid para 73; either by incorporating the terms of the Covenant itself, or by developing domestic formulations of the Covenant rights as part of a UK Bill of Rights

⁷⁴ Ibid para 163; see also submissions to the JCHR inquiry from Democratic Audit 'Economic and Social Rights for the UK' (2003) and JUSTICE 'Inquiry into the Concluding Observations of the UN Committee on Economic, Social and Cultural Rights - Joint Committee on Human Rights' (2003)

⁷⁵ Ibid paras 158 - 164

⁷⁶ Joint Committee on Human Rights, 'A Bill of Rights for the UK?', Twenty-Ninth Report, 10 August 2008, HL 165-I/HC 150-I; and Evidence of Jack Straw to Joint Committee on Human Rights inquiry into a Bill of Rights for the UK?, 21 May 2008; see also Foster S, 'Finally: a Bill of Rights for the UK?' (2008) 13(2) *Coventry Law Review* 8; Klug F, 'A Bill of Rights: Do We Need One or Do We Already Have One?' [2007] *Public Law* 701

⁷⁷ Between July 2007, when the Green Paper on '[t]he Governance of Britain' was published, coincidentally with the UK's Fifth Periodic Report to the UN Committee on Economic, Social and Cultural Rights discussed above, and May 2008, when the Justice Secretary, Jack Straw, gave evidence to the JCHR inquiry.

⁷⁸ Joint Committee on Human Rights, 'A Bill of Rights for the UK?' Twenty-Ninth Report of session 2007-08, HL 165-I/HC 150-I. 10 August 2008, para 160

⁷⁹ Ibid para 163

that the rights are not enforceable by individuals, but rather that the courts have a very circumscribed role in reviewing the measures taken by the government.⁸⁰ The Committee examines three potential models for incorporation, before recommending inclusion of rights to health, education, housing and an adequate standard of living.⁸¹ It helpfully provides some draft Articles at Annex 1.⁸²

In May 2009, three weeks before the UK ratified the CRPD,⁸³ a large UK delegation⁸⁴ travelled to Geneva to be examined by the Committee in the latest stage in their increasingly fractious ‘constructive dialogue’. Although the delegation’s brief must be to defend the UK’s ‘inability’ to incorporate ICESCR rights into the British legal system, as set out in the Fifth Report, it would seem that discourse at home has shifted, albeit incrementally, from the position in 1997, when ‘the general term ‘human rights’ as applied by the Committee, [was] not one frequently in use in the UK...’.⁸⁵ Could it be that this shift offers the prospect of compromise to resolve the apparent confrontation between government and Committee? The following section describes discussion at the 2009 meeting of incorporation, progressive realisation, and justiciability of economic, social and cultural rights; of the Optional Protocol to the ICESCR, and of Bills of Rights; and of the invisibility of Covenant rights in UK domestic discourse.

⁸⁰ Ibid para 192

⁸¹ Ibid para 196

⁸² For further discussion of the constructive dialogue to this point see Bates E, ‘The United Kingdom and the International Covenant on Economic, Social and Cultural Rights’ in McCorquodale R and Baderin M (eds) *Economic, Social and Cultural Rights in Action* (Oxford University Press 2007)

⁸³ On 9 June 2009, with three reservations relating to service in the armed forces, education, and social security appointments, and one declaration relating to education

⁸⁴ 23 members from Ministry of Justice, Foreign and Commonwealth Office, Scotland Government, Welsh Assembly Government, Northern Ireland Office of the First Minister, Home Office, Government Equalities Office, Department for Innovation, Universities and Skills, Department for Children, Schools and Families, Department for Work and Pensions, Department of Health, Department for Business, Enterprise & Regulatory Reform, Department for Communities & Local Government, headed by Ministry of Justice.

⁸⁵ Committee on Economic, Social and Cultural Rights, Seventeenth Session, Summary record of the 36th meeting, E/C.12/1997/SR.36, 27 November 1997, para 47; and see above

The 2009 meeting⁸⁶

Incorporation

The leader of the UK delegation,⁸⁷ opening proceedings, emphasises the 'high value' the UK places on the work of the Committee, and the respect it has for the Committee's 'advice'.⁸⁸ He emphasises the UK's commitment to 'vigorous development' of relevant policy, pursuing a 'progressive agenda' through the Welfare State. He reiterates that '[i]t is the Government's clear view that, for the UK, democratically elected representatives are better placed than are the judiciary to make politically sensitive decisions on resource allocation'; and that 'Parliamentary sovereignty remains the cornerstone of the UK constitution'.⁸⁹ Already, this Statement is plainly couched in the language of traditional domestic legal discourse, where Parliament is sovereign, and non-justiciable economic, social and cultural 'policy' is delivered through the welfare state. Covenant rights are referred to throughout as 'principles and objectives',⁹⁰ their implementation as 'policy',⁹¹ and the rights themselves as welfare 'entitlements'.⁹² Whilst the government's on-going Bill of Rights and Responsibilities consultation⁹³ is highlighted, there is no hint of the incremental shifts in the government's thinking described above.

⁸⁶ At the time of writing, there are only partial Summary Reports of this meeting available on the UN Treaty Body database. They relate to the 15th and 16th sessions on Wednesday 13th May 2009. The proceedings of the earlier opening session on Tuesday 12th May 2009 are therefore reported here from a draft copy of the Opening Statement by the leader of the UK delegation, available on the day, and the writer's notes taken at the meeting. It has not been possible to cross-check these notes against an official record. They have, however, been checked against the record published by the International Service for Human Rights, who were also present. See Method in Chapter 1 above

⁸⁷ Dr Vijay Rangarajan, Constitution Director, Ministry of Justice; his draft statement was made available to the public in hard copy on the day. See Appendix 1 below

⁸⁸ UK Examination, 12/13 May 2009, Opening Statement, para 4. It least one Committee member finds this introduction 'provocative': the recommendations of the Committee are NOT just 'advice': 'you need a stronger word'. Dr Rangarajan responds that maybe 'advice' does not carry the right connotations, but the UK takes the Committee's contributions 'extremely seriously'.

⁸⁹ Para 11

⁹⁰ Paras 10, 13,

⁹¹ Paras 2, 4, 5, 9, 10,

⁹² Para 19

⁹³ Lord Chancellor and Secretary of State for Justice *Rights and Responsibilities: developing our constitutional framework* (Cm 7577, 2009)

The Committee expresses disappointment at the UK's position.⁹⁴ It seems to them that the UK is 'still holding on to its inflexible approach'⁹⁵ whereby Covenant rights are not justiciable or understood as rights: 'it hasn't changed at all'.⁹⁶ The UK has ratified the Covenant, but is saying it is bound only at international level, not domestic level; that obligations are progressive only; that Parliament is best. Covenant obligations are not being implemented or taken seriously.⁹⁷ Moreover, lack of direct applicability of international law to domestic law should not affect incorporation:⁹⁸ most countries apply and implement ESCR all over the world.⁹⁹ The UK's reasons for non-incorporation in its Fifth Report do not make sense. It seems to the Committee that the government does not *wish* domestic courts to enforce Covenant rights. That raises questions about ratification, and needs to change.¹⁰⁰

Delegates explain again that the UK does not incorporate international treaties, that the ECHR was an exception, and that EU law has direct effect regarding some ESC rights. They accept that some of the UK's arguments, such as vagueness of the Covenant's language, 'may have lost their force'.¹⁰¹ However, the Committee should look at the UK's achievements and future plans, even though they may not be expressed in terms of the Covenant.¹⁰² The UK is not hostile to economic, social and cultural rights, but keen to see their realisation. The problem is not direct applicability of the *text* of the Covenant, but the need for Parliament to legislate, which causes legal and practical difficulties. They cannot see change in the near future, although the government has an open mind, as evidenced in their current Bill of Rights consultation.¹⁰³

⁹⁴ Mr Riedel

⁹⁵ Mr Pillay

⁹⁶ Ibid

⁹⁷ Ibid

⁹⁸ Mr Kedzia

⁹⁹ Ms Riera

¹⁰⁰ Ms Riera

¹⁰¹ Rosemary Davies, Ministry of Justice

¹⁰² Ibid

¹⁰³ Discussed below

Acting Chair Ms Bras Gomes notes that the government ‘disagrees with the Committee on a number of issues.’ On the one hand, it agrees that ‘economic, social and cultural rights are as important as and indivisible from civil and political rights’,¹⁰⁴ yet on the other it treats them as part of the welfare state, not as rights. Why are they not indivisible at *practical* level? How does the government see these obligations? It makes no reference to ‘fulfilment’.¹⁰⁵

Progressive realisation

The UK’s Opening Statement repeatedly emphasises the ‘progressive’ nature of implementation under Article 2,¹⁰⁶ reflecting the UK’s understanding that ‘although some rights require immediate realisation, the obligation under the Covenant is one of progressive realisation’.¹⁰⁷

As noted in Chapter 2 above, unlike its equivalent in the ICCPR, Article 2 ICESCR allows for the ‘progressive realisation’ of the Covenant rights, ‘to the maximum of available resources’. However, according to the Committee’s General Comments,¹⁰⁸ this is not to be interpreted as indefinite procrastination. Ratifying States undertake to ‘take steps...with a view to achieving’ realisation of the rights; that undertaking is ‘unqualified’.¹⁰⁹ Steps taken ‘must be deliberate, concrete and targeted as clearly as possible towards meeting the obligations recognized in the Covenant.’¹¹⁰ Moreover, a ‘minimum core obligation’ must be met ‘to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights...’.¹¹¹ Failure to do so constitutes breach of a State’s obligations.¹¹² Beyond this minimum, the Covenant imposes on States the three levels of obligation described in Chapter 3 above: to respect, protect and fulfil the rights concerned. Failure to perform any one of these three obligations, albeit progressively, also

¹⁰⁴ Fifth Report, para 75

¹⁰⁵ Ms Bras Gomes

¹⁰⁶ Opening Statement paras 9, 10, 11, 13, 16

¹⁰⁷ *Ibid* para 11

¹⁰⁸ General Comments 3 and 9

¹⁰⁹ General Comment 3 para 2

¹¹⁰ *Ibid*

¹¹¹ General Comment 9 para 10

¹¹² See also the Limburg Principles and Maastricht Guidelines

constitutes a violation of the rights.¹¹³ States are to act in a way reasonably calculated to realise the enjoyment of each right;¹¹⁴ and to achieve specific targets to satisfy a detailed substantive standard.¹¹⁵ Any deliberately retrogressive measures must be fully justified.¹¹⁶ These are some of the substantive obligations established in international law to which CRPD Article 4(2) on socio-economic rights refers.

The Committee notes the UK's statement that some rights require immediate realisation whilst others may be implemented progressively. They ask which, in the UK's view, are which?¹¹⁷ but receive no specific answer.¹¹⁸

The Committee also wants to know why the UK thinks that ESC rights are not justiciable. In their view, justiciable ESC rights contribute to good government, but they are only applicable in administration or courts if spelled out in domestic legislation:¹¹⁹ a right which cannot come to court is not a right.¹²⁰ 'Do you see the State as Messiah? How can you do that?' asks one Committee member in frustration.¹²¹

Justiciability

The question of justiciability again serves to illustrate the polarised understandings of the two parties to this discussion. On the one hand, the Committee has travelled a long way from the idea of economic, social and

¹¹³ Maastricht Guidelines para 6: 'The obligation to respect requires States to refrain from interfering with the enjoyment of economic, social and cultural rights... The obligation to protect requires States to prevent violations of such rights by third parties... The obligation to fulfil requires States to take appropriate legislative, administrative, budgetary, judicial and other measures towards the full realization of such rights.'

¹¹⁴ The 'obligation of conduct' Maastricht Guidelines para 7

¹¹⁵ The 'obligation of result' *ibid.* These standards are being developed through, *inter alia*, the use of benchmarks. See Hunt P, 'The Right to Health: A Way Forward at the International Level' in Hunt P, *Reclaiming Social Rights: International and Comparative Perspectives* (Dartmouth Publishing Co Ltd 1996); Hunt P, Novak M and Osmani S, 'Human Rights and Poverty Reduction Strategies: a discussion paper'

¹¹⁶ General Comment 3 para 9

¹¹⁷ Mr Zhan, Mr Pillay, Mr Antagana

¹¹⁸ The International Human Rights Service reports that 'the delegation asked for permission to send in a written response at a later date': International Service for Human Rights, Treaty Body Monitor <http://www.ishr.ch/treaty-body-monitor/cescr#42> 3

¹¹⁹ Mr Kedzia

¹²⁰ Ms Riera

¹²¹ Unidentified speaker (male)

cultural rights as non-justiciable 'principles and objectives'. In its General Comment 9,¹²² it points out that, in addition to States' general duty to provide an effective remedy where human rights are breached,¹²³ 'there are a number of other provisions in the [Covenant], including articles 3, 7(a)(i), 8, 10(3), 13(2)(a), (3) and (4) and 15(3)¹²⁴ which would seem to be capable of immediate application by judicial and other organs in many national legal systems.'¹²⁵ The incorporation of ESC rights by many countries around the world, and the development there and at the UN¹²⁶ of a growing body of ESCR jurisprudence,¹²⁷ has contributed to a renewed understanding of ESC rights as full, justiciable rights on a par with, and inseparable from, their civil and political counterparts.

This understanding of justiciability goes further than the provision of specific national legislation. As Langford explains,

[w]hat is novel is not the adjudication of social interests. Domestic legislation in many countries provides a measure of judicially enforceable labour and social rights. What is significant is that the more

¹²² General Comment 9 'The Domestic Application of the Covenant' 03/12/98, E/C.12/1998/24, CESCR

¹²³ See Universal Declaration of Human Rights Article 8: 'Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by constitution or by law'

¹²⁴ General Comment 9 para 5; Article 3 proclaims the equal right of men and women to the enjoyment of economic, social and cultural rights. Article 7(a)(i) concerns fair wages and equal remuneration for work of equal value, particularly equal conditions of work and pay for women. Article 8 sets out the right of everyone to form and join trade unions, and the right to strike. Article 10(3) refers to the protection of children and young persons, including protection from economic and social exploitation. Article 13(2)(a) requires the provision of free and compulsory primary education; 13(3) freedom for parents to choose schooling for their children in line with their religious and moral convictions; 13(4) freedom to establish and direct educational institutions. Article 15(3) requires respect for the freedom indispensable for scientific research and creative activity. Further, continues the Committee, 'there is no Covenant right which could not, in the great majority of systems, be considered to possess at least some significant justiciable dimensions.'

¹²⁵ A view supported, *inter alia*, at a 2006 Pacific regional judicial colloquium of 40 international jurists: SUVA Declaration 2006 <http://www.interights.org/suva> accessed 3.8.10

¹²⁶ For instance by the Human Rights Committee: see Scheinin M, 'Human Rights Committee: not only a committee on civil and political rights' in Langford M (ed) *Social Rights Jurisprudence: emerging trends in international and comparative law* (Cambridge University Press 2008)

¹²⁷ See Chapter 2 above; also Langford (2008); Centre on Housing Rights and Evictions, *Litigating Economic, Social and Cultural Rights: Legal practitioners Dossier*, December 2006; Ghai, Y, Cottrell, J, (eds) *Economic, Social and Cultural Rights in practice: the Role of Judges in Implementing Economic, Social and Cultural Rights*, London, Interights, 2004; Interights case law database <http://www.interights.org/search/index.html> last accessed 3.9.12; Liebenberg S, 'Adjudicating the Positive Duties Imposed by Economic, Social and Cultural Rights' (2006) 15 INTERIGHTS Bulletin, 109

durable human rights dimensions of these social values..., whether captured in constitutions or international law, are being adjudicated. ¹²⁸

This international legal discourse that recognises and adjudicates the ‘durable human rights dimensions of social values’ is one with which the members of the Committee strongly identify: it is the reason for and the objective of their existence as a Committee, and shapes all of their work. As we have seen, it also strongly shapes, *inter alia*, the CRPD. As Langford continues,

[t]his is not to downplay the role of legislation from either a principled or pragmatic perspective. It is often more precise and contextualised and has the direct authoritative and democratic imprimatur of the legislature. But legislative rights are not always sufficient to protect human rights, and they are subject to amendment by a simple majority of the population.¹²⁹

The UK, on the other hand, has failed to travel down that road. From their neo-liberal national perspective, successive UK governments have persisted in viewing socio-economic rights not as ‘rights’, but as non-justiciable guiding ‘principles’ – a position strongly reflected once again in the delegation’s 2009 Opening Statement. The UK argues that it has ‘specific laws, policies and practices’ in place to progress that realisation, and thus to meet its obligations under the Covenant. Moreover, ‘a wealth of advice and guidance’¹³⁰ ensures that people know about their welfare entitlements, and those entitlements can be enforced through political and administrative systems: through judicial review in the courts, through ‘various specialised independent tribunals, and by reference to the independent Parliamentary Commissioners (*sic*) for Administration (Ombudsmen).’¹³¹ So, from the UK’s perspective, what is the Committee’s problem?

¹²⁸ Langford (2008) 3

¹²⁹ *Ibid*

¹³⁰ Replies by the Government of the United Kingdom of Great Britain and Northern Ireland to the list of issues (E/C.12/GBR/Q/5) to be taken up in connection with the consideration of the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland (E/C.12/GBR/5), E/C.12/GBR/Q/5/Add.1, 26 March 2009, para 4

¹³¹ *Ibid* para 5

The Committee tries to explain. It reassures the delegation that the role of the Committee is not to take the place of Parliament.¹³² However, it questions the adequacy of judicial review as a remedy for vulnerable groups.¹³³ People in difficult situations have a double bind: difficulty of the situation and difficulty of getting redress. They need access to legal remedies.¹³⁴ The UK should not be afraid of involving the judges: allocation of resources is a matter of reasonableness and proportionality,¹³⁵ concepts that judges are used to applying.

However, the delegation persists in its view that resources are a matter for elected Parliaments not judges. Internationally, judges such as those in India or South Africa have gone further than the UK would feel acceptable.¹³⁶

This dialogue calls up previous discussion between the UK and the Committee when they were negotiating the text of the ICESCR's new Optional Protocol.

Optional Protocol

An Optional Protocol to the ICESCR, allowing for individual and group petition to the Committee by those claiming to be victims of violation of Covenant rights, was adopted by the General Assembly on 10 December 2008.¹³⁷ During negotiation of the Protocol, the UK expressed its view that '[s]ignificant questions remained in relation to the [ESCR] Committee's competence to consider national decisions on resource allocation',¹³⁸ and its

¹³² See General Comment 3

¹³³ Mr Riedel, Mr Schreiber

¹³⁴ Mr Kedzia

¹³⁵ Mr Riedel

¹³⁶ Rosemary Davies; Indian judges have developed a system of Public Interest Litigation, South African judges interpret the economic, social and cultural rights set out in the South African constitution (for example *The Government of the Republic of South Africa and Others v Grootboom and Others* Case CCT 11/00, 4 October 2000)

¹³⁷ Thus bringing this Covenant in line with the ICCPR (see Chapter 2 above). Optional Protocol to the International Covenant on Economic, Social and Cultural Rights, GA/RES/63/117, <http://www2.ohchr.org/english/bodies/cescr/docs/A-RES-63-117.pdf>, accessed 7.2.11. The Protocol opened for signature in 2009, and at the time of writing is not yet in force, requiring 10 ratifications. There were 40 signatories and 8 parties at 4.9.12.

¹³⁸ ESCR Protocol Open-ended Working Group, Third session, para 21, E/CN.4/2006/47 <http://www2.ohchr.org/english/issues/escr/intro.htm> accessed 21.1.10

concern 'about granting the Committee powers to assess a State party's obligations to fulfil economic, social and cultural rights'.¹³⁹ It argued¹⁴⁰ that

a comprehensive approach might not be viable in situations where all of the rights contained in the Covenant were not enshrined at national level and suggested that one option could be to limit communications [under the Protocol] to claims of discrimination.¹⁴¹

In line with its dualist system, the UK generally has a tentative approach to the right of petition to UN Committees. Historically, the only outside bodies to which a British citizen might resort have been the European Court of Human Rights¹⁴² or, indirectly, the European Court of Justice.¹⁴³ In 2005, in an exploratory gesture,¹⁴⁴ the UK acceded to the new Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), allowing individuals or groups claiming to be victims of CEDAW rights violation to 'submit communications' to that Convention's monitoring committee.¹⁴⁵ An independent evaluation of the 'CEDAW experiment' to identify any practical benefits, to assess costs, and to consider wider implications¹⁴⁶ had just reported at the time of the Geneva meeting.

In Geneva, the Committee asks whether the UK will sign the [new ICESCR] Optional Protocol.¹⁴⁷ The delegate responds that the UK is not against the Protocol on principle, but is not convinced of its practical use. After all, UN Committees are not courts, and individuals in the UK can use domestic courts and tribunals. The UK has been testing out the process by ratifying

¹³⁹ Ibid para 92

¹⁴⁰ Supported by India, ibid para 29

¹⁴¹ The UK also questioned provisions on the inquiry procedure, and on international cooperation; ibid paras 71 and 94

¹⁴² The UK accepted right of petition to the European Court of Human Rights in 1966

¹⁴³ UK courts must give effect to directly applicable European Union law, and interpret domestic law as far as possible consistently with European Union law. Where any question is not clear, the Supreme Court must, and the lower courts and Tribunals may, refer to the European Court of Justice for a preliminary ruling. See for instance *Coleman v Attridge Law* C-303/06 [2008] IRLR 722 (ECJ)

¹⁴⁴ 'So as to enable [the Government] to consider on a more empirical basis the merits of the right to individual petition which exists under a number of UN treaties': 'International Human Rights Instruments: the UK's position' July 2004, para 12(a)

¹⁴⁵ Optional Protocol to the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) A/RES/54/4, Article 2

¹⁴⁶ Murdoch J, 'The Optional Protocol to the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW): The Experience of the United Kingdom; an evaluation' (Ministry of Justice 2008) <http://www.justice.gov.uk/publications/docs/un-optional-protocol-women.pdf> accessed 4.7.10

¹⁴⁷ Mr Riedel, Mr Shreiber

the CEDAW Protocol, but there is not yet enough empirical evidence on which to judge its usefulness. In the meantime, the government will consider ratifying other Optional Protocols, including that of the CRPD, to gather a database of evidence.

Bills of Rights

The UK's Opening Statement draws the Committee's attention to the recent [New Labour] government consultation on a British Bill of Rights and Responsibilities.¹⁴⁸ This document¹⁴⁹ explains that

[a]lthough economic, social and cultural rights are not currently incorporated directly into UK law... [t]he Government remains committed to meeting social and economic needs equitably through its policy decisions and legislative programme. It continues to do this on the basis of democratically elected representatives making decisions in Parliament on the allocation of scarce resources.¹⁵⁰

Following emphasis on the importance of responsibilities in the welfare state, the Paper explains that

[i]n drawing up a Bill of Rights and Responsibilities, the Government would not seek to create new and individually enforceable legal rights in addition to the array of legal protections already available. However, it welcomes discussion on whether there could be advantages in articulating constitutional principles which can be drawn from existing welfare provisions. It might be possible to distil the values which frame our welfare system in order to reflect, in one coherent document, certain social and economic guarantees and the responsibilities and conduct expected of individuals.¹⁵¹

We have noted above the contribution of the JCHR to that debate, where it recommends inclusion of rights to health, education, housing and an adequate standard of living. The UN Committee asks whether these recommendations have been implemented.¹⁵² Committee members have also looked at the Government's consultation document: they conclude that the consultation relates to civil and political rights, not economic, social and

¹⁴⁸ Opening Statement para 18

¹⁴⁹ 'Rights and Responsibilities: developing our constitutional framework', Ministry of Justice, March 2009, Cm 7577; see also Ministry of Justice 'The Governance of Britain' Cm 7170 July 2007

¹⁵⁰ 'Rights and Responsibilities' para 3.48

¹⁵¹ Ibid para 3.53

¹⁵² Mr Pillay

cultural rights. The Northern Ireland Human Rights Commission is also in the process of preparing a Bill of Rights for Northern Ireland. The Committee notes that that Commission has a mandate in favour of economic, social and cultural rights being justiciable and enforceable. Will the UK government enact the resulting Northern Ireland Bill of Rights? And include Covenant rights in a UK Bill of Rights?

The UK delegation replies that, following the consultation, a Bill might include some economic, social and cultural rights. The Government does not see directly enforceable rights as appropriate, because 'people in the UK have so many already.'¹⁵³ Questions about the Northern Ireland Bill of Rights cannot be answered yet, as discussions are still in progress.¹⁵⁴

The ensuing fate of the Northern Ireland Bill of Rights serves to illustrate the tensions created by devolution mentioned above. The Northern Ireland Human Rights Commission (NIHRC) presented its advice to the Government on the possible content of a Bill of Rights for Northern Ireland in December 2008.¹⁵⁵ This advice was thus available to the Government and to the Committee prior to their 2009 meeting. It included, *inter alia*, constitutional rights to education, identity and culture, language, health, adequate standard of living, accommodation, work, environmental rights, and social security. Almost a year later, and six months after the Geneva meeting, the Westminster Government's response¹⁵⁶ simply referred consideration of the Commission's advice to the ongoing national consultation on a potential Bill of Rights and Responsibilities for the UK as a whole, discussed above. The NIHRC's reply was barely polite: the Commission

finds itself in the position of analysing a paper that: 1. demonstrates a lack of understanding of the purpose and functions of a Bill of Rights; 2.

¹⁵³ Rosemary Davies

¹⁵⁴ Mr Rangarajan

¹⁵⁵ In line with its statutory mandate to 'advise on the scope for defining... rights supplementary to those in the European Convention on Human Rights, to reflect the particular circumstances of Northern Ireland, drawing as appropriate on international instruments and experience,' Belfast Agreement 1998

¹⁵⁶ 'A Bill of Rights for Northern Ireland: next steps', Northern Ireland Office, November 2009 http://www.nio.gov.uk/consultation_paper_-_a_bill_of_rights_for_northern_ireland_next_steps.pdf accessed 20.8.10

fails to take appropriate account of international human rights standards; 3. appears to be suggesting the lowering of existing human rights standards in Northern Ireland; 4. fails to satisfy the minimum common law consultation requirements; and 5. misrepresents the advice given by the Commission.¹⁵⁷

The 2009 national debate on a Bill of Rights, too, has now been overtaken by events.¹⁵⁸

Nevertheless, according to the 2009 delegation in Geneva, one consequence of that national debate will be enhanced 'awareness of, and civic participation and engagement with, economic, social and cultural rights in the UK'.¹⁵⁹ This links into another issue raised by the Committee prior to the meeting.

Visibility

It has been argued above that economic, social and cultural rights have been invisible in UK human rights discourse; and that only recently might that invisibility have begun, incrementally, to change. The first question in the Committee's list of issues arising from the UK's Fifth Report runs as follows:

1. Please provide further detailed information on the measures taken by the State party to increase awareness of the provisions of the Covenant and their application among judges, public officials, police and law enforcement officers, medical practitioners, nurses and other health-care professionals, teachers, social workers and the public at large.

The UK replies:

1. The UK Government is fully committed to a vigorous development of economic, social and cultural policy within the UK. Nevertheless ...[i]t believes that domestic law and specific official guidance provide officials with the best framework for delivery of services to the public. .. the Government considers it more appropriate for training and guidance for public officials and service providers to focus on their duties under the specific laws and policies which they are required to

¹⁵⁷ Northern Ireland Human Rights Commission, Response to Government consultation on Northern Ireland Bill of Rights, 17 Feb 2010

¹⁵⁸ In March 2011, the Coalition Government launched a new Bill of Rights Commission chaired by Sir Leigh Lewis, former Permanent Secretary for the Department of Work and Pensions, to report by the end of 2012. See also Political and Constitutional Reform Select Committee Inquiry, June/July 2011.

¹⁵⁹ Opening Statement para 18

implement, rather than on the provisions of the Covenant as such. The Government does not believe that further awareness raising of the general provisions of the Covenant would be of practical benefit to officials delivering specific services, or to improved standards of service.¹⁶⁰

Moreover, '[t]he Government does not believe that further raising of awareness of the provisions of the Covenant would be of practical benefit to the general public', as '[t]here is a wealth of advice and guidance from NGOs, charities and other independent organisations about the rights under the Covenant...'.¹⁶¹

The Government is confident that, in general, people in the United Kingdom are aware of their economic, social and cultural rights... the benefits and services provided by the Welfare State... have become so deeply engrained in the culture of the UK that they are universally regarded as "rights".¹⁶²

The Equality and Human Rights Commission (EHRC), in its submission to the Committee, disagrees. Despite their strong support from the British public, economic, social and cultural rights

do not have the same level of understanding as civil and political rights in Britain, since the primary focus of the government's guidance has been on the Human Rights Act 1998... Indeed the language of the government primarily refers to the rights as part of the "Welfare State", not as universal human rights standards which are often interdependent to the enjoyment of civil and political rights...¹⁶³

The EHRC calls for the government to take a human rights based approach to Covenant rights and obligations to ensure that the rights are taken into consideration in the development of relevant legislation and policy.¹⁶⁴

Again, the Committee finds itself 'very disappointed', by the Government's response on this issue.¹⁶⁵

¹⁶⁰ UK Replies to list of issues, E/C.12/GBR/Q/5/Add.1 para 2

¹⁶¹ Ibid para 4

¹⁶² Ibid para 3

¹⁶³ Equality and Human Rights Commission, 'Submission to the United Kingdom's Fifth Periodic Report under the International Covenant on Economic Social and Cultural Rights' (EHRC 2009) 9

¹⁶⁴ Ibid 10

¹⁶⁵ Mr Pillay

Following the meeting in 2009, the Committee's concluding observations were forthright:

The Committee urges the State party to ensure that the Covenant is given full legal effect in its domestic law, that the Covenant rights are made justiciable, and that effective remedies are available for victims of all violations of economic, social and cultural rights. The Committee reiterates its recommendation that, irrespective of the system through which international law is incorporated in the domestic legal order (monism or dualism), following ratification of an international instrument, the State party is under a legal obligation to comply with such an instrument and to give it full effect in its domestic legal order. In this respect, the Committee again draws the attention of the State party to its General Comment No. 9 (1998) on the domestic application of the Covenant.¹⁶⁶

Despite the apparent incremental shift in government thinking noted by the JCHR, no compromise has been found to resolve the confrontation between government and Committee. What implications for the hegemonic project working to transform the CRPD myth into imaginary might be deduced from this 'not-so-constructive' dialogue?

Discursive re-articulation and the perils of interlegality

Examination of the UK's dialogue with the UN Committee on Economic, Social and Cultural Rights reveals, as Ms Bras Gomes comments, that the UK 'disagrees with the Committee on a number of issues'. They range through incorporation, progressive realisation, justiciability, the Optional Protocol, the content of Bills of Rights and awareness-raising/visibility – that is, through all of the key aspects of Covenant implementation. Most important for this thesis is evidence in the dialogue of strong resistance on the part of successive UK governments to any recognition of these rights as rights, or to any enforcement of their more durable human rights dimensions, whether by their own citizens or by the Committee itself. Instead, the UK

¹⁶⁶ Concluding Observations of the Committee on Economic, Social and Cultural Rights, E/C.12/GBR/CO/5, 22 May 2009, para 13

persists in re-articulating socio-economic rights as ‘principles and objectives’ to guide politicians in formulating ‘welfare’ policy. As Ms Bras Gomes continues: on the one hand, the UK agrees that economic, social and cultural rights are as important as civil and political rights, yet on the other it treats them as part of the welfare state, not as rights. ‘Why’, she asks, ‘are they not indivisible at *practical* level?’¹⁶⁷

Transformation in thinking from ‘welfare’ to ‘rights’ is fundamental to the CRPD’s emancipatory purpose. In the Convention text, the traditional dichotomy is no longer relevant: both ‘sets’ of rights are equally and indivisibly important to the repositioning of disabled people in the world, and to the realisation of all Convention rights. Yet, despite the UK’s participation in CRPD negotiations, this fundamental shift in understanding has not taken place at national level. As can be seen from the ‘constructive’ dialogue, it continues to be persistently and forcefully resisted by successive UK governments in the face of strong international pressure. We may indeed ask, with Ms Bras Gomes: why?

The constructive dialogue is a dialogue between two different legal dimensions: international and national – in Santos’ terms, world-place and citizen-place. The dynamic interplay within and between such legal dimensions produces what Santos calls legal constellations, or ‘interlegality’. The interplay during this dialogue is - albeit diplomatically - antagonistic, leading to impasse and mutual frustration. Part of this non-communication may be explained by the differing scales of law involved in the discussion. For the UK, the Covenant is too small-scale to be interpreted as other than principles or guidance: it prefers its specific, larger-scale domestic law to give effect to those principles. On the other hand, the Committee is not satisfied that such specific large-scale law is capable of encompassing the durable nature of the Covenant’s terms. Their differences, however, go further. Santos describes forms of law as ‘revolving doors through which different forms of power and knowledge circulate’.¹⁶⁸ Further understanding of this

¹⁶⁷ Ms Bras Gomes

¹⁶⁸ Santos (2002) 417

impasse may thus be gleaned from examination of some of the 'forms of power and knowledge', or discourses, at play in this constructive dialogue. The Committee is made up of 18 'experts' in the field of ESC rights from a variety of nations, cultures and legal settings. By their nature, experience and position, these individuals identify strongly with the international discourse of economic, social and cultural rights as rights. It is this discourse that provides them with their 'subject positions'¹⁶⁹ as social agents in our dialogue. They are engaged in a hegemonic project to bring about their vision of how states, economies and civil societies should be organised.¹⁷⁰ Since the Committee's inception, it has worked to clarify the norms contained in the Covenant, to expand its information base, and to implement an effective system for monitoring States' performance.¹⁷¹ To further increase the discourse's hegemony, the Committee has produced 21 General Comments,¹⁷² which are supported by the Limburg Principles,¹⁷³ the Maastricht Guidelines¹⁷⁴ and other declarations.¹⁷⁵ The Covenant rights are increasingly adjudicated by other UN bodies, by regional human rights bodies and by national courts around the world.¹⁷⁶ As the Committee points out to the UK delegation, most countries now apply and implement economic, social and cultural rights, through a variety of legal systems. From its near-dislocation by the Cold War, through the work of the Committee and others,¹⁷⁷ this discourse is growing in hegemony: it is succeeding in redefining the terms of the political debate and in setting a new agenda, where its norms and the durable human rights dimensions of its values are

¹⁶⁹ See Chapter 1 above

¹⁷⁰ Torfing (1999) 302

¹⁷¹ See e.g. Alston P, 'The Committee on Economic, Social and Cultural Rights' in Eide A, Krause C and Rosas A, *Economic, Social and Cultural Rights: A Textbook* (Brill 2001) 489

¹⁷² See <http://www2.ohchr.org/english/bodies/cescr/comments.htm> last accessed 4.9.12

¹⁷³ Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights, E/CN.4/1987/17, Annex

¹⁷⁴ Maastricht Guidelines on Violations of Economic, Social and Cultural Rights, Maastricht, January 22-26, 1997

¹⁷⁵ Such as the Bangalore Declaration and Plan of Action 1995

¹⁷⁶ See Langford (2008); Langford M and Nolan A, *Litigating Economic, Social and Cultural Rights: Legal Practitioners Dossier* (Centre on Housing Rights and Evictions 2006); and Interights case law database <http://www.interights.org/database-search/index.htm> last accessed 3.9.12; cases may also be sourced on www.ohchr.org or www.escr-net.org/caselaw/.

¹⁷⁷ Including Special Rapporteurs, UN agencies, NGOs, NHRIs, International Commission of Jurists and others

recognised, accepted and applied.¹⁷⁸ The place of economic, social and cultural rights in the CRPD is one manifestation of that success. In Geneva, the Committee alternately cajoles and presses the UK delegation to offer some olive branch or compromise, to show some willingness to take elements of this discourse on board. But to no avail.

The UK not only fails to recognise this new agenda, it actively rejects it, resisting all attempts to shift it from its position. Economic, social and cultural rights as rights remain invisible in domestic human rights discourse, re-articulated as 'principles and objectives' and as welfare entitlements. As we saw in Chapter 1, such exclusion is a typical response where a hegemonic discourse meets an element that is incapable of being accommodated because it directly negates its own meanings. If the discourse of economic, social and cultural rights as rights is diametrically opposed to dominant UK domestic legal/political discourse, it will be incapable of being accommodated into the UK legal system. The UK's Fifth Report proclaims as much.¹⁷⁹

We have recognised above that the UK is often seen as one of the most neo-liberal States in Western Europe, and we have noted the influence of liberal free-market thinkers such as Hayek on domestic political discourse. A brief excursion into Hayek's position on economic, social and cultural rights may help to illustrate some reasons why the UK shows such strong resistance to the Committee's efforts.

In *Law, Legislation and Liberty*,¹⁸⁰ Hayek sets out 'a new statement of the liberal principles of justice and political economy'. Volume 2 is concerned with 'the mirage of social justice'. Here, Hayek differentiates between 'plain justice' – 'the moral precepts men have evolved for the guidance of their

¹⁷⁸ As Justice Albie Sachs explains, '[t]here is a growing acceptance all over the world that certain core fundamental values of a universal character should penetrate and suffuse all governmental activity, including the furnishing of the basic conditions for a dignified life for all. I believe that 21st-century jurisprudence will focus increasingly on socio-economic rights.' Albie Sachs, *Social and Economic Rights: Can They Be Made Justiciable?* (Southern Methodist University School of Law 1999) 18, quoted in Langford (2008) frontispiece

¹⁷⁹ 'the Government is not convinced that it can incorporate the rights contained in the ICESCR in a meaningful way within the British legal system.' UK Fifth Report, para 74

¹⁸⁰ Hayek FA, *Law, Legislation and Liberty: a new statement of the liberal principles of justice and political economy* (Routledge & Kegan Paul 1982)

individual actions'¹⁸¹ - and the demand for 'social justice', which is 'addressed not to the individual, but to society'. A liberal, free market-based 'society',¹⁸² he argues, is incapable of acting for a specific purpose. To achieve 'social justice', therefore, the members of society would need to organise themselves so as to make it possible to assign particular shares of the product of society to the different individuals or groups.¹⁸³ Hayek admits that

the manner in which the benefits and burdens are [currently] apportioned by the market mechanism would in many instances have to be regarded as very unjust *if* it were the result of a deliberate allocation of particular people [original emphasis]. But this is not the case. Those shares are the outcome of a process the effect of which on particular people was neither intended nor foreseen by anyone when the institutions first appeared – institutions which were then permitted to continue because it was found that they improve for all or most the prospects of having their needs satisfied. To demand justice from such a process is clearly absurd, and to single out some people in such a society as entitled to a particular share evidently unjust.¹⁸⁴

From this view of 'social justice', Hayek proceeds to consider justice and individual rights.¹⁸⁵ Here, he holds that

[t]he time-honoured political and civil rights...constitute essentially a demand that so far as the power of government extends it ought to be used justly....¹⁸⁶

These neutral negative rights 'are merely a complement of the rules protecting individual domains'.¹⁸⁷ Socio-economic rights, by contrast, are positive rights

for which an equal or even higher dignity is claimed. These are claims to particular benefits to which every human being as such is presumed to be entitled without any indication as to who is to be under the obligation to provide those benefits or by what process they are to be provided.¹⁸⁸

¹⁸¹ Ibid p 63

¹⁸² As distinguished from 'government'

¹⁸³ Hayek (1982) 64-65

¹⁸⁴ Ibid 6

¹⁸⁵ 'Justice and Individual Rights', Appendix to Hayek (1982) Chapter 9,101-106

¹⁸⁶ Hayek (1982) 102

¹⁸⁷ Ibid 103. This perspective is reflected in the extract from the UK's core document quoted above: '... the possession of rights and freedoms is an inherent part of being a member of our society. Rights...are not conferred by the Government, they already exist unless Parliament decides that the needs of society are such that they should be restricted in some specific way...' UK Core Document 1992, para 133

¹⁸⁸ Ibid 103

They cannot be claimed against ‘society’, because ‘society’ ‘cannot think, act, value or “treat” anybody in a particular way’.¹⁸⁹ For such claims to be met, therefore,

the spontaneous order which we call society must be replaced by a deliberately directed organization... whose members would have to do what they are instructed to do. They would not be allowed to use their knowledge for their own purposes but would have to carry out the plan which their rulers have designed to meet the needs to be satisfied. From this it follows that *the old civil rights and the new social and economic rights cannot be achieved at the same time but are in fact incompatible: the new rights could not be enforced by law without at the same time destroying that liberal order at which the old civil rights aim...*¹⁹⁰ (emphasis added)

Hayek’s views illustrate the more extreme neo-liberal arguments against socio-economic rights.¹⁹¹ However, they help to show how, for supporters of such views, the discourse of economic, social and cultural rights as rights with which the Committee so strongly identifies might be understood as incompatible with, and thus incapable of accommodation into, national neo-liberal capitalist discourse. There would then remain no alternative but to exclude the concept of economic, social and cultural rights as rights, to render it invisible in national discourse, and to seek to re-articulate its elements, where necessary, as compensatory welfare entitlements resting in the gift of the State. Such exclusion and re-articulation confirms and strengthens the constitutive outside of the national discourse. The process accentuates the relations of equivalence at play in the dialogue, as evidenced in the defensive stance of the UK in 2002 as it insists that ‘it will not accept any charge of having evaded’ its international obligations.¹⁹² In 2009, the UK’s invitation to the Committee to accept this partial re-articulation, asking them to look at the UK’s achievements and future plans, even though they may not be expressed in terms of the Covenant, is not taken up. Nevertheless, as the leader of the UK delegation comments, the UK’s position is unlikely to change in the near future.

¹⁸⁹ Ibid

¹⁹⁰ Ibid

¹⁹¹ Less extreme, though liberal, views might be gleaned from Rawls or Dworkin, among others

¹⁹² Committee on Economic, Social and Cultural Rights, Twenty-eighth session, Summary Record of the 12th Meeting, 6 May 2002 para 36

Conclusion

Examination of the UK's constructive dialogue with the UN Committee on Economic, Social and Cultural Rights reveals disagreement on incorporation, progressive realisation, justiciability, the Optional Protocol, the content of Bills of Rights and awareness raising/visibility – that is, on all key aspects of Covenant implementation. The UK's strong resistance to any recognition of these rights as rights, or to any enforcement of their more durable human rights dimensions, raises questions about its implementation of the ICESCR. It also raises questions about the UK's capacity to make the transformation in thinking from 'welfare' to 'rights', which is fundamental to implementation of the CRPD.

Discourses seek to dominate or organise a field of meaning in a particular way, by weaving together different discursive strands.¹⁹³ In international disability/human rights discourse, the 'strand' of economic, social and cultural rights as rights plays a key role, not only in practice, by enabling the exercise of all CRPD rights, but also in understanding the re-positioning of disabled people from welfare recipients to rights-holders vital to its hegemonic success. The UK's position as evidenced in the constructive dialogue demonstrates that it has not yet made – indeed, that it resists - that vital transition in understanding. The question then arises as to how the international disability/human rights myth will fare in a domestic context that so strongly resists acknowledgement of one of its central elements. As Flóvenz suggests,

one might come to the conclusion that in those States in which economic and social rights have not been sufficiently implemented until now, there may arise some problems in implementing the Convention as a whole.¹⁹⁴

The UK consistently maintains that it 'will not ratify a treaty unless the Government is satisfied that domestic law and practice enable it to

¹⁹³ Howarth and Stavrakakis (2000) 2

¹⁹⁴ Flóvenz, B, 'The Implementation of the UN Convention and the Development of Economic and Social Rights as Human Rights', in Arnandóttir and Quinn 2009, 260

comply'.¹⁹⁵ Three weeks after the Geneva meeting, on 9 June 2009, the UK ratified the CRPD,¹⁹⁶ undertaking to 'ensure and promote the full realisation of all human rights and fundamental freedoms for all disabled people in its jurisdiction'.¹⁹⁷ The Explanatory Memorandum required by the ratification process¹⁹⁸ makes it clear that

[t]he Convention does not aim to establish new human rights for disabled people but sets out with greater clarity the obligation on States to promote, respect, and ensure the human rights that disabled people already have, so that they are treated on an equal basis with other people.¹⁹⁹

It explains that the Convention

encompasses civil and political, as well as economic, social and cultural rights. These rights cover all areas of life including: the right to life, liberty and security of the person; access to justice; *personal mobility; health; education; work; recreation*; and provision for equal recognition before the law.²⁰⁰ (emphasis added)

¹⁹⁵ United Kingdom of Great Britain and Northern Ireland, Report to Universal Periodic Review, 1st session, 7-18 April 2008, A/HRC/WG.6/1/GBR/2, 2008; see also Anne McGuire, Minister for Disabled People, Statement to Parliament, Tuesday 6th May 2008

¹⁹⁶ With four reservations, relating to employment in the Armed Forces, immigration, review of benefit appointees and mainstream/special education; and one declaration relating to education. Joint Committee on Human Rights 'UN Convention on the Rights of Persons with Disabilities: Reservations and Interpretative Declaration' Twelfth Report of Session 2008-09, HL Paper 70 HC 397, 17 April 2009. See also Simon J-L, 'Convention on the Rights of Persons with Disabilities' (2009) Address to UK Parliamentarians, Regional Seminar for the 12+ Group, London, 27-28 April 2009. Two months later, on 7 August 2009, the UK ratified the Convention's Optional Protocol. The Minister for Disabled People, Jonathan Shaw MP, announced on 3 February 2009 the government's intention to sign the CRPD OP as 'a further demonstration of our commitment to the UN Convention on the Rights of Disabled People, and to the principle of ensuring that disabled people can enjoy their human rights on an equal basis with non-disabled people.' As his colleague, Lord McKenzie explained, 'we considered that signing the Optional Protocol would underline the messages in the convention about respect for the human rights of disabled people. Signature of the Optional Protocol to the Disability Convention does not set a precedent for acceding to other complaints mechanisms which will continue to be considered on a case by case basis.' Parliamentary Under-Secretary of State, DWP, Lord McKenzie of Luton, in reply to written question asked by Lord Lester of Herne Hill, HL1340, 12 Feb 2009, Hansard Col WA223. Anne McGuire, Minister for Disabled People who signed the ratification stated on 21.3.12 (at the launch of the JCHR Report into the right to independent living) that at the time she considered the CRPD to be 'hard', not 'soft', law.

¹⁹⁷ CRPD Article 4(1) General obligations

¹⁹⁸ Explanatory Memorandum on the United Nations Convention on the Rights of Persons with Disabilities laid before Parliament on 3 March 2009, with the Command Paper containing the text of the Convention (Cm7564): Jonathan Shaw, Parliamentary Under-Secretary of State for Work and Pensions, Statement to Parliament, 3 March 2009.

¹⁹⁹ Ibid para 2 (subject matter)

²⁰⁰ Ibid para 3

This apparent recognition of economic, social and cultural rights as rights, however, is fleeting. Further down the Memorandum, when setting out the Government's actions to ensure that disabled people in the UK have 'comprehensive and enforceable' rights, the language changes. Here, the rights are referred to as 'civil and human rights', identified as those already available under the Disability Discrimination Act 1995 and the Human Rights Act 1998.²⁰¹ Economic, social and cultural rights as rights have again become invisible.

To expand its hegemony, a discourse must attempt to dominate the field of meaning, establish new systems of social relations and provide new subject positions in line with its particular norms, values and perceptions. However, we have seen that the UK's ownership²⁰² of one key element of CRPD discourse is missing. The remainder of this thesis assesses the impact of the UK's mis-understanding of economic, social and cultural rights on the ability of international disability/human rights discourse to expand its hegemony in England through the 'revolving door' of the Convention.

Taking CRPD Article 19, the right to live independently and be included in the community, as a case study, the following Chapters examine in turn the 'specific laws, policies and practices'²⁰³ relating to independent living in England. **Chapter 6** examines the understandings reflected in independent living policy for signs of re-organisation of the field of meaning in line with the CRPD myth. **Chapter 7** investigates legislation for potential progress towards new CRPD-compatible systems of social relations. Social relations are at their most dynamic where policy and law are delivered to the individual through the administrative justice system. **Chapter 8** explores administrative decision-making for evidence of CRPD-compatible emancipatory practice.

²⁰¹ Ibid para 10

²⁰² Quinn G, "Resisting the Temptation of Elegance": Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in Arnandóttir and Quinn (2009) 256

²⁰³ UK Fourth Report to the Economic, Social and Cultural Rights Committee, para 2.01: The United Kingdom gives effect to its obligations under the Covenant on Economic, Social and Cultural Rights by means of specific laws, policies and practices which implement the various rights set out in the Covenant.

Chapter 9 explores the capacity of available redress systems to influence policy, law and practice in line with the CRPD drafters' hegemonic project.

Chapter 10 brings the thesis to its conclusion.

Chapter 6

Independent Living in England: Policy

Introduction

A political project, such as that driving realisation of the Convention myth, will attempt to weave together different strands of discourse in an effort to dominate or organise a field of meaning. It will seek to establish systems of social relations between different objects and practices, and to provide subject positions with which social agents identify, in line with its re-description of the world. If it succeeds, it will redefine the terms of the political debate and set a new agenda.

The disability/human rights project has succeeded at international level: '[d]isability has moved to the core of the UN human rights agenda in theory'.¹ It is encapsulated in a unique international legal order which projects all of the rights through the experience of disability and puts in place systems for further expansion of its hegemony. We have seen that Convention as hegemonic in intent, as expressive or emancipatory law, as a 'revolving door through which different forms of power and knowledge circulate.'² Whether it succeeds in its hegemonic intent is another question, which depends, at least in part, on the constellations of power and knowledge already circulating in the domestic sphere. The remainder of this thesis examines some of those constellations in the context of Article 19 in England, and

¹ Quinn (2009) 256

² Santos (2002) 417

attempts to assess potential for the Convention to influence understandings, systems and identities to set a new, CRPD-compatible agenda here.

When the UK ratified the UN Convention on the Rights of Persons with Disabilities, it undertook to 'ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities...'³

Among the measures States are required to take to that end are:

- (a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
- (b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities; and
- (c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes.⁴

In addition, under Article 4(3), States are required to 'closely consult with and actively involve' disabled people, through their representative organisations, in the development and implementation of legislation and policies, and in other decision-making processes that relate to them.

Among the rights the UK has undertaken to realise is Article 19. This requires ratifying States to recognise and to take effective and appropriate measures to facilitate the equal right of all disabled people to live in the community with choices equal to others, and their full inclusion and participation in the community. Article 19 has been identified in Chapter 4 as encapsulating core elements of disability/human rights discourse and as clarifying the means through which other Convention rights are realised. As a 'hybrid' right, it exemplifies the Convention's fusion between the two 'sets' of rights: realisation of its socio-economic provisions is pre-requisite for exercise of its civil and political rights to autonomy and participation, which in turn are pre-requisite for the exercise of other Convention rights. How these socio-economic provisions are implemented will therefore have a determinative effect on success or otherwise of the Convention's hegemonic project.

³ Article 4(1)

⁴ Article 4(1)

Yet we have seen that the UK persists in re-articulating economic, social and cultural rights as non-justiciable 'guiding principles' to be implemented through the specific policies, laws and practices of its welfare state, demonstrating that it has not yet made – indeed that it resists – the vital transformation in thinking from 'welfare' to 'rights' demanded by both the UN Committee on Economic, Social and Cultural Rights and the CRPD.

The impact of this fundamental re-articulation on the Convention's hegemonic prospects will be analysed through the 'specific policies, laws and practices'⁵ of the welfare state as they relate to the economic, social and cultural rights engaged in implementation of Article 19:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance, necessary to support living in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

For a discourse to succeed in redefining the debate and setting a new agenda, it must influence understandings in the field of meaning, establish new systems of social relations between objects and practices, and provide subject positions with which social agents can identify.⁶ **Chapter 7** will examine the systems of social relations sedimented in independent living legislation in England; **Chapter 8** the systems, relationships and identities circulating in current independent living practice; and **Chapter 9** the capacity of redress systems to influence independent living policy, law and practice in line with the CRPD drafters' hegemonic project. First, **this Chapter** analyses the field of meaning within which independent living policy in England is shaped.

⁵ United Kingdom of Great Britain and Northern Ireland, Fifth Periodic Report to the Economic, Social and Cultural Rights Committee, July 2007, 2.10

⁶ See Chapter 1 above

The domestic social space

Overview

In the international sphere, disability/human rights discourse has succeeded in redefining the terms of the political debate and in setting a new agenda. That agenda re-articulates liberal 'ableist' understandings of 'normality', autonomy and equality through the experience of *dis*-ability to produce a re-description of the world and of the place of disabled people in it. The practice it engenders reflects the nature of the new discourse in its holistic and participatory approach that takes the views and lived experience of disabled people as its principal point of departure. In the English domestic sphere, we find a very different social space from that at international level. The foundations of capitalist discourse in England, with its idiosyncratic form of individualism, run deep.⁷ Understandings of economic, social and cultural rights are not the only element of disability/human rights discourse to be articulated differently at national level: equality and disability, too, are understood in different ways.

One curious idiosyncrasy of British liberal discourse has been that equality and human rights have been 'kept separate'.⁸ Despite early enactment of non-discrimination law, equality is only beginning to be acknowledged as a fundamental human rights value.⁹ Equality law is considered by many to be

⁷ See Chapter 5 above

⁸ United Kingdom of Great Britain and Northern Ireland, Sixth Periodic Report to the Human Rights Committee, CCPR/C/GBR/6, 18 May 2007, para 66, footnote 52: '[u]nder UK law, the issues of equality and human rights are kept separate, although the [Equality and Human Rights Commission] will be able to look into both subject areas.'

⁹ See for instance the 2010 revision of 2003 Department of Health guidance on eligibility criteria for adult social care, where the section headed 'Equality and Human Rights' consists of three paragraphs on equality with no mention of human rights: Department of Health 'Prioritising Need in the Context of Putting People First: a whole system approach to eligibility for social care – guidance on eligibility criteria for adult social care, England 2010' (2010) Gateway ref 13729, paras 90-92. See also for instance Gearty C, 'Equality of Esteem: the Ethical basis for human rights' (2004) Presentation to Discrimination Law Association conference 'Understanding Equality: the Need for Discrimination' 13 December 2004; Gearty C, 'Can Human Rights Deliver Real Equality?' (2007) 5th Annual Legal Action Group conference, 19 November 2007

unduly 'politically correct'¹⁰ or to burden business with unnecessary 'red tape'¹¹ – both characteristics seen as interfering negatively with individual and market freedom.

Moreover, liberal discourse assumes an 'able' autonomous human 'subject', free to live his life how he chooses, fettered only occasionally by the State.¹² The related discourse of 'normality' relies for its own constitution on the exclusion of *dis*-abled people not only physically through segregation but also in terms of identity.¹³ All of these discursive elements can be found in the history of disability policy in England.

Poor Laws¹⁴ relegated the 'impotent' poor to the workhouse¹⁵ and ensured that their situation was 'less eligible' than that of the 'independent labourer of the lowest class'.¹⁶ People with physical impairments were segregated into 'special schools' or hospitals,¹⁷ where 'crippled' children were 'straightened out' physically and behaviourally,¹⁸ and war veterans and paraplegics

¹⁰ Home Secretary and Minister for Women and Equality Theresa May said: 'Equality has become a dirty word because it has come to be associated with the worst aspects of pointless political correctness and social engineering. ... We need to move away from this old approach and make equalities work for everyone... Government will no longer dictate how people should behave. Instead we will put in place an architecture to support business and wider society to do the right thing.' Home Office Press release, 'May: political correctness won't lead to equality', 17 November 2010, <http://www.homeoffice.gov.uk/media-centre/press-releases/political-correctness>

¹¹ 'The Government is determined to take a hard look at anything which imposes bureaucratic burdens... This red tape challenge spotlight gives you the opportunity to look at all provisions in the Equality Act and tell us if they are too bureaucratic and burdensome for the benefit they bring, whether they could be simplified or better implemented, or if you think they should be kept exactly as they are.' Government 'Red Tape Challenge', <http://www.redtapechallenge.cabinetoffice.gov.uk/themehome/equalities-act/> accessed 5.8.11

¹² See Chapter 2 above

¹³ See Chapter 1 above

¹⁴ Such as the Poor Law Act of 1601. This required each of 15,000 parishes to elect overseers of the poor to levy a compulsory property rate, to put the 'undeserving' able-bodied poor to work and to supply outdoor relief to the 'deserving' or 'impotent' poor who were elderly, sick or infirm. Borsay A, *Disability and Social Policy in Britain since 1750: a History of Exclusion* (Palgrave Macmillan 2005) 20

¹⁵ Borsay (2005) chapter 2

¹⁶ Ibid

¹⁷ See for example Sullivan M, 'Subjected Bodies: Paraplegia, Rehabilitation and the Politics of Movement' in Tremain S (ed) *Foucault and the Government of Disability* (University of Michigan Press 2005) 27 – 29.

¹⁸ Striker HJ, *A History of Disability* (Michigan University Press 1999) cited in Borsay (2005) 49

'rehabilitated'¹⁹ to 'rescue' them from the 'human scrap-heap'.²⁰ Those too old to be 'normalised' might be sent to the poor law infirmaries, 'put to bed and kept there', stigmatised as 'parasites' on the national economy.²¹ 'Idiots', 'lunatics' and 'persons of unsound mind' were incarcerated in asylums, along with people with 'mental deficiencies' such as impaired coordination, sight or hearing, and 'moral deficiencies', such as pregnancy outside marriage.²² Many were subjected to psychiatric experimentation with electro-convulsive therapy or psychosurgery.²³

These institutional developments, with their physical segregation, social, medical and psychiatric objectification and control, negation of identity and concomitant experiences of abuse and oppression, feature strongly in the shared history of disabled people.²⁴ Alongside such institutional experience, however, many disabled people lived, with or without 'poor relief', in the community. Here, as Borsay describes,

[f]aced with poor wages, joblessness and the extra costs of impairment, disabled people cobbled together a makeshift domestic economy of

¹⁹ As Finklestein describes his experience, 'The aim of returning the individual to normality is the central foundation stone upon which the whole rehabilitation machine is constructed. If, as happened to me following my spinal injury, the disability cannot be cured, normative assumptions are not abandoned. On the contrary, they are reformulated so that they not only dominate the treatment phase searching for a cure but also totally colour the helper's perception of the rest of that person's life. The rehabilitation aim becomes to assist the individual to be 'as normal as possible'.' Oliver M, *Understanding Disability: from Theory to Practice* (MacMillan 1996) 105, quoted in Borsay (2005) 60; see also Tara's experience of 'special school' in Chapter 1 above

²⁰ Guttman L, 'History of the Stoke Mandeville Hospital, Aylesbury', (1967) 34 *Paraplegia* 115, quoted in Borsay (2005) 60

²¹ T Thane P, *Old Age in English History: Past Experiences, Present Issues* (Oxford University Press, 2000) 450, 452 cited in Borsay (2005) 64; for update on equality and older people see Harding T, 'The Long and Winding Road – towards dignity and equality in old age' Help the Aged lecture, 25 October 2006

²² See for instance Wright D, *Mental Disability in Victorian England: the Earleswood Asylum 1847-1901* (Clarendon Press 2001); The Willard Suitcase Exhibit Online at <http://www.suitcaseexhibit.org/indexhasflash.html> last accessed 15.9.12; 'Telling Lives' theatre production by Cul-de-Sac Theatre Group 2012

²³ Fennell P, *Treatment Without Consent: Law, Psychiatry and the Treatment of Mentally Disordered People since 1845* (Routledge 1996) cited in Borsay (2005) 85. 'The Ministry of Health reported that in the 12 years from 1942, 10,365 leucotomies were carried out, two-thirds of them on people with schizophrenia.' Borsay (2005) 86. See also Kesey K, *One Flew over the Cuckoo's Nest* (Penguin 1962). This was also the height of the Eugenics Movement, which led, *inter alia*, to the mass-murder of disabled people by the Nazi regime. See Chapter 3 above, footnote 114

²⁴ See for instance Union of the Physically Impaired Against Segregation 'Policy Statement' (UPIAS 1974/5) section 6; Barnes C, 'A Legacy of Oppression' in Barton L, Oliver M, *Disability Studies: Past Present and Future* (The Disability Press 1997); Charlton (2000)

support from family and community as well as from mutual aid, charitable assistance and state relief.²⁵

Some made a living exhibiting themselves to the public in 'freak shows',²⁶ trading on negative fascination with difference.²⁷

Conditions for disabled people in England have improved immeasurably since the days of the Poor Laws. As the 20th century progressed, and social attitudes changed, the workhouse was replaced by the public assistance institution, and draconian psychiatric treatments were largely overtaken by a 'pharmacological revolution'.²⁸ With foundation of the 1940s Beveridge/Marshall welfare state,²⁹ poor law infirmaries became NHS geriatric wards, psychiatry a branch of medicine within the NHS, and public assistance institutions became residential homes run by local authorities or the charity sector. As limited rights of appeal against mental health detention were introduced,³⁰ numbers resident in mental and 'sub normality' hospitals began to fall. From the 1960s, as disabled people mobilised to counter their oppression, a programme of hospital closure³¹ gave rise to a new discourse of 'care in the community'.

²⁵ Borsay (2005) 200; see also Turner W, 'Human Rights, Royal Rights and the Mentally Disabled in Late Medieval England' (2009) Compass Interdisciplinary Virtual Conference, 19-30 October 2009

²⁶ See National Fairground Archive, University of Sheffield, <http://www.nfa.dept.shef.ac.uk/history/shows/freaks.html>; Wellcome Collection blog re Royal College of Physicians 'Reframing Disability' exhibition, London 2011, <http://wellcomecollection.wordpress.com/2011/05/11/re-framing-disability> accessed 19.10.11;

²⁷ 'If we're going to get looked at anyway, we might as well get paid for it.' These are the words of Sophie Partridge, a disabled focus group participant, who took part in a new exhibition at the Royal College of Physicians', Wellcome Collection blog, supra

²⁸ Though this can also lead to oppressive mis-use, such as the over-prescription of anti-psychotic drugs to people with dementia; http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=389 accessed 28.9.12

²⁹: *Report of the Inter-Departmental Committee on Social Insurance and Allied Services* (The Beveridge Report) (Cmnd 6404) November 1942; Marshall TH, 'Citizenship and Social Class' in Marshall TH (ed) *Citizenship and Social Class and Other Essays*, (Cambridge University Press 1950); Taylor-Gooby P, 'Welfare Reform in the UK: the Construction of a Liberal Consensus' in Taylor-Gooby P, *Reframing Social Citizenship* (Oxford University Press 2009). For an overview of British disability policy from the Second World War to 2011, see Shah S and Priestley M, *Disability and Social Change: Private Lives and Public Policies* (Policy Press 2011) Chapter 1

³⁰ Mental Health Act 1959

³¹ Initiated by Enoch Powell Minister for Health in his 'Water Tower' speech to Conservative Party conference, March 1961

However, despite the social model of disability being the British disabled people's movement's 'big idea', the medical model with its 'normalisation' discourse³² still predominates in many powerful quarters;³³ paternalistic service provision which assumes dependency persists; the principle of 'less eligibility' still lingers in the social security system;³⁴ and disabled people's organisations often struggle to survive and to have their voices heard.³⁵ In this domestic sphere, respect for their experience and expertise regarding identity, survival and dignity cannot be assumed.

With economic, social and cultural rights rendered invisible, equality seen by many as interfering negatively with freedom, and liberal 'normality' discourse still powerful, domestic understandings in England constitute, at first glance, a challenging context for expansion of the international disability/human rights project. We will find some of those challenges below. Nevertheless, disabled people's independent living discourse has achieved a substantial degree of success. Following a brief historical background, this chapter traces its fortunes from 2005.

Disabled people's influence

In England, as elsewhere, disabled people have responded to oppression and negation of their identity in many ways.³⁶ From the 1960s,³⁷ a strong

³² As Finklestein describes his experience, 'The aim of returning the individual to normality is the central foundation stone upon which the whole rehabilitation machine is constructed. If, as happened to me following my spinal injury, the disability cannot be cured, normative assumptions are not abandoned. On the contrary, they are reformulated so that they not only dominate the treatment phase searching for a cure but also totally colour the helper's perception of the rest of that person's life. The rehabilitation aim becomes to assist the individual to be 'as normal as possible.' Oliver (1996) 105; see also Tara's experience of 'special school' in Chapter 1 above

³³ See Chapters 7 – 9 below

³⁴ Beresford P, Fleming J, Glynn M, Bewley C, Croft S, Branfield F and Postle K, *Supporting People: towards a person-centred approach* (Policy Press 2011) 40-41

³⁵ Disability LIB 'Less Courses, more conversations': Disabled People's Organisations (DPOs) and Mainstream Capacity Building, (Disability LIB 2010); Maynard Campbell S, Maynard A and Winchcombe M, 'Mapping the Capacity and Potential for User-Led Organisations in England: a summary of the main findings from a national research study commissioned by the Department of Health' (Equal Ability CIC 2007); Disability LIB 'Thriving or Surviving' (Scope 2008); Woodin S, 'Mapping User-Led Organisations: User-Led Services and centres for Independent/Integrated/inclusive Living: A Literature Review Prepared for the Department of Health' (University of Leeds 2006)

³⁶ Their social antagonistic discourse can be traced back to the late 19th century: Campbell (1997) 79

catalyst was resistance to the institutionalisation promoted and serviced by the large impairment charities.³⁸ In the 1970s, the Union of the Physically Impaired Against Segregation (UPIAS)³⁹ became ‘founders of this philosophy that relocated the burden of disability from the individual’s problem to the way society was structured,’⁴⁰ the future social model of disability. Here, as in the USA, we find emphasis on political organisation, on self-determination, non-segregation, on choice, control and inclusion, captured in the ‘Nothing about us without us’ mantra.⁴¹ In England, however, as Barnes explains,

[i]t is evident that unlike the work of their American counterparts, [British] accounts suggest that the basis of disabled people’s oppression is founded upon the material and ideological changes which occurred as a result of the emergence of capitalist society.⁴²

For instance, Finkelstein argued that ‘disability is the direct result of the development of western industrial society.’⁴³ More recently, the British Disabled People’s Movement, like its international counterpart, has expanded to encompass a wide range of approaches and perspectives.⁴⁴

³⁷ Hunt P (ed) *Stigma: The Experience of Disability* (Geoffrey Chapman 1966); UPIAS (1974/5); Barnes (1991); Campbell (1997)

³⁸ Jane Campbell tells us that in England, ‘[i]n the late 1960s disabled people began to question as a collective, the modus operandi of a plethora of predominantly impairment charities. The charities, along with the quasi medical and social service professions who also dictated the direction and pattern of our lives began to come in for more overt criticism.’ Campbell (1997) 78-90

³⁹ Formed following a letter to the Guardian dated 20th September 1972 from a Leonard Cheshire Home resident, Paul Hunt (Leeds Disability Archive)

⁴⁰ Campbell (1997)

⁴¹ Disability LIB (2008) 6. Whilst this thesis refers broadly to the ‘social model of disability’, neither the concept nor the content of such a model is undisputed among disability activists: see for example Light R, ‘Social Model or Unsociable Muddle?’ (DAA undated); Oliver M and Barnes C, ‘Disability Politics and the Disability Movement in Britain: where did it all go wrong?’ (2006) Leeds Disability Archive; Shakespeare T, *Disability Rights and Wrongs* (Routledge 2006); Abberley P ‘The Concept of Oppression and the Development of a Social Theory of Disability’ (1997), Leeds Disability Archive; Finkelstein V, ‘The ‘Social Model of Disability’ and the Disability Movement’ (2007) Leeds Disability Archive

⁴² Barnes C, ‘A Legacy of Oppression’ in Barton L, Oliver M, *Disability Studies: Past Present and Future* (The Disability Press 1997) 9; see also Oliver M, *The Politics of Disablement* (Palgrave Macmillan 1990); Evans J, ‘The Independent Living Movement in the UK’ in Alonso JVC (ed) *El Movimiento de Vida Independiente, Experiencias Internacionales* (Luis Vives 2003) www.independentliving.org/docs6/evans2003.html

⁴³ Finkelstein V, *Attitudes and Disabled People* (World Health Organisation 1980)

⁴⁴ Goodley (2010); Leeds Disability Archive

The British Disabled People's Movement also gave birth to a range of organisations of disabled people (DPOs).⁴⁵ In response to their roots, British DPOs strongly differentiate themselves from organisations for disabled people, such as the large high-profile disability charities challenged by UPIAS.⁴⁶ DPOs range from small unfunded self-help groups; through local access or self-advocacy groups; to medium-sized charitable organisations, including Centres for Independent Living, providing front-line services, supporting smaller DPOs, and campaigning for disability rights.⁴⁷ Their national voice is provided by a small number of national DPOs⁴⁸ offering structural support and campaigning on the wider political stage.⁴⁹

One outcome of the campaigning activities of British disabled people and their organisations was enactment in 1995 of the first Disability Discrimination Act in Europe. From its limited beginnings, this Act developed incrementally to include not only a duty not to discriminate in specific fields such as employment, education and housing, but also a positive public sector duty to promote disability equality.⁵⁰ This last provision came into force in 2006, imposing a general duty on all public authorities, when carrying out their

⁴⁵ See Barnes C and Mercer G, *Independent Futures: creating user-led disability services in a disabling society* (Policy Press 2006); Maynard Campbell *et al* (2007); Disability Lib (2008)

⁴⁶ 'Whereas DPOs work to the social model of disability, with a commitment to self-determination, rights and equality, organisations 'for' disabled people often work to a medical model, looking to 'normalise' the individual rather than to change society, providing segregated services, and raising money through charitable activities which portray disabled people as 'tragic' victims. The success of such fundraising contributes to wide disparity in income – and thus in capacity and power - between DPOs and the disability charities, creating further resentment and hostility' (Disability LIB 2008, 13). In 2004, an attempt was made to overcome these hostilities when Scope (a large disability charity) and Disability Awareness in Action (an organisation of disabled people) published a Statement of Collaboration on the Human and Civil Rights of Disabled People (Miller *et al* 2004, 17). 'However, distrust remains, not least because some disability charities now argue that they fit the definition of a DPO, adopting the language of rights without necessarily adapting their ideology or activities accordingly' (Disability LIB 2008, 13).

⁴⁷ Maynard Campbell *et al* (2007); Disability LIB (2008)

⁴⁸ For national pan-disability infrastructure and campaigning organisations, see UK Disabled People's Council (UKDPC) <http://www.ukdpc.net/ukdpc/index.php> last accessed 5.9.12; Disability Rights UK <http://www.disabilityrightsuk.org/> last accessed 5.9.12. Other national DPOs spring from a particular experience of disability. Prominent among these are People First, run by and for people with learning disabilities, and Shaping Our Lives, 'an independent user-controlled organisation, think tank and network' with a diverse membership and focus on 'user involvement' in research and training

⁴⁹ Disability LIB (2008) 18

⁵⁰ Disability Discrimination Act 1995, as amended by Disability Discrimination Act 2005, Part 5 (ss49A – 49F); see also Disability Rights Commission, 'Ten years of the DDA' Bulletin (Disability Rights Commission 2005)

functions, to 'have due regard' to the elimination of disability discrimination and the promotion of equality.⁵¹ A further 'specific' duty required key public authorities to publish a Disability Equality Scheme, setting out how it would assess the impact of its activities on disabled people. This 'specific' disability duty differed from those under race and gender legislation in two ways: firstly, by requiring that disabled people be involved in producing and reviewing the Scheme, with their involvement recorded in the Scheme; and secondly, by requiring key Secretaries of State⁵² to report every three years on progress made towards disability equality across their policy sectors, and on co-ordinated actions proposed to make further improvements.⁵³ The Disability Equality Duty (DED) thus moved UK disability equality law from the formal individualistic understanding of non-discrimination as civil liberty to a more 'transformative'⁵⁴ understanding of equality requiring systemic proactive action.⁵⁵ It also began to build a holistic framework within government to address and take forward disability equality policy. Regulators prepared to audit all public bodies on their equality and human rights compliance.⁵⁶

⁵¹ DDA95 s49A

⁵² The 11 secretaries of State subject to this duty in 2008 were: Business, Enterprise and Regulatory Reform; Children, Schools and Families; Communities and Local Government; Culture, media and Sport; Environment, Food and Rural Affairs; health; Home Office; Innovation, Universities and Skills; Justice; Transport and Work and Pensions. All published their first reports in December 2008

⁵³ Office of Disability Issues, 'Secretary of State Reports on Disability Equality: overview', December 2008, Foreword. They reported for the first (and only) time in 2008

⁵⁴ Fredman S, 'Disability Equality: a Challenge to the Existing Anti-discrimination Paradigm?' in Lawson A and Gooding C, *Disability Rights in Europe* (Hart 2005); O'Conneide C, 'Disability Discrimination' in Bamforth N, Malik M and O'Conneide C, *Discrimination Law: Theory and Context*, 1st ed (Sweet & Maxwell 2008); Lawson A, *Disability and Equality Law in Britain: the role of reasonable adjustment* (Hart 2008); Hepple B, 'The new Single Equality Act in Britain' (2010) 5 Equal Rights Review 11

⁵⁵ See Chapter 2 above. Also Disability Rights Commission 'The Duty to Promote Disability Equality: Statutory Code of Practice, England and Wales' (DRC 2005); Disability Rights Commission 'The Disability Equality Duty and Involvement: Guidance for public authorities on how to effectively involve disabled people' (DRC 2006); Disability Rights Commission 'Doing the Duty: an overview of the Disability Equality Duty for the public sector' (DRC 2006). For one example of practical application, see Dyer L, 'Involving Service Users and Carers – the Mersey Care Way' (Mersey Care NHS Trust 2008);

⁵⁶ Audit Commission, *Human Rights: Improving Public Service Delivery*, London, Audit Commission 2003; Noronha N de, 'Assessing Equality and Human Rights in local public services' (2009) presentation to 'Equality, Human Rights and Good Relations: evidence based interventions and policy making' seminar, University of Liverpool, 21 May 2009

Although the DED did not spring from the CRPD,⁵⁷ it was in many ways consistent with its ethos and its requirements, requiring proactive structural and attitudinal change in line with CRPD Articles 8 and 9, co-ordinated action within government in line with Article 33(1), and the involvement at all levels of disabled people in line with Articles 4(3) and 33(3). It also contributed to their access to services under Article 19.⁵⁸

Disabled people's independent living campaigns also succeeded in introducing some elements of 'entitlement'⁵⁹ and choice⁶⁰ into the paternalistic 'care' system instituted by the post-war welfare state. One early breakthrough was enactment in 1970 of the Chronically Sick and Disabled Persons Act, section 2 of which placed a duty on local authorities to provide assistance in the home.⁶¹ Soon after, members of two disabled people's projects⁶² convinced their local authorities that their residential care funding should be used instead to pay for self-managed housing and support in the community. A national network of disabled people's organisations providing advice and information was set up in 1978,⁶³ and the first UN International Year of Disabled People in 1981 prompted the formation of a number of DPOs⁶⁴ in response to local demand for peer support for independent living.

⁵⁷ Public sector equality duties had been introduced in Northern Ireland, (Northern Ireland Act 1998, s75), Wales (Government of Wales Act 1998, s120) and the Greater London Authority (Greater London Authority Act 1999, s33) as part of the process of devolution in 1998, and had been shown to produce results. Provisions for NI specifically include disability; for Wales and London the provisions cover 'all people', thus much wider than the current discrimination 'strands', though relating to 'opportunity, rather than 'outcome'. They had also been recommended by the influential Hepple Report of 2000 (Hepple B, Cousey M and Choudhury T, *Equality, A New Framework: Report of the independent review of the enforcement of UK anti-discrimination law* (Hart 2000)) and by the Disability Rights Task Force which preceded the Disability Rights Commission. An incipient race equality duty introduced in 1976 was considerably strengthened following the Stephen Lawrence inquiry and a gender equality duty followed hard on the heels of DDA Part 5A, in 2007.

⁵⁸ See Chapter 9 below

⁵⁹ See discussion of Chronically Sick and Disabled Persons Act 1970 s2 and National Health Service and Community Care Act 1990 in Chapter 7 below

⁶⁰ Community Care (Direct Payments) Regulations 1997 SI 1997/734, now Health and Social Care Act 2001 s57(1) and (2)

⁶¹ Discussed further in Chapters 7 and 8 below

⁶² Derbyshire Coalition of Disabled People and 'Project 81', set up by three residents of a Leonard Cheshire Home, later the Hampshire Coalition of Disabled People

⁶³ Disablement Information and Advice Line, or DIAL UK, formed by the Derbyshire Coalition of Disabled People in 1978

⁶⁴ Such as DIAL Chester; Project 81 developed into the Hampshire Coalition of Disabled People in 1982

It was also in 1981 that the first Green Paper on 'Care in the Community' set the seeds for the policies discussed below. A national Independent Living Fund (ILF) was subsequently set up 'to enable disabled people to live independent lives in their community rather than in residential care.'⁶⁵ In 2010, the Fund had over 21,000 beneficiaries.⁶⁶

Another notable success for disabled people was enactment of the Community Care (Direct Payments) Act in 1996. This introduced direct payments as an alternative to local authority-provided services for individuals who choose to employ their own personal assistants.⁶⁷ As we saw in Chapter 4 above, control plays a strong part in disabled people's independent living discourse in relation to both anti-dependence and individual empowerment. Direct Payments were hailed as increasing that control, enabling choice in how, and by whom, services were provided.⁶⁸ As Stevens *et al* recognise,

[i]n this light, choice is constructed as a means to overcome oppression and is related to concepts of autonomy, inclusion, rights and citizenship. Critically, choice is therefore conceived in terms of a wider conception of autonomy, and related to choice of lifestyle, activities and living arrangements... Addressing cultural and philosophical attitudes to disability and older people was given equal importance.⁶⁹

⁶⁵ In 1988 to run for 5 years. When the initial fund closed in 1993, a new Fund was established to supplement support provided by the local authority. To qualify (2010 figures), the claimant must be receiving support from their local authority amounting to at least £340 a week, or £17,680 a year; have less than £23,000 in capital; and be receiving the highest rate care component of Disability Living Allowance.

<http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/OtherBenefitsAndSupport/DG4019444> accessed 7.8.11

⁶⁶ 21,792 users, receiving average quarterly payment of £1300.47, totalling £84,985,456.70 per quarter. Independent Living Fund, User Profile Analysis, Results up to quarter ending June 2010. <http://www.dwp.gov.uk/docs/user-profiles-0610.pdf> accessed 7.8.11

⁶⁷ Community Care (Direct Payments) Act 1996; see further Pridmore A 'Disability Activism, Independent Living and Direct Payments' Paper for 'Independent Living and Direct Payments: the National Picture' Conference, Leeds 22 March 2006, Leeds Disability Archive

⁶⁸ As pioneered by disabled people's organisations, Direct Payments are characterised by: self-assessment and self-definition of support needs; choice of who works with the disabled person, with the right to hire and fire; the disabled person defining what the personal assistant does and how; and recognition of the value and importance of support from disabled people's organisations – offering advocacy, independent information, training, advice and administrative back-up – to enable disabled people to set up and run their own schemes. Morris (1993); see also Blyth C and Gardner A 'We're not asking for anything special': direct payments and the carers of disabled children' (2007) 22(3) *Disability & Society* 235

⁶⁹ Stevens *et al* 'Assessing the Role of Increased Choice in English Social Care Services' (2011) 40(2) *Journal of Social Policy* 257, 259

Despite slow uptake, Direct Payments have now developed into wider concepts of 'personal budgets' and 'personalisation' discussed further below.

By 2005, disabled people had developed in the social model of disability a powerful political tool. A range of local and national DPOs had grown to provide voice and support for independent living. Their campaigning had contributed to the enactment of discrimination law and its development from formal to substantive, from individual to systemic; and to an, albeit limited, shift in service provision from institution to community,⁷⁰ and from local authority control to individual control. As Jenny Morris comments,

[t]he recasting of the welfare agenda... has not only been played out within the politics of Old Labour, New Labour and the New Right, but has also been profoundly influenced by the grassroots movements amongst those groups who are particularly reliant on the welfare state for their life chances.⁷¹

In 2005, disabled people's lobbying for independent living achieved a further breakthrough: the Prime Minister's Strategy Unit produced a report,⁷² which identified independent living as one of four key elements in its strategy for 'Improving the Life Chances of Disabled People' (The Life Chances Report).⁷³

⁷⁰ But see for instance Scourfield P 'What matters is what works'? How discourses of modernization have both silenced and limited debate on domiciliary care for older people' (2006) 26(1) *Critical Social Policy* 5

⁷¹ Morris J, 'Independent Living: the role of evidence and ideology in the development of government policy' (2005) Paper delivered at Cash and Care Conference, Social Policy Research Unit, University of York, 12-13th April 2005. Gearty C 'Putting Lawyers in their Place: the Role of Human Rights in the Struggle against Poverty' (undated) 15

⁷² Drawn up jointly with four other government departments: Department of Work and Pensions, Department of Health, Department of Education and Skills and Office of the Deputy Prime Minister, and with strong input from disabled people: see Morris (2005)

⁷³ Prime Minister's Strategy Unit, 'Improving the Life Chances of Disabled People', January 2005 http://www.cabinetoffice.gov.uk/strategy/work_areas/disability.aspx last accessed 13.6.12 (Life Chances Report)

Improving Life Chances

The Life Chances Report sets out to ‘bring disabled people fully within the scope of the “opportunity society”’.⁷⁴ Its ‘ambitious vision’ is that

by 2025, disabled people should have the same opportunities and choices as non-disabled people and be respected and included as equal members of society.⁷⁵

Four areas are identified as central to future strategy to bring this vision about, one of which is helping disabled people to achieve independent living.⁷⁶ This is to be achieved

by moving progressively to individual budgets for disabled people, drawing together the services to which they are entitled and giving them greater choice over the mix of support they receive in the form of cash and/or direct provision of services... measures should also be taken to improve the advice services available to disabled people and to address existing problems with suitable housing and transport... This package of measures...should deliver improved outcomes for disabled people, their families and wider society in the short, medium and long-term.⁷⁷

The Report identifies two main barriers to achieving its aims, which

are evident across all aspects of disabled people’s lives – in where they live, their personal relationships, their opportunities for education, training and employment; access to healthcare; access to leisure activities; and participation in the life of their local community and in wider society.⁷⁸

Firstly,

[t]he support which society makes available to people with a range of different impairments is generally not fitted to the person. Instead, disabled people are expected to fit into services.⁷⁹

⁷⁴ Ibid 4

⁷⁵ Ibid; see also Morris J, ‘Citizenship and disabled people’ (2005) Paper for DRC Seminar ‘Equal Rights... equal responsibilities?’ February 2005

⁷⁶ the other three are improving support for families with young disabled children, facilitating a smooth transition into adulthood, and improving support and incentives for getting and staying in employment

⁷⁷ Life Chances Report, Executive Summary, 4

⁷⁸ Ibid para 4.2, 60

⁷⁹ Ibid

Secondly,

[p]olicies and practice do not pay enough attention to enabling disabled people to be active citizens, or to supporting disabled people to help themselves.⁸⁰

Within these broad categories, specific problems are identified. One is 'a welfare system which assumes dependency' - an assumption reflected in the culture of health and social care structures, with 'a failure to see expenditure on independent living as a form of social and economic investment.'⁸¹ Another is the 'silo-based' approach of government bodies, which results in a fragmented and inflexible⁸² rather than a comprehensive and cost-effective approach to meeting disabled people's needs.⁸³ The resulting, often inadequate, responses to need lead to poor quality of life and unequal opportunities, and may even exacerbate disability.⁸⁴ Assessment often focuses on eligibility for services rather than on the individual's needs, thereby denying choice and control and leading to additional demands on services.⁸⁵ Inflexible service provision combined with unsuitable housing has led some people to move into residential care against their wishes. At the time of the Report, increasing numbers of people with learning disabilities, mental health needs and physical or sensory impairments were being placed in residential care,⁸⁶ where they 'often have little or no further

⁸⁰ Ibid

⁸¹ Ibid

⁸² Morris J, "One town for my body, another for my mind": *Services for people with physical impairments and mental health support needs* (Joseph Rowntree Foundation/York Publishing Services 2004). For instance, '[t]he failure of services to meet the needs of people with learning disabilities and people who are deaf or hearing impaired, who also have mental health support needs, has been... well documented': Life Chances Report, 63, referencing Foundation for People with Learning Disabilities, *Count Us In: The report of the Committee of Inquiry into meeting the mental health needs of young people with learning disabilities* (Mental Health Foundation 2002); Department of Health, *A Sign of the Times: Modernising mental health services for people who are deaf* (DoH 2002)

⁸³ Life Chances Report, 61

⁸⁴ 'It is often inadequate responses to need that lead to a poor quality of life and unequal opportunities, rather than impairment itself: poor quality of life may be created by a failure to meet needs relating to impairment; by disabling barriers that make worse or create impairment or illness; or by services which are disabling in themselves, such as unreliable assistance to get up in the morning in time to get to work, which leads to loss of job, unemployment and negative effect on mental and physical health.' Ibid, 61

⁸⁵ Ibid 65

⁸⁶ Ibid 66; placements in residential care of those with learning disabilities or mental health support needs increased by 20% and 40% respectively between 1997 and 2002, and the numbers of people with physical and/or sensory impairments in residential care was also increasing.

contact with the funding authority... [m]any people have a very low quality of life and some experience serious abuse.’⁸⁷ Further barriers to independent living identified in the Report include low income, the negative attitudes of transport providers, and the failure of general policies and services, such as planning initiatives, libraries and leisure centres to take disabled people into account.

We will return to these issues below and in following Chapters. However, it becomes evident already that the concerns identified in the Life Chances Report coincide closely with the requirements set out in Article 19 of the Convention. We find disabled people deprived of choice of living arrangement, placed in residential care for lack of housing options or support, contrary to Article 19(a). We find paternalistic, fragmented and disabling provision of individual support services, contrary to Article 19(b). And we find failure on the part of services and facilities for the general population to respond to disabled people’s needs, contrary to Article 19(c). Underlying all of these issues is a welfare system that assumes dependency, whose discourse permeates the cultures of health and social care systems and institutions, and results in *dis*-abling services which negate the rights to choice, inclusion and participation at the core of Article 19 and of the Convention. The existing field of meaning, with its systems and identities, is in need of reorganisation if it is to reflect CRPD discourse.

The Life Chances Report proceeds to identify ‘what works’ in addressing these issues. Firstly, it highlights the importance of involving disabled people and their organisations in the development and implementation of policy and the delivery of services, echoing disabled people’s mantra of ‘Nothing about us without us’, and the participatory ethos of the Convention. The Report argues that ‘disabled people are best placed to take the lead in identifying their own needs and in identifying the most appropriate ways of meeting such needs’: the most effective responses are those ‘personalised’ to individual

⁸⁷ Ibid 67, referencing Pring J, ‘The frequency and potential consequences of the failure to visit learning-disabled adults in out of area placements’ (2004) 9(2) Learning Disability Review 35; see also Chapter 3 footnote 121

need,⁸⁸ enabling control, sharing power and acknowledging disabled people's expertise. Furthermore, says the Report, 'effective support addresses all aspects of someone's life, instead of fragmenting their lives across different services and/or funding mechanisms': this is a holistic exercise, addressing all aspects of exclusion. To enable this transformation, '[d]isabled people need access to high-quality information and advice services, as well as to supported, independent advocacy': the Report recommends that 'by 2010, each locality... should have a user-led organisation modelled on existing CILs'.⁸⁹ It points out that 'effective use of resources supports family and friendship networks and enables access to mainstream society', anticipating the Article 19 right to be included in the community. The Report thus strongly reflects the core elements of disabled people's independent living discourse as described in Chapter 4: it suggests anti-dependence and inclusion, self-determination with collective peer support, change in social relations and holistic action.⁹⁰

The aims and understandings of the Life Chances Report fit closely with those of the drafters of the CRPD, and with the terms of Article 19. However, at the time, the Convention was still in negotiation, and, despite the UK's involvement in those negotiations, there is no reference to them in the Life Chances Report. Instead, the understandings of independent living which shape the Report came directly from the multi-disciplinary project team set up to prepare it.⁹¹ The team's Expert Group on independent living included

⁸⁸ Life Chances Report, 72

⁸⁹ Ibid, recommendation 4.3

⁹⁰ See also Massie B, 'Finding the Wormhole: Achieving equal citizenship for disabled people' (2006) 4th Annual Disability Lecture, St John's College, Cambridge University, 9 May 2006: 'we will only secure a future of equal human and civil rights through a strategy which positively transforms society's expectation of disabled people'. For a response to the Life Chances Report from one disabled people's organisation, see Gibbs D, 'Public Policy and Organisations of Disabled People' (2005) Seminar presentation to University of Leeds Centre for Disability Studies, 22 April 2005; for a discussion led by disabled people's organisation on what needs to happen to fulfil the commitments set out in the Life Chances Report, see Morris J, 'Centres for Independent Living/Local user-led organisations: a discussion paper' (Valuing People Support Team 2006)

⁹¹ This included a Strategy Unit team comprising civil servants and others with expertise in economics, policy-making and disability issues, an Advisory Group and three Expert Groups. The team conducted bilateral discussions, shadowed disabled people in variety of settings, conducted focus group consultations with disabled people and others and received written submissions: Life Chances Report, Annex C, D and E

long-term disability activists and service users, as well as others involved in service provision.⁹² As Jenny Morris⁹³ explains,

[t]he adoption of the *Improving Life Chances* report is ... a reflection of the success of the disability movement in challenging the notion that, if you need assistance to go about your daily life, then you are a 'dependent person'.⁹⁴

A government Office for Disability Issues (ODI), guided by an advisory group of disabled people,⁹⁵ was set up to coordinate work across government departments to help deliver its 'Improving Life Chances' commitments. Over the next 3 years, the ODI undertook research on the costs and benefits of independent living⁹⁶ and housing adaptations,⁹⁷ conducted an Independent Living Review and published an Independent Living Strategy.⁹⁸ It supported the introduction of individual budgets which bring together a variety of funding streams, with a view to reducing bureaucracy and increasing choice and control.

⁹² For list, see Life Chances Report, Annex B

⁹³ Consultant and member of the Strategy Unit team closely involved in drafting the Report

⁹⁴ Morris (2005) 8. Morris also highlights the role of research in the development of independent living policy in England at this time. Starting with the Joseph Rowntree Foundation, some research funders began to adopt, to a greater or lesser extent, a social model of disability in their guidance for researchers. This entailed the involvement of disabled people at all stages of the research, including setting the agenda and influencing its practice. It was this kind of research, primarily funded by the JRF, which influenced the Strategy Unit's report (Morris, *ibid*, 9-10). It comprised research into the meaning of independent living; and into comparative experiences of residential care, community care and direct payments (Morris, 1983); work on the costs and benefits of independent living (Zarb *et al*, 1994; Zarb *et al* 2000); and on the experiences of people with learning disabilities (People First 1994) and older people (Tozer *et al*, 1995). Thus, '[b]y the time the Prime Minister's Strategy Unit started its scoping work on the 'Improving Life Chances' project in 2003, there was a body of research and evaluations, informed by the social model of disability, which both put forward a definition of independent living and made the case for policies that would deliver this aim.'" (Morris, *ibid*, 14)

⁹⁵ Equality 2025, <http://odi.dwp.gov.uk/equality-2025/index.php> last accessed 5.9.12

⁹⁶ Hurstfield, J, Parashar, U and Schofield, K. SQW Ltd, 'The Costs and Benefits of Independent Living' (Office for Disability Issues 2007); see also Blanck C, Scherman A and Sellin K 'The price of freedom of choice, self-determination and integrity: a report from the Knowledge Project' JAG 2006

⁹⁷ Heywood F and Turner L, *Better Outcomes, Lower Costs: implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence*, (Office for Disability Issues 2007)

⁹⁸ 3 March 2008 <http://www.officefordisability.gov.uk/working/independentlivingstrategy.asp> ; see also Office for Disability Issues *Roadmap 2025: achieving disability equality by 2025* (2009); and Williams B, Copestake P, Eversley J and Stafford B, 'Experiences and Expectations of Disabled People' (Office for Disability Issues 2008)

A 2006 Green Paper⁹⁹ set out a vision for transforming the lives of people using social care by giving them more control and choice over their care, to be achieved by wider use of direct payments in the form of ‘individual budgets’, with a greater role for ‘self-assessment’. A further initiative by the Department of Health¹⁰⁰ was followed in 2007 by a ‘Concordat’¹⁰¹ between six government departments¹⁰² promising to

put people first through a radical reform of public services, enabling people to live their own lives as they wish, confident that services are of high quality, are safe and promote their own individual needs for independence, well-being and dignity.¹⁰³

The agreement proposed setting up a new ‘personalised’ adult social care system,¹⁰⁴ supported by ring-fenced funding¹⁰⁵ ‘to help councils to redesign and reshape their systems over the next 3 years’.¹⁰⁶

In 2008, the Department of Work and Pensions conducted ‘a wide ranging consultation on the future of welfare,¹⁰⁷ whose objective was ‘a social revolution’: an 80 per cent employment rate to reduce social exclusion - ‘the next step in the onward march of equal rights’.¹⁰⁸ The ensuing White Paper¹⁰⁹ heralded an ‘empowering welfare state’, in which ‘everyone has personalised support and conditions to help them get back to work, underpinned by a simpler benefits system and genuine choice and control for

⁹⁹ Department of Health, *Independence, Well-being and Choice*, Cm 6499, 21 March 2005

¹⁰⁰ Department of Health, ‘Our health, our care, our say: a new direction for community services’, Cm 6737, 31 January 2006

¹⁰¹ ‘Putting People First: a shared vision and commitment to the transformation of adult social care’

www.dh.gov.uk/en/PUBLICATIONSANDSTATISTICS/PUBLICATIONS/PUBLICATIONSPOLICYANDguidance/dh_081118 accessed 26.8.08

¹⁰² And others concerned with social care: the Local Government Association, the Association of Directors of Adult Social Services, the NHS, representatives of independent sector providers, the Commission for Social Care Inspection and others

¹⁰³ ‘Putting People First’, supra

¹⁰⁴ See Department of Health Local Authority Circular LAC(DH)(2008)1

¹⁰⁵ totalling £520 million

¹⁰⁶ LAC(DH)(2008)1; and LAC(DH)(2009)1

¹⁰⁷ Secretary of State for Work and Pensions, *No one written off: reforming welfare to reward responsibility* (Cm 7363, 2008) www.dwp.gov.uk/welfare-reform/noonewrittenoff accessed 27.8.08

¹⁰⁸ Ibid Executive Summary, para 6

¹⁰⁹ Department of Work and Pensions, ‘Raising expectations and increasing support: reforming welfare for the future’ (Cm 7506, 2008)

disabled people'.¹¹⁰ These proposals were welcomed by disabled people as including both a strong commitment to disability equality in the workplace and increased financial support for those unable to work.¹¹¹

'Individual budgets'¹¹² had been piloted in 13 English local authorities between 2005 and 2007.¹¹³ Though welcomed by some service users as alternative to receiving conventional social care services, there were difficulties in including funding streams other than local authority social care funds due to poor engagement between different agencies, and restrictions on how resources could be used.¹¹⁴ However, proposals for pooled budgets re-emerged in the Department of Work and Pensions' *Right to Control* scheme¹¹⁵ under the Welfare Reform Act of 2009. Further policy papers from the New Labour government in 2009 and 2010 reported on progress by local authorities in making Personal Budgets the norm,¹¹⁶ and endorsing them as part of a future 'National Care Service'.¹¹⁷

In all of these developments, we can trace the increasing adoption of key elements of disabled people's discourse. Together, they illustrate a developing policy couched in a language of 'independence', 'choice', 'control'

¹¹⁰ Ibid, Quick-read text, para 1.2

¹¹¹ 'NCIL welcomes 'no one written off' welfare reform green paper', National Centre for Independent Living, July 2008 ~ [Welfare reform draft NCIL release July 08.doc](#)

¹¹² Designed to bring together council-provided social care for adults, Supporting People funding, Independent Living Fund, Disabled Facilities Grant, Integrated Community Equipment Services, and Access to Work.

http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Individualbudgets/DH_089510 accessed 4/4/12

¹¹³ Thanks here to Bethan Harris of Garden Court Chambers for her update on 'Personalisation: the transformation of adult social care,' Legal Action Group, November 2010

¹¹⁴ The National Evaluation of the Individual Pilot programme, October 2008:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089505 last accessed 19.3.11; the IBSEN study, Glendinning, C, Challis, D,

Fernandez, J-L, Jacobs, S, Jones, K, Knapp, M, Manthorpe, L, Moran, N, Netten, A, Stevens, M and Wilberforce, M, *Evaluation of the Individual Budgets Pilot Programme: final report*, the IBSEN study (Social Policy Research Unit, University of York, 2008)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089505 last accessed 19.3.11

¹¹⁵ <http://www.dwp.gov.uk/newsroom/press-releases/2010/dec-2010/dwp177-10-131210.shtml> accessed 4.4.12

¹¹⁶ Secretary of State for Health, *Shaping the Future of Care Together* (Cm 7673, 2009)

¹¹⁷ Secretary of State for Health, *Building the National Care Service* (Cm 7854, 2010); the New Labour government also passed legislation providing for free domiciliary care for older people

which echoes disability activists' calls for change.¹¹⁸ They evidence a growing recognition at national level of the need for a holistic approach, and a determination to bring about radical change in the way that disabled people are supported to live independently as active members of the community. Throughout these developments, disabled people worked closely with and within government, and government appeared to be listening: 'co-production' became a new buzz-word,¹¹⁹ and relations of difference prevailed.¹²⁰ They augured well for implementation of Article 19 of the Convention. Local authorities, too, were taking action: by April 2010, 42 out of 152 councils had made good progress towards personalisation,¹²¹ and a new comprehensive National Care Service was being planned.¹²² Alongside these government-led developments, a private member's Disabled Persons (Independent Living) Bill was presented to Parliament, where it received support from the House of Lords.¹²³

The independent living policy initiated by the 2005 Life Chances Report originated not from the concurrent CRPD negotiations, but from the multi-disciplinary team¹²⁴ set up to prepare it. Although that policy relies strongly on principles of autonomy, dignity, freedom and inclusion, it is not couched in the language of human rights,¹²⁵ and they remain absent from the ODI's

¹¹⁸ See for instance DIAL Barnsley 'Your Choice: an independent report looking at choice and control and disabled people' (DIAL Barnsley 2009)

¹¹⁹ Needham C 'Co-production: an emerging evidence base for adult social care transformation' (Social Care Institute for Excellence 2009)

¹²⁰ See for example Department of Health, 'User-led Organisations (ULO) Project Policy' September 2007 Gateway reference 8470; Department of Health, *Putting People First: Working together with user-led organisations*, 19 March 2009 Gateway reference 11108; Department of Health 'Wave 1 Action and Learning Sites 2008-09 Final Report' July 2009

¹²¹ ADASS, *Putting People First: 2nd year progress* (ADASS 2010) http://www.adass.org.uk/index.php?option=com_content&view=article&id=328&Itemid=453 accessed 13.4.11

¹²² Department of Health, 'Building the National Care Service' (Cm 7854, 2010)

¹²³ But not from government. For discussion see Chapter 7 below

¹²⁴ Including the disability activists and service users of the Expert Group: Morris (2005)

¹²⁵ The Life Chances Report mentions human rights just once, in a footnote on page 48. It reads: 'In addition to the legislation described in Chapter 1 [Disability Discrimination legislation and various administrative projects], the Human Rights Act (1998) guarantees the right to life, right to liberty, to privacy, to freedom from degrading treatment, right to marry and found a family, and the right to education, subject to compatibility with primary legislation; and the Scottish Executive, Northern Ireland Assembly, Welsh Assembly Government and the Greater London Authority all have positive duties to promote equality.' For an early discussion of independent living as a right, see Parker C, 'Independent Living and the Human Rights Act 1998' (2004) paper commissioned by the Disability Rights

Independent Living Strategy three years later.¹²⁶ It was not until 2008 that the work of the ODI began to be acknowledged on its website as ‘contributing towards the Government’s work to ratify’ the CRPD¹²⁷ in preparation for its designation as the ‘coordination mechanism within government’ tasked with facilitating implementation under Article 33(1) of the Convention.¹²⁸ Even after ratification, the revised 2010 government guidance on eligibility for adult social care,¹²⁹ though upholding values of dignity, equality and respect, contains just one section headed ‘Equality and Human Rights’.¹³⁰ This consists of three paragraphs on equality with no mention of human rights, let alone of economic, social and cultural rights, of the CRPD or of Article 19. Given the highly politicised nature of civil and political rights discourse in the UK while this policy was being developed, it is perhaps understandable that the policy-makers chose not to venture there.¹³¹ The exclusion of economic, social and cultural rights from this discourse, however, as we have seen, is more deeply ingrained.¹³²

Commission, The Social Care Institute for Excellence and The National Centre for Independent Living, December 2004; Parker C, ‘Is there a right to independent living?’ (2007) Paper for Session 1 of the joint Disability Rights Commission and British Institute of Human Rights seminar ‘A Right to Independent Living – Rhetoric or Reality?’ 3 September 2007 and Clements L ‘Honoured in the breach: statutory and policy impediments to realising the right to independent living’ (2007) *ibid*.

¹²⁶ <http://odi.dwp.gov.uk/docs/wor/ind/ilr-executive-report.pdf> accessed 15.4.11

¹²⁷ www.officefordisability.gov.uk/working/independentlivingstrategy.asp accessed 18.8.08

¹²⁸ See Chapter 3 above

¹²⁹ Department of Health ‘Prioritising Need in the Context of Putting People First: a whole system approach to eligibility for social care – guidance on eligibility criteria for adult social care, England 2010’ (2010) Gateway ref 13729

¹³⁰ *Ibid* 30

¹³¹ Though others were not so bashful – see the Disabled People (Independent Living) Bill, Chapter 7 below

¹³² Even the ODI’s 2011 Initial Report to the UN Committee on the Rights of Persons with Disabilities fails to present a human rights-based approach: <http://odi.dwp.gov.uk/docs/disabled-people-and-legislation/un-convention-draft-report.pdf>, accessed 6.8.11: ‘The Government intends to help ensure that disabled people have a fair chance to live the lives they choose and to be independent of the welfare state where this is right for them. This approach is evident in education, housing, health and social care, transport and in reform of the welfare system, and is reflected in each of the relevant articles of this report’, para 143: Removing barriers. <http://odi.dwp.gov.uk/docs/disabled-people-and-legislation/uk-initial-report.pdf> accessed 4.4.12. See also Equality and Human Rights Commission, *Human Rights Inquiry* (EHRC 2009) 19: ‘There is very clear reluctance on the part of many public authorities to use the specific language of human rights. There is a tendency to use values based language only because of fear that human rights are too complex to understand, or because of confusion about the relationship between human rights and equality. This inhibits the possibility of understanding and giving proper effect to human rights.’

Nevertheless, when the policy developments described so far are placed alongside ‘transformative’ progress in implementation of the Disability Equality Duty,¹³³ it appears in early 2010 that, despite the invisibility of economic, social and cultural rights, discursive elements compatible with the aims of the CRPD drafters’ hegemonic project, and of Article 19, are progressing well. Policy has generally moved away from exclusion and segregation in line with Article 19(a); independent living, as understood by disabled people, is established at the centre of government disability policy, with increasing profile and control by disabled people of the services required under Article 19(b); and proactive equality duties are in place, with built-in involvement of disabled people in line with Article 4(3), to bring about structural change in line with Article 19(c).

However, as Hodgkins comments, whilst independent living

has become very much the new order in terms of disability support provision.... the associated ideologies remain potentially unchecked and of liability in terms of the oppressive relations concerning disabled people in the manner in which the rhetoric of new reform retains elements of the old oppression, albeit reframed.¹³⁴

We have identified ‘independent living’ as an important nodal point in disabled people’s discourse.¹³⁵ Nodal points are effective because they are empty signifiers,¹³⁶ allowing the discourse to incorporate new discursive elements with which a range of actors can identify, thus absorbing social antagonisms and neutralising dislocations. We have seen this process in action between 2005 and 2010, as independent living becomes ‘the new order in terms of disability support provision’.

Empty signifiers, by their nature, are equally open to re- or mis-appropriation by other, more powerful discourses, and to application in contexts far removed from the principles and practices from which they grew.¹³⁷ In the

¹³³ Outlined above

¹³⁴ Hodgkins, S.L., ‘Discursing Disability: the Personal and Political Positioning of Disabled People in Talk and Textwork’ PhD Thesis, University of Northampton, September 2008, 245

¹³⁵ See Chapter 4 above

¹³⁶ See Chapter 1 above

¹³⁷ See Chapters 1 and 4 above

absence of a stabilising legal framework which recognises the durable human rights dimensions of social values,¹³⁸ the ideologies associated with independent living ‘remain potentially unchecked and of liability’.¹³⁹ Oppressive structures have the capacity to reproduce themselves through ‘the myriad power relationships in everyday life.’¹⁴⁰ The international human rights framework seeks to counter that oppression through its emancipatory legal order in which economic, social and cultural rights play a pivotal role. Without that protection, understandings of independent living, and the services essential to its realisation, are wide open to re-articulation by other, more powerful, discourses, and to dislocation by unforeseen events. We see examples in the events that followed.

Re-articulation

In May 2010, a General Election led to formation of a Conservative/ Liberal Democrat Coalition government. Its Coalition Agreement confirmed that this

Government believes that people needing care deserve to be treated with dignity and respect. We understand the urgency of reforming the system of social care to provide much more control to individuals and their carers, and to ease the cost burden that they and their families face.¹⁴¹

New Labour’s ‘Transforming Social Care’ agenda and the ‘trailblazer’ pilots of personal budgets under *Right to Control*, both of which were in mid-flow,

¹³⁸ Langford (2008) 3

¹³⁹ Hodgkins (2008); Barnes C, ‘Independent Futures: policies, practices and the illusion of inclusion’ (2006) Background notes to a verbal presentation to the European Network for Independent Living, 3 November 2006, Leeds Disability Archive accessed 15.3.11

¹⁴⁰ Charlton (2000)

¹⁴¹ ‘The Coalition: our programme for government’ Her Majesty’s Government, May 2010, 30. The Coalition also promised a Commission on long term care; break down of barriers between health and social care funding; extension of the roll-out of personal budgets ‘to give people and their carers more control and purchasing power’; and improvements to availability of community-based respite care and in-work support. See Postscript below for update.

have continued under the new government.¹⁴² However, deep public funding cuts introduced in response to the banking crisis, together with reformulation of independent living policy in line with the new government's strongly free market-based ideology, have had a significant impact on the prospects of the hegemonic project and Article 19.

Service provision

In November 2010, the Coalition published its 'Vision for Adult Social Care', setting out 'overarching principles' and giving 'context for future reform'.¹⁴³ The vision builds on and accelerates many aspects of New Labour's 'transformation'. Like New Labour, the new Government seeks to shift power 'from central to local, from state to citizen, from provider to people who use services'.¹⁴⁴

Prevention is seen as 'the first step': 'it is always better to prevent or postpone dependency than deal with the consequences'.¹⁴⁵ This is

best achieved through community action, working alongside statutory services. We need to inspire neighbourhoods to come together to look out for those who need support.¹⁴⁶

This 'Big Society' approach to social care

means unlocking the potential of local support networks to reduce isolation and vulnerability... [and] must focus on what people can do for each other.¹⁴⁷

Councils should support carers,¹⁴⁸ make full use of new technology,¹⁴⁹ provide re-ablement,¹⁵⁰ work closely with health service providers¹⁵¹ and

¹⁴² Though now clothed in Coalition language: Putting People First Consortium, 'Think Local, Act Personal: a sector-wide commitment to moving forward with personalisation and community-based support' (2011)

¹⁴³ Department of Health 'Vision for Adult Social Care: Capable Communities and Active Citizens', 16 November 2010, gateway reference 14847 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121508 accessed 19.3.11

¹⁴⁴ Ibid para 9.3. This process is now based on seven principles: prevention, personalisation, partnership, plurality, protection, productivity and people.

¹⁴⁵ Ibid para 3.2

¹⁴⁶ Ibid para 3.3

¹⁴⁷ Ibid para 3.5

¹⁴⁸ Ibid para 3.10

¹⁴⁹ Ibid para 3.11

bring employment and housing services together to improve well-being and meet emerging needs – all CRPD-compatible measures, promoted as

improv[ing] outcomes for individuals and return[ing] savings to other areas, such as housing, health, social care and the criminal justice system.¹⁵²

Like its predecessor, this government sees securing the best outcomes for people as its objective,¹⁵³ and agrees that people, not providers, should have choice and control over their care, as this will protect their dignity and freedom and enhance their quality of life. The vision is ‘to make sure that everyone can get the personalised support they deserve’.¹⁵⁴ With this in mind, the roll-out of personal budgets, ideally as a cash payment ‘to give maximum flexibility and choice’,¹⁵⁵ is accelerated to become the norm for everyone who receives on-going care and support.¹⁵⁶ We are reminded¹⁵⁷ that ‘[e]ven those with the most complex needs can benefit from personalised services’.¹⁵⁸ Personalisation also requires ‘wholesale change – a change of attitude by councils and staff, reform of financial and management and information systems, and reduction of inflexible block contracts’.¹⁵⁹ It is the job of councils to ensure that everyone can get the information and advice they need to achieve ‘real autonomy and choice’,¹⁶⁰ whether directly from the council, or through local support, advocacy and brokerage services provided by voluntary – including user-led - organisations.¹⁶¹ Again, these objectives are compatible with disabled people’s independent living discourse and with

¹⁵⁰ Ibid para 3.12

¹⁵¹ Ibid para 3.13

¹⁵² Ibid para 3.14

¹⁵³ ‘Our focus is not on the process but on the outcomes of greater choice, control and independence, and ultimately better quality of life.’ *ibid* para 4.6

¹⁵⁴ *Ibid* para 4.1. Councils are working towards government target of all eligible users to receive personal budgets by April 2013: ADASS Report on Personalisation Survey September 2011, Directors of Adult Social Services, <http://www.adass.org.uk/> accessed 29.10.11

¹⁵⁵ *Ibid* para 4.3

¹⁵⁶ According to Sarah Pickup, President of ADASS, ‘adult social services are moving fairly consistently and swiftly in the direction of travel set out in the Concordat between Government departments, agencies and ADASS signed in December 2007.’ ‘Use of personal budgets leaps by nearly 40%’ ADASS Press release, 20 June 2012

¹⁵⁷ *Ibid* para 4.2

¹⁵⁸ *Ibid*

¹⁵⁹ *Ibid*

¹⁶⁰ *Ibid* para 4.8

¹⁶¹ *Ibid*

the CRPD. When we examine how these objectives are to be implemented, however, we find some changes in approach.

Delivery is strongly consumer-orientated, aiming for a 'broad market of high quality service providers' to match the variety of people's needs. Here, councils, with their NHS partners, have a role in 'stimulating, managing and shaping' a 'thriving social market in which innovation flourishes.' Partnership working between individuals, communities, and statutory, private and third sector organisations will result in better outcomes for people, and achieve efficiencies and savings.¹⁶² Contracting systems must be

fair and proportionate and enable micro and small social enterprises, user-led organisations and voluntary organisations to compete to deliver personalised services.¹⁶³

The choice and competition thus generated 'can be a powerful tool to drive up quality and reduce and control costs.'¹⁶⁴ There is strong emphasis on cost control: '[n]ow, quality and efficiency can no longer be seen as two separate objectives – we must deliver both'.¹⁶⁵ Though local health and social care authorities retain a facilitating role, the market is expected to supply the required variety and quality of services to meet consumer demand at reduced cost. The Audit Commission, which has led on regulation of public bodies' equality and human rights compliance,¹⁶⁶ is abolished.¹⁶⁷

The workforce delivering this vision will be employed not only in traditional health and social care structures, but also 'mutuals, employee-owned co-operatives, user-led organisations, existing independent sector employers and individual people who use care and support.'¹⁶⁸ Individual disabled people making use of personal assistants will be reminded of their

¹⁶² Ibid paras 5.6 and 5.7

¹⁶³ Ibid para 5.10

¹⁶⁴ Ibid para 7.16

¹⁶⁵ Ibid para 7.23

¹⁶⁶ Noronha N de, 'Assessing Equality and Human Rights in local public services' (2009) presentation to 'Equality, Human Rights and Good Relations: evidence based interventions and policy making' seminar, University of Liverpool, 21 May 2009

¹⁶⁷ For latest developments, see <http://www.audit-commission.gov.uk/aboutus/future/Pages/default.aspx> accessed 4.4.12

¹⁶⁸ 'Vision for Adult Social Care' para 8.1. Organisations will be able to challenge local authorities where they believe they could provide services differently or better.

‘responsibility to be a good employer and to train, recruit and retain staff.’¹⁶⁹ The extension of independent Social Work Practices¹⁷⁰ to adult social care ‘should result in greater choice and control over the services that local people purchase.’¹⁷¹ Here, it is local people, not the local authority, who are the ‘purchasers’.

Under the Coalition, then, the shift ‘from state to citizen’,¹⁷² which was welcomed as an exercise in ‘co-production’ by disabled people under New Labour, becomes even more radical.¹⁷³ The ‘wholesale change’ in attitudes and systems results not in a National Care Service but in ‘Open Public Services’.¹⁷⁴ free competition and the ‘rational economic man’¹⁷⁵ will ensure that a broad range of high quality and cost-effective local services are available to all. The State’s role is to facilitate this ‘thriving social market’, whilst power and control is devolved to ‘communities’ and it is the job of ‘neighbourhoods’ to look out for those who need support. Once more, ‘care *in* the community becomes care *by* the community’.¹⁷⁶ Disabled people have been repositioned, not as rights-holders, or as ‘co-producers’, but as individual consumers and employers, stimulating market competition by making choices about how and where they spend their personal budgets, and responsible for their own ‘welfare’ outcomes. Their organisations, too, have been de-politicised: whilst DPOs are recognised as potentially offering ‘very individualised solutions’,¹⁷⁷ and are supported to fulfil that function,¹⁷⁸

¹⁶⁹ *ibid* para 8.6

¹⁷⁰ ‘Lansley backs independent practices to support older people’, <http://www.communitycare.co.uk/Articles/2010/11/05/115743> accessed 4.4.12. Social Care Practices ‘are professional partnerships of social workers, voluntary sector organisations and private sector organisations independent of the council that operate as social enterprises.’ (‘A Vision for Social Care’ para 8.11). They have been piloted in children’s services. They are designed to reduce bureaucracy for social workers, give them more day-to-day control over cases, improve staff satisfaction and make more flexible use of resources. (Community Care, *supra*)

¹⁷¹ *Ibid* para 8.11

¹⁷² *Ibid* para 9.3 ‘This vision for social care demonstrates the Government’s values of freedom, fairness and responsibility, shifting power from central to local, from state to citizen, from provider to people who use services...’

¹⁷³ *Ibid* para 8.11

¹⁷⁴ Cabinet Office, ‘Open Public Services White Paper’, CM8145, 11 July 2011

¹⁷⁵ See for instance Taylor-Gooby P (ed) *Welfare States Under Pressure* (Sage 2001)4

¹⁷⁶ Department of Health and Social Security, ‘Growing Older’, 1981; Morris J, ‘Independent Living and Government Policy: Triumph or Tragedy?’ (2011) Seminar for Leeds University Centre for Disability Studies, 23 March 2011

¹⁷⁷ ‘Vision for Adult Social Care’, para 5.4

they are just one category on a list of micro and small providers who deserve a 'fair and proportionate' chance to enter the competition for delivery of services. Independent living policy has been re-articulated in line with the Coalition's own style of individualistic economic liberalism: 'nothing about us without us' has become 'nothing about me without me'.¹⁷⁹

The UK government, as duty-holder under the Convention, has undertaken to 'take effective and appropriate measures' to facilitate the full enjoyment by all disabled people of their right to live independently and be included in the community. The individualised and market driven solutions envisaged by the Coalition government may constitute one effective method for facilitating that enjoyment. Indeed, for some disabled individuals, personalisation, with its focus on outcomes, choice and control, has proved an effective route to increased independence and quality of life.¹⁸⁰ However, as the UN Committee on Economic, Social and Cultural Rights warned in 1994,

[g]iven the increasing commitment of Governments around the world to market-based policies, it is appropriate in that context to emphasize certain aspects of States parties' obligations. One is the need to ensure that not only the public sphere, but also the private sphere, are, within appropriate limits, subject to regulation to ensure the equitable treatment of persons with disabilities.... Where such protection does not extend beyond the public domain, the ability of persons with disabilities to participate in the mainstream of community activities and to realize their full potential as active members of society will be severely and often arbitrarily constrained... in such circumstances it is incumbent on Governments to step in and take appropriate measures to temper, complement, compensate for, or override the results produced by market forces.¹⁸¹

¹⁷⁸ On 20 July 2011, a £3m programme to disabled people's user-led organisations was launched by Maria Miller, Minister for Disabled People, <http://odi.dwp.gov.uk/odi-projects/user-led-organisations.php> accessed 4.7.11

¹⁷⁹ 'Vision for Adult Social Care' 14

¹⁸⁰ The IBSEN study: Glendinning, C, Challis, D, Fernandez, J-L, Jacobs, S, Jones, K, Knapp, M, Manthorpe, L, Moran, N, Netten, A, Stevens, M and Wilberforce, M, *Evaluation of the Individual Budgets Pilot Programme: final report*, the IBSEN study (Social Policy Research Unit, University of York, 2008); Beresford *et al* (2011); SCIE Social Care TV video, 'Personalisation for someone with a physical disability' <http://www.scie.org.uk/socialcaretv/video-player.asp?guid=91834b9d-26ef-44ba-9055-c9720606edf9> accessed 9.8.11; ODI videos; In Control, 'Research on Person-centred Planning' (2006) 14(2) *Journal of Integrated Care*

¹⁸¹ UN Committee on Economic, Social and Cultural Rights, General Comment 5: Persons with Disabilities, 9/12/94, para 12; see also O'Connell P 'On Reconciling Irreconcilables: Neo-Liberal Globalisation and Human Rights' (2007) 7(3) *Human Rights Law Review*, 483

The radical shift of responsibility for individual outcomes from state to individual also threatens to steer English independent living discourse away from wider international human rights understandings. Quinn and Degener identify solidarity as one of the four 'core values of the human rights mission':

mutual ties and obligations exist between people by virtue of their shared membership of a political community. Freedom does not exist in a vacuum – it must be made tangible and this often means buttressing the system of basic freedoms by substantive social and economic supports.¹⁸²

We have recognised the sedimentation of this value of solidarity in the durable nature of economic, social and cultural rights, their vital enabling role in the context of disability, and their integrated projection in the Convention map, including Article 19. As we have seen, the UK translates these rights through its welfare state.

There have been many changes to the welfare state in England since the original post-war settlement, particularly since the 1980s when local authority involvement in direct service provision was reduced to a residual role, and local services became increasingly subject to market disciplines, such as charging, competition and contracting.¹⁸³ For Taylor-Gooby,

welfare state citizenship rests on values of reciprocity, inclusion, and institutional trust, [but] the shift towards an individualisation of responsibility for welfare outcomes constrains reciprocity, contradicts inclusion and undermines important aspects of trust.¹⁸⁴

He finds that the reform programmes 'based loosely on an individual rational actor theory of agency'¹⁸⁵ undergone in all European welfare states, particularly since the 1980s, and particularly in the UK,¹⁸⁶ have eroded the

¹⁸² Quinn and Degener (2002) 19

¹⁸³ Loughlin M, 'Restructuring of Central-Local Government Relations' in Oliver D and Jowell JL (eds) *The Changing Constitution* (Oxford University Press 2000) 145-6; see also Beresford P and Turner M, 'It's Our Welfare' (1997) Report of the Citizens' Commission on the Future of the Welfare State (National Institute for Social Work 1997)

¹⁸⁴ Taylor-Gooby P, *Reframing Social Citizenship* (Oxford University Press 2009) 3

¹⁸⁵ Taylor-Gooby P (ed) *Welfare States under Pressure* (Sage 2001) 4

¹⁸⁶ Taylor-Gooby, P 'Welfare Reform in the UK: the Construction of a Liberal Consensus', in Taylor-Gooby (2009) 147: 'The UK has made the most rapid and far-reaching welfare state reforms in any of the countries considered in this book...'

base of public support for inclusive state provision.¹⁸⁷ In that situation, he concludes,

[t]he public and government commitment to supporting those at the bottom which underlies social inclusion falters. Collective defences against the impact of inequality... on social cohesion are weakened.¹⁸⁸

Several commentators identify a contradiction between the individualism of a Direct Payments approach and the need for collectivity in the responsibility for welfare.¹⁸⁹ Stevens *et al* conclude¹⁹⁰ that

the focus on choice of service and resources is at best insufficient and potentially counter to the overall goals of independent living and increased autonomy and rights as expressed both by [New Labour] government and the Independent Living Movement... This can be seen as a problem, not with the abstract concept of choice, but in the specific emphasis given in public policy to the market model of individual agents making free purchasing choices.¹⁹¹

They offer three critiques. Firstly, whilst Direct Payments and IBs may act as a market-driven alternative to properly funded and co-produced public services, the question remains

whether individual purchasing choices will cumulatively create a sort of 'trickle-up' effect on service development and quality, which will thereby impact on market supply.¹⁹²

Secondly,

[g]iving people using services more of a role in assessing their own needs and in making choices about the kinds of services they want to 'purchase' involves a challenge to existing power relationships with professionals, such as social workers, who have previously been key players in these decisions.¹⁹³

¹⁸⁷ Taylor-Gooby (2009) 3

¹⁸⁸ Ibid 190; we can see evidence of this, for instance, in the present discourse of welfare as 'privilege', and withdrawal of social security benefits or housing as 'punishment' – see for instance 'London riots: Wandsworth council moves to evict mother of charged boy' <http://www.guardian.co.uk/uk/2011/aug/12/london-riots-wandsworth-council-eviction?INTCMP=SRCH> accessed 5.9.12

¹⁸⁹ Sapey B and Pearson J, 'Do Disabled People Need Social Workers?' (2004) 11(3) *Social Work and Social Sciences Review*; Ziv N, 'The Social Rights of People with Disabilities' in Barak-Erez D, Gross A M (eds) *Exploring Social Rights* (Hart 2011) 394

¹⁹⁰ from data collected for evaluation of Individual Budgets (IB) pilots: the IBSEN study, Glendinning *et al* (2008)

¹⁹¹ Stevens M, Glendinning, C, Jacobs, S, Moran, N, Challis, D, Manthorpe, J, Fernandez, J-L, Jones, K, Knapp, M, Netten, A, Wilberforce, M, 'Assessing the Role of Increased Choice in English Social Care Services', (2011) 40(2) *Journal of Social Policy* 257, 271

¹⁹² Ibid 262

¹⁹³ Ibid. These relationships will be considered further in Chapter 8 below

Stevens *et al*'s third critique relates to equity. 'Shopping around' for a service requires information about availability, cost and quality, and the insight, energy and ability to identify better buys. The necessary information must be made available and accessible in order to make choices real. Even with that information, those with such competences, or access to willing relatives or brokerage services, are likely to gain most from the increased choice, while those without risk poorer outcomes. As we have seen in Chapter 2 above, policies based on individual rational actor theory of agency are insufficient to bring about equality for those who exercise their autonomy in different ways.¹⁹⁴

Disabled people's philosophy of independent living encompasses all of these concerns. Whilst individual empowerment and control are vital, they also contribute to a collective responsibility for social change. That collective responsibility is founded in reciprocity, inclusion and trust, as practised in disabled people's organisations. Changing power relationships is seen as key to emancipation from oppression; and provision of information about one's options a 'basic need' of independent living. These core aspects of disabled people's understanding of independent living are excluded from the Coalition government's re-articulation of New Labour's 'transformation' agenda. Whilst civil and political rights to autonomy and participation set out in the head of Article 19 are enthusiastically embraced, their economic, social and cultural counterparts, without which they cannot be exercised, are stripped of collective responsibility for their equal realisation.¹⁹⁵

Whereas in April 2010, it seemed that, despite the absence of economic, social and cultural rights in domestic discourse, the understandings of the CRPD's drafters, and of Article 19(a) and (b) were progressing well in the

¹⁹⁴ Mégret (2008a) and Chapter 2 above; see also Morris J 'Rethinking Disability Policy' Viewpoint (Joseph Rowntree Foundation 2011)

¹⁹⁵ See also Dean H, 'From Poverty Reduction to Welfare Rights: A Social Policy Perspective on Human Rights' (2006) Crossing the Boundaries: The Place of Human Rights in Contemporary Scholarship conference, London School of Economics and Political Science, 24 March 2006, 1: 'The paper... demonstrates the extent to which welfare rights are marginalised through two countervailing, yet mutually contradictory, hegemonic preoccupations: the first – which may be of either neo-liberal or neo-conservative provenance – is with individual (as opposed to collective) responsibility; the second – which dates from the so-called 'cultural turn' in progressive political thinking – is with issues of identity and recognition (rather than with redistribution).'

domestic field of meaning, in 2011 such progress seems less certain.¹⁹⁶ Whilst elements of autonomy and choice are emphasised, their delivery is 'at best insufficient and potentially counter to the overall goals of independent living',¹⁹⁷ deprived of its collective reciprocity, inclusion and trust. Hayekian understandings of individual rights and social justice are again in the ascendant.¹⁹⁸

Systemic equality duties aimed at structural change in line with Article 19(c) are also under pressure.

Equality

Immediately before the General Election, the Disability Discrimination Act 1995 was subsumed into the Equality Act 2010. The Disability Equality Duty (DED) was merged into a Single Equality Duty covering all nine of the new Act's 'protected characteristics'.¹⁹⁹ The new Coalition government decided to implement the new general duty to 'have due regard to' the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations,²⁰⁰ and to consult on whether or not to continue with the specific duty to produce Equality Schemes.²⁰¹

As seen above, the specific DED²⁰² required disabled people to be actively involved in production of Disability Equality Schemes, in line with CRPD

¹⁹⁶ Morris J, 'Independent Living and Government Policy: Triumph or Tragedy?' (2011) Seminar for Leeds University Centre for Disability Studies, 23 March 2011

¹⁹⁷ Stevens *et al* (2011)

¹⁹⁸ See for example Morris J, 'Rethinking Disability Policy' (Joseph Rowntree Foundation 2011): 'Some aspects of the arguments made by disability organisations have been capitalised on by the politics and ideology driving recent and current policies in ways which disadvantage disabled people.'

¹⁹⁹ Equality Act 2010 s149. For further discussion of the effects on disability equality law of this process, see Lawson A, 'Disability and Employment in the Equality Act 2010: Opportunities Seized, Lost and Generated' (2011) 40(4) *Industrial Law Journal* 359. For discussion of compatibility of the Equality Act with the CRPD, see Lawson, *ibid* and Butlin SF, 'The UN Convention on the Rights of Persons with Disabilities: Does the Equality Act 2010 Measure up to UK International Commitments?' (2011) 40(4) *Industrial Law Journal* 428

²⁰⁰ This duty came into force in April 2011

²⁰¹ Coalition Government Public Sector Equality Duty consultation Aug-Nov 2010

²⁰² Unlike other equality 'strands': race and gender discrimination law included specific equality duties, but without parallel provisions on involvement and Secretary of State reports

Article 4(3),²⁰³ and promoted holistic action across government through the requirement for regular Secretary of State reports, in line with Article 33(1). These provisions no longer stand.²⁰⁴ In their place, key public bodies²⁰⁵ must publish, at least annually, information to demonstrate their compliance with the general Equality Duty; and to set equality objectives that the public body itself thinks it should achieve, at least every four years.²⁰⁶ According to the Ministerial Statement accompanying the Regulations,

[t]he publication of this information will ensure that public authorities are transparent about their performance on equality. This transparency will drive the better performance of the equality duty without burdening public authorities with unnecessary bureaucratic processes, or the production of superfluous documents. Public authorities will have flexibility in deciding what information to publish, and will be held to account by the people they serve.²⁰⁷

There is no requirement for the involvement of disabled people in this process, or for Secretary of State Reports.

At the same time, the Equality Act itself has appeared on the Cabinet Office 'Red Tape Challenge' website, where all are offered

the opportunity to look at all provisions in the Equality Act and tell us if they are too bureaucratic and burdensome for the benefit they bring, whether they could be simplified or better implemented, or if you think they should be kept exactly as they are.²⁰⁸

The Equality and Human Rights Commission responsible for overseeing the Act faces a 60% cut in funding,²⁰⁹ and statutory Codes of Practice relating to the Public Sector Equality Duty are cancelled by the government.²¹⁰

²⁰³ See for instance OPM 'Involvement for Real Equality: the benefits for public services of involving disabled people', Report for the Disability Rights Commission, September 2007

²⁰⁴ The whole of the DDA95 was repealed by the Equality Act 2010, Schedule 27; for further discussion of changes to the public sector equality duty see Hepple B, 'Enforcing Equality Law: Two Steps Forward and Two Steps Backwards for Reflexive Regulation' (2011) 40(4) *Industrial Law Journal* 315; Fredman S, 'The Public Sector Equality Duty' (2011) 40(4) *Industrial Law Journal* 405

²⁰⁵ Listed in Schedules 1 and 2 of the Draft Regulations

²⁰⁶ The Equality Act 2010 (Specific Duties) Regulations 2011, in force 10 September 2011.

²⁰⁷ This written ministerial statement was laid in the House of Commons on 28 June 2011 by Lynne Featherstone, and in the House of Lords by Baroness Verma of Leicester.

²⁰⁸ See <http://www.redtapechallenge.cabinetoffice.gov.uk/themehome/equalities-act/> accessed 10.8.11

²⁰⁹ See http://just-fair.co.uk/hub/single/equality_and_human_rights_commission_facing_a_60_cut_in_funding_11/8/11; for background on the EHRC see for example Lester A and Beattie K, 'The New

Equality, too, is thus re-articulated to conform to the neo-liberal agenda. Disabled people's involvement in public sector equality duties is dismantled, along with incipient holistic cross-government frameworks as 'unnecessary bureaucratic processes'. Equality law itself is undermined as potentially 'burdensome' and its monitoring weakened. Here, too, central elements of the disability/human rights project are contested by powerful domestic discourse. Contrary to international requirements,²¹¹ progress towards the systemic equality required for realisation of Article 19(c) is in retrogression.

The Convention's hegemonic project also faces another problem.

Dislocation

Dislocation is the destabilisation of a discourse resulting from the emergence of events beyond its control. The global economic crisis which began in 2008 is one such event. Governments around the world continue to struggle to manage its consequences, adopting a range of tactics with varying success. The UK Coalition government's approach has been to instigate deep public funding cuts in order to cut borrowing.²¹² Local authorities have taken the brunt of these cuts, shouldering in real terms reductions in funding of 28% over four years.²¹³ At the same time, new funding for adult social care of £1.5bn over that period was announced, with a further £1bn to be transferred from the NHS to support joint working. According to the Local Government Association, this additional funding will be insufficient to meet an estimated rise in the annual cost of adult social care by 2014-15 of around £6bn.²¹⁴ Moreover, these new funds are not ring-fenced, leaving local authorities free

Commission for Equality and Human Rights' [2006] Public Law 197; Klug F, 'Establishment of the Commission for Equality and Human Rights: implications for the public sector' (2004) Westminster Explained 36: An assessment of the impact of the HRA, 7 December 2004

²¹⁰ Equality Act PSED Statutory Codes of Practice cancelled 8.3.12, though EHRC will proceed with non-statutory codes. <http://www.equalityhumanrights.com/legal-and-policy/equality-act/equality-act-codes-of-practice/> accessed 8.3.12

²¹¹ ICESCR Article 2 and Gen Comment 9 – principle of non-retrogression

²¹² Local Government Association Briefing, 'The Spending Review 2010', 20 October 2010 <http://www.lga.gov.uk/lga/aio/14462985> accessed 7.8.11

²¹³ Tapering from £28.5bn in 2010-11 to £22.9bn in 2014-15; compared with cuts of 8.3% overall across all department budgets; *ibid*

²¹⁴ *Ibid*; see also Department of Health, Dilnot report, 'Fairer Care Funding', 4 July 2011, <http://www.dilnotcommission.dh.gov.uk/2011/07/04/commission-report/> accessed 12.8.11

to cut their social care budgets in real terms in the face of overall budgetary pressures; and some have done so.²¹⁵

Since 2003, local authorities have been required to follow statutory guidance when designing their eligibility criteria for care provision. That guidance²¹⁶ sets out four bands of eligibility: critical, substantial, moderate and low. They may be broadly summarised as follows:

- 'critical' means that life is at risk, or there is great risk of serious illness or harm;
- 'substantial' covers situations of abuse or neglect, and/or where the *majority* of personal care routines, work or education, social relationships and/or family responsibilities cannot be sustained;
- the inability to sustain *several* of these personal, work and social routines and responsibilities constitute the 'moderate' band; and
- 'low' eligibility applies where *one or two* such roles or responsibilities cannot be undertaken.²¹⁷

Over recent years, councils have increasingly raised the threshold of eligibility for social services. Immediately before the 2010 Spending Review,²¹⁸ 72% of councils provided services only to those falling into the substantial or critical bands, with 3% meeting critical needs only. In a high proportion of local authorities, savings in adult social care spending will therefore involve restricting eligibility to those with critical needs only: where life is not at risk, and there is not great risk of serious illness or harm, no service will be provided. As Jane Campbell points out, '[i]f disabled people cannot access services unless they have the highest level of need, then all

²¹⁵ See *R (on the application of W) v Birmingham City Council*; *R (on the application of M, G and H) v Birmingham City Council* [2011] EWHC 1147 (Admin), discussed in Chapter 9 below

²¹⁶ Department of Health 'Fair Access to Care Services' LAC (2002) 13 issued under Local Authorities Social Services Act 1970 s7(1); Department of Health 'Fair Access to Care Services: guidance for eligibility criteria for adult social care' 2003 (FACS); revised as Department of Health 'Prioritising Need in the Context of Putting People First: a whole system approach to eligibility for social care – guidance on eligibility criteria for adult social care, England 2010' (2010) Gateway ref 13729

²¹⁷ See FACS and Prioritising Need, *supra*

²¹⁸ A survey based on Freedom of Information responses from 97 out of the 152 English councils conducted by Community Care Magazine in September 2010; <http://www.communitycare.co.uk/Articles/2010/09/15/115321/councils-to-deny-social-care-support-to-all-but-most-needy.htm> accessed 7.8.11

the empowering, transforming delivery in the world will not change the inequality they experience'.²¹⁹

Public funding cuts also affect other areas of disabled people's lives.²²⁰ Among them, the Independent Living Fund was closed to new applicants in 2010, and is set to close altogether in 2015, facing many with loss of employment or return to institutional care;²²¹ the cost of an additional bedroom needed for disability reasons²²² will no longer be met by housing benefit, causing living arrangements to be unaffordable; and the benefit on which many rely to meet the additional costs of impairment is further 'reformed' to achieve a 20% budget reduction.²²³ In 2011, the JCHR conducted an inquiry into implementation of the right of disabled people to independent living. It concluded that

the range of reforms proposed to housing benefit, Disability Living Allowance, the Independent Living Fund, and changes to eligibility criteria risk interacting in a particularly harmful way for disabled people... As a result, there seems to be a significant risk of retrogression of independent living and a breach of the UK's Article 19 obligations.²²⁴

As we have seen in Chapter 5, any deliberately retrogressive measures must be fully justified in the international arena.²²⁵

²¹⁹ Campbell J, 'Social Care as an Equality and Human Rights Issue' (2008) 'Independently' Newsletter, National Centre for Independent Living, February 2008, 9

²²⁰ See also Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living', Twenty-third Report of Session 2010-12, HL Paper 257, HC 1074, 1 March 2012, Chapter 5; Shah S and Priestley M, *Disability and Social Change: private lives and public policies* (The Policy Press 2011) Chapter 8

²²¹ See for instance John Evans' evidence to the Joint Committee on Human Rights inquiry into Implementation of the Right of Disabled People to Independent Living; and JCHR (2012) *supra*

²²² For instance, for use by a personal assistant providing 24-hour care. This proposal was later reversed following legal action: see *Burnip v Birmingham City Council*, *Trengrove v Walsall Metropolitan Council*, *Gorry v Wiltshire Council* [2012] EWCA Civ 629, 15 May 2012

²²³ Becoming Personal Independence Payment in place of Disability Living Allowance. It has been estimated that around 450,000 disabled people will be worse off: see The Children's Society, Citizens Advice and Disability Rights UK, 'Holes in the safety net: The impact of Universal Credit on disabled people and their families' (The Children's Society 2012). See also Shah S and Priestley M, *Disability and Social Change: Private Lives and Public Policies* (Policy Press 2011) Chapter 8

²²⁴ JCHR (2012) 50; see also Wood C, 'For disabled people, the worst is yet to come... Destination Unknown: Summer 2012' (Demos 2012)

²²⁵ UN Committee on Economic, Social and Cultural Rights, General Comment 3, para 9

Some resistance to these negative discursive trends is just visible. Disabled people lobby and demonstrate.²²⁶ A consortium of organisations from across the social care sector, including some DPOs, takes forward New Labour's Putting People First project.²²⁷ The role of economic, social and cultural rights in a time of austerity moves up the agenda in legal and academic discussion.²²⁸ And, finally, the Joint Committee on Human Rights highlights Article 19, insisting that the CRPD is hard, not 'soft' law;²²⁹ and the Minister for Disabled People commits to basing the forthcoming Disability Strategy on the CRPD.²³⁰

Conclusion

This Chapter has examined the understandings reflected in independent living policy in England for signs of re-organisation of the field of meaning in line with the CRPD myth. From a long history of exclusion, policy relating to independent living in England has undergone a number of discursive transitions: from the Poor Laws to the post-war welfare state, to 'care in the community', non-discrimination and personalisation. Since the 1960s in particular, disabled people themselves have profoundly influenced the policy agenda, developing the social model of disability, resisting discrimination and claiming control of services. From 2005, under the New Labour government, it seems that, despite the invisibility of economic, social and cultural rights in domestic discourse, the concerns underlying Article 19 have been recognised, and work is in train to put in place systems to address them. Elements of disabled people's independent living discourse are adopted by government; the need for holistic approach and radical change are

²²⁶ Such as the Hardest Hit campaign, demonstrating a return to relations of equivalence; see also Strathclyde Centre for Disability Research and Glasgow Media Unit, in association with Inclusion London, 'Bad News for Disabled People: How the newspapers are reporting disability', University of Glasgow (2011)

²²⁷ Think Local, Act Personal, <http://www.thinklocalactpersonal.org.uk/> last accessed 7.9.12

²²⁸ For instance, 'Economic and Social Rights in a Time of Austerity', seminar, Faculty of Laws, University of Oxford, 30 June 2011; 'Human Rights Symposium: Realising Economic, Social and Cultural Rights in the UK', Law Society, 21/22 October 2011

²²⁹ JCHR (2012) 66

²³⁰ The government's 2011 discussion paper, *Fulfilling Potential*, did not invite feedback from disabled people on human rights or other legislative rights for disabled people. <http://odi.dwp.gov.uk/docs/fulfilling-potential/fulfilling-potential-discussion.pdf> ; JCHR (2012) 8; And see Postscript below

acknowledged; co-production becomes a new buzz-word; and relations of difference prevail, allowing potential for discursive expansion.

However, the 'nodal point' of 'independent living' is an empty signifier, open to re- or mis-appropriation by other, more powerful, discourses. Without protection of the international human rights framework, including recognition of the durable nature of economic, social and cultural rights, understandings of independent living remain wide open to re-articulation or dislocation. From 2010, re-articulation of New Labour's 'co-production' model of personalisation through the individualistic and market-driven discourse of the Coalition government, combined with the dislocation of global economic crisis, has resulted in a range of policy developments which reverse earlier progress and set implementation of Article 19 into regression.²³¹

Despite international jurisprudence requiring that the durable nature of economic, social and cultural rights and their indivisibility from their civil and political counterparts are recognised and implemented at domestic level,²³² they remain invisible in the domestic field of meaning throughout the developments described above. So too does the 'revolving door' through which international disability/human rights discourse seeks to circulate its re-description of the world: the CRPD itself, including Article 19, is absent from policy discussion.²³³ Only in 2011 do some small elements of resistance to this invisibility begin to re-appear, bolstered in 2012 by a strong JCHR report on Article 19. Meanwhile, a number of widely varied understandings of independent living circulate in the policy field: from established and still dominant assumptions of dependency, through New Labour's (and disabled people's) understandings of co-production, to the Coalition government's individualistic and market-based interpretation and disabled people's and human rights supporters' rights-based perspectives.

²³¹ JCHR (2012)

²³² UN Committee on Economic, Social and Cultural Rights, General Comments 3 and 9

²³³ From 2008 the ODI has continued to tread a delicate path between acting as 'focal point' for CRPD Art 33(2) and following successive governments' resistance to the concept of economic, social and cultural rights as rights. See, for instance *Fulfilling Potential*, consultation on disability strategy, 2011, and UK Initial Report to the UN CRPD Committee.

In the domestic field of meaning, then, despite some initial progress, the CRPD drafters' hegemonic project is encountering re-articulation, dislocation and regression. Though it may take comfort from strong domestic emphasis on individual civil and political rights to autonomy and choice, without recognition of the economic, social and cultural rights required to enable their exercise, the hegemonic project is at serious risk.²³⁴

As well as seeking to dominate the field of meaning, the project must also establish systems of social relations. One method of articulating and regulating those systems is law. In 2008, the ODI acknowledged that 'there is a gap between national policy and people's real experiences.'²³⁵ It nonetheless did not feel that new legislation was necessary, hoping instead that its Independent Living Strategy would 'begin to fill the gap'.²³⁶ Others disagreed. In 2006 and subsequent years, a private member's Disabled Persons (Independent Living) Bill was introduced in Parliament. In 2008, the Law Commission embarked on a review of existing legislation relating to adult social care. Both are considered in **Chapter 7**.

²³⁴ See also Shah and Priestley (2011) Chapter 8

²³⁵ ODI Independent Living Strategy 2008. <http://odi.dwp.gov.uk/docs/wor/ind/ilr-executive-report.pdf> now archived, accessed 30.8.11. The Coalition's Disability Strategy, which looks to build on the 2008 strategy, is expected shortly at the time of writing (September 2012) – see above.

²³⁶ Ibid

Chapter 7

Independent Living in England: Legislation

Introduction

In the domestic policy field, the CRPD remains invisible and its drafters' hegemonic project faces a combination of antagonism, re-articulation, dislocation and regression which puts it at considerable risk. Within that field of meaning, if it is to achieve hegemony, disability/human rights discourse must establish new systems of social relations in line with its re-description of the world. One method of doing so is through law. Indeed, CRPD Article 4(1) requires States Parties to adopt all appropriate legislative measures to implement Convention rights,²³⁷ and to modify or abolish existing laws and regulations that discriminate against disabled people.²³⁸

We have seen in Part 1 that Article 19 is a hybrid right, exemplifying the Convention's fusion between the two 'sets' of rights, so that realisation of its socio-economic provisions is a pre-requisite for exercise of its civil and political rights to autonomy and participation, and thus to implementation of the Convention as a whole. One might assume, therefore, that 'appropriate legislative measures' for its implementation would address its civil, cultural, economic, political and social elements on an equal basis, as interdependent and indivisible rights. In England, however, despite international rhetoric to the contrary, the two sets of rights are not indivisible at practical level:²³⁹ the transition from 'welfare' to 'rights' thinking in relation to the economic, social and cultural rights essential for implementation of Article 19 has not taken place.

²³⁷ Article 4(1)(a)

²³⁸ Article 4(1)(b)

²³⁹ See Ms Bras Gomes, Chapter 5 above

Moreover, while radical re-interpretations of social care delivery circulate in the policy arena,²⁴⁰ the legislative framework has failed to keep up. Current legislation governing Article 19 services has its roots in the 1940s welfare state. It reflects seriously out-dated understandings, and has become 'exceptionally tortuous'.²⁴¹ Whilst the New Labour government was not prepared to legislate, a private member's Disabled Persons (Independent Living) Bill was introduced unsuccessfully to Parliament between 2006 and 2009,²⁴² and in 2008 the Law Commission launched a review of adult social care legislation.

Unlike its predecessor, the Coalition government does intend to introduce new legislation. Its timeline for reform of adult social care incorporates the Law Commission's review,²⁴³ as well a separate report from a Commission on the Funding of Care and Support.²⁴⁴ These two reports, along with the Coalition's 'Vision for Social Care',²⁴⁵ will feed into a White Paper²⁴⁶ followed by a Social Care Reform Bill.²⁴⁷ The legal dimension of independent living discourse in England, like the field of meaning,²⁴⁸ is in flux.

The drafters of the Social Care Reform Bill will undertake the task of mapping this fluctuating discursive terrain. They will have available, as we have seen in Chapter 6, a number of widely varied understandings of independent living: from established and still dominant assumptions of dependency, through New Labour's (and disabled people's) understandings of co-production, to the Coalition government's market-based interpretation and disabled

²⁴⁰ See Chapter 6 above

²⁴¹ *R (F) v Wirral Borough Council* [2009] EWHC 1626 (Admin), (2009) 12 CCLR 452 at [8] by McCombe J. Quoted in Law Commission Scoping Report 2008, and Consultation Document para 1

²⁴² It was supported by the House of Lords, but not by Government – see for instance Baroness Royall of Blaisdon, Hansard 15 Dec 2006 col 1815 - so was not debated in the House of Commons

²⁴³ June 2011

²⁴⁴ The Dilnot Report, July 2011

²⁴⁵ Discussed in Chapter 6 above

²⁴⁶ Originally promised by end of 2011, subsequently postponed to April 2012, and finally published July 2012; see Postscript below

²⁴⁷ Department of Health 'Vision for Adult Social Care: Capable Communities and Active Citizens' (2010), supra, 7. The Draft Bill was published alongside the White Paper in July 2012. See Postscript below

²⁴⁸ See Chapter 6 above

people's rights-based perspectives. International economic, social and cultural rights jurisprudence, which might provide coherence and precedent, is not available. In its absence, which central ideology will fix the direction and meaning of this legal order? Which discursive elements – or their combinations – will be reflected in the new Social Care Reform Bill? Which will drive the projection decisions of the drafters to increase the accuracy of one feature whilst distorting the accuracy of another? How the legislators complete their task will not only reflect the central ideology and discursive elements they choose, but will also impact on the capacity of international disability/human rights discourse to influence domestic systems of social relations, and on the lives of disabled people through the social realities they create.²⁴⁹

This Chapter investigates the dynamics of these various 'constellations of power and knowledge' as the players concerned in this challenging project work to produce 'a simple, consistent, transparent and modern framework for adult social care law'²⁵⁰ without reference to economic, social and cultural rights. Following a brief overview of the current legislative framework, the Chapter explores the Law Commission's review, alongside the Independent Living Bill, and relates them to the requirements of Article 19 CRPD.

Current legislative framework

In contrast to policy-makers' adoption of the language of 'independent living', 'choice', and 'control', legislation continues to use the paternalistic language of 'needs' and 'care'.²⁵¹ The national statute that currently provides the gateway to independent living support services in England and Wales is the NHS & Community Care Act 1990 (NHSCCA). This Act sets out a system for

²⁴⁹ See Chapter 1 above

²⁵⁰ Law Commission, *Adult Social Care: Scoping Report* (2008)

²⁵¹ Beresford P, 'What Future for Care?' (2008) Joseph Rowntree Foundation Viewpoint, September 2008; Social Care Institute for Excellence, 'Response to Law Commission Consultation Paper on Adult Social Care' (2010)

assessment which is the first point of contact for access to all 'community care' services.

Under NHSCCA s47(1)²⁵² local authorities have a broad duty to assess any person in their area who may be in need of services. Once an assessment has been conducted, the local authority has discretion under s47(1)(b) as to whether or not to make any provision, applying a system of eligibility criteria.²⁵³ Where it appears to the local authority that the person being assessed is a disabled person, s47(2) empowers the local authority to make a decision as to the services that person requires under section 4 of the Disabled Persons (Services, Consultation and Representation) Act 1986 (DP(SCR)A).²⁵⁴

This last provision takes us on a journey. Despite its mention only of the 1986 Act, s47(2) in effect refers back to s2 of the Chronically Sick and Disabled Persons Act of 1970 (CSDPA), which in turn refers back to s29 of the National Assistance Act 1948 (NAA), one of the founding statutes of the post-war welfare state. Section 29 of the NAA delegates power to local authorities to make 'welfare arrangements for blind, deaf, dumb and crippled persons, etc'²⁵⁵ over eighteen, including those 'who suffer from mental disorder of any description', or who are 'substantially and permanently handicapped by illness, injury, or congenital deformity...'²⁵⁶ The 'welfare arrangements' that might be made include 'instruction in their own homes or elsewhere in methods of overcoming the effects of their disabilities',²⁵⁷

²⁵² s47(1) of the NHSCCA states:

... where it appears to a local authority that any person for whom they may provide or arrange for the provision of community care services may be in need of any such services, the authority –

(a) shall carry out an assessment of his needs for those services; and

(b) having regard to the results of that assessment, shall then decide whether his needs call for the provision by them of any such services.

²⁵³ See Chapter 6 above, and below

²⁵⁴ 'Without his requesting them to do so.' This provision addresses a problem inherent in the 1986 Act which requires that the disabled person make a request before any local authority obligation to assess is triggered: since many disabled people are unaware of their entitlement to an assessment, they are unlikely to make such a request.

²⁵⁵ NAA48 s29 heading

²⁵⁶ NAA48 s29(1)

²⁵⁷ s29(4)(b)

providing 'workshops where such persons may be engaged... in suitable work',²⁵⁸ and hostels for those engaged in such work or training.²⁵⁹ They may be helped to dispose of the produce of their work,²⁶⁰ and/or provided with 'recreational facilities in their own homes or elsewhere'.²⁶¹ A local authority may keep a register of the people for whom such arrangements have been made.²⁶² From this paternalistic baseline, enactment of the Chronically Sick and Disabled Persons Act in 1970 was seen by the disabled people's movement as a landmark achievement,²⁶³ not least because its s2 is worded in such a way as to suggest that it imposes a duty rather than a discretionary power on the local authority to provide specific domiciliary services - such as help in or adaptation to the home, transport to local authority services, meals, or a telephone - as part of the exercise of its functions under NAA s29.²⁶⁴

Other 'community care services' that might be accessed via a NHSCCA s47 assessment include residential care, maternity support, aftercare services for people detained under the Mental Health Act 1983, and welfare services for 'old people'.²⁶⁵ Additionally, the Children Act 1989 empowers the local authority to provide a variety of services and/or accommodation to a child under 18.²⁶⁶

²⁵⁸ s29(4)(c)

²⁵⁹ *Ibid*

²⁶⁰ s29(4)(e)

²⁶¹ s29(4)(f)

²⁶² s29(4)(g)

²⁶³ See for example Barnes C, 'Disability Rights: Rhetoric and Reality in the UK' (1995) 10(1) *Disability & Society* 111, 115

²⁶⁴ '... it shall be the duty of that Authority to make those arrangements in exercise of their functions under the said section 29 [NAA]', CSDPA70 s29(1). CSPDA s2 continued to be understood by disabled people as a duty until the *Gloucestershire* decision (*R v Gloucestershire County Council ex parte Barry*, [1997] AC 584; [1997] All ER 1; (1997) 1 CCLR 40 – discussed in Chapter 9 below) effectively reduced it to a discretion by holding that the local authority was entitled to take its resources into account, *inter alia*, in deciding whether or not to provide a service under s2.

²⁶⁵ Defined under s46 NHSCCA as 'services which a local authority may provide' under

(a) Part III of the National Assistance Act 1948 [residential care]

(b) Section 45 of the Health Services and Public Health Act 1968 [promotion of the welfare of old people]

(c) Section 21 of and Schedule 8 to the National Health Service Act 1977 [maternity support]; and

(d) Section 117 of the Mental Health Act 1983 [aftercare services for people who have been detained under that Act]

²⁶⁶ Or 21 in some cases; Children Act 1989 ss17 and 22

NHSCCA s47(3) requires the local authority conducting the assessment to invite relevant health and/or housing authorities to take part in the assessment.²⁶⁷ Resistance to such joint working at local level has been such that further legislation²⁶⁸ and guidance²⁶⁹ on this issue have been found necessary over the past two decades, and the issue continues to challenge development of a holistic independent living discourse.²⁷⁰ However, whether through health, housing or community care channels, the law provides for a range of possible housing outcomes to such assessment, from nursing or residential care,²⁷¹ through public housing,²⁷² or supported housing,²⁷³ to adaptations or equipment to enable a person to stay in their own home.²⁷⁴ This framework offers, in theory, a range of housing options compatible with Article 19(a).²⁷⁵

The manner in which assessment is carried out is left to each local authority.²⁷⁶ As we saw in Chapter 6, since the days of the Poor Laws, it has fallen to the local community – ‘the Parish’ - to administer ‘relief’. Under the welfare state, the duty to provide welfare services falls to the elected local authority, and, since the 1970s,²⁷⁷ to its social services department. Each such authority has discretion as to how it implements that duty within the

²⁶⁷ Although health and housing authorities do not have a legally enforceable duty to respond, the duty to cooperate is reinforced by joint guidance issued by the Departments of Health and the Environment. Conversely, the Homelessness Act 2002 requires social services authorities to assist housing authorities in the formulation of their homelessness strategies, and the related 2002 Code of Guidance re-emphasises the importance of joint working.

²⁶⁸ Including, for instance, the Health Act 1999 extending duty to co-operate; the Health and Social Care Act 2001, Part III creating ‘care trusts’ that have responsibility for commissioning both health and social care services; and the Health and Social Care Act 2012

²⁶⁹ For instance, the Continuing Care (National Health Service Responsibilities) Directions 2004, which require the Strategic Health Authority to ‘take such steps as are reasonable’ to obtain the agreement of the local authorities in its area to its proposed eligibility criteria for continuing health care.

²⁷⁰ See for example the Coalition ‘Vision for Adult Social Care’ (2010)

²⁷¹ Under either s21 National Assistance Act 1948 (local authority) or NHS Act 1977 (health)

²⁷² Under Parts 6 (general duty) or 7 (homelessness) of the Housing Act 1996

²⁷³ See Clements L, *Community Care and the Law*, 3rd ed (Legal Action Group 2007) 466 - 471

²⁷⁴ Disabled Facilities Grants under Housing Grants, Construction and Regeneration Act 1996

²⁷⁵ But see *Coughlan and Bernard*, discussed below and Chapter 9

²⁷⁶ NHSCCA s47(4): assessment ‘shall be carried out in such manner and take such form as the local authority consider appropriate.’

²⁷⁷ Local Authority and Social Services Act 1970

framework of national statute. In practice, a number of Regulations and Directions from the Secretary of State,²⁷⁸ supplemented by a plethora of smaller-scale circulars, Executive Letters, and guidance have been issued over the years to assist local authorities in their duties.²⁷⁹

The result is a three-stage assessment process: 1) the gathering of information about the person's 'community care needs'; 2) a decision on which 'needs' call for the provision of services, through the application of 'eligibility criteria';²⁸⁰ and 3) the preparation of a 'care plan' explaining which 'care needs' must be met and detailing the services to be provided to meet them.²⁸¹ As noted above, the language in which this process is couched²⁸² is far from that of 'choice' or 'control' found in the policy arena; and further still from any concept of 'rights'. Once a particular 'need' is recognised in an individual's 'care plan',²⁸³ the local authority has a duty to provide services to meet it.²⁸⁴ The application of eligibility criteria varies widely between local authorities, leading to wide geographical discrepancies in service provision. S47(5) allows for the temporary provision of services prior to assessment in a situation of 'urgency'.

Enactment of the Community Care (Direct Payments) Act in 1996 allowed some service users for the first time to receive their allotted social service provision in cash rather than in kind. Direct Payments have been gradually extended to a wider group of recipients,²⁸⁵ and have led to Individual Budgets

²⁷⁸ Relating *inter alia* to provision of residential accommodation; welfare arrangements; services for expectant and nursing mothers; complaints procedures; and choice of residential accommodation. See Clements (2007) Appendix B

²⁷⁹ See Clements (2007) *supra*, Table of circulars and guidance, xlvii-lviii

²⁸⁰ Eligibility criteria are discussed further below and in Chapter 7

²⁸¹ A financial assessment to determine who pays and how much should be the final stage in this process.

²⁸² And often the process itself – see Chapter 8 below

²⁸³ 'The assessment process commences with the potential service user coming to the notice of the social services authority and ends with a decision as to whether or not he or she is entitled to services. If services are required, then the next stage is the preparation of a care plan which describes and quantifies the services and specifies how (and by whom) they are to be delivered.' Clements (2004) 59

²⁸⁴ Such as the Laming letter (CI(92)34) and the *Gloucestershire* decision noted above and discussed in Chapter 9 below

²⁸⁵ Including those with learning difficulties, people over 65, and carers, disabled parents and disabled children aged 16 or 17. The Health and Social Care Act of 2001 enables direct

and personalisation as described in Chapter 6. Local authorities were notoriously slow in developing and promoting their direct payments schemes, to the extent that regulations were introduced in 2003²⁸⁶ imposing an obligation to make direct payments where the person meets certain conditions.²⁸⁷

Unlike NHS health services, social services are not free at the point of delivery: eligibility is means-tested. The Health and Social Services and Social Security Adjudications Act 1983 (HASSASSA)²⁸⁸ allows local authorities to recover such charge (if any) for services as they consider 'practicably reasonable' for the individual to pay.²⁸⁹ This covers both residential²⁹⁰ and domiciliary services,²⁹¹ provided in kind or through Direct Payments.²⁹² Different local authorities reach different conclusions as to what charges they 'consider reasonable', leading to a 'postcode lottery' in relation to charging, with wide variations between local authority areas.²⁹³

payments to be made to disabled parents, to parents of disabled children and to a disabled child aged 16 or 17.

²⁸⁶ Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003 SI 2003/762

²⁸⁷ Ibid Regulations 2, 3 and 4: where the person appears to be capable of managing a direct payment with or without assistance, is entitled to services, agrees to a direct payment, and the local authority is satisfied that the person's needs for the relevant service will be met.

²⁸⁸ s17

²⁸⁹ HASSASSA Section 17(3) states that:

(3) If a person –

(a) avails himself of a service to which this section applies, and

(b) satisfies the authority providing the service that his means are insufficient for it to be reasonably practicable for him to pay for the service the amount which he would otherwise be obliged to pay for it,

the authority shall not require him to pay more for it than it appears to them that it is reasonably practicable to pay.

²⁹⁰ However, where the service is the provision of residential care under NAA48 Part III, contrary to apparent long-standing (mis)understanding by individuals, social services departments and governments, HASSASSA does not impose any obligation on the resident to sell their property, or grant any power to the authority to oblige the resident to do so. Rather, this section allows for the creation of an interest-free 'charge by way of legal mortgage' on the resident's property, to be discharged on sale of the property or on death of the resident. In practice, the widespread (mis)understanding of this provision has led many to sell their homes prematurely. See the Dilnot Report discussed in Postscript below.

²⁹¹ With the exception of free after-care services provided under the Mental Health Act 1983 s17 to those who have been sectioned under that Act.

²⁹² Direct payments are means-tested, with the service user contributing '*the amount (if any) which it would be reasonably practicable for him to pay to the authority by way of reimbursement or contribution*', Health and Social Care Act 2001, s57(3)(c)(ii)

²⁹³ See for instance Clark L, 'A comparative study on the effects of community care charging policies for personal assistance users' submitted for degree of Master of Arts in Disability Studies, University of Leeds 2006

While policy has embraced the discourse of ‘personalisation’ as promoting autonomy and choice, in line with the head of Article 19, the ‘social welfare’ legislation currently governing the range of services required to support independent living under Article 19(b) continues to reflect a dominant ‘welfare’ discourse. As the Social Care Institute for Excellence points out,

both ‘needs’ and ‘eligibility’ are concepts rooted in the Poor Law, casting people who may need social care as supplicants, rather than individuals in control of their own lives who may require care and support to help them live their lives as they wish.²⁹⁴

The Law Commission’s Scoping Report²⁹⁵ underlines the quantity and complexity of the law, identifying 34 relevant Acts of Parliament,²⁹⁶ and notes its outdated concepts that favour institutional care for disabled and older people, its offensive, stigmatising language, and its potential incompatibility with European Convention rights.²⁹⁷ It is maybe unsurprising, then, that this out-dated²⁹⁸ body of law has given rise to many difficulties in its application. These include wide and unpredictable geographical variations in the availability and processes of assessment, eligibility, service provision and charging, resulting, *inter alia*, in uncertainty and risk for disabled people wishing to move from one local authority area to another – the ‘portability’ problem; duplication of bureaucracy;²⁹⁹ and the on-going failure of statutory bodies to work together;³⁰⁰ all of which result in significant avoidable costs for local authorities, the State and disabled people alike.³⁰¹ For the latter, the cost is not just financial: it includes restriction or denial of the physical, social

²⁹⁴ SCIE Response to Law Commission Adult Social Care Consultation <http://www.scie.org.uk/news/mediareleases/2010/010710.pdf> accessed 4.3.11, para 25.

²⁹⁵ Law Commission, Adult Social Care: Scoping Report (2008)

²⁹⁶ *Ibid*, Appendix A p 137

²⁹⁷ *Ibid*, Part 2

²⁹⁸ *R (F) v Wirral Borough Council* [2009] EWHC 1626 (Admin), (2009) 12 CCLR 452 at [8] by McCombe J.

²⁹⁹ Maynard-Campbell, Sue, and Maynard-Lupton, Alice, ‘Bureaucratic Barriers to Normal Day-to-Day Activity’, MusclePower! 2000, available on Leeds Disability Studies Archive <http://www.leeds.ac.uk/disability-studies/archiveuk/>; see also Life Chances Report discussed in Chapter 6 above

³⁰⁰ Evidenced, *inter alia*, in *R v North East Devon Health Authority ex parte Coughlan* [2001] QB 213; QB 47 BMLR 11 Dec 1998; (1999) 2 CCLR 285; (2000) 51 BMLR 1 CA; the Life Chances Report; and the Coalition ‘Vision for Adult Social Care’ (2010)

³⁰¹ Law Commission (2008)

and psycho-emotional support required for the exercise of their right to independent living.³⁰²

When the UK ratified the CRPD, it undertook, *inter alia*, to replace discriminatory laws and practices with Convention-compatible ones.³⁰³ It has yet to fulfil this undertaking.³⁰⁴ Yet the tensions that might lead to its fulfilment are evident. As Ed Mitchell comments,

[t]he personalisation initiative is a radical re-engineering of the provision of care services. The governing community care legislation, however, reflects an earlier, often more paternalistic era. This means that personalisation strains at the boundaries of the legislation governing adult social services.³⁰⁵

Conversely, as the Law Commission identifies,

[d]ifficult law may also have the effect of stifling innovation and the multiple layers of law can make it difficult to promote flexibility and new policy approaches in practice.³⁰⁶

Two contrasting attempts have recently been made to address these problems. The Disabled Persons (Independent Living) Bill (the Independent Living Bill/ILB) first presented to Parliament in 2006,³⁰⁷ and the Law Commission's 2008 Review of Adult Social Care are considered next. Santos' cartography of law again provides assistance.

³⁰² As evidenced in a substantial body of research, including that undertaken by the Legal Services Research Centre, the Commission for Social Care Inspection, the Disability Rights Commission, the Equality and Human Rights Commission, the Joseph Rowntree Foundation, and the Office for Disability Issues, as referenced in this thesis. See also, for instance, Morris J, 'Independent Living and community care: a disempowering framework' (2004) 19(5) *Disability & Society* 429; Coalition on Charging, 'Charging into Poverty? Charges for care services at home and the national debate on adult care reform in England' (Coalition on Charging 2008)

³⁰³ Article 4(1) (a) and (b)

³⁰⁴ See for instance Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living', Twenty-third Report of Session 2010-12, HL Paper 257, HC 1074, 1 March 2012; Clements L, 'The disability rights convention and the right to independent living' (2008) *Nov Legal Action* 27

³⁰⁵ *Community Care Magazine*, 23.10.08

³⁰⁶ Law Commission (2008) para 1.4

³⁰⁷ Unless otherwise stated, references to the Independent Living Bill are references to the version given its first reading in the House of Lords on 23 November 2009. The 2009-10 session of Parliament then prorogued, and the Bill made no further progress.

Mapping adult social care

Like the drafters of the CRPD map, those working to produce ‘a simple, consistent, transparent and modern framework for adult social care’³⁰⁸ in England must translate the complex social reality of independent living support here into a two-dimensional legal order. To create this medium-scale map, they must define its central ideology and the limits of its operation, and they must organise the legal space within. This will inevitably involve some distortion of reality, and because choices have to be made, that distortion will not be neutral. Despite the widely varying understandings of independent living competing for hegemony in English political discourse, the process of projection ‘needs to be consistent and thorough if the map is to be credible and ‘accurate’.³⁰⁹ One international framework of understandings which might provide some conceptual coherence, as well as legal precedents and guidance - that of economic, social and cultural rights - is unavailable, excluded from the domestic discursive field by successive UK governments’ reluctance to recognise or incorporate its understandings.³¹⁰

In order to explore potential for compatibility in current developments with the UK’s undertakings to replace discriminatory laws and practices with CRPD-compatible ones,³¹¹ this section compares two recent attempts at redrawing the domestic legal map: the Law Commission’s 2008-2011 Review of Adult Social Care and the Health and Social Care (Independent Living) Bill 2006-2009.

The Law Commission launched its review with a Scoping Report. The Commission’s role, it says, is to undertake law reform, not to make ‘political judgements about the setting of spending priorities or the making of value

³⁰⁸ Law Commission (2008)

³⁰⁹ British Cartographic Society, see Chapter 1 above

³¹⁰ See Chapter 5 above

³¹¹ CRPD Article 4(1)(a) and (b)

judgements about rights and responsibilities'.³¹² These are a matter for government. It acknowledges that

[d]rawing a clear distinction between law reform, on the one hand, and political policy on the other is not always easy... where the two meet it can be difficult to disentangle them.³¹³ [Nevertheless,] [t]he big decisions about how much of a welfare state we should have and how it should be funded are not decisions for us....³¹⁴

Already we find an essentially 'welfare' approach, with deference to politicians on allocation of resources.

A subsequent Consultation Paper³¹⁵ proposed a single adult social care statute for England and Wales,³¹⁶ setting out the duties imposed and powers conferred on local authorities. It would be backed by larger-scale statutory instruments, such as regulations, and, at a third level, by guidance, possibly in the form of a statutory Code of Practice. Central to the statute would be the community care assessment, the eligibility decision and the formation of a care plan.³¹⁷ The Law Commission's consultation and final report are considered below, and compared with the terms of the Independent Living Bill.

Maps have centres and boundaries, and project their multi-faceted realities in different ways, according to their purpose, cultural context and the ideologies of the cartographers. So also the drafters of a legal order define the centre and limits of its operation and organise the legal space within. Comparison between the Law Commission's proposals and the Independent Living Bill begins with their central purpose and principles.

³¹² Law Commission (2008) para 1.9

³¹³ *ibid* para 1.10

³¹⁴ Law Commission Consultation Paper (2010) para 1.2

³¹⁵ *ibid*

³¹⁶ 'Unless policy in Wales diverges enough to require statutes for England and Wales' Provisional Proposal 2-1. The Commission's Final Report (2011) suggests separate statutes for each nation.

³¹⁷ See above

Centre: purpose and principles

Law Commission

The Law Commission's objective is

to review the law under which residential care services, domiciliary and community services, support for carers and adult protection is provided. The ultimate aim would be to provide a coherent legal structure, preferably in the form of a single statute, for these services.³¹⁸

The approach adopted is to create, as far as possible,

a neutral legal framework that is not wedded to any particular policy and is capable of accommodating different policies and practices in the future, [whilst maintaining] the core entitlements and rights that are crucial to the existing community care legal framework.³¹⁹

The problem with this approach, as we have seen throughout this thesis, is that the legal framework resulting from this project – whatever it is - will never be, to any extent, neutral. In this highly politicised context, every word that is used, every concept that is included or excluded, every procedural power relationship built into the system will have meaning. Projections which distort reality are unavoidable. The very attempt at neutrality can be seen as a political statement: it works to exclude or minimise the emancipatory/expressive function of the law which is fundamental to its contribution to the 'deep reconstruction' required for the overturning of oppression. Contrary to CRPD Article 4(3), there is no reference here to the involvement of disabled people in the review of the legislation, though many disabled people, carers, older people and their organisations took it upon themselves to respond.³²⁰

The Consultation Paper lists a number of 'general concepts with a view to considering whether they are capable of forming the basis of statutory principles.'³²¹ They are:

³¹⁸ Law Commission (2008) Impact Assessment Part 5, 129

³¹⁹ Law Commission Consultation Paper (2010) Summary para 4

³²⁰ 123 responses in total, see <http://www.justice.gov.uk/lawcommission/350.htm> accessed 1.5.11

³²¹ Law Commission, 'Adult Social Care – a consultation paper', Consultation Paper 192 (2010)

1. that decision-makers must maximise the choice and control of service users
2. person-centred planning
3. that a person's needs should be viewed broadly
4. the need to remove or reduce future need
5. the concept of independent living
6. an assumption of home-based living
7. dignity in care
8. the need to safeguard adults at risk from abuse and neglect

Despite CRPD ratification, there is no reference here to human rights, including economic, social and cultural rights, to the CRPD, or to Article 19.

The Paper then asks whether any of these principles

are capable of being *the primary principle of the legislation*;... the *first* and *paramount* consideration whenever social services makes a decision or takes action.³²² (original emphasis).

Here, consultees are asked to consider the central or 'fixed point' of the map:³²³ which, if any, of these 'general concepts' should take precedence in shaping projection decisions?

A large majority of consultees³²⁴ agreed that there should be a statement of principles included in the statute, that overarching principles could guide decision-making and clarify the aims of the statute as a whole.³²⁵ There was much less consensus regarding which principles should be included, with

³²² Ibid para 12, Question 3-9

³²³ 'A physical or symbolic space in a privileged position around which the diversity, the direction and the meaning of other spaces are organised'. Santos (2002) 423, and see Chapter 3 above

³²⁴ Out of a total of 231 responses to the consultation, 87 expressed a view on this question, of which 79 supported the inclusion of a statement of principles: Law Commission Adult Social Care Consultation Responses: Statutory Principles (ASCCR (2011)) <http://www.justice.gov.uk/lawcommission/350.htm> accessed 1.5.11

³²⁵ ASCCR (2011), para 1.8. They would provide a useful foundation and focus for decision-makers and practitioners (Vale Older People's Strategy Forum and Compassion in Dying, para 3.3); help people to understand their rights (Counsel and Care, para 3.13); provide an important educational function (Equality and Human Rights Commission, para 3.14); and help to make the aims of the legislation accessible (Care Quality Commission, para 3.20). The few who disagreed felt that statutory principles would make the law difficult to interpret (BUPA Care Homes, para 3.26), inflexible (ibid para 3.27), or would lead to unnecessary litigation (Belinda Schwere para 3.28).

maximising choice and control, dignity in care and safeguarding adults at risk seen by many³²⁶ as essential to the provision of adult social care. Person-centred planning, viewing a person's needs broadly, the need to remove or reduce future need and independent living were supported by a smaller majority.³²⁷ Given that personalisation, holistic assessment and prevention have featured as integral to national policy founded on independent living since 2005, it may seem odd that these principles achieve relatively less support from Law Commission consultees.³²⁸ When we look in more detail at consultees' arguments for and against the principle of 'independent living', however, we find a dichotomy. On one hand, those familiar with disabled people's understandings of the concept³²⁹ are strongly supportive of its inclusion and primacy, believing that it should become 'the first and paramount consideration whenever social services make a decision or take action.'³³⁰ Others, by contrast, are less clear about its meaning, and thus about its relevance. They raise concerns about a lack of legal clarity,³³¹ the danger of raising unrealistic expectations,³³² the principle's application in the

³²⁶ Maximising choice and control: 61 out of 83 that expressed a view; dignity in care: 62 out of 78; safeguarding: 53 out of 68. ASCCR (2011): Statutory Principles

³²⁷ Person-centred planning: 47 out of 73; viewing needs broadly: 48 out of 71; removing future need: 49 out of 71; independent living: 44 out of 82.

³²⁸ Out of a total of 231 submissions, 82 expressed a view on the principle of independent living. Of those, 44 felt it should be included, 25 felt it should not, and 13 held an equivocal position. ASCCR (2011) para 3.130

³²⁹ Such as the ODI: 'The adult social care statute should be based on the concept of independent living, with emphasis on: choice and control – disabled people having choice and control over the support they need to go about their daily lives; and co-production – involving those who are affected by the policy at every stage of policy development, implementation and delivery'; or National Centre for Independent Living: 'We agree that the future adult social care statute should include a statement or principles, or a purpose clause. This statement or clause should make it unequivocally clear that the purpose is to enable disabled people to live independently – i.e. take full part in society, and achieving potential in all areas of life (family, school, community, employment)...', National Centre for Independent Living and RADAR Joint Response to the Law Commission Adult Social Care Consultation (2010) 5

³³⁰ Disability Wales, ASCCR (2011) para 3.129

³³¹ Such as Cartrefi Cymru: 'Given that the concept of "independent living" is so difficult to pin down and encompasses such a wide range of aims and principles we agree that it would not lend itself to a legally enforceable statement of principle.' ASCCR (2011) para 3.135

³³² Such as Gateshead Advocacy Information Network and North Tyneside Council, ASCCR (2011) para 3.146

context of differing housing options,³³³ and even potential conflict with the principle of choice and control.³³⁴

In its Final Report, the Law Commission chooses ‘well-being’ as its central principle. It offers no definition of ‘well-being’, but provides a checklist of seven factors that must be considered when a decision is made. These are hedged around with exceptions and provisos which offer opportunity for the individual to be side-lined. For instance, the decision-maker should assume that the person is the best judge of their own well-being, *except in cases where they lack capacity to make the relevant decision*,³³⁵ the individual’s views, wishes and feelings should be followed *wherever practicable and appropriate*; individuals should be given the opportunity to be involved in assessment, planning, development and review of their care and support *as far as is practicable in the circumstances*; and, where it is necessary to interfere with the individual’s rights and freedoms, the least restrictive solution should be used *wherever that is practicable*.

During consultation, in conformity with the Law Commission’s list of ‘general concepts’, human rights are barely mentioned. However, on the final two pages of the Law Commission’s analysis of responses we find ‘Further suggestions for principles’, including non-discrimination³³⁶ and human rights. The Joseph Rowntree Foundation considers that a statement of principles should

begin with, and be framed by, explicit reference to the role of adult social care in promoting and protecting human and civil rights and entitlements.³³⁷

Older people in Wales argue that statutory principles should

³³³ Such as Carers UK, ASCCR (2011) para 3.141

³³⁴ Such as Disability Law Service, ASCCR (2011) para 3.142; Royal College of Physicians of Edinburgh, *ibid* para 3.144

³³⁵ See CRPD Article 12 and discussion in Chapter 3 above

³³⁶ RNIB and Guide Dogs: ‘Whilst the principle of non-discrimination is clearly stated elsewhere in legislation we consider that it has never been clearly stated in relation to the provision of social care – for example, where older people are refused assistance or provided with more limited services.’ ASCCR (2011) para 3.236

³³⁷ ASCCR (2011) para 3.237

reflect “human rights principles and be based on rights, choice, dignity and independence”. Any proposed statutory principles should be measured against the United Nations Principles for Older Persons and other similar UN Conventions.³³⁸

And, finally, we find reference to the CRPD. The Equality and Human Rights Commission suggests using either the UN Principles for Older Persons or the preamble to the CRPD³³⁹ as ‘platform’ for further development. No-one mentions Article 19(b).

Tessa Harding reminds the Law Commission that “the principles themselves “do not need to be reinvented for the purpose of this statute”:

They should be based on the existing principles embodied in the Human Rights Act and in the United Nations Convention on Human Rights. People who need the support of social care services are no different from anyone else: they just need some help to secure the same rights as others. It is about respect for the individual and his or her dignity and autonomy and the absolute duty of the state to promote these.³⁴⁰

Indeed, such principles have been drafted before, not only in the Human Rights Act, the UN Principles for Older Persons and the CRPD but also in the private member’s Health and Social Care (Independent Living) Bill debated and passed on three occasions by the House of Lords between 2006 and 2009, which, along with its international counterparts, also finds itself invisible in the Law Commission’s consultation.

Independent Living Bill

The original Health and Social Care (Independent Living) Bill (ILB)³⁴¹ was drafted for Lord (Jack) Ashley of Stoke by the Disability Rights Commission,³⁴² informed, in line with CRPD Article 4(3), by wide consultation

³³⁸ ASCCR (2011) para 3.240 – reflecting different progress in discursive transformation in Wales amongst older people

³³⁹ Not the CRPD itself

³⁴⁰ ASCCR (2011) para 3.243

³⁴¹ Then called the Disabled Persons (Independent Living) Bill; discussion of the Bill, unless otherwise stated, refers to the 2009 text.

³⁴² Disability Rights Commission ‘A Briefing on Lord Ashley’s Disabled Persons (Independent Living) Bill’ (DRC 2006); Disability Rights Commission, Equal Opportunities Commission and Carers UK, ‘The Future: Who Cares’ (2006)

with organisations of disabled people, older people and carers, some of whom came together to campaign for its adoption.³⁴³ The Bill

seeks to enable people with disabilities to make decisions about what care and assistance they receive, and about their living arrangements, by providing rights and entitlements to independent living.³⁴⁴

Its purpose is to

ensure that disabled persons enjoy the same choice, freedom, dignity, control and substantive opportunities as persons who are not disabled at home, at work, and as members of the community...³⁴⁵

The Bill is clear about its principles:

1(3) Disabled persons should be able to exercise choice, freedom and control and enjoy personal dignity and substantive opportunities to participate fully in work, family life, education, public, community and cultural life.

1(4) Disabled persons are the best judge of their own requirements and therefore any practical assistance and associated support allocated to disabled persons following assessment should be based on their own choices, lifestyle preferences and aspirations.

1(5) Any action taken or decision made under this Act in relation to a disabled person's living arrangements and accommodation should ensure that each disabled person is empowered to determine his own living arrangements in relation to –

- (a) the type of accommodation or setting in which he wishes to live; and
- (b) with whom he shares that accommodation or living space.

Discrimination against disabled people is prohibited on a list of 11 grounds, including 'impairment or any aspect of their appearance or behaviour which might lead others to make unjustified assumptions about them';³⁴⁶ and

³⁴³ 'Our Lives, Our Choices' campaign, RADAR Briefing on the Health and Social Care (Independent Living) Bill, December 2009; National Centre for Independent Living 'Independent Living Bill and Adult Care Reform: Making the Connections' (NCIL 2008)

³⁴⁴ Official summary of the Bill, 2009 <http://services.parliament.uk/bills/2009-10/healthandsocialcareindependentlivinghl.html>, accessed 6.5.11

³⁴⁵ s1(1); 'and consequently to ensure that families and carers of disabled persons enjoy greater health, wellbeing, equality and opportunities to participate in social and economic life' was added to original version by later amendment

³⁴⁶ Independent Living Bill 2009, s1(10)(c)

positive steps should be taken to correct any disadvantage or social exclusion arising from such discrimination.³⁴⁷

Under sections 1(6), 1(7) and 1(8), disabled children's views and aspirations should be given due weight; and they should be supported to express those views and to participate actively in decision-making on their behalf. Disabled adults, too, should be enabled and empowered to make their own decisions, with support where necessary. Two further principles relate to the avoidance of reliance on care and support provided by a child or young person which may impair their health, well-being, education or leisure opportunities; and to the protection of the health, well-being and substantive opportunities of all carers, including parents of disabled children.

Under s1(11):

Any action taken or decision made under this Act, for or on behalf of a disabled person, should be done or made with due regard to the need to respect and promote his human rights and the principles set out in this Act.

All those with duties under this Act shall carry out those duties to the maximum extent of their available resources.³⁴⁸

Here we find a purpose and list of principles in line with those of the CRPD and with Article 19. The respect and promotion of disabled people's human rights is clearly stated as a primary principle governing all actions and decision-making,³⁴⁹ in line with CRPD Article 1. General principles include choice, freedom and control, dignity and participation, in line with CRPD Article 3 and the head of Article 19; and self-determination in the arrangement of personal assistance and support in line with Article 19(b). Article 19(a) is reflected in the power to determine one's living arrangements under s1(5); CRPD Article 3(h)³⁵⁰ in respect for the rights of children, both disabled and as 'carers'; and CRPD Article 12³⁵¹ in support for adult decision-

³⁴⁷ Ibid s1(10)

³⁴⁸ Independent Living Bill 2009 s1(14)

³⁴⁹ Ibid s1(11)

³⁵⁰ CRPD Article 3(h): Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

³⁵¹ CRPD Article 12: Equal recognition before the law

making. The Bill's s1(10) prohibition of discrimination against disabled people comes close to the CRPD Article 5(2) prohibition 'on all grounds', echoing the CRPD Article 3(d) principle of respect for difference and the CRPD Article 5(4) permission to take positive action to address the consequences of discrimination. Whilst there is no overt acknowledgement that the services in question are economic, social and cultural rights, there is recognition that they should be provided 'to the maximum of available resources' in line with ICESCR Article 2(1) and CRPD Article 4(2).

On the one hand, then, we have a Law Commission review whose 'neutral' purpose and proposed principles make no reference to human rights, and whose final report proposes that individual 'well-being' rather than independent living should be the basis for all decisions made and actions carried out under the statute.³⁵² On the other hand, we have an Independent Living Bill which takes respect for and promotion of disabled people's human rights as its primary objective. How do these two very different central positions define the limits and project the content of their respective legal orders to 'facilitate full enjoyment by persons with disabilities'³⁵³ of the right to independent living, as required by CRPD Article 19?

Boundaries: defining the limits

With an eye on the exclusionary definitions in current legislation, the Law Commission does not propose to include a central definition of a **disabled person** or service user, arguing that such definitions can be stigmatising, and too broad to serve any useful legal purpose. Instead a person should be eligible for services if they have an 'assessed eligible need'³⁵⁴ determined through the assessment process.

The Independent Living Bill, by contrast, does provide a definition, which echoes that of the CRPD:³⁵⁵

³⁵² Law Commission, 'Adult Social Care' (LawCom 326, 2011) HC 941, Part 4

³⁵³ CRPD Article 19

³⁵⁴ Law Commission Consultation Paper (2010) para 38, provisional proposal 9-3

³⁵⁵ See Chapter 3 above

“disabled person” means a person of any age... who –
(a) has a physical, neurological or sensory impairment, a learning disability, a mental health problem, an illness or health condition, or
(b) has had an illness or health condition, and who faces barriers to independent living...³⁵⁶

We may recall here the arguments for and against a definition of ‘persons with disabilities’ during the CRPD negotiations, and the role of the definition there in both retaining flexibility and the possibility of dynamic evolution, and preventing governments or courts resiling from commitments by adopting excessively narrow or exclusionary interpretations.³⁵⁷

For the Law Commission, ‘**services**’ are defined negatively through maintaining and clarifying the existing divides between health and social care provision,³⁵⁸ and positively through a short but inexhaustive list of ‘community care services’³⁵⁹ which closely reflects the services covered by existing legislation:

- residential accommodation [NAA48 s21]
- community and home-base services [NAA48 s29; CSDPA70 s2]
- advice, social work, counselling and advocacy services, [NAA48 s29, LASSA70 s6, Children Act 89 ss 17 & 21, etc, Mental Health Act 1983 s117] or
- financial or any other assistance [e.g. Children Act 89 s17(6); Disabled Facilities Grants, etc]

The corresponding Independent Living Bill list includes practical assistance, such as equipment and technology, personal care and help around the home, shopping, and assistance to participate in education, family life, employment, or social life; and ‘associated support services’ such as mobility or low vision training, various therapies, prosthetics or continuing or palliative health care; ‘or any other matter which would enable the disabled person to enjoy

³⁵⁶ Independent Living Bill s3

³⁵⁷ G Burca G de, ‘The European Union in the Negotiation of the UN Disability Convention’ (2010) 35(2) European Law Review 174, 190; and see Chapter 3 above

³⁵⁸ Law Commission Final Report (2011) Recommendation 51

³⁵⁹ Ibid, Recommendation 28. The Government, in its consultation response, considers the ‘term and concept of “community care services” rather outdated. With the move to personal budgets and self-directed support, we have an opportunity to modernise the language we use...’ Government Response, para 39; and see Postscript below

independent living...'.³⁶⁰ The provision of adaptations to the home remains mandatory.

Law Commission services must be provided in accordance with the well-being principle, which must also be directed to a list of **outcomes**:

- health and emotional well-being;
- protection from harm;
- education, training and recreation;
- the contribution made to society; and
- securing rights and entitlements.

Again, these outcomes are little different in essence from those underlying the paternalistic 'welfare arrangements' of the 1948 Act.³⁶¹

The Independent Living Bill also defines 'independent living' in terms of outcomes. Here 'independent living' means

disabled persons enjoying the same choice, freedom, dignity, control and substantive opportunities as persons who are not disabled at home, at work, and as members of the community in order to improve outcomes for disabled persons in relation to: -

- (a) their individual autonomy;
- (b) their confidence and security;
- (c) respect for and full enjoyment of their rights to privacy and family life;
- (d) their participation in education, life-long learning, training and recreation;
- (e) the contribution made by them to society, including their participation in voluntary work and employment;
- (f) their social and economic well-being;
- (g) their participation in community and public life; and
- (h) their physical and mental health and emotional well-being.³⁶²

Another non-exhaustive list determines minimum outcomes to be secured:

- (a) ensuring freedom from physical risk, inhuman or degrading treatment
- (b) ensuring dignity within, and control over, a person's personal living environment
- (c) the full enjoyment of the right to personal development and to establish and maintain family and other social relationships
- (d) support for participation in the life of the community
- (e) support to participate in essential social and economic activities

³⁶⁰ Independent Living Bill s15(3)

³⁶¹ See extracts from NAA s29 above

³⁶² Independent Living Bill s3

- (f) support to access an appropriate range of recreational and cultural activities³⁶³

Whilst the boundaries of the Law Commission's map reflect the status quo, the Independent Living Bill's boundaries are more emancipatory and inclusive. Within these contrasting boundaries, how do the drafters organise the legal space?

Projection: organising the legal space³⁶⁴

Law Commission

Law Commission proposals envisage two levels at which adult social care should be provided. At the universal level, the local authority provides information, advice and assistance to those who have not had, or do not want, an assessment, or are not eligible for services. This duty ties in with the policy focus on prevention and the authority's role as facilitator and stimulator of a local services market. At the second level, 'targeted' social services are provided following a community care assessment.

The duty-holders here are local authorities. They retain their duty to undertake a 'community care' assessment where it appears to them that a person may have 'community care needs'. The low qualifying threshold for an assessment is thus retained,³⁶⁵ as is a general duty to promote co-operation between themselves and other 'relevant organisations', such as housing, education and health authorities. The problem of 'portability' of support services between authorities is addressed through an enhanced duty on both local authorities to co-operate.³⁶⁶ The receiving authority must carry out an assessment, explain in writing if they decide to offer a significantly

³⁶³ Ibid s15(6)

³⁶⁴ Santos defines projection as 'the procedure by which the legal order defines the limits of its operation, and organizes the legal space inside them.' Santos (2002) 430, and see Chapters 1 and 3 above

³⁶⁵ The duty to assess is triggered where it appears to a local authority that a person may have needs that could be met by community care services. Law Commission, 'Adult Social Care' (LawCom 326, 2011) HC 941, Summary, para 12

³⁶⁶ 'This would allow a local authority to request assistance from another local authority or other body and the requested body would have to give due consideration to the request.' Ibid, Summary, para 40

different support package, and must continue to provide the original package until the new assessment is completed.

The assessment should focus on the person's needs and the outcomes they wish to achieve,³⁶⁷ rather than 'the person's suitability for a particular existing service.'³⁶⁸ Local authorities are required to 'consult with' the individual and their carer, 'except if consultation is not realistically possible in the circumstances'.³⁶⁹ In place of the present plethora of guidance on assessment procedure, the Secretary of State would make regulations which require at a minimum that assessors

adopt a proportionate approach to assessment, having regard to the needs of the individual; carry out a specialist assessment in specified circumstances; and consider all needs during an assessment, irrespective of whether they can be or are being met [by others].³⁷⁰

The principles of 'person-centred approach' and 'viewing a person's needs broadly' proposed in the consultation are embedded here.

Once needs are assessed, eligibility criteria are applied. Again, guidance is replaced by regulations, this time setting out national eligibility criteria, supplemented by a Code of Practice specifying how criteria should be set at local level, including a minimum level of provision.³⁷¹

If, following assessment, no eligible needs are found, reasons must be given to the individual in writing. Where eligible needs have been determined, the duty to meet them becomes an individual duty, enforceable through judicial review,³⁷² and a care and support plan must be produced. Its form and content will be prescribed in regulations, including a requirement that plans are set out in writing and signed on behalf of the local authority.³⁷³ There is

³⁶⁷ Law Commission, 'Adult Social Care' (LawCom 326, 2011) HC 941, Recommendation 9

³⁶⁸ Ibid para 8

³⁶⁹ Ibid Recommendation 11

³⁷⁰ Ibid, Summary para 14. See also Part 5 of the Report

³⁷¹ Ibid, Summary para 17, Recommendation 17

³⁷² Ibid, Recommendation 16

³⁷³ Ibid, Summary para 28; Recommendations 31 and 32

no option of self-assessment, and no requirement for signature of agreement by the individual, though a copy should always be made available to them.³⁷⁴

The proposed statute would provide for development of personal budgets and extension of Direct Payments to residential care. The current Choice of Accommodation Directions,³⁷⁵ which require a local authority, under certain conditions,³⁷⁶ to accommodate a person at a place of their choice in England or Wales, would be replaced by regulations. As Clements observes, the current Directions 'constitute one of the few examples of genuine choice that individuals have in relation to their community care services'.³⁷⁷ Whether or not this duty was strengthened by being given a statutory basis would depend on the wording of the regulations. Provision would also be made for regulations establishing a charging regime, including maintenance of existing exceptions.³⁷⁸

Whilst these projections consolidate and strengthen aspects of the existing 'community care' regime, particularly through the use of secondary legislation, the underlying 'welfare' discourse is unchanged. In line with its objective, the Law Commission has proposed a coherent legal framework for the provision of services, with focus on individual well-being and outcomes, and capable of accommodating different policies and practices in the future. Though tidier, the map has not essentially changed.

³⁷⁴ The Law Commission 'recognise the particular concern that service users are involved and, as far as possible, are able to take ownership of the care and support plan. In our view, this involvement would be encouraged in a number of ways. We recommend in Part 4 (Statutory Principles) the introduction of statutory principles which would apply to the provision of a care and support plan and would require, amongst other matters, that service users should be fully involved wherever appropriate and possible. Second, we recommend above that the code of practice should provide further guidance on when it would be appropriate to authorise other individuals or organisations to produce the care and support plan. On this basis we do not consider that any additional legal provisions are necessary.' Ibid, para 8.53

³⁷⁵ National Assistance Act (Choice of Accommodation) Directions 1992

³⁷⁶ (1) The accommodation is suitable in relation to the person's assessed needs; (2) to do so would not cost the authority more than what it would usually expect to pay for accommodation for someone with the individual's assessed needs; (3) the accommodation is available; and (4) the person in charge of the accommodation is willing to provide accommodation, subject to the council's usual terms and conditions. NAA48(Choice of Accommodation) Directions 1992, para 3

³⁷⁷ Clements L, *Community Care and the Law*, 3rd ed (Legal Action Group, 2007) 165

³⁷⁸ Such as aftercare under s117 of the Mental Health Act 1983, which is free.

The Independent Living Bill projects the same multi-dimensional social reality differently.

The Independent Living Bill

Having established the holistic and inclusive reach of its legal order, the Bill sets out 'general duties in relation to independent living'.³⁷⁹ At national level, the Secretary of State must prepare and implement a national independent living implementation plan,³⁸⁰ setting out costs and benefits, a national resource allocation framework and a national workforce development plan. In doing so, the Secretary of State has a duty to consult and involve disabled people, older people, parents of disabled children, carers, organisations representing those people, representatives of local authorities and NHS bodies, statutory, voluntary and private service providers, and inspection bodies. This is not designed to be a paternalistic, top-down process, but a hegemonic project involving a range of social actors, including disabled people and others whose support requirements are in issue.

At local level, each local authority and NHS body has a duty to promote independent living for disabled people.³⁸¹ Local authorities must secure, as far as reasonably practicable, the availability of a range of housing and support resources detailed in the Bill.³⁸² Like the Convention, this Bill is expanding its scale: national, medium-scale law is detailing the routes to be taken at local level to reach the required destination. Here too, reasonable steps must be taken to involve disabled people and others, including service providers.³⁸³ NHS bodies have similar duties,³⁸⁴ and both local authorities and NHS bodies have a duty to cooperate with each other and with other

³⁷⁹ Independent Living Bill, Chapter 1

³⁸⁰ *Ibid*, s4

³⁸¹ *Ibid*, s5: communication support; independent advocacy; equipment and adaptations; advice, information and support, including to manage individual budgets; an appropriate and sufficient range of residential accommodation and housing-related support and services; an appropriate and sufficient range of employment opportunities and services; and an appropriate and sufficient range of respite services for disabled people and carers.

³⁸² *Ibid*, s6(1) and (2)

³⁸³ *Ibid* s.6(3) disabled people, particularly those from ethnic minorities, older persons, parents of disabled children, carers, organisations representing those groups of people, and providers of independent living services in their area, including those in the voluntary and private sectors.

³⁸⁴ *Ibid*, s7

‘relevant partners’ to promote independent living;³⁸⁵ to prepare and implement an independent living strategy;³⁸⁶ and to enhance capacity among local service providers.³⁸⁷ These provisions are shored up through inspection and enforcement by independent regulatory bodies.³⁸⁸

National and local duties combine to try to ensure that the holistic services and conditions for independent living are in place, and that all concerned have a role in designing and developing them. Whilst the duties rest firmly on national and local statutory organisations, the experiences of disabled people and others, and of voluntary and private sector providers are an integral and respected part of the project.

In contrast to the ‘welfare’ approach of the Law Commission, on this map statutory duties are matched by individuals’ rights. Service users have a right to independent living, including rights to information, advice and assistance, to independent advocacy, and to holistic, self-directed assessment of their requirements. The language here is not about ‘needs’ and ‘entitlements’, but ‘requirements’, ‘assistance’ and ‘support’. The responsible authorities have a duty to ensure that disabled people are ‘empowered to define [their] own requirements’,³⁸⁹ assisted by independent advocate and/or communication worker if required. An individual approaching assessment must be informed of their rights and referred appropriately. Assessments must be carried out within a specified time, by suitably trained staff;³⁹⁰ interim arrangements can be made in urgent situations.

Once arrangements to be made have been identified, the authority has a duty to provide, and the individual has the right to choose how they receive their allocation of resources: in the form of a direct payment, indirect payment,³⁹¹ or in kind from the relevant authority. As seen above, the Bill

³⁸⁵ Ibid, s8

³⁸⁶ Ibid, s9

³⁸⁷ Ibid, s11

³⁸⁸ Ibid, Part 3

³⁸⁹ Ibid, s14(2)

³⁹⁰ Including in equality issues and relevant impairments or health conditions

³⁹¹ To a person or organisation for management on their behalf

provides a long, non-exhaustive list of the possible kinds of arrangements that might be made³⁹² and the outcomes to be secured.³⁹³

Part 4 of the Independent Living Bill deals with housing. Here, no disabled person should be placed in ‘a care establishment or other institutional setting’ unless

- (a) the disabled person wishes to be admitted to such a setting,
- (b) such arrangements best meet the requirements of the disabled person (as opposed to being expedient on financial grounds), and
- (c) the proposed placement is not due to absence of accessible or supported (or both) housing options or alternative independent living services in the community.³⁹⁴

Here we find a strong reiteration of the *anti*-dependence element of the philosophy of independent living, as well as direct reflection of CRPD Article 19(a).

Though mapping the same terrain, these two approaches to legislative reform project very different pictures of the world. On the Law Commission map, power rests in the hands of the local authority: apart from the making of regulations, central government has little part to play. The checklist to protect the individual’s ‘well-being’ and contribution to the assessment process is hedged around with exceptions; the service user may sometimes not even be consulted, and their agreement to the assessment is not required. This map reflects social reality as it stands today: although some language has changed, established oppressive assumptions of dependency are not far away, New Labour’s (and disabled people’s) understandings of co-production have almost slipped out of view, and rights remain invisible. This is law as reflecting dominant discourse, containing and regulating the existing social order.

³⁹² Including ‘any other matter which would enable the disabled person to enjoy independent living...’ See p236 above and Independent Living Bill s15(3)

³⁹³ Ibid

³⁹⁴ Ibid, s21. In addition, the Independent Living Bill covers Local Housing Allowance for additional bedrooms (s31); the allocation of housing by local authorities, including for those wishing to move out of residential accommodation (s32); the creation of a ‘disability housing service’, with a register of accessible properties (s33); and changes to building and planning legislation (ss35, 36 and 37).

On the Independent Living Bill map, central as well as local government take ownership of a hegemonic project in which all stakeholders are involved, and which seeks to bring about fundamental change. If this Bill were fully implemented, a new system of social relations would be established: the holistic services and conditions for independent living would be in place, and power relations between service user and provider would everywhere be reframed. Article 19, the means to exercise of all Convention rights, would be on its way to realisation, and the CRPD myth on its way towards imaginary. As Santos explains,

while regulation guarantees order in society as it exists in a given moment and place, emancipation is the aspiration for a good order in a good society in the future... the success of emancipatory struggles resides in their capacity to transform themselves into a new form of regulation, whereby good order becomes order.³⁹⁵

On this occasion, the emancipatory Independent Living Bill failed to bring about that transformation.

Next steps

At the time of writing,³⁹⁶ the Coalition's White Paper and Social Care Reform Bill have not been published. However, some insight may be gained into the government's possible approach through its Response to the Law Commission's consultation.³⁹⁷ Here, the Coalition recognises that expectations have changed.³⁹⁸ They want to see

a situation where people are empowered to make decisions and take responsibility for their own health and well-being. The system must support and encourage people to make choices and in taking control of their lives. Professionals need to work in collaboration with each other

³⁹⁵ Santos (2002) 2-3

³⁹⁶ August 2011 – but see Postscript below

³⁹⁷ See also oral evidence of Rt Hon Grant Shapps, Paul Burstow and Maria Miller to Joint Committee on Human Rights inquiry into Implementation of the Right of Disabled People to Independent Living, Tuesday 25 October 2011

³⁹⁸ Department of Health, 'The Government Response to Law Commission Consultation Paper 192: review of the law on adult social care' (2010)

and the individual to get the best possible outcomes...This is about doing things with people, not for, or to, them.³⁹⁹

This promises well for a reframing of relations between individual service user and provider away from a paternalistic 'welfare' model. However, as we saw in Chapter 6, those relations are less between local authority and service user as between individual consumer and a market of independent and voluntary sector providers.⁴⁰⁰

The Government states categorically that it does not 'anticipate that there will be rights to specific services stated in the statute',⁴⁰¹ though it does support the inclusion of statutory principles, whose purpose, in its view, 'is to assist decision-makers in exercising their functions, rather than to establish enforceable legal duties'.⁴⁰² While describing the Law Commission's suggested principles as 'a good starting point', the response refrains from suggesting alternatives.

Several respondents felt that the Law Commission's consultation was far too narrow in scope.⁴⁰³ The Government agrees:

[i]t is... important that any list [of services] is broadly defined and not set in such a way that constrains the flexibility and innovation that has, for instance, been seen in the way that direct payments have been used for support and services beyond the traditional view of what constitutes community care services. We prefer a focus on outcomes and a broad list of activities that could deliver desired outcomes (choice, control, independent living, etc).⁴⁰⁴

As we have seen, the Law Commission's final report conforms to the traditional list, with the addition of 'or any other assistance'. It does reflect the government's focus on outcomes, but the outcomes chosen do not include choice, control or independent living.

³⁹⁹ Ibid, 5

⁴⁰⁰ Ibid, 5-6

⁴⁰¹ Ibid, para 23

⁴⁰² Ibid, para 7

⁴⁰³ For instance, In Control, para 4; Local Government Ombudsman, 1 and 2

⁴⁰⁴ Department of Health, 'The Government Response to Law Commission Consultation Paper 192: review of the law on adult social care' (2010) para 39

The Government wants assessment to identify not only 'needs that can be met by social care services', but also more holistic needs;⁴⁰⁵ and supports co-produced self-assessment.⁴⁰⁶ Production of the care plan, too, should be

couched in terms of co-production with the individual and/or their representative. It is also important that other key agencies, such as the NHS, play their full part in care planning to ensure that resulting services are joined up from the outset.⁴⁰⁷

Interestingly, the government wants to consider further whether personal budgets are the best way to ensure that local authorities maximise individuals' autonomy, or whether to 'take a broader approach' (undefined).⁴⁰⁸

It is also concerned about language, finding the term and concept of 'community care services' rather outdated, and that the term 'social care needs' does not reflect people's experience or encourage innovative responses.⁴⁰⁹ It suggests that 'we have the opportunity to modernise the language we use',⁴¹⁰ but again without offering alternatives.

The Government's position, then, appears to sit somewhere between the Law Commission's proposals and the Independent Living Bill. Although it will not enact rights-based legislation, it is not content either with the Law Commission's cautious endorsement of the status quo. The ILB's strategic approach to wholesale social change is rejected: both Government and Law Commission agree that no strategic planning provisions should be included in the statute,⁴¹¹ and top-down regulation is anathema. The focus instead is on individual autonomy and freedom to make choices, in line with the Coalition's consumerist discourse, and regulation by market forces. As we found in the policy field in Chapter 6, current Government thinking emphasises individual autonomy and choice while distancing itself from the collective elements of independent living discourse, resulting in partial understanding of the

⁴⁰⁵ Ibid, para 16

⁴⁰⁶ Ibid, para 13

⁴⁰⁷ Ibid, para 52

⁴⁰⁸ Ibid, para 25

⁴⁰⁹ Ibid, para 12

⁴¹⁰ Ibid, para 39

⁴¹¹ Ibid, para 90

requirements of Article 19. However, the Government's response also incorporates – at individual though not at strategic level - elements of New Labour's (and disabled people's) discourse of co-production; understandings of the holistic nature of independent living; and recognition of the need for a change in social relations: to 'doing things with, not for, or to' disabled people.

Again, there is no mention of the CRPD or of Article 19 in the government's response to the Law Commission – along with economic, social and cultural rights more generally, they remain invisible.

Conclusion

CRPD Article 4(1) requires States Parties to adopt all appropriate legislative measures to implement Convention rights,⁴¹² and to modify or abolish existing laws and regulations that discriminate against disabled people.⁴¹³ Where the hybrid Article 19 right to live independently and be included in the community is concerned, 'appropriate legislative measures' to implement civil and political rights to autonomy and participation require equally appropriate measures to implement the economic, social and cultural rights required for their exercise. Current legislation relating to the socio-economic elements of Article 19 remains founded not in 'rights' but in 'welfare' thinking. It is highly complex, out-dated, framed in offensive language, and is potentially incompatible even with civil and political European Convention rights.⁴¹⁴ If the requirements of Article 4(1) are to be met, existing legislation must be modified or abolished, and 'appropriate legislative measures' put in its place.

Though responding to internal pressures rather than CRPD requirements, Coalition government plans to enact new legislation provide an opportunity for CRPD Article 4(1) requirements to be met. Santos describes forms of law as 'revolving doors through which different forms of power and knowledge

⁴¹² Article 1(a)

⁴¹³ Article 1(b)

⁴¹⁴ Law Commission Scoping Report (2010)

circulate'⁴¹⁵ at once reflecting and creating different forms of social reality. We have seen in Chapter 6 that a variety of understandings of independent living circulate in the domestic field of meaning: from established and still dominant assumptions of dependency, through New Labour's (and disabled people's) understandings of co-production, to the Coalition government's consumerist interpretation and disabled people's rights-based perspectives. How the drafters of the Social Care Reform Bill map their terrain will not only reflect the discursive elements and projections they choose, but will also impact on the ability of international disability/human rights discourse to influence domestic systems of social relations, and on the lives of disabled people through the social realities they create.

This Chapter has examined two contrasting approaches to legislative reform which might shape the new legislation. The Law Commission map offers a 'neutral' centre based on a qualified principle of 'well-being', narrow boundaries reflecting the status quo, and projections which consolidate and strengthen aspects of the existing 'community care' regime whilst leaving the underlying oppressive 'welfare' discourse unchanged. The Independent Living Bill, by contrast, takes respect for and promotion of disabled people's human rights as its central objective, sets emancipatory and inclusive boundaries, and applies projections which set in train a participatory hegemonic project to bring about fundamental and holistic change in line with the terms, purpose and ethos of the CRPD.

The government itself appears to favour an approach between the two. On the one hand, it focuses on individual autonomy, supporting a change in individual relations towards co-production and holistic assessment. At the same time, it rules out both rights-based and strategic approaches, to re-balance responsibility for 'welfare' outcomes from the State to the individual. As in the policy field, the side-lining of State responsibility threatens equity and collective reciprocity, hampering any opportunity for the CRPD drafters' hegemonic project to establish new systems of social relations in line with

⁴¹⁵ Santos (2002) 417

disability/human rights understandings. Indeed, the 'revolving door' through which such forms of power and knowledge are designed to circulate - the CRPD itself, with Article 19 and the economic, social and cultural rights essential for its implementation - remains closed.⁴¹⁶ Whilst Article 19 rights to individual autonomy and choice are likely to be strongly supported in the forthcoming Social Care Reform Bill, the economic, social and cultural rights required for their exercise appear set to remain invisible, leaving the domestic legal map essentially unchanged. The legal dimension of domestic independent living discourse, like its field of meaning, thus faces the CRPD drafters' hegemonic project with a partial and unstable base for bringing about its 'deep reconstruction' of the world.

'Welfare' policy and law are delivered to individuals through the administrative justice system. It is here that social relations are at their most dynamic, as disabled people experience the decisions and interactions that affect their daily lives. **Chapter 8** examines administrative decision-making relating to independent living services in England. It explores the potential for administrative power relationships, systems and practices in this setting to oppress or to emancipate, reflecting and influencing the identities of all concerned.

⁴¹⁶ But see Joint Committee on Human Rights recommendations for legislative underpinning of independent living, JCHR (2012) 24-7

Chapter 8

Independent Living in England: Decision-making

Introduction

The UN Convention on the Rights of Persons with Disabilities demands paradigm change. In this thesis, paradigm change is conceptualised as coming about through hegemonic articulation and re-articulation of discursive elements to dominate the field of meaning, to influence social structures and relationships, and to shape the identities of social actors. Part 1 of the thesis explains that disability/human rights discourse set a new agenda at international level. The resulting hegemonic formation – the CRPD - sediments a new myth: a re-description of the world and of the place of disabled people in it. In this new world, impairment is no longer seen as aberration but as universal human variation, disabled people no longer as dependent welfare recipients but as equal and valued holders of all human rights. For that re-description to be transformed from myth to imaginary, disability/human rights discourse must succeed in setting a new agenda not only at international level, but also in domestic settings.

Part 2 of this thesis considers the capacity or otherwise of the CRPD to support such hegemony in England. Chapter 5 has highlighted the resistance of successive UK governments to recognition of the equal, indivisible and interdependent nature of all human rights, and to incorporation of economic, social and cultural rights into UK domestic law. This has raised the question of how, if at all, such imbalance in human rights protection might affect the capacity of the CRPD to influence paradigm change in England. The question is explored through examination of the understandings, systems and identities circulating in the domestic field. Taking Article 19, the right to live independently and be included in the community as ‘barometer’,

Chapter 6 has examined understandings in the field of meaning, as evidenced through independent living policy in England. Focussing on law as one method of articulating and regulating systems of social relations, Chapter 7 has investigated how the various understandings of independent living circulating in the policy arena might be encapsulated in new legislation.

Understandings, structures and identities are dynamic and interwoven components of any discursive process: as understandings shape structures and practices, so the identities of social actors are both influenced by and reflected in those understandings and structures. The subject positions of everyone involved in the legal and political developments discussed so far are as important to those developments as are the understandings and systems of social relations themselves. As Quinn observes, paradigm change requires ‘socialisation’: that actors adopt new beliefs and behavioural patterns, thereby becoming socialised to align policy (law and practice) with Convention values to bring about meaningful change.¹ Independent living law and policy are delivered to individuals through the administrative justice system: the world of the citizen meets that of the household and community. While focussing on administrative decision-making, this Chapter attempts to draw out and to illustrate some ways in which the identities of individuals may be influenced by, and themselves influence, the possibility of meaningful change.

The English administrative justice system has been defined as comprising ‘the administrative decisions by public authorities that affect individual citizens and the mechanisms available for the provision of redress’.² Administrative decisions are made by a large and varied number of public bodies: government, arms-length agencies, local authorities, NHS bodies, housing providers, private contractors exercising public functions and more. There is an equivalent variety of administrative redress processes available,

¹ Quinn G, ‘Resisting the Temptation of Elegance’: Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?’ in Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009) 219

² Nuffield Foundation (2007) <http://www.nuffieldfoundation.org/administrative-justice> accessed 16.1.08; see also Sunkin M, ‘Keep Up the Momentum’ (2006) Autumn, Tribunals 9

depending on the issue and the public (or private) body involved, ranging from internal complaints and appeals, through mediation, Tribunals, judicial review and the Ombudsman. As we have seen in Chapter 5, it is these ‘welfare’ procedures on which the UK relies for delivery and enforcement of its international economic, social and cultural rights obligations.

The services required to support independent living under Article 19 are accessed through local authority social services departments via a three-stage assessment process.³ As Jackson J has commented, ‘[t]he environment in which local authorities operate in the field of adult care is not legally coherent and bristles with intricate regulation.’⁴ Moreover, care provision is in transformation towards ‘personalisation’, though that concept remains open to a variety of expectations,⁵ interpretations and dislocations,⁶ and legislation which might help to clarify interpretation is as yet⁷ undrafted.⁸ It is at the level of administrative justice, however, that the vast majority of disabled people experience the decisions and interactions that affect their daily lives. As Beresford *et al* identify, the practice of people who work face to face with service users

is at the heart of social care. It is where the aims and ideologies of agencies and policy-makers intersect with the lives, rights, needs and desires of service users.⁹

If the emancipatory values and purpose of the Convention can achieve hegemony here, maybe resistance, re-articulation and dislocation at national

³ See Chapter 7 above. 1) the gathering of information about the person’s ‘community care needs’; 2) a decision on which ‘needs’ call for the provision of services, through the application of ‘eligibility criteria’; and 3) the preparation of a ‘care plan’ explaining which ‘care needs’ must be met and detailing the services (or budget) to be provided to meet them.

⁴ *London Borough of Hillingdon v Steven Neary, Mark Neary and the Equality and Human Rights Commission* [2011] EWHC 1377 (COP) 9 June 2011, para 19

⁵ ‘[E]xpectations for moves to personalisation and self-directed support seemed to be changing within a year, from ‘transformation’ (the government’s term), to continued progress where there was grass-roots commitment, but limited progress beyond this.’ Beresford *et al*, *Supporting People: towards a person-centred approach* (Policy Press 2011) 354, citing Glasby J and Littlechild R, *Direct payments and personal budgets: Putting personalisation into practice*, 2nd ed, (The Polity Press 2009)

⁶ See Chapter 6 above

⁷ At the time of writing: January 2012 – but see Postscript below

⁸ See Chapter 7 above

⁹ Beresford (2011) 223

level will present the CRPD drafters' project with less of a challenge. After all, as Eleanor Roosevelt remarked, human rights begin

in small places, close to home – so close and so small that they cannot be seen on any map of the world. Yet they are the world of the individual person: the neighbourhood he lives in; the school or college he attends; the factory, farm or office where he works. Such are the places where every man, woman and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning here, they have little meaning anywhere...¹⁰

Pleasence *et al* identify that

[t]he problems to which the principles of civil law apply today are not abstract 'legal problems.' They are not problems familiar only to lawyers, or discussed only in tribunals and civil courts. They are for the most part the problems of 'everyday life' – the problems people face as constituents of a broad civil society... [T]hese problems today involve numerous issues of basic social well-being.¹¹

In England, people experiencing illness or impairment are more likely than others to experience the kinds of problems that bring them into contact with the administrative justice system.¹² They experience more of those problems, and they are more likely to experience the kinds of spiralling 'clusters' of problems that can undermine their quality of life, their independence,¹³ and, as Carol Thomas suggests, their psycho-emotional wellbeing.¹⁴ How the administrative system responds to those problems will

¹⁰ *Teaching Human Rights* (United Nations 1963) 1, quoted in Jayawickrama N, *The Judicial Application of Human Rights Law* (Cambridge University Press 2002)

¹¹ Pleasence P, Buck A, Balmer N, O'Grady A, Genn H and Smith M, *Causes of Action: Civil Law and Social Justice* (Legal Services Research Centre 2004) 1. They comment that '[t]his is despite a more recent 'backlash against rights', characterised by internal review and complaints procedures'. It should be noted that the continuous English and Welsh Civil and Social Justice Survey on which these conclusions are based does not identify 'community care' problems, or disputes with social services, as one of its 18 problem categories. Those categories are: discrimination, consumer, employment, neighbours, owned housing, rented housing, homelessness, money/debt, welfare benefits, divorce, relationship breakdown, domestic violence, children, personal injury, clinical negligence, mental health, immigration, and unfair treatment by the police.

¹² Pleasence P, Genn H, Balmer NJ, Buck A and O'Grady A, 'Causes of Action: First Findings of the LSRC Periodic Survey' (2003) 30(1) *Journal of Law and Society*, 11; Pleasence *et al* (2004); Pleasence P, Balmer N and Buck A, *Causes of Action: Civil Law and Social Justice* 2nd ed (Legal Services Research Centre 2006); Office of the Deputy Prime Minister, *The Drivers of Social Exclusion: a review of the literature for the Social Exclusion Unit in the Breaking the Cycle series* (Social Exclusion Unit 2008)

¹³ O'Grady A, Pleasence P, Balmer NJ, Buck A and Genn H, 'Disability, social exclusion and the consequential experience of justiciable problems' (2004) 19(3) *Disability & Society* 259

¹⁴ Thomas C, *Sociologies of Disability, 'Impairment' and Chronic Illness: Ideas in Disability Studies and Medical Sociology* (Palgrave 2007)

therefore have a substantial impact, one way or another, on realisation of disabled people's Article 19 right to independent living under the Convention, and thus on realisation of all Convention rights. This Chapter examines administrative decision-making in the field of independent living, before Chapter 9 turns to systems for redress where decision-making is challenged.

Decision-making

The concept of 'administrative justice' has been theorised in a number of ways. Davis¹⁵ focuses on the discretion afforded to administrative officials in their day-to-day work. He finds that the Dicey/Hayek versions of the rule of law express an ideal, 'but none is based upon a down-to-earth analysis of the practical problems with which modern governments are confronted'.¹⁶ Moreover, their version of the rule of law is violated all the time: 'a startlingly high proportion of all official discretionary action pertaining to administration of justice is illegal or of doubtful legality',¹⁷ and the courts have neither the power nor, possibly, the will to substitute their own decisions. In this situation what counts, Davis says, is power, not authority.¹⁸ Questions will often be decided on the basis of considerations other than justice, such as facts, policy, resources, politics, or ethics.¹⁹ Such exercise of discretionary power by the decision-maker is not always undesirable: it may be indispensable for individualised justice, and provides an important source of creativeness in government and law – but only when properly used. Davis suggests that unnecessary discretionary power should be eliminated, and that the remainder should be confined, structured, monitored and selectively enforced to improve the quality of justice.

¹⁵ Davis KC, *Discretionary Justice: A Preliminary Inquiry* (University of Illinois Press 1969)

¹⁶ *Ibid* 33

¹⁷ *Ibid* 12

¹⁸ *Ibid* 13

¹⁹ *Ibid* 25

For Mashaw,²⁰ the 'justice' element of administrative justice encompasses 'those qualities of a decision process that provide arguments for acceptability of its decisions.'²¹ He suggests three models of administrative justice: bureaucratic rationality, professional treatment and moral judgement.²² 'Bureaucratic rationality' is defined in factual and technocratic terms: the individual adjudicator assesses real facts, which are then processed not through that decision-maker's personal preferences or intuitions, but through a managerial system structured by rules and checking.²³ The 'professional treatment' model similarly includes collection of information, but also includes intuition, personal examination and counselling. This model is seen as a service to the client/patient, to improve his well-being, with the organisation providing a more lateral network, rather than a hierarchical command structure.²⁴ Under Mashaw's 'moral judgement' model, the legitimating value is 'fairness': the decision-maker offers a neutral promise of a full and equal opportunity to obtain one's entitlements.²⁵ It is tension between these competing models that provides the dynamics of programme development.²⁶ However, it is bureaucratic rationality which dominates, with professional treatment and moral judgement in supporting roles.²⁷ For Mashaw, such dominance is a good thing: bureaucratic rationality is a promising form of administrative justice, as it permits the effective pursuit of collective ends without inordinately sacrificing individualistic or democratic ideals.²⁸

The contributions of Davis and Mashaw have been influential in administrative justice theory.²⁹ More recently, Adler³⁰ has built on Mashaw's

²⁰ Mashaw JL, *Bureaucratic Justice: Managing Social Security Disability Claims* (Yale University Press 1983)

²¹ Ibid 24

²² Ibid 25

²³ Ibid 26

²⁴ Ibid 28

²⁵ Ibid 31

²⁶ The US Social Security Administration Disability Program is the focus of his discussion. See Mashaw (1983) 31

²⁷ Ibid 37

²⁸ Ibid 222

²⁹ Among others; see for instance Jowell J, 'The Legal Control of Administrative Justice' [1973] Public Law 178; Baldwin R, Hawkins K, 'Discretionary Justice: Davis Reconsidered' [1984] Public Law 570; Baldwin R, Houghton J, 'Circular Arguments: the Status and Legitimacy of Administrative Rules' [1986] Public Law 239

work to identify six models of administrative justice, each of which is associated with different legitimating values, primary goals, organisational structures and cognitive techniques – see Table 2 below. In addition to Mashaw’s bureaucratic, professional and legal³¹ models, Adler identifies the rise in managerial, consumerist and market models of administration. Here, legitimating goals are, respectively, efficiency gains, consumer satisfaction or profit making; modes of decision-making emphasise managerial autonomy, consumer participation or matching supply to demand; and accountability centres on performance indicators, consumer charters or owners/shareholders.³² We may see reflected here the policy re-articulations discussed in Chapter 6, from post-war top-down bureaucracy³³ to increased professionalism³⁴ to ‘New Public Management’,³⁵ co-production³⁶ and the Coalition’s ‘thriving social market’.³⁷

Like Mashaw, Adler understands these models as competitive, with trade-offs between them likely to result in the dominance of one model, though not to the exclusion of others.³⁸ He assumes that

groups in particular settings produce discourses that reflect their interests, and that discursive struggles lie at the heart of power struggles that are endemic in every setting.³⁹

³⁰ Adler M, ‘A Socio-Legal Approach to Administrative Justice’, (2003) 25(4) Law & Policy 323

³¹ ‘Adler prefers the term ‘legal’ to ‘moral judgement’ as he argues that this better reflects the values inherent in it.’ Gulland J, ‘Complaining, Appealing or Just Getting It Sorted Out: complaints procedures for community care service users’, PhD University of Edinburgh, 2007, 42

³² Ibid 333

³³ Such as Marshall TH (ed) *Citizenship and Social Class and Other Essays*, (Cambridge University Press 1950)

³⁴ Establishment of social work in the 1970s: Local Authority and Social Services Act 1970

³⁵ Introduced by Conservative government in the 1980s to ‘modernise’ the public sector

³⁶ Under New Labour personalisation agenda

³⁷ Coalition government ‘Vision for Social Care’; for further discussion of these changes and their effect on administrative justice, see for instance Gamble A and Thomas R, ‘The Changing Context of Governance: Implications for Administrative Justice’ in Adler M, (ed) *Administrative Justice in Context* (Hart Publishing 2010)

³⁸ Adler describes four research projects which applied this theoretical framework in empirical research on administrative justice, relating to the impact of computerisation on social security data in the UK, discretionary decision-making in the Scottish prison system, the assessment of special educational need in England and Scotland, and the computerisation of social security in thirteen countries.

³⁹ Adler (2003) 338-9

Table 2 Six Normative Models of Administrative Justice

Model	Mode of Decision-Making	Legitimizing Goal	Mode of Accountability	Characteristic Remedy
Bureaucratic	Applying rules	Accuracy	Hierarchical	Administrative review
Professional	Applying knowledge	Expertise	Interpersonal	Second opinion or complaint to a professional body
Legal	Asserting rights	Legality	Independent	Appeal to a court or tribunal (public law)
Managerial	Managerial autonomy	Efficiency gains	Performance indicators	Publicity
Consumerist	Consumer participation	Consumer satisfaction	Consumer Charters	“Voice” and/or compensation through Consumer Charters
Market	Matching supply and demand	Profit-making	To owners or shareholders	“Exit” and or court action (private law)

From Adler, M, 'A Socio-Legal Approach to Administrative Justice'⁴⁰

⁴⁰ Adler (2003) 333

Dynamics between models will thus reflect the concerns, bargaining strengths and interests of institutional actors as they seek to construct an optimum mix for each particular administrative activity. Hegemonic outcomes are importantly shaped and structured by these internal dynamics, as well as by external and contextual factors, such as national policy, legislation or case law.

Thus we find an administrative justice system where more or less discretionary power is exercised by individual decision-makers, controlled and validated through a variety of competing models (or discourses) of administrative justice, each with its own legitimating values, goals, structures and knowledges. The dynamics within and between such discourses as they operate in any one organisation will reflect not only the external influences of law and policy, but also the subject positions and bargaining power of the various institutional actors, setting up complex constellations of interlegality. Adler suggests that, whilst these discursive struggles always exist, they are particularly evident in periods of flux,⁴¹ such as the current ‘transformation’ of delivery of adult social care.

Into this mix, in the context of the administration of Article 19 services, come(s) the concept(s) of ‘personalisation’. We have seen that one source⁴² of ‘personalisation’ in English independent living policy was the 2005 Life Chances Report, which in turn drew its understandings not from the CRPD but from the influences of the British disabled people’s movement.⁴³ An essential element of that discourse is *anti*-dependence as response to oppression,⁴⁴ with its concomitant elements of ‘choice’, ‘control’ and inclusion

⁴¹ Ibid 338-9

⁴² The Disabled Peoples’ Movement personalisation agenda chimed with an already expanding discourse of ‘choice’ in public service provision which began in the 1980s and continued under New Labour. See for instance Clarke J, Smith N and Vidler E, ‘The Indeterminacy of Choice: Political, Policy and Organisational Implications’ (2006) 5(2) *Social Policy & Society* 327

⁴³ See Chapter 6 above.

⁴⁴ See for example Jenny Morris: ‘[t]he adoption of the *Improving Life Chances* report is... a reflection of the success of the disability movement in challenging the notion that, if you need assistance to go about your daily life, then you are a ‘dependent person’. Morris J, ‘Independent Living: the role of evidence and ideology in the development of government

as resistance to dependency and exclusion,⁴⁵ and its social model understanding of disability. Here, in line with disability/human rights discourse, independent living demands a change in social relations, as key to holistic restructuring of attitudes and environment – respect for difference and a ‘deep reconstruction of our world’.⁴⁶ As we saw in Chapter 6, the introduction of ‘personalisation’ and ‘choice’ into public service delivery may potentially enable at least partial progress towards hegemonic expansion of the CRPD myth. It also directly challenges existing models of administrative justice, the subject positions of those who identify with them, and existing power relationships between the ‘service user’ and those, such as social workers, who have previously been key players in administrative service decisions.⁴⁷

Clarke, McDermont and Newman examine what happens when the logic⁴⁸ of administrative justice encounters public service reforms based on a commitment to consumer or user choice.⁴⁹ They argue that

[a]s an organisational logic for public services... choice generates a number of political, policy and practice difficulties, [imposing] a framework for decision-making which – at best - runs counter to the principles and normative framework of administrative justice.⁵⁰

‘Service users’ are repositioned from passive recipients to self-directing consumers who expect their wishes to be satisfied. Choice

re-imagines the power relations of public service – and the sorts of knowledge that matter. Consumers may be intrinsically knowledgeable

policy’ (2005) Paper delivered at Cash and Care Conference, Social Policy Research Unit, University of York, 12-13th April 2005

⁴⁵ See for instance Morris, J, *Independent Lives: Community care and disabled people* (Macmillan 1993) 21: ‘... people who are disabled by society’s reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives...’

⁴⁶ Stein MA, ‘Disability Human Rights’ (2007) 95(1) California Law Review 75

⁴⁷ Stevens *et al* (2011) 262

⁴⁸ Clarke *et al*’s use of the word ‘logic’ aligns with Laclau’s ‘discourse’ and Santos’ ‘constellation’: ‘logics’ are heterogeneous; they interact, producing tensions in particular sites; are translated through active, dynamic processes. Each is intrinsically imperfect, its installation (hegemony) contingent, conditional and potentially unstable; gives rise to contestation (social antagonism); and is constituted through borrowing of partial elements from other logics which bring with them other meanings or inflections that may not be suppressed or silenced. *Ibid* 29

⁴⁹ Clarke J, McDermont M and Newman J, ‘Delivering Choice and Administering Justice: Contested Logics of Public Services’ in Adler (2010)

⁵⁰ *Ibid* 26

(knowing about their own needs/desires/wants) or may be helped to become 'well informed' consumers. Consumers are the empowered agents of the consumer choice logic while 'service providers'... are subordinated to their demands.⁵¹

Such logics 'attempt to govern 'conduct' – the conduct of particular sorts of actors and the practices of the organisational setting that these actors inhabit'⁵² - including the 'discursive struggles' between models of administrative justice and their supporters identified by Mashaw and Adler as endemic to the administrative justice system. We may recall, for instance, the initial resistance on the part of many local authorities to implementation of Direct Payments legislation.⁵³

Where the logic of consumer choice meets the logic of administrative justice, Clarke *et al* argue that 'the contestation takes on a distinctive quality because the two logics share a commitment to deliver fairness and equality.'⁵⁴ However, particularly where available resources are insufficient to meet demand - such as in adult social care - choice cannot provide the only governing logic: it must be mediated and managed in a public service context. This may lead to frustration, mistrust and perceived injustice, requiring restoration of the promise of equity and fairness through the alternative logic(s) of administrative justice. Note, for instance, the tensions between the expectations raised by the ADASS questionnaire described below, and the Resource Allocation System used to determine levels of individual support funding. According to Clarke *et al*, the contested co-existence of these two logics

produces instabilities, dilemmas and tensions for those involved in public services... because they carry very different conceptions of the public, of how it is to be served, and of how equality, equity, fairness or justice might be realised.⁵⁵

We will see evidence of these instabilities below.

⁵¹ Ibid 27

⁵² Ibid 28

⁵³ See Chapter 6 above

⁵⁴ Clarke *et al* (2010) 42

⁵⁵ Ibid 43

Introduction of CRPD disability/human rights discourse into this already complex picture demands even more of those attempting to take realisation of 'personalisation' forward, as they seek to construct an optimum mix for this administrative activity. As we have seen in Part 1 above, the equality and autonomy which are its goal are not simply constituted through their standard liberal understandings. Instead, disability/human rights discourse fundamentally challenges traditional liberal understandings of equality and autonomy. Hill's seven conditions for the exercise of autonomy cannot be assumed for those who have been excluded from the human franchise; 'persons with disabilities... are not autonomous in the same way as persons without disabilities';⁵⁶ formal equality and the limited positive obligations of the human rights framework⁵⁷ are insufficient to bring about the 'deep reconstruction' of understandings, structures and identities required to overturn oppression. Even if the tensions identified by Clarke *et al* were to be resolved, as Stevens *et al* identify,

the focus on choice of service and resources is at best insufficient and potentially counter to the overall goals of independent living and increased autonomy and rights as expressed... by... the Independent Living Movement.⁵⁸

The CRPD and Article 19 demand more.⁵⁹ Realisation of the Article 19 right to live independently and be included in the community requires recognition of the durable nature of the economic, social and cultural rights necessary for its exercise, and their equal implementation in practice.⁶⁰

The current 'transformation' in the administration of adult social care thus poses both opportunities and very substantial challenges for implementation of the emancipatory values and purpose of the Convention and Article 19.

⁵⁶ Mégret (2008a)

⁵⁷ O'Conneide C, 'Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and New Possibilities' in Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

⁵⁸ Stevens *et al* (2011)

⁵⁹ See Chapter 2 above; Market-based 'choice' alone is insufficient to protect disabled people's ability to participate and to realise their full potential on an equal basis with others (ESCR Committee General Comment 5); it fails to implement values of solidarity (Quinn and Degener 2002), reciprocity, inclusion and institutional trust (Taylor-Gooby 2009) and it may not, in practice, provide equity (Stevens *et al* 2011)

⁶⁰ See for instance Ms Bras Gomes, Chapter 5 above

Hegemonic expansion of disability/human rights discourse here will depend not only on national legal and political ownership - which, as we have seen is not yet secured⁶¹ - but also on the interplay of competing discourse(s) in each local organisation, and on the understandings, identities and actions there of individual players – their ‘socialisation’⁶² to align their practice with meaningful, Convention-compliant change.

So how might these discursive contestations translate into practice? How do social service departments tasked with delivering ‘personalisation’ understand their role? What administrative systems have they put in place? And how do those understandings and systems impact on the exercise of discretionary power, on the identities and relationships of decision-makers and disabled service users, on the ‘socialisation’ of individual players? To what extent, if any, is there potential for realisation here of the change in social relations required for expansion of the CRPD myth in Eleanor Roosevelt’s ‘small places’ where human rights begin?

Some examples of the exercise of discretionary power, and its influences on systems and identities are considered next.

Discretionary power

In 2005, the Life Chances Report identified ‘a welfare system which assumes dependency’ – an assumption reflected in the culture of health and social care structures, and leading to inadequate, even disabling, responses to need.⁶³ The Report made recommendations which, although not rights-based, fit closely with the aims of the drafters of the CRPD and with the terms of Article 19.⁶⁴ Here, the desired administrative model shifts from

⁶¹ See Chapters 5-7 above

⁶² Quinn (2009)

⁶³ See also Council for Social Care Inspection, ‘Lost to the System? The Impact of Fair Access to Care’, CSCI 2008; Hurstfield, J, Parashar, U and Schofield, K. SQW Ltd, ‘The Costs and Benefits of Independent Living’ (Office for Disability Issues 2007)

⁶⁴ See Chapter 6 above. The Report recommended involving disabled people in development and implementation of policy and in delivery of services; ‘personalising’ responses to individual need; enabling control, sharing power and acknowledging disabled

bureaucratic/professional towards a more consumerist/participative logic which involves and empowers the service user. Welfare policy developments since 2005 have adopted, and then re-articulated, elements of the Life Chances Report's discourse with a view to 'transforming' the delivery of welfare services.

In 2008, the New Labour government invested effort and money⁶⁵ into its Transforming Social Care agenda.⁶⁶ Local councils and their regional networks were required to 'make real and measurable progress to achieve the systems changes that will deliver the transformation of social care for their local populations'⁶⁷ by 2011. First reports on progress⁶⁸ found that workforces were being restructured and new job roles created. Some authorities transferred staff or functions to independent organisations, including user-led organisations.⁶⁹ New academic qualifications were being developed and new assessment and resource allocation systems designed and piloted. As we saw in Chapter 6, the Coalition government has built on and accelerated aspects of this 'transformation' process, whilst re-articulating it to fit a strongly individualised and market-oriented agenda. At the time of writing, councils are 'generally making good progress' towards providing personal budgets for all who qualify by 2013;⁷⁰ and the administrative model looks set to shift again, towards management of supply and demand and legitimisation through market competition, and away from public accountability.

However, particularly in a fluctuating political, legal and economic climate such as that described above, and in the absence of a stabilising legal

people's expertise; holistically addressing all aspects of the person's life; and providing access to high quality information and advice, with a user-led organisation in each locality by 2010

⁶⁵ Including increase in core Revenue Support Grant of 1% a year 2008-2011; Social Care Reform Grant totalling £520 million over same period: LAC(DH)(2008)1

⁶⁶ See Department of Health 'Transforming Adult Social Care' LAC(DH)(2008)1; Department of Health 'Transforming Adult Social Care' LAC (DH)(2009) 1

⁶⁷ Ibid

⁶⁸ ADASS, 'Putting People First: Workforce Study', June 2010

http://www.puttingpeoplefirst.org.uk/library/Resources/Personalisation/Localmilestones/Putting_People_First_Workforce_Study.pdf accessed 29.10.11

⁶⁹ London Borough of Richmond upon Thames and Essex County Council

⁷⁰ ADASS Report on Personalisation Survey September 2011 <http://www.adass.org.uk/> 29.10.11

framework which includes economic, social and cultural rights, the understandings underlying these developments 'remain potentially unchecked and of liability'.⁷¹ The discursive struggles endemic to administrative justice organisations are particularly evident in periods of flux;⁷² and whilst the exercise of discretionary power may have positive and creative impact when properly used,⁷³ oppressive structures, such as a welfare system that assumes dependency, have capacity to maintain and reproduce themselves through 'the myriad power relationships in everyday life'.⁷⁴ It is here at administrative level that these power relationships come most sharply into focus, both within and between organisations, and between organisations and their service users.

Consider, for instance, the conduct of the local authority in the *Neary* case.⁷⁵ Deprivation of Liberty Safeguards (DOLS) under the Mental Capacity Act 2005 were introduced in response to the European Court of Human Rights' ruling in *Bournewood*,⁷⁶ specifically to protect the right of individuals not to be arbitrarily detained, and to put in place rights to advocacy and review.⁷⁷ Hillingdon LBC, however, used a sequence of DOLS for precisely opposite ends: to prevent Stephen Leary's return home to the care of his father, and to extend his detention, potentially indefinitely. Although the actions of the Council were recognised by the judge as arising from misjudgement rather than from lack of commitment,⁷⁸ they read as a catalogue of oppressive misuse of administrative discretionary power.⁷⁹

In *Neary*, the judge recognised within the Council 'a disorganised situation where nobody was truly in charge and it was consequently possible for

⁷¹ Hodgkins SL, 'Discoursing Disability: the Personal and Political Positioning of Disabled People in Talk and Textwork', PhD Thesis, University of Northampton, September 2008

⁷² Adler (2011) 338-9

⁷³ Davis (1969)

⁷⁴ Charlton (2000) Chapter 3

⁷⁵ *London Borough of Hillingdon v Steven Neary, Mark Neary and the Equality and Human Rights Commission* [2011] EWHC 1377 (COP) 9 June 2011. See Chapter 9 below for further discussion.

⁷⁶ *R (L) v Bournewood Community and Mental Health NHS Trust* (1998) UKHL 24 ; *HL v United Kingdom* 45508/99 (2004) EHRR 471

⁷⁷ See further Chapter 9 below

⁷⁸ *Neary* para 16

⁷⁹ See Davis (1969), and 'decision-making', above

nobody to take responsibility'⁸⁰ - a situation allowing wide scope for use or misuse of discretionary power, and which continued even when the Council's actions were under strong and public challenge. The authority's true position was kept from Stephen Neary's father from the start,⁸¹ its tactic being rather to manage and to resist his opposition.⁸² Hillingdon's approach became increasingly adversarial: life-changing professional decisions were withheld from Mr Neary, possibly to avoid further challenge;⁸³ evidence of Steven's unhappiness was misinterpreted as justifying detention, his psychologist's opinion curtailed,⁸⁴ and the validity of his father's data undermined,⁸⁵ and Mr Neary's objections were omitted from administrative reports.⁸⁶ When court action became a possibility, 'a clear decision was taken not to allow Mr Neary to demonstrate that he could look after Steven at home with support';⁸⁷ reinstatement of Steven's support package was refused;⁸⁸ and a psychologist's report unfavourable to Hillingdon's position was deliberately withheld for six weeks.⁸⁹ It took the Council a further two months to action its decision to make an 'extraordinarily wide-ranging'⁹⁰ application to the Court

⁸⁰ *Neary* para 33(2)

⁸¹ *Ibid* para 46

⁸² *"There is always going to be something or other that Mr Neary will bring up and more often than not we are having to appease his needs rather than Steven's, however I want Steven to remain at [the support unit]..."**ibid* para 56

⁸³ *Ibid* para 57

⁸⁴ *Ibid* para 77: 'These letters hardly provided a neutral summary of events as a basis for professional advice.' Para 80: 'The social worker sent an immediate e-mail to a psychologist who had been asked to assess Steven, marked "confidential" and emphasising **"Mr Neary is unaware that we may need to keep Steven at [the support unit] or a place similar and he's not to be informed of this possibility."** The psychologist duly reported that Steven lacks capacity to decide things for himself.' (original emphasis)

⁸⁵ *Ibid* paras 58 and 59

⁸⁶ *Ibid* para 60

⁸⁷ *Ibid* para 112

⁸⁸ *Ibid* para 146

⁸⁹ *Ibid* para 114

⁹⁰ *Ibid* para 122: It asked for the following orders: 1. a declaration that Steven Neary lacks the mental capacity to decide where he should live and what contact he should have with his family. 2. a declaration that it is lawful for Hillingdon Council to place Steven Neary in appropriate residential accommodation identified by the council and to make arrangements for Steven to be detained and restrained in such accommodation. 3. A declaration that it is in the best interests of Steven for contact between Steven and his parents Mr and Mrs Neary to be supervised and at the discretion of Hillingdon Council. 4. A declaration that it is lawful for Hillingdon Council to make arrangements for the supervision and restraint of Steven when he is in the community and this will include when Steven visits the homes of Mr or Mrs Neary. 5. Permission to Hillingdon Council to commission experts to assess Steven regarding the identification of the triggers and assaulting others. (*sic*) 6. A declaration that it is lawful for Hillingdon Council to make long-term welfare decisions regarding the future care

of Protection. On the eve of the hearing, the Council circulated a 'sorry document, full of contentious and inaccurate information, and creating a particularly unfair and negative picture of Steven and his behaviour.'⁹¹

Hillingdon's response to the Neary family's request for assistance illustrates the potential for oppressive structures to 'maintain and reproduce themselves through the myriad power relationships in everyday life'.⁹² As the judge describes, the Council

acted as if it had the right to make decisions about Steven, and by a combination of turning a deaf ear and force majeure, it tried to wear down Mr Neary's resistance, stretching its relationship with him almost to breaking point.⁹³

Of course, not all local authorities respond in this way. Indeed, until the events leading to this judgement, the relationship between the Neary family and Hillingdon LBC had been positive, with the Council providing 'extremely high levels of support... as part of a genuinely cooperative partnership with the family'.⁹⁴ There are many examples of good practice from around the country where such partnerships succeed in producing emancipatory outcomes.⁹⁵ However, it must also be borne in mind that, as Davis identifies, 'a startlingly high proportion of all official discretionary action pertaining to administration of justice is illegal or of doubtful legality',⁹⁶ and that the number of judicial review challenges is infinitesimal compared with the scale of administrative decision-making as a whole. Moreover, challenging such oppressive behaviour, particularly by those directly affected, requires high levels of articulateness, physical stamina and psycho-emotional strength: not

and residence of Steven Neary. 7. Orders regarding the disclosure of information and images relating to Steven and others particularly on social network sites.

⁹¹ For which it later apologised; *Neary* para 7

⁹² Charlton (2000) Chapter 3

⁹³ *Neary* para 27

⁹⁴ *Ibid* para 5

⁹⁵ See for instance Social Care Institute for Excellence videos:

<http://www.scie.org.uk/socialcaretv/latest.asp>; Oxfordshire County Council videos: <http://www.takingcontroloxon.org.uk/wps/wcm/connect/occ/Taking+control/Home/Video+library/>, both accessed 16.9.12

⁹⁶ Davis (1969) 12

everyone has Mr Neary's perseverance.⁹⁷ As Jackson J remarks, Hillingdon's approach

might actually have succeeded, with a lesser parent than Mr Neary giving up in the face of such official determination. Had that happened, Steven would have faced a life in public care that he did not want and does not need⁹⁸

in direct contravention of CRPD Article 19.

Examples of the kinds of individual and organisational understandings of power relationships described above can also be found sedimented in administrative decision-making systems.

Systems⁹⁹

CRPD Article 19 services are accessed through a community care assessment. Under s47 NHSCCA,¹⁰⁰ each local authority has discretion, within national guidance,¹⁰¹ as to the manner in which assessment is carried out, how eligibility criteria are applied, and whether, and how much, service-users will be charged. Each is also free to design its own assessment questionnaire. The questionnaire will guide the first component of the assessment process: the gathering of information about the person's 'community care needs' so that a decision on eligibility can be made. It will thus shape assessment and resource allocation. How the questionnaire is framed will also shape the assessment experience, both for the care assessor and for the potential service-user. That experience, again, may be

⁹⁷ See, for instance Runswick-Cole, K 'The Tribunal was the most stressful thing: more stressful than my son's diagnosis or behaviour': the experiences of families who go to the Special Educational Needs and Disability Tribunal (SENDisT) (2007) 22(3) Disability & Society 315; Hurstfield *et al*, 'Monitoring the Disability Discrimination Act (DDA) Phase 3', Disability Rights Commission, 2004

⁹⁸ *Neary* para 28

⁹⁹ This section draws on a presentation given by the writer at the 2010 Disability Studies Conference: Collingbourne T, 'Administrative Justice? Realising the Right to Independent Living' (2010) Disability Studies Conference, Lancaster University, 9 September 2010

¹⁰⁰ See Chapter 7 above

¹⁰¹ Department of Health 'Fair Access to Care Services' LAC (2002) 13

Department of Health 'Fair Access to Care Services: guidance for eligibility criteria for adult social care' 2003; Department of Health 'Prioritising Need in the Context of Putting People First: a whole system approach to eligibility for social care – guidance on eligibility criteria for adult social care, England 2010' (2010) Gateway ref 13729

emancipatory or oppressive, as illustrated by the following comparison between two assessment questionnaires produced in response to the 'personalisation' agenda.¹⁰²

The Association of Directors of Adult Social Services (ADASS) has designed a 'Personal Needs Questionnaire' which, it suggests, might be used by councils as a tool for resource allocation.¹⁰³ According to ADASS, this questionnaire is based on principles of partnership, citizenship, the social model of disability, and the respectful, dignified and simple use of language; it is designed to be outcome-focussed, fair, transparent and sustainable.¹⁰⁴

The front page explains that:

The aim of the questionnaire is to give an indication of how much money you may need to live your life as an equal citizen and achieve some or all of these general outcomes:

1. to stay healthy, safe and well
2. to have the best possible quality of life, including life with other family members, if this is what you choose
3. to participate as an active citizen, increasing independence where possible
4. to have maximum choice and control
5. to live your life safely, free from discrimination or harassment
6. to achieve economic well-being and have access to work and/or benefits if you choose to do so
7. to keep your personal dignity and be respected by others.

Although there is no reference here to the CRPD, these outcomes mirror the Convention's central principles of respect for dignity, autonomy and independence, of non-discrimination, participation and choice, as well as

¹⁰² See Appendix 2 for full copies of both forms.

¹⁰³ ADASS, Common Resource Allocation Framework, updated June 2010, www.puttingpeoplefirst.org.uk/Topics/Latest/Resource/?cid=6376& accessed 3.8.10

¹⁰⁴ Ibid 8

some key Convention articles,¹⁰⁵ including socio-economic rights and Article 19.

The front page also seeks to reassure the person concerned that this questionnaire is only a guide - the next stage will be to plan the support needed together - and that all information will be kept confidential. The individual is thus encouraged to take part in the assessment process without fear of undue risk. This is followed by 12 pages of short statements, clearly set out under those 'outcome' headings, for the person and/or the assessor to tick as appropriate. There are just 4 or 5 statements per page, with plenty of space around them. They include, for instance,

- 2.1.d I always need support to keep myself safe
- 4.c I often need support to make decisions and organise my life
- 5.e I want to be part of my community and regularly need a lot of support to do this
- 6.b I need occasional support with my parenting role
- 9.1.d I always need support to manage my actions

An unpaid carer providing support is also asked about the effects of caring on their daily life, ranging from

- 11.1.a It causes me no concern in my daily life

to

- 11.1.d It has a critical impact on my daily life and affects my health and well-being

This form comes across as accessible, positive and empowering. It focuses on the support required to achieve independence, choice and control – in line with CRPD Article 19 - and to respect dignity and social relationships. Production of the questionnaire is informed by understandings of emancipation, co-production and shared expertise, in line with Adler's consumerist/participatory model of administration, and with CRPD

¹⁰⁵ Such as Article 15 freedom from exploitation, violence and abuse; Article 25 right to health; Article 23 respect for home and family; Article 27 work and employment; Article 28 adequate standard of living; Article 29 participation in political and public life; and Article 30 participation in cultural life, recreation, leisure and sport.

requirements for the active involvement of disabled people in the decisions that relate to them.¹⁰⁶

However, this questionnaire is not mandatory, and is not being used by at least one of the Councils involved in piloting the new 'personalised' service delivery. This Council has developed a form of its own, headed, in the old style, as a 'Community Care Assessment'. The form runs to 23 pages, under 16 headings such as 'memory', 'feelings and behaviour', 'social functioning', 'cooking', 'eating' and 'housework', and so on. Under each heading, it asks the person (or assessor on their behalf) to tick the phrase that best describes themselves. One page may include up to 15 questions to tick or not tick. They include, *inter alia*:¹⁰⁷

B2.a.3 I need assistance to make even the simplest day to day decisions and plans. Decisions are consistently poor and unsafe & support is needed at all times.

E3.a I have been found wandering about for no apparent reason, or, I can suddenly 'bolt' and run away

E3.d I have been told my behaviour in public has been causing concern and is thought to be inappropriate

E1.f People are concerned that I look unhappy or worried

and

E3.e I have been resisting care

By signing the form, the individual gives consent to their information being 'shared with professionals in other organisations, such as health services, housing services or voluntary organisations' – they thus abdicate control of that often very personal knowledge.¹⁰⁸ The back page contains a table of

¹⁰⁶ See CRPD Article 4(3) and Part 1 above

¹⁰⁷ Both questionnaires can be found in full in Appendix 2

¹⁰⁸ Though with some provisos: the consent form allows for withdrawal of permission at any time, and continues: 'I am aware that I can say if there is any particular organization, or person, that I do not want to see my information, and that you will not share this information without me knowing about this or agreeing to this.' The general tenor of this questionnaire, however, does not invite confidence that such reservations would be made, honoured or enforced

eligibility needs that clearly shows that the Council will only fund needs that come into the critical or substantial criteria bands.

This questionnaire is strongly informed by managerial (efficiency) / professional (we know best), models of administrative justice. It offers no acknowledgement of or respect for the individual's autonomy or dignity, no understanding of or reference to equality, participation or choice. Moreover, this form is based in medical model understandings of disability. It focuses on individual functioning, or 'mal-functioning': the failure to function 'normally'. In filling in the form, not only does the person have to accept that '*dis*-abled', excluded, 'less' identity,¹⁰⁹ they have to repeatedly argue in its favour in order to qualify for support. Some of the questions require them to reinforce that experience by reporting the negative attitudes of others towards them. This exclusionary process is further highlighted by the concept of 'resisting care.' Here we see blatant evidence of the questionnaire-writer's view of relations of power between service provider and individual: 'care' is not something which is mutually agreed between equals, but is determined and imposed by the service provider. Resistance by the individual constitutes negative behaviour to be controlled and disciplined.¹¹⁰

These two forms exemplify the potential both for emancipatory and for oppressive regulation within the 'transformation' process. The first presents as accessible and positive, focusing on emancipatory outcomes; the second as threatening, complicated and confusing, focusing on oppressive 'mal-function', exclusion and discipline of the individual. Their comparison illustrates something of the opportunities and challenges for CRPD discourse as it enters the administrative justice field. Different people or organisational cultures may internalise and translate the same requirements in widely differing ways, to widely differing effect. The 'socialisation' of individuals

¹⁰⁹ See Chapter 2 above

¹¹⁰ See also discussion of disciplinary practices in the context of disability benefit administration in Shildrick M and Price J 'Breaking the Boundaries of the Broken Body' (1996) 2(4) *Body & Society* 93, 99-107; Jolly D 'The Government of Disability: economics and power in welfare and work' (2003) 18(4) *Disability & Society* 509

required for reconstruction of our world in line with CRPD understandings is not yet fully accomplished in this arena.

Once completed, however, whichever form is used, it will be 'marked'. Eligibility criteria will be applied. The ticks will be allotted a numerical value and entered into a computerised Resource Allocation System. This will produce a percentage, which will be converted into a sum of money. The calculation will vary from one local authority to another, in line with their resources. So we return abruptly from the logic of choice and consumer participation to the logic of administrative justice, with its dominant discourse of bureaucratic justice, and its liberal understandings of equity and fairness in the allocation of limited resources. As Clarke *et al* conclude, 'something always stands between choice and outcome',¹¹¹ including, inevitably, the question of resources.¹¹²

Questionnaires such as those described above form the basis for face-to-face¹¹³ meetings between the care assessor and the individual. How they are framed, the understandings they reflect, the structures they impose, and the relationships they engender are key to the assessment experience, for both participants. How that interaction proceeds will both reflect and shape the identities of all concerned.¹¹⁴

Identities

We have seen how oppressive assumptions rooted in the discourse of 'normality' exclude the *dis*-abled individual, negating their identity; and how individuals internalise and respond to such exclusion in various ways, from

¹¹¹ Clarke *et al* (2010) 42

¹¹² This thesis has consciously avoided discussion of resources as being a major topic worthy of a separate, different study. However, the topic is touched on in Chapter 6 in discussion of dislocation, and in the Postscript in examination of the Government's 2012 'progress report' on funding reform.

¹¹³ Or sometimes telephone

¹¹⁴ See for instance Goodley (2010) Chapter 6: 'Un/conscious selves and subjectivities are manufactured through our inter-action with others.' 85

denial to open confrontation, self-blame or resignation.¹¹⁵ Disability studies researchers have developed a range of analytical positions¹¹⁶ which ‘focus on the psychological anxieties and distresses caused by the social relations of disability.’¹¹⁷ Goodley’s review of this literature¹¹⁸ describes the emotional labour of being a ‘good crip’ in the face of ‘everyday, mundane and relentless examples of cultural and relational violence’¹¹⁹ – when the self has to act in ways that fit the expectations of others; and the experience of ‘corpsing’, or freezing,¹²⁰ when those expectations demand too much. Coping with the daily indignities of exclusion is described as ‘psychologically draining’;¹²¹ and living in a hostile world as potentially leading to profound consequences, with repression of the pain of rejection manifesting in emotional self-invalidation and, at worst, self-harm.¹²² Here, we re-join Carol Thomas’s identification of the

negative social reaction to biological, cognitive, sensory or psychological difference [as] a form of social oppression involving... the socially engendered undermining of [disabled people’s] psycho-emotional well-being.¹²³

In this context, the process of assessment may be anticipated or experienced by the disabled individual as just one more highly intrusive and

¹¹⁵ See Chapter 1 above

¹¹⁶ See Goodley (2010) Table 6.1, 86

¹¹⁷ Reeve D, ‘Negotiation disability in everyday life: the experience of psycho-emotional disability’, unpublished PhD thesis, University of Lancaster 2008, 53, quoted in Goodley (2010) 86

¹¹⁸ Goodley (2010) Chapter 6

¹¹⁹ See for instance Equality and Human Rights Commission, ‘Hidden in Plain Sight: Inquiry into Disability-Related Harassment’ (EHRC 2011)

¹²⁰ ‘where the social actor fails to maintain the management of their emotional labour and the illusion of stability.’ Goodley (2010) 92

¹²¹ ‘Now, you might need to decide if you want to insist on a comfortable table in a good location instead of being relegated to a spot near the kitchen door. Sometimes, when all you want is a good night out such things are not worth the battle. We have to choose our battles.’ Perreault, 2004, quoted in Goodley (2010) 92

¹²² Goodley (2010) 97; see also Maynard-Campbell, Sue, and Maynard-Lupton, Alice, ‘Bureaucratic Barriers to Normal Day-to-Day Activity’, MusclePower! 2000, available on Leeds Disability Studies Archive <http://www.leeds.ac.uk/disability-studies/archiveuk/> for examples of individual experiences including ‘giving up’; also, for example, the case of Fiona Pilkington <http://www.guardian.co.uk/uk/2011/may/24/fiona-pilkington-police-misconduct-proceedings> accessed 6.8.11

¹²³ See Chapter 1 above; see also for instance Speed E, ‘Patients, consumers and survivors: A case study of mental health service users discourses’ (2006) 62 *Social Science and Medicine*, 28

psychologically draining demand required to meet the expectations of service providers, with all the range of psycho-emotional responses that entails.

It is also an experience that is likely to recur. The Life Chances Report describes the experience of a 24-year-old wheel chair user moving into her first flat and starting her new job. In the first year she has to deal with six different assessments: for a wheelchair, for support at work, for adaptations to her flat, for social services support and the Independent living Fund, and for her liability to make financial contributions towards these services.¹²⁴ Each of these assessments, along with any relating to social security entitlement or health care, is likely to be periodically reviewed, and will be further reviewed if her circumstances change. Moreover, it is likely that the practitioners conducting each assessment will change over time, requiring new explanations and new relationships to be made. In some circumstances, such as discharge from hospital, the assessment may be 'multi-disciplinary', requiring the individual to deal with a range of different professionals at once. In these situations, one or more bad experiences may feed into the individual's anticipation of and response to the next assessment, potentially building into a highly oppressive overall effect on identity and psycho-social wellbeing.¹²⁵ Current work on 'personalisation' recognises some of these concerns.¹²⁶

¹²⁴Prime Minister's Strategy Unit, 'Improving the Life Chances of Disabled People', January 2005, 49; see also Maynard-Campbell (2000)

¹²⁵ See for instance Maynard-Campbell (2000); Genn H, *Paths to Justice: what people do and think about going to law* (Hart 1999); Pleasance *et al*, *Causes of Action: civil Law and Social Justice*, 2nd ed (Legal Services Commission, 2006); Pleasance P, Buck A, Balmer N (eds) *Transforming Lives: law and social process* (Legal Services Commission 2007). O'Grady A, Pleasance P, Balmer NJ, Buck A and Genn H, 'Disability, social exclusion and the consequential experience of justiciable problems' (2004) 19(3) *Disability & Society* 259 See also Strathclyde Centre for Disability Research and Glasgow Media Unit, in association with Inclusion London, 'Bad News for Disabled People: How the newspapers are reporting disability', University of Glasgow, 2011

¹²⁶ 'As local authorities gear up to make personal budgets available to more and more people who use services, they need to find ways to keep the personal budget process 'personal'. With high workloads and resource constraints this is easy to say and very difficult to do. There may, however, be a number of steps which can be taken to avoid the personal budgets becoming 'bureaucratized'. Perhaps the first is acknowledging the very central place of the relationship between personal budget holders and their social care practitioner or care-coordinator. This human factor cannot be underestimated, and so giving staff support, training and time to work with personal budget holders properly is crucial...' Social Care Institute for Excellence, 'Keeping personal budgets personal: learning from the

Another contributing factor to the potentially oppressive nature of the assessment relationship is unlikely to disappear, however 'properly' the assessment is conducted: the possibility that assessment or review will result in refusal, reduction or withdrawal of the assistance the individual requires for his or her daily functioning. For instance, Mr Neary found relations with his social worker 'quite awkward' since the idea of review of Steven's support package was brought up:

this fear remained "*tattooed on [his] brain*" and from that point on he was worried about the consequences of rocking the boat. Indeed, when he finally put his foot down... and directly asked for Steven's return, Hillingdon's immediate response was that the necessary support package would not be made available. Mr Neary became understandably emotional when describing how powerless he had felt.¹²⁷ (original emphasis)

As Jackson, J comments, 'the suggestion that [Hillingdon] might withdraw its support for Steven at home was always likely to have a chilling effect.'¹²⁸ Moreover, such 'chilling' responses may not be confined to dispute situations, but may come about in the process of 'routine' review. For example, Direct Payments may be retrospectively terminated without warning pending review of assessment, apparently without consideration for the practical or psychological implications for the service user themselves, or for their legal responsibilities towards the personal assistants they employ.¹²⁹

Beresford *et al* examine a range of research which has highlighted the qualities service users value in their interactions with social workers.¹³⁰ These include approachability, honesty, understanding, reliability, helpfulness and time to listen; respect, treating with equality and being non-judgemental. The ideal social worker would be '[s]omeone who doesn't regard you as a

experiences of older people, people with mental health problems and their carers', SCIE Report 40, February 2011

¹²⁷ Neary para 146

¹²⁸ Ibid para 155(2)

¹²⁹ Such as redundancy procedures and payments. 'Please can you call our office on the above number at your earliest convenience. Your Direct Payments ended on 01/03/2011 and this cannot be renewed until a review has taken place.' Dated 3.3.11, received 6.3.11 by individual employing several part-time personal assistants

¹³⁰ Beresford *et al* (2011) Chapter 8; see also Glynn M, Beresford P, Bewley C, Banfield F, Butt J, Croft S, Pitt KD, Fleming J, Flynn R, Parmore C, Postle K and Turner M 'Person-centred Support: what service users and practitioners say' (Joseph Rowntree Foundation 2008)

client, but treats you as an ordinary human being and trusts you.’¹³¹

According to Parton,

[t]he central message that comes across time and time again is that it is not the particular model or technique used by the social workers but the quality and value of the experience.¹³²

However, we have seen that the co-existence of logics of administrative justice with the logic of consumer choice ‘produces instabilities, dilemmas and tensions’ for providers too, with conflicting ‘conceptions of the public, of how it is to be served, and of how equality, equity, fairness or justice might be realised.’¹³³ Mr Neary’s social worker was also finding their relationship difficult, for different reasons. As the worker most closely involved in direct discussions with Mr Neary, she expressed her discomfort with Hillingdon’s deceit,¹³⁴ and eventually gave Mr Neary ‘a glimpse, but not a full view’¹³⁵ of the Council’s thinking, provoking tensions with more senior staff, who considered that they were ‘acting legally on everyone’s behalf.’¹³⁶ We see here evidence of Adler’s ‘discursive struggles’¹³⁷ reflecting the bargaining strengths and interests of Hillingdon’s institutional actors. Mr Neary complained to his MP of encountering ‘institutionalised defensive practice’, feeling ‘backed into a corner’ and ‘frozen out’.¹³⁸

Social care practitioners responding to Beresford *et al*’s ‘change and development’ inquiry into person-centred support¹³⁹ also identify tensions

¹³¹ De Winter and Noom (2003), quoted in Beresford *et al* (2011) 226

¹³² Parton N, ‘Reconsidering professional practice’ (date?) 33(1) British Journal Of Social Work 1, cited in Beresford P, Fleming J, Glynn M, Bewley C, Croft S, Branfield F and Postle K, *Supporting People: towards a person-centred approach* (Policy Press 2011) 227

¹³³ Clarke *et al* (2010) 43

¹³⁴ Neary para 87: Home visits “are taking place and Mr Neary is still of the opinion that Steven is going home, I’m aware that even though as professionals we have voiced our concerns amongst each other, we have not spoken to Mr Neary about this directly. I understand that the decision on where Steven should live is not down to us, however by not informing Mr Neary with our concerns is like saying that we are “ok” on Steven going back.”

¹³⁵ *Ibid* para 93

¹³⁶ *Ibid* para 89

¹³⁷ See above

¹³⁸ Neary para 70

¹³⁹ The Standards We Expect project aimed to: work closely with a number of local services and their users to learn ways of overcoming barriers to person-centred support; share learning about empowering approaches to support with a wider network; and explore opportunities to bring about change to the existing social care system or point to more radical reform for a better system of support. See Beresford *et al* (2011)

between 'person-centred', bureaucratic/managerial and professional demands.¹⁴⁰ They cite increasing bureaucratisation and complexity, and its effect on the nature of their relationship with the individual being assessed;¹⁴¹ and express frustration at having to meet conflicting 'top-down' indicators.¹⁴²

Beresford *et al* find that

[p]reoccupation with bureaucratic targets and other measures often conflict with the implementation of person-centred support and preventative approaches. Measures employed are frequently inconsistent with moves to more independent living.¹⁴³

Nevertheless, '[s]ome services and practitioners have sought to develop 'softer' more sensitive measures consistent with independent living',¹⁴⁴ reflecting changes in service culture which benefit service users and support them to achieve better outcomes.¹⁴⁵ Thus we see in some areas, and within some statutory organisations, potential social actor identification with, and adaptation of administrative systems towards, more CRPD-compatible understandings, though still with no explicit recognition of their basis in human rights law or principles.

¹⁴⁰ 'But the pressure does mount up at times. The admin[istrative] pressures and the organisational pressures go against you and the work you are doing with people. **Practitioner**' Beresford *et al* (2011) 192. See also Ellis K, 'Human Rights, professional practice and social care: the findings of a small scale research study' (2004) presentation to 'Disability Studies: from theory to practice' conference, University of Lancaster 26-28 July 2004

¹⁴¹ 'Forms and paperwork can become a barrier. It can take a very long time to do. I had a client who had to stop and have a Mars bar so she didn't slip into a diabetic coma while I was there, because I had been there so long. It starts to become a bit abusive! I think I should go and let these people have some lunch. **Practitioner**' Beresford *et al* (2011) 191; 'It's the lack of connection again isn't it and the lack of relationship, you know. It becomes a paper exercise... I find increasingly that my work is becoming a paper exercise. **Practitioner**' Beresford *et al* (2011) 193

¹⁴² 'One of our biggest problems is dealing with the top coming down, is performance indicators which have been set by the government and that's what's leading the service. And that's nothing to do with what individuals want – a person-centred approach. Again, we're encouraged to do reviews and assessments and things, hit targets, deadlines and things, which in our work doesn't necessarily apply. **Practitioner**'; '... indicators like how many people get intensive home care and how many people get direct payments. But then we have some, [where] the more you do of one, the less you do of others – the more home care – the less direct payments. It's like being put on the spot and told to run in two directions at the same time. You can't do it! **Practitioner**' Beresford *et al* (2011) 193

¹⁴³ Beresford *et al* (2011) 219

¹⁴⁴ *Ibid* 219-20

¹⁴⁵ 'One of the things that I feel we can improve is to promote person-centred planning and see how people are achieving good outcomes because that's *their* goals, but not the government's goal, or the actual management's goal and the only people who should be having good outcomes is the client. **Not known**' Beresford *et al* (2011) 198

One organisational space where these tensions are less evident is found in Disabled People's Organisations (DPOs) or CILs.¹⁴⁶ DPOs have long campaigned for and developed alternative approaches to delivery of service provision which offer relations of respect, equality and empowerment in place of disrespect, discipline and oppression.¹⁴⁷ Since 2005, such organisations have begun to be recognised by policy-makers as playing an important role in the realisation of independent living.¹⁴⁸ Under current policies, they have been acknowledged as offering 'very individualised solutions', and provided with additional funding.¹⁴⁹ Local authorities are encouraged to give them a 'fair and proportionate' chance to compete in the 'social market'.¹⁵⁰ Indeed, some authorities have already transferred staff or functions to user-led organisations in a spirit of co-production.¹⁵¹

There has always been tension for DPOs between acceptance of public sector¹⁵² contracts necessary for financial survival and the independence required for political activism; and between coalitions of disabled people who focus only on that activism and those who also provide services.¹⁵³ Current

¹⁴⁶ Though they are not without internal 'discursive struggles' of their own. See the work of Disability LIB, <http://www.disabilitylib.org.uk>; Barnes C, Mercer G, *Independent Futures: creating user-led disability services in a disabling society* (Policy Press 2006); *Independently*, Newsletter of NCIL (now part of Disability Rights UK); Maynard-Campbell S, Maynard A and Winchcombe M, 'Mapping the Capacity and Potential for User-Led Organisations in England: a summary of the main findings from a national research study commissioned by the Department of Health' (Equal Ability CIC 2007); Disability LIB 'Thriving or Surviving: Challenges and Opportunities for Disabled People's Organisations in the 21st Century' (Scope 2008)

¹⁴⁷ See Chapter 4 above

¹⁴⁸ See Life Chances Report, and Chapter 6 above

¹⁴⁹ As was noted in Chapter 6 above, DPULO's have long struggled for financial survival. The Strengthening DPULO Programme was launched in July 2011, and by May 2012, more than half a million pounds had been paid out. <http://www.dwp.gov.uk/newsroom/press-releases/2012/may-2012/dwp056-12.shtml> accessed 6.8.12

¹⁵⁰ Coalition 'Vision for Adult Social Care': see Chapter 6 above

¹⁵¹ See 'discretionary power', above; also Social Care Institute for Excellence, 'A Commissioner's Guide to Developing and Sustaining User-led Organisations' SCIE Guide 36 <http://www.scie.org.uk/publications/guides/guide36/> last accessed 16.9.12

¹⁵² Some DPOs still function from premises within hospital settings, some from social services departments. Barnes C and Mercer G, *Independent Futures: creating user-led disability services in a disabling society* (Policy Press 2006) 110

¹⁵³ See Rachel Hurst in Chapter 2 above: 'This is very important. It was not about getting services... It was purely and simply as an organisation which reflected the voice of disabled people and supported rights and equalisation of opportunities.'

government policies thus present both opportunities and threats to this widely varied group of organisations.¹⁵⁴ Barnes and Mercer identify that

for organisations of disabled people, user involvement risks being turned into an exercise to give legitimacy to budget-driven service reforms rather than a means of recognising disabled people's rights as service users.¹⁵⁵

Just as the expansion of CRPD-compatible understandings depends on disabled people maintaining their hold on the meaning of 'independent living', so also the extent to which DPOs succeed in countering this threat to their established role in the current economic and political climate will help to determine the application of those understandings in practice. If CRPD Articles 4(3) and 33(3) are to be realised, they must undoubtedly play a central role.

Conclusion

Disabled people are more likely than others to experience the kinds of problems which bring them into contact with the administrative justice system. How that system responds to those problems will have a substantial impact on their Article 19 rights, and therefore on realisation of all Convention rights. This Chapter has examined administrative decision-making in the field of independent living. It has considered varying models of administrative justice identified by Davies, Mashaw and Adler, with their modes of decision-making, legitimating goals and modes of accountability; and has explored how these varying models might respond to concepts of 'personalisation' and choice. A dynamic discursive field is revealed,

¹⁵⁴ 'Thriving or Surviving: Challenges and Opportunities for Disabled People's Organisations in the 21st Century', published by Scope on behalf of Disability LIB Alliance, February 2008; Barnes and Mercer (2006)

¹⁵⁵ Barnes and Mercer (2006) 94; see also Barnes C, 'Disability Activism and the Price of Success: A British Experience' (2007) 1(2) *Intersticios: Revista Sociológica de Pensamiento Critico* 15: 'The success of the disabled people's movement in bringing disability issues and independent living on to the mainstream political agenda is a major achievement. But that achievement inevitably results in incorporation. Whilst this is to some degree unavoidable it is also the case that incorporation more often than not results in neutralisation. This is the opposite of what is needed...' 27; see also Disability LIB 'Comprehensive Spending Review: what it will mean for DPOs' (Disability LIB 2010)

influenced not only by external and contextual factors, but also by the concerns, interests and bargaining strengths of institutional actors. Moreover, tensions between competing models are particularly evident in periods of flux, such as the current transformation of adult social care delivery. Concepts of personalisation and choice challenge traditional power relationships, whilst potentially leading to frustration for service users and further instabilities and dilemmas for service providers. It has been argued here that CRPD understandings demand more: that realisation of the Article 19 right to live independently and be included in the community requires recognition of the durable nature of the economic, social and cultural rights necessary for its exercise, and their equal implementation in practice.¹⁵⁶ As O'Grady *et al* conclude, 'a systematic change in direction at the wider, societal, level is... required.'¹⁵⁷

We have seen in previous Chapters that the CRPD-drafters' rights-based understandings of independent living have encountered antagonism, re-articulation, dislocation and regression in the domestic field of meaning; that the legal dimension of independent living discourse in England provides a partial and unstable base for bringing about its 'deep reconstruction' of the world; and that the CRPD itself, Article 19 and the economic, social and cultural rights essential for their realisation remain largely invisible in domestic discourse. Administrative decision-makers function within these discursive surroundings, as well as within their own institutional settings and subject positions. Nevertheless, if emancipatory CRPD discourse is to expand its hegemony in the 'small places' where human rights begin,¹⁵⁸ it must bring about the 'socialisation' of those individual players and institutions to align their practice with meaningful, Convention-compliant change. Only then will the administrative justice system offer a fertile space for expansion of the Convention-drafters' project. As Leandro Despouy recognised in 1993,

[i]t might appear elementary to point out that persons with disabilities are human beings – as human as, and usually even more human than, the rest. The daily effort to overcome impediments and the

¹⁵⁶ See Ms Bras Gomes, Chapter 5 above

¹⁵⁷ O'Grady *et al* (2004) 271

¹⁵⁸ Eleanor Roosevelt, see Introduction above

discriminatory treatment they regularly receive usually provides them with special personality features, the most obvious and common of which are integrity, perseverance and a deep spirit of comprehension and patience in the face of a lack of understanding and intolerance. However, this last feature should not lead us to overlook the fact that as subjects of law they enjoy all the legal attributes inherent in human beings and hold specific rights in addition.¹⁵⁹

Individuals working in administrative decision-making exercise discretionary power. The various models of administrative justice discussed above seek to structure the use of that power and to 'provide arguments for the acceptability'¹⁶⁰ of their decisions. Examination of some examples of the exercise of discretionary power helps to gauge the extent of 'socialisation' or otherwise of institutions and individual players in line with the emancipatory purpose of the Convention. The *Neary* case has served to illustrate the potential for oppressive institutional power to maintain and reproduce itself through 'the myriad power relationships of everyday life', in direct contravention of Article 19. Comparison of two assessment questionnaires has demonstrated the potential for both emancipatory and oppressive systems within the 'transformation' process, tempered always through the bureaucratic logic of resource allocation. Examination of the process of assessment has traced potential for both oppressive and emancipatory experiences influencing identities of both service users and practitioners.

These brief excursions show that, despite examples of good practice, the 'socialisation' of institutions and individuals required for realisation of CRPD understandings is not yet accomplished in the field of administrative decision-making. The 'small places', where disabled people experience the interactions that affect their daily lives, continue to offer very substantial challenges for implementation of the emancipatory values of the Convention and Article 19.

Finally, in line with CRPD Article 4(3) and 33(3), it has been argued that DPOs can offer their well-established expertise in providing alternative,

¹⁵⁹ Despouy L, 'Human Rights and Disabled Persons', Human Rights Studies Series, number 6 (UN Centre for Human Rights, 1993)

¹⁶⁰ Mashaw (1983) 24

Convention-compliant, approaches to the design and delivery of services to resolve some of the tensions identified above and help to take the CRPD-drafters' hegemonic project forward.

So far, Part 2 of the thesis has shown that, in the absence from domestic discourse of economic, social and cultural rights, CRPD understandings of independent living face re-articulation, dislocation and regression; legislative developments promise, at best, a partial and unstable base for the development of compatible systems of social relations; and administrative decision-making continues to oppress many of those it purports to serve. The development of CRPD-compatible understandings and systems, and the 'socialisation' of organisations and individuals in line with Convention values are thus frustrated. **Chapter 10** will offer some recommendations to government on how to address these mis- and partial understandings of the law and its consequent mis- and partial implementation. First, however, **Chapter 9** considers whether existing redress systems might help to redefine the terms of the debate. As the economic, social and cultural rights set out in Article 19 are understood in England not as rights, but as 'welfare entitlements' in the gift – or denial – of the State, their enforcement lies through a range of political and administrative channels.¹⁶¹ Potential for these systems to influence the domestic debate towards a new, Convention-compatible, agenda is explored next.

¹⁶¹ See Chapter 5 above, and UK Fifth Report to Economic, Social and Cultural Rights Committee

Chapter 9

Independent Living in England: Redress

Introduction

To recapitulate, States Parties are the primary duty-holders under the CRPD. They deliver their international law obligations through domestic policy, law and administration. How they do so will be shaped by the constellations of power and knowledge already circulating in their national arenas. Whether, or to what extent, the hegemonic project of the CRPD drafters succeeds in setting a new agenda will therefore depend on those domestic discourses in each ratifying State.

Part 2 of this thesis has found that successive UK governments have rejected the international discourse of economic, social and cultural rights, choosing instead to re-articulate them as welfare entitlements. This failure to make the transition in understanding from 'welfare' to 'rights' has put in question domestic reception of the disability/human rights myth and thus implementation of the CRPD. Taking Article 19 as case study, Chapters 6 to 8 have found that, without the protection of an economic, social and cultural rights framework, understandings of independent living in England face re-articulation and dislocation resulting in threat of regression; welfare-based legislation provides a partial and unstable base for reconstruction; and the administrative decision-making process through which policy and law are delivered to individuals continues, despite pockets of good practice, to oppress many of those it purports to serve. In this national arena, therefore, the CRPD drafters' hegemonic project faces considerable challenge to its mission to bring about the 'deep reconstruction' required by the Convention.

The administrative justice system comprises not only decision-making, but also ‘the mechanisms available for the provision of redress.’¹ Despite the UN Committee’s disapproval, it is on these procedures that the UK relies for enforcement of its international economic, social and cultural rights obligations.² This Chapter explores the capacity of such mechanisms to influence policy, law and practice towards more CRPD-compatible understandings.

An individual dissatisfied with a local authority social services decision has a number of possible options for seeking redress.³ They are:

- the local authority complaints procedure
- their local councillor or MP
- the default powers of the Secretary of State
- complaint to the Local Government Ombudsman
- judicial review
- action for damages

Action for damages is likely to apply only in a small number of specific cases, and is unlikely to be successful.⁴ The default powers of the Secretary of State⁵ have never been used, although, as Disability Alliance suggests, a letter to the Department of Health alleging that the local authority has failed to comply with its statutory community care duties may prompt that authority to review its actions.⁶ A similar response may result from contact with the local councillor or MP, or from threat of judicial review or complaint to the Ombudsman. Formal complaints, however, are generally channelled through local authority complaints procedures: it is normally necessary to exhaust this

¹ Nuffield 2007

² See Chapter 5 above

³ See also Clements L, *Community Care and the Law*, 5th ed (Legal Action Group 2012) chapter 19; Greaves I, *Disability Rights Handbook: April 2011-April 2012* (Disability Alliance 2011)

⁴ Disability Law Service ‘English Social Services Complaint Procedure’ www.dls.org.uk accessed 6.2.12

⁵ Under the Local Authority Social Services Act 1970 s7D: (1) If the Secretary of State is satisfied that any local authority has failed, without reasonable excuse, to comply with any of their duties which are social services functions... he may make an order declaring that authority to be in default with respect to the duty in question....

⁶ Greaves (2011)

internal process before complaining to the Ombudsman or applying for judicial review. While human rights issues may be raised at any level,⁷ legally binding human rights decisions in this field are confined to judicial review.⁸

This Chapter explores the contributions of local authority complaints procedures, judicial review, and the Local Government (LGO) and Parliamentary and Health Service Ombudsmen (PHSO) to potential development of more CRPD-compatible domestic discourse.

Local Authority Complaints

Public sector complaints procedures came about, at least in part,⁹ in response to the 'Citizens' Charter' discourse of the early 1990s. Individuals were seen as entitled to explanations, or apologies, when services went wrong, and service providers were expected to take action to put problems right. In Adler's terms,¹⁰ complaints draw on a 'co-production/consumerist' approach, to the extent that they involve, and give 'voice' to, the service user, and a 'bureaucratic/managerial' approach, as their ostensible aim is to improve service quality: they do not provide an opportunity to appeal against the merits of a local authority decision. However, research has consistently suggested that even these limited administrative objectives have not been effectively met.

Most people who are dissatisfied with decisions do not make a complaint, even if they want to.¹¹ There are many reasons for this, identified, *inter alia*,

⁷ Although each local authority must include complaints statistics in Annual Reports, there is no requirement to disaggregate statistics by category or content, such as human rights issues

⁸ But see below for discussion of the Ombudsman's approach to human rights implementation

⁹ For early work on complaints procedures, see for instance Birkinshaw P, *Grievances, Remedies and the State* (Sweet & Maxwell 1985); Seneviratne M, Cracknell S, 'Consumer Complaints in Public Sector Services' (1988) 66(2) *Public Administration* 181

¹⁰ See Chapter 8 above

¹¹ Preston-Shoot M, 'A Triumph of Hope over Experience? Accountability: the Case of Complaints Procedures in Community Care' (2001) 35(6) *Social Policy and Administration* 701; see also National Audit Office 'Feeding Back? Learning from complaints handling in

by Genn,¹² Pleasence *et al*,¹³ and others.¹⁴ Users of social services are not 'willing consumers' who can 'exit' if dissatisfied; they may have no access to information¹⁵ or to independent advice or advocacy;¹⁶ they may fear victimisation, or reduction or withdrawal of services; they may feel that there is no point in making complaints;¹⁷ or may simply be too exhausted, discouraged or 'psychologically drained'¹⁸ – or, in the worst cases, intimidated¹⁹ – to do so. Moreover, the care provider or local authority may simply fail to respond, effectively blocking the complaint from entering the system.²⁰

The four research studies discussed by Preston-Shoot find that people rarely feel sufficiently 'safe and encouraged' to exercise their 'right' to complain.²¹ Indeed, one might surmise that the more serious the potential complaint, the less likely the complainant may be to feel 'safe and encouraged' to complain. On the other hand, a minority feel empowered by using administrative redress procedures to 'stand up for themselves' or their relatives,²²

health and social care', HC835, session 2007-2008, 10 October 2008, Executive Summary, para 7

¹² Genn (1999)

¹³ Pleasence *et al* (2006); O'Grady *et al* (2004)

¹⁴ Hurstfield *et al* (2004); Runswick-Cole (2007); Wood D 'Acting on complaints about mental health service: implications of power imbalances' (1996) 10(3) *Journal of Management in Medicine* 31; Sbaraini S and Carpenter J, 'Barriers to complaints: a survey of mental health service users' (1996) 10(6) *Journal of Management in Medicine* 36; Adler M and Gulland J, 'Tribunal Users' Experiences, Perceptions and Expectations: a literature review' (Council on Tribunals 2003)

¹⁵ 'There was a strong sense in all four [focus] groups that people did not have enough information about what they might expect to receive and that this lack of knowledge limited their ability to complain' Gulland J, 'Complaining, Appealing or Just Getting It Sorted Out': complaints procedure for community care service users', PhD thesis, University of Edinburgh, 2007, 301. Most councils now have information about their complaints procedures online, though some service users may not have access to the internet

¹⁶ See for instance Lord Chancellor's Department and Law Centres Federation 'Legal and Advice Services: a Pathway Out of Social Exclusion' (2001); Gee A and Holdsworth M (ed) 'Regeneration and Renewal: a good practice guide for London advice agencies' (London Advice Services Alliance 2002); Benson/Waterhouse Consultancy with DIAL Waltham Forest, 'Hidden Benefits: the value of DIAL advice work' (DIAL UK 2003)

¹⁷ Gulland thesis (2007) 301

¹⁸ See Chapter 8 above; and Goodley (2011)

¹⁹ Such as in situations of abuse, such as Winterbourne View: BBC Panorama 'Undercover Care: the Abuse Exposed' BBC1, Winterbourne View, Tues May 31 2011

²⁰ Local Government Ombudsman, Office for Public Management, 'Complaints about privately funded and arranged adult social care' (2011) Executive Summary 3

²¹ Preston-Shoot (2001) 703

²² See, in the context of Special Education Needs Tribunals, Runswick-Cole (2007): 'Despite the many negative aspects of pursuing a claim to the Tribunal, a minority of parents find the

demonstrating a social antagonistic challenge to the oppressive effect of negative experiences on identity and psycho-emotional wellbeing identified by Thomas.²³

Issues giving rise to complaints are many and varied. LGO research²⁴ identifies, *inter alia*, poor standards and quality of care, lack of continuity of care, staffing issues, poor communication with users or relatives, nutrition or medication, missing personal possessions and financial disputes. This research particularly highlights problems with the conduct and actions of local authorities in relation to assessment for Direct Payments.²⁵

Once complaints are made, understandings vary as to their purpose. Complainant respondents to Gulland's 2007 doctoral research study²⁶ understood the act of complaining in different ways, partly according to what they were complaining about. As noted above, the complaints procedure is not an appeal process: there is no formal right of appeal against the substance of a social services decision. Nevertheless, some respondents thought of their complaints in 'legal' terms, as appeals against decisions.²⁷ Some wanted independent, adversarial adjudication.²⁸ Others saw

process empowering, particularly in developing their advocacy skills. This sometimes has positive outcomes for the parents as they become more confident and pursue different life experiences, including career changes and advocating for others.' See also, in the context of Employment Tribunals, Hurstfield *et al* (2004); and in the context of Tribunals more generally, Adler and Gulland (2003)

²³ See Thomas (2007), Goodley (2011) and Chapter 1 above

²⁴ Local Government Ombudsman 'Complaints about privately funded and arranged adult social care' (2011) 2

²⁵ Echoing again resistance within some organisations to the logic of choice and its attendant change in power relations. See Chapters 6 and 8 above

²⁶ Gulland thesis (2007) exploring the earlier complaints procedure in Scotland. See also Gulland J, 'Complaints Procedures and Ombudsmen' in Adler M, ed, *Administrative Justice in Context* (Hart 2010)

²⁷ 'A lot of people would just think 'That's it, they've made a decision you can't do anything about it'. They don't know that they can appeal. I told them right away that I was going to appeal and I did.' Respondent, Gulland thesis (2007) 297

²⁸ 'I think there should be somebody appointed who's not beholden to social work in any shape or form... Their job is to defend people against the state if you like. ... I don't know of anybody who will fight for people's rights when the home help doesn't do her job.' Gulland *ibid* 296, quoting respondent Ian Grant; prior to their abolition with introduction of the 2009 Regulations, efforts had been made to address the lack of independence of social services complaints panels, including by moving their role to the then independent regulating body, the Commission for Social Care Inspection. See Health and Social Care (Community Health and Standards) Act 2003 for enabling provisions. See also Williams C and Ferris K, 'Proposals to Transfer Complaints Panels to the Commission for Social Care Inspection –

complaining as a way of making their 'voice' heard – a more 'consumerist' understanding.²⁹ And some, at least in part, saw it as an attempt to get the local authority to improve services for others – a more 'managerial' stance.³⁰ Ferris³¹ confirms these mixed understandings, adding as motivation the wish to have a member of staff disciplined.

By contrast, service managers or complaints officers taking part in both studies tended to focus on the 'consumerist' task of ensuring that the complainant's 'voice' was heard.³² They were less concerned with enforcing rights, and, contrary to the expectations of complainants, they did not see the complaints procedure as an effective management tool.³³ Gulland concludes that

[t]his disjunction between the views of complainants, who expect their complaints to be fed into management decision making, and staff, who do not, creates problems for the effectiveness of the procedure... The differences in perceptions between complainants and staff as to the purpose of the procedure may exacerbate people's sense of injustice.³⁴

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²⁹ 'Then this was ongoing and nobody was doing a thing, nobody was listening. So I thought 'That's it then' and then I complained.' Gulland thesis (2007) 289; As this quote suggests, complaints often have a 'history', involving long-term relationships between service user and provider and a series of incidents that culminate in a complaint: Simons K, 'I'm Not Complaining, But... Complaints procedures in social services departments' (Joseph Rowntree Foundation 1995)

³⁰ 'If something needs sorted then I'll do it. It's not just for me – there's other people out there in the same position as I was in – so it's for other people out there.' Gulland thesis (2007) 292; see also Sullivan J in *Bernard* (discussed below) at para 39.

³¹ Ferris K, 'An analysis of the complaints review panel under part III of the Children Act 1989 and NHS & Community Care Act 1990.' PhD thesis, University of Sheffield, 2006, 250

³² 'While the DCO cannot guarantee that the complainant will be satisfied with the actual outcome, they... can certainly try and make the process itself a satisfactory one.' Ferris thesis (2006) 249

³³ 'They felt that complaints were too few in number to be significant, and that if complaints raised a more general problem, they would already be aware of it.' Gulland thesis (2007) 315; 'There are clearly times when redress will be needed, but these can be reduced by learning from complaints and improving performance so that problems are tackled in the long term. The problem is that some Local Authority Areas are not doing this, as they are resolving issues on an individual basis and not tackling the underlying causes. There is a danger that by having a complaints procedure they may inadvertently become complacent, thinking that they are doing all they can.' Ferris thesis (2006) 266. See also Phelps L and Williams A, 'The Pain of Complaining: CAB ICAS Evidence of the NHS Complaints Procedure' (Heswell Citizens Advice Bureau 2005); Centre for Public Scrutiny and Local Government Ombudsman, 'Aiming for the Best: using lessons from complaints to improve public services', July 2011, <http://www.lgo.org.uk/publications/advice-and-guidance#focus> accessed 15.1.12

³⁴ Gulland thesis (2007) 315-6

Ferris agrees that

[i]t is therefore of the utmost importance that... the DCO [Designated Complaints Officer] clarify the outcomes that the complainant is hoping to achieve.³⁵

Perhaps partly because expectations are so confused and potentially conflicting, and partly because of the instabilities and tensions underlying power relationships,³⁶ complaints can also exacerbate relations between complainant and provider. While some complainants appear to see the social services department as a 'mysterious bureaucracy' making arbitrary decisions,³⁷ they may themselves be seen negatively by managers as 'serial complainers... who are looking to take it as far as they can, for a range of reasons.'³⁸ These tensions can sometimes give rise to overtly oppressive behaviour, such as transfer of 'blame' to the complainant.³⁹ When combined with difficulties for the complainant in navigating the complaints process,⁴⁰ and the frequent lack of availability of independent advice and advocacy,⁴¹ such defensive response can defeat all but the most articulate and persistent.⁴² As LGO research confirms,

[m]aking a complaint can be a difficult and daunting experience, which impacts on complainants' emotions, health and wellbeing. Some complaints [take] years to resolve.⁴³

³⁵ Ferris thesis (2006) 249

³⁶ See Clarke *et al*, Chapter 8 above

³⁷ Gulland thesis 301

³⁸ Social work manager respondent to Gulland thesis, 303

³⁹ See National Audit Office (2008) para 11; Local Government Ombudsman 'Complaints about privately funded and arranged adult social care' (2011) 4: 'The research identified many examples of poor practice in complaints handling. These can be summarised as: failure to 'take on' the complaint; poor communication with the complainant; complainant experiencing negative repercussions as a result of complaining; failure to investigate/weak investigation; shunting of responsibility/lack of liaison with more than one organisation involved; lack of timescale/delays; lack of follow up/implementation of agreed actions resulting from complaint'

⁴⁰ National Audit Office (2008), Executive Summary, para 8; Abraham A, 'The Parliamentary Ombudsman and Administrative Justice: shaping the next 50 years', Tom Sargent lecture (2011), <http://www.ombudsman.org.uk/about-us/media-centre/ombudsmans-speeches/2011/the-parliamentary-ombudsman-and-administrative-justice-shaping-the-next-50-years2/1> accessed 11.3.12

⁴¹ National Audit Office (2008) *supra* para 9

⁴² Birkinshaw P, 'Grievances, Remedies and the State – Revisited and Re-appraised' in Adler M (ed) *Administrative Justice in Context* (Hart 2010) 357; House of Commons Select Committee on Public Administration, *When Citizens Complain*, Fifth Report session 2007-8, HC409; and Government response, HC997

⁴³ Local Government Ombudsman (2011) Executive Summary 5

Many complaints are successfully resolved through internal complaints procedures.⁴⁴ However, there are no data on how many people withdraw from the complaints process despite being dissatisfied with the response they have received.⁴⁵

Local authority and health service complaints procedures were combined under new Regulations in 2009.⁴⁶ Under these provisions, each local authority must designate a 'responsible person'⁴⁷ to ensure statutory compliance and remedial action; and a 'complaints manager' to manage and promote the complaints process.⁴⁸ Anyone receiving or affected by services from the authority⁴⁹ may make a complaint,⁵⁰ orally, in writing or electronically,⁵¹ within a 12-month time limit.⁵² The authority must acknowledge the complaint,⁵³ and offer to discuss process and timescales with the complainant.⁵⁴ The complaint must be investigated 'speedily and efficiently', keeping the complainant informed of progress. On completion, a written response, signed by the 'responsible person', and explaining investigation, conclusions and any remedial action⁵⁵ must be sent to the

⁴⁴ For instance, Sheffield City Council's 'Annual Report of complaints received about Adult Social Services' for 2009-10 reports that 211 adult social care complaints were received during the year, of which 5 were withdrawn, 116 remained live, 1 progressed to review stage and 8 were investigated externally. 'Of the 90 concluded complaints: 47% had identified clear service failures which were remedied; 40% were resolved through negotiation with the customer; and 9% resulted in no action being necessary.' 63% of complainants reported that 'the response fully addressed the complaint'. *ibid* 4-5

⁴⁵ National Audit Office (2008) *supra* para 14; see also Gulland J 'Independence in complaints procedures: lessons from community care' (2009) 31(1) *Journal of Social Welfare and Family Law*, 59; Gulland J 'Taking complaints seriously: the role of informality in complaints about public services' (2011) 10(4) *Social Policy and Society*

⁴⁶ Local Authority Social Services and National Health Service Complaints (England) Regulations 2009, SI 2009/309; see also Department of Health 'Listening, Responding, Improving: a guide to better customer care' Gateway ref 11215, 26 Feb 2009; Gulland J 'Second-tier reviews of complaints in health and social care' (2006) 14(3) *Health and Social Care* 206

⁴⁷ In the case of a local authority, this should be the Chief Executive Officer of the authority: regulation 4(4)(a)

⁴⁸ Regulation 4(1) and Regulation 16

⁴⁹ Or their representative, for instance for a child or person who lacks capacity under the Mental Capacity Act 2005

⁵⁰ Regulation 5

⁵¹ Regulation 13(1)

⁵² Regulation 12

⁵³ Within 3 working days

⁵⁴ Regulation 13(7)

⁵⁵ Regulation 14

complainant, who must also be advised of their right to complain further to the Local Government or Health Service Ombudsman.⁵⁶

These Regulations streamline earlier separate health and local authority provisions, removing both an initial 'local resolution' stage and a third 'panel hearing' stage⁵⁷ before completion of the internal process.⁵⁸ On the face of the Regulations, they thus remove any statutory requirement for initial mediation, or for more 'legal' resolution before a Panel,⁵⁹ leaving a purely 'bureaucratic' exercise. However, in practice, at least some local authorities⁶⁰ have used the new Regulations to work more closely with their local health counterparts, and to introduce new ways of working that seek to 'make a complaint simpler, more user-friendly and far more responsive to people's needs'.⁶¹ Approached in this way, the new provisions potentially allow for increased flexibility in how each complaint will be handled,⁶² and for a more supportive and 'outcome-focussed' process for the complainant, including through informal advocacy and mediation, and/or, if appropriate, the possibility of formal adjudication where other methods have failed.⁶³

⁵⁶ Depending on the focus of the complaint. See for instance the role of the Health Service Ombudsman in relation to health/local authority responsibilities following *Coughlan* – Chapter 8 above. There are various provisions for co-operation and referral between authorities (Regulations 9, 10,11) and complaints must be recorded, monitored, and included in annual reports (Regulations 17 and 18). There is no requirement to inform the complainant of their right to apply for Judicial Review.

⁵⁷ For details, see Williams C, Ferris K, *Complaints Panels in Social Care* (Russell House Publishing 2010). Following introduction of the Human Rights Act 1998, there were concerns that Complaints Panels were insufficiently independent of local authorities to comply with Article 6 ECHR. Plans were made, later shelved, to transfer responsibility for such Panels to the then regulator, the Commission Social Care Inspection. For discussion, see Williams C and Ferris K, 'Proposals to Transfer Complaints Panels to the Commission for Social Care Inspection – Throwing the Baby out with the Bath Water?' (2005) 27 *Journal of Social Welfare and Family Law* 199

⁵⁸ Local Authority Social Services Complaints (England) Regulations 2006

⁵⁹ For discussion of the history of social services complaints procedures, see Ferris thesis (2006) Chapters 1 and 9

⁶⁰ Including Doncaster Metropolitan Borough Council: Directorate of Adults and Communities, 'Complaint and Compliments', Annual Report 2010-2011, available from DMBC Complaints Manager www.doncaster.gov.uk

⁶¹ *Ibid* 3. These may include provision of information in accessible formats, support for service users in making a complaint, mandatory training for front-line staff and managers, and the development of systems for 'capturing' both complaints and compliments to encourage a 'listening, learning culture': *ibid* 4

⁶² Previous regulations set statutory time limits on each stage of the process: these no longer apply, with timescales negotiated with each complainant

⁶³ See for example Doncaster MBC, *supra*, Appendix 1 Complaints Procedure

However, not all local authorities respond in the same way to such changes⁶⁴ - how they do so will depend on the discursive struggles and identities of social actors in each institution⁶⁵ - and mechanisms for sharing learning from complaints between institutions, so that the same mistakes are not repeated again and again, are insufficient.⁶⁶ Moreover, as Gulland describes,

[p]olicy reviews of complaints procedures rarely address head on the issue of power relations between public services and 'service users'... in the field of social care, the power relationships and expectations of both service users and staff are not simple....⁶⁷

A complaint may relate not to a one-off event, but to a long-term problematic relationship between the complainant and the service provider; may be part of a wider range of interlinked problems experienced by the complainant;⁶⁸ and/or may change over time, as new issues emerge or new events take place.⁶⁹ It may in turn be met by a closed, reactive, defensive response which resists real and sustained learning.⁷⁰ To what extent the new Regulations succeed in bringing about a responsive, outcome-focussed process which meets the varied expectations of complainants consistently in all of these circumstances and across all local authorities remains to be seen.⁷¹ As Buck *et al* identify,

⁶⁴ Sheffield City Council, for instance, has found introduction of the new Regulations 'challenging'. Whilst describing the new system as 'one-stage', it reports that '[t]he majority of complaints are resolved by the service. Some complaints are investigated by independent investigating officers who will make recommendations to senior managers. Some appeals processes exist and are utilised for those complaints about decisions which meet the scope of the relevant appeal panel. Mediation as an alternative form of resolution method is yet to be developed... [and] an optional escalated stage' has been introduced before approach to the Ombudsman. Sheffield City Council Annual Report of complaints received about Adult Social Care Services, Communities Portfolio, 1 April 2009 - 31 March 2010. There is no mention in this Report of partnership with local health bodies, other than to note that they, not the Council, deal with mental health complaints. Quality of complaint resolution, learning and service improvement and customer satisfaction are reported to have increased, but at the expense of response timescales: *ibid* 2

⁶⁵ See Chapter 8 above

⁶⁶ Abraham A, PHSO Report *Responsive and Accountable? The Ombudsman's review of complaint handling by government departments and public bodies 2010-11*, 25 October 2011

⁶⁷ Gulland J, 'Complaints Procedures and Ombudsmen' in Adler, M, ed, *Administrative Justice in Context* (Hart 2010) 462

⁶⁸ See for instance Pleasence *et al* (2006); O'Grady *et al* (2004)

⁶⁹ Pleasence *et al* (2006) 470

⁷⁰ Abraham A, PHSO Report (2011) *supra*

⁷¹ At the time of writing (Feb 2012) no published research into implementation of the 2009 regulations was found

'users' perceptions of dealing with government departments and other public authorities ... are often experienced as a complex journey – sometimes a bumpy one – from one part of officialdom to another.⁷²

Complainants may be left frustrated and exhausted by the complaints system,⁷³ and at the end of the day, resolution of their substantive problem may remain unresolved.

The capacity of internal complaints procedures to influence local decision-making towards more emancipatory, CRPD-compatible understandings thus relies, like the decision-making itself, on development of those understandings through national policy, law and the wider administrative justice system, as well as within each local institution. As we have seen in Chapter 8, that transformation has not yet been accomplished.

Two further options are available to a dis-satisfied complainant: complaint to the Ombudsman or, if appropriate, application to the High Court for judicial review. Both bring the complaint to the national stage. The following section considers the capacity for judicial review to influence policy, law and practice towards more CRPD-compatible understandings. The corresponding capacity of the Ombudsmen is considered below.

Judicial review⁷⁴

Judicial review provides the only 'legal' recourse for those seeking to challenge social care decisions in England.⁷⁵ Its modern development as a

⁷² Buck T, Kirkham R and Thompson B, *The Ombudsman Enterprise and Administrative Justice* (Ashgate 2011) 59

⁷³ Abraham A, PHSO Report (2011)

⁷⁴ For a full discussion of judicial review and socio-economic rights in England, see Palmer E, *Judicial Review, Socio-Economic Rights and the Human Rights Act* (Hart 2009); see also King JA, 'United Kingdom: Asserting Social Rights in a Multi-layered System' in Langford M (ed) *Social Rights Jurisprudence: emerging trends in international and comparative law* (Cambridge University Press 2008); O'Connell C, 'Socio-economic Entitlements and the UK Rights Framework' (2005) Irish Human Rights Commission Conference on Economic, Social and Cultural Rights: Model of Enforcement, Dublin, 9/10 December 2005; Le Sueur A, Sunstein M and Murkens J, *Public Law: texts, cases and materials* (Oxford University Press 2010)

mechanism for securing redress against the state took place over the second half of the 20th century, partly in response to growth of the welfare state.⁷⁶ Since 2000, the Human Rights Act has significantly enhanced the courts' role,⁷⁷ requiring judges

to scrutinise a statute to conform to overarching normative principles such as dignity rather than simply to seek to find out what Parliament intended in a particular case.⁷⁸

This picture of judicial review is of 'a process principally concerned with grand issues of principle'⁷⁹ and with imposing the rule of law, including, latterly, European Convention law, on the executive. As such it has played a central role in the development of administrative law,⁸⁰ and offers a potentially effective mechanism for hegemonic development of disability/human rights discourse in this field.⁸¹

However, as Sunkin *et al* demonstrate, far from being a 'more leisured engagement between citizen and authority in the High Court', in practice judicial review is used,

often by the most marginalised groups against some of the most hard-pressed local authorities in relation to some of the most intractable resource allocation issues.⁸²

⁷⁵ A situation confirmed by the Law Commission in its proposals for adult social care legislation at Recommendation 16: see Chapter 7 above

⁷⁶ For history, see for instance Le Sueur A, Sunkin M and Murkens J, *Public Law: texts, cases and materials* (Oxford University Press 2010); or Carroll A, *Administrative & Constitutional Law*, 5th ed (Pearson-Longman 2009)

⁷⁷ In human rights cases, HRAs2: court must take into account ECHR jurisprudence; s3: court must interpret legislation in a way which is compatible with Convention rights; s4: court may make declaration of incompatibility. Note also introduction of principle of proportionality into UK judicial reasoning.

⁷⁸ Gordon R, QC 'I am a mental health lawyer – how is the Human Rights Act helping my practice? Human Rights developments in mental health law' (Human Rights Lawyers Association 2005) para 8

⁷⁹ Sunkin M, Calvo K, Platt L, Landman T, 'Mapping the Use of Judicial Review to Challenge Local Authorities in England and Wales', [2007] Public Law 545, 567

⁸⁰ See for instance Wade W and Forsyth C, *Administrative Law*, 10th ed (Oxford University Press 2009), Craig P, *Administrative Law*, 6th ed (Sweet & Maxwell 2008), Le Sueur and Sunkin (2010), Bailey SH, Jones B and Mowbray AR, *Bailey, Jones and Mowbray: Cases, Materials and Commentary on Administrative Law*, 4th Rev ed (Sweet & Maxwell 2005)

⁸¹ See, for instance, Poole T, 'The Reformation of English Administrative Law' (2009) 1 Cambridge Law Journal 142

⁸² Sunkin *et al* (2007)

The success of such marginal groups is by no means assured: as the UN ESCR Committee highlights,⁸³ there are many elements of the courts' procedures and jurisprudence which factor against claimant satisfaction in this kind of judicial review case.

One is the traditional 'constitutional imperative of judicial self-restraint'⁸⁴ or deference to Parliament. Although the degree of such deference may have lessened over time,⁸⁵ and despite the courts' new power to make Declarations of Incompatibility under the Human Rights Act,⁸⁶ judicial deference remains an essential component of the constitutional balance of powers.⁸⁷ It was this imperative which led to Lord Greene MR's arguing in *Wednesbury*⁸⁸ that delegated discretion should only be challenged 'in a strictly limited class of case', and setting a very high standard for what constitutes irrational behaviour on the part of public bodies.⁸⁹ Again, this high bar to interference by the court has lowered over time.⁹⁰ Nevertheless, as O'Conneide comments, it has had the effect of 'essentially immunising large areas of public authority decision-making from any meaningful possibility of a successful judicial review'.⁹¹

Where the case relates to socio-economic decisions, further constraints apply. The area of 'welfare' decision-making is seen in England as the province of politicians rather than of judges,⁹² and the judges themselves

⁸³ See Chapter 5 above

⁸⁴ Irvine H, 'Judges and Decision-makers: the theory and practice of *Wednesbury* review' [1996] Public Law 59

⁸⁵ Griffith JAG, *The Politics of the Judiciary*, 2nd ed (Fontana 1981); see also, for instance, Lord Bridge in *Bugdaycay v Secretary of State for the Home Department* [1987] 1 All ER 940: 'where decisions might put the applicant's life at risk, the court should apply 'the most anxious scrutiny'

⁸⁶ Human Rights Act 1998 s4

⁸⁷ For current debate on this issue see the exchange between Lord Sumption and Sir Stephen Sedley: Sumption J, 'Judicial and Political Decision-making: the uncertain boundary', The F.A. Mann Lecture (2011); Sedley S, 'Judicial Politics: Stephen Sedley on the separation of powers' (2012) 34(4) London Review of Books 15 <http://www.lrb.co.uk/v34/n04/stephen-sedley/judicial-politics> accessed 17.2.12

⁸⁸ *Associated Provincial Picture Houses Ltd v Wednesbury Corporation* [1948] 1 KB 223

⁸⁹ Where the body has considered all relevant, and no irrelevant factors, it is only if the body has nevertheless come to a conclusion so unreasonable that no reasonable authority could ever have come to it that the court can interfere.

⁹⁰ See Lord Bridge in *Bugdaycay*, ftnote 85 above – though see discussion below

⁹¹ O'Conneide (2005); King (2008)

⁹² Because the allocation of public resources raises complex issues which impact on a wide variety of actors, and because there are different political views about the best way to

recognise the limitations in their competence to address 'polycentric' administrative issues.⁹³ In the absence of constitutional recognition of economic, social and cultural rights, they remain reluctant to interfere with public authority decisions involving substantial resource allocation, or to order the provision of 'welfare' services.⁹⁴

Moreover, like internal complaints discussed above, the process of judicial review concerns procedural rather than substantive issues. The court's focus is on the behaviour of the public authority: was that behaviour legal, rational, fair? Was it compatible with European Convention rights? If not, the court is unlikely to substitute its own decision,⁹⁵ rather referring the issue back to be decided again through a legal/rational/fair/compatible process which may result in a repeat of the original substantive decision.

Despite such constraints and frustrations for the claimant,⁹⁶ and despite considerable practical barriers to access to justice,⁹⁷ judicial review constitutes the closest expression in England of Adler's 'legal' model of administrative redress, with its legitimating goal of legality, and independence and impartiality as its modes of accountability.⁹⁸ Judicial review cases

allocate such resources: see United Kingdom Fifth Report to UN Economic, Social and Cultural Rights Committee, and Chapter 5 above

⁹³ Griffith (1981); Munby J: 'it is not the task of a judge when sitting judicially – even in the administrative court – to set out to write a textbook or practice manual or to give advisory opinions', *East Sussex* (discussed below) para 163

⁹⁴ Unlike their counterparts in some other parts of the world, such as India, where judges have developed a system of public interest litigation; or South Africa, where the Constitutional Court has developed a 'reasonableness' jurisprudence to decide cases relating to socio-economic rights. As seen in Chapter 5 above, these are considered by the UK government to have gone 'further than the UK would find acceptable'. See also Langford (2008); O'Connell (2005); Palmer (2009). For further, see Sumption (2011) and Sedley (2012)

⁹⁵ See for instance *R (Rogers) v Swindon NHS Primary Care Trust, Secretary of State for Health* [2006] EWCA Civ 392, where the Court of Appeal quashed the Primary Care Trust's policy that led to refusal of funding for Ms Rogers's treatment as being irrational, but refused to order funding of her treatment.

⁹⁶ See also O'Brien and Gooding, 'Final Reflections', DRC Legal Bulletin, Legacy Edition, (Disability Rights Commission 2007)

⁹⁷ Including unavailability of legal aid – see Legal Aid, Sentencing and Punishment of Offenders Act 2012; lack of access to expert information and advocacy; and the high proportion of applications rejected at the permissions stage. In 2011, 57.1% (6391) of applications were refused, 10.9% (1220) accepted, with 32% (3589) in progress. In that year, 174 applicants, or 16 per 1000 decisions, won their case (Rogers S, 'Judicial Review Statistics: how many cases are there and what are they about?' Guardian Datablog <http://www.guardian.co.uk/news/datablog/2012/nov/19/judicial-review-statistics#data> accessed 16.2.13)

⁹⁸ See Chapter 8 above

relating to independent living services have been brought before the courts, engaging both common law jurisprudence and the 'civil and human rights' guaranteed under the Disability Discrimination Act 1995 and the Human Rights Act 1998,⁹⁹ thereby potentially 'open[ing] the door to certain types of legal claim that could be described as involving an assertion of socio-economic rights'.¹⁰⁰ This section examines a selection of such cases.

Common law

Before introduction of the Human Rights Act in 2000, traditional common law jurisprudence, including such doctrines as *Wednesbury* unreasonableness and deference on socio-economic issues, prevailed.¹⁰¹ In 1995, the Court of Appeal stated categorically¹⁰² that the decision on allocation of a limited health budget was 'not a judgment which the court can make.'¹⁰³ Subsequent relaxation of the rules of standing, however, combined with refinement of the public law doctrine of exclusivity¹⁰⁴ gradually led to greater readiness on the part of some judges to become involved in complex multi-faceted politically sensitive disputes.¹⁰⁵

The *Gloucestershire* case¹⁰⁶ provided important early clarification of local authority duties under the NHS and Community Care Act 1990 (NHSCCA).¹⁰⁷

⁹⁹ See Explanatory Memorandum on the United Nations Convention on the Rights of Persons with Disabilities laid before Parliament on 3 March 2009, with the Command Paper containing the text of the Convention (Cm7564); and Chapter 4 above

¹⁰⁰ O'Conneide (2005); see also Massie B, 'Reflections on the Role of the Judiciary in Enhancing or Restricting the Civil Rights of Disabled People' (Disability Rights Commission 2004)

¹⁰¹ See King (2008)

¹⁰² When considering the refusal on resource grounds of potentially life-saving treatment for a ten-year-old child: *R v Cambridge Health Authority ex parte B* [1995] 2 All ER 129

¹⁰³ *Ibid*, Sir Thomas Bingham, MR at 133

¹⁰⁴ *O'Reilly v Mackman* [1983] 2 AC 237 excluded any alternative to judicial review as a form of litigation to secure redress against the State. That rule was subsequently relaxed in *Wandsworth LBC v Winder* [1985] AC461 and *Roy v Kensington & Chelsea Family Practitioner Committee* [1992] 1 AC 624. Arguments abound about the necessity for, and the scope of, this public/private divide. See for instance Oliver D and Jowell JL (eds) *The Changing Constitution* (Oxford University Press 2000)

¹⁰⁵ Palmer E, 'Resource Allocation, Welfare Rights – Mapping the Boundaries of Judicial Control in Public Administrative Law' (2000) 20(1) *Oxford Journal of Legal Studies* 63; Syrett K 'Of resources, rationality and rights: emerging trends in the judicial review of allocative decisions' (2000) 1 *Web Journal of Current Legal Issues* 1

¹⁰⁶ *R v Gloucester County Council ex parte Barry*, [1997] 2 All ER 1(HL)

<http://www.publications.parliament.uk/pa/ld199697/ldjudgmt/jd970320/barry01.htm> last

The case concerned the withdrawal on resource grounds¹⁰⁸ of laundry and cleaning services from an older man, living alone. The claimant argued that the authority had acted unlawfully in withdrawing services without having reassessed his needs, and requested a declaration that in carrying out the reassessment the Council was not entitled to take into account its resources.

At first instance, McCowan J confirmed that s2 CSDPA¹⁰⁹ created a duty specific to the individual rather than a more general 'target' duty; and that no reduction or withdrawal of services should take place without prior re-assessment of the individual's needs.¹¹⁰ However, it would be 'impractical and unrealistic' to expect the local authority not to take resources into account, though they should be 'no more than one factor' in the overall assessment. McCowan J then recognised what might be considered a 'core minimum' similar to that required by the UN Committee on Economic, Social and Cultural Rights,¹¹¹ albeit dressed in common law arguments of 'reasonableness':

Certain persons would be at severe physical risk if they were unable to have some practical assistance in their homes. In those situations, I cannot conceive that an authority would be held to have acted reasonably if they used shortage of resources as a reason for not being satisfied that some arrangement should be made to meet those persons' needs.¹¹²

The Appeal Court differed, holding¹¹³ that resources should not be taken into account;¹¹⁴ but the House of Lords¹¹⁵ overturned that decision,¹¹⁶

accessed 8.3.12; discussion here of this and following cases is supported by, *inter alia*, Clements L, *Community Care and the Law*, 4th ed (Legal Action Group 2007)

¹⁰⁷ Implementation of the NHSCCA90 was delayed for three years to allow Councils time to prepare for the changes. It came into force in April 1993.

¹⁰⁸ Mr Barry was informed by letter that the service was being withdrawn because central government funding to the Council had been cut by £2.5m and there was 'nowhere near enough to meet demand.'

¹⁰⁹ See Chapter 7 above

¹¹⁰ Following the court's decision on this point, 'the Council reassessed some 1,500 people in receipt of services under s2 of the 1970 Act. As a result of the reassessment the number was reduced to 1,060.' Lord Lloyd in *Gloucestershire*, House of Lords [1997] All ER 1

¹¹¹ See Chapter 5 above

¹¹² McCowan J (1997) 1 CCLR 19 at 31G

¹¹³ By a majority of two to one: Swinton-Thomas LJ and Sir John Balcombe - Hirst LJ dissenting [1996] 4 All ER 421

¹¹⁴ 'In assessing and reassessing whether it is necessary to make arrangements to meet [the applicant's needs under s2], a local authority is not entitled to take account of the resources available to such local authority.' [1997] AC 584

effectively collapsing the s2 'duty to provide' into a discretionary power, albeit with McCowan J's 'core minimum' unchallenged.

Gloucestershire was criticised at the time,¹¹⁷ and a line of subsequent judgements excluded consideration of resources from provision of education, disabled facilities grants, the duty to assess and charging for residential care,¹¹⁸ leading Palmer to conclude that the courts might be moving towards a more 'rights-based conception of public law'.¹¹⁹ However, *Gloucestershire* remains as precedent in the field of Article 19(b) services, as will be seen below.

Disability discrimination law

Disability discrimination law has also been called into play in the question of resources. Local authorities have been required since 2003 to apportion

¹¹⁵ By a majority of three to two. [1997] 2 All ER 1. Secretary of State for Health joined the proceedings. As Lord Lloyd comments, '[i]t is as well that he [the Secretary of State] should be [joined] for it is the failure of central government to supply the funds necessary to enable the council to carry out what I regard as their statutory duty which, departing from the fine words contained in the government White Paper *Caring for People: Community Care in the Next Decade and Beyond...*, has put the council into what the Divisional Court called an impossible position; ...even if the council wished to raise the money themselves to meet the need by increasing council tax, they would be unable to do so by reason of the government imposing rate-capping.' Lord Lloyd in *Gloucestershire*, House of Lords [1997] All ER 1

¹¹⁶ At both appeal levels, *Gloucestershire* was a close decision. In the House of Lords, for instance, Lord Lloyd, finding for Mr Barry, considered that '[t]he passing of the 1970 Act was a noble aspiration. Having willed the end, Parliament must be asked to provide the means'; whereas Lord Nicholls 'can see no basis for reading into the section [CSDPA s2] an implication that... cost is to be ignored' and does 'not believe Parliament intended that to be the position.' Lord Nicholls refers the claimant back to *Wednesbury* unreasonableness as the ground for potential remedy.

¹¹⁷ Rayment B, 'Ex parte Barry in the House of Lords' and 'Clements L, 'The Collapsing Duty', both in (1997) 2(3) *Judicial Review*; Palmer E and Sunkin M 'Needs: Resources and Abhorrent Choices' (1998) 61(3) *Modern Law Review* 401

¹¹⁸ A differently constituted House of Lords in *Tandy* found the majority's reasoning in *Gloucestershire* 'very doubtful', (*R v East Sussex County Council ex p Tandy* [1998] 2 All ER 769) upholding a mandatory obligation under s298 of the Education Act 1993 to deliver home tuition services to a sick child unable to attend school, irrespective of the resources available to the authority at the time. The Court of Appeal took a similar line in *Sefton*, (*R v Sefton MBC ex p Help the Aged* [1997] EWCA Civ 2265 [1997] 4 All ER 532) when it quashed the authority's policy of ignoring statutory capital disregards when charging for residential care under s21 NAA48 and National Assistance (Assessment of Resources) Regulations 1992. Other judges followed suit, excluding the consideration of resources from the allocation of mandatory disabled facilities grants (Dyson J in *R v Birmingham CC ex p Taj Mohammed* [1998] 3 All ER 788) and from the duty to carry out an assessment (Scott Baker J in *R v Bristol CC ex p Penfold* (1998) 1 CCLR 315)

¹¹⁹ Palmer E, 'Resource Allocation, Welfare Rights – Mapping the Boundaries of Judicial Control in Public Administrative Law' (2000) 20(1) *Oxford Journal of Legal Studies* 63

services in line with four bands of eligibility: critical, substantial, moderate and low.¹²⁰ As resources have become stretched, and particularly since the 2010 Spending Review, councils have increasingly raised the threshold of eligibility for Article 19(b) services, leaving many assessed needs unmet.¹²¹ From 2006, however, the Disability Equality Duty (DED)¹²² required all public bodies to take a proactive¹²³ and comprehensive stance towards disability equality in everything they do.¹²⁴ This general public sector duty has been applied in the courts to challenge cuts in eligibility.¹²⁵

Under DDA s49A,¹²⁶ public authorities must 'have due regard'¹²⁷ to the need to eliminate discrimination and promote equality. The Courts began by establishing that failure to meet this duty could be challenged as a freestanding legal issue through judicial review.¹²⁸ They then took a

¹²⁰ See Chapter 6 above. The criteria may be broadly summarised as follows: 'critical' means that life is at risk, or there is great risk of serious illness or harm; 'substantial' covers situations of abuse or neglect, and/or where the *majority* of personal care routines, work or education, social relationships and/or family responsibilities cannot be sustained; the inability to sustain *several* of these personal, work and social routines and responsibilities constitute the 'moderate' band; and 'low' eligibility applies where *one or two* such roles or responsibilities cannot be undertaken.

¹²¹ In June 2012, ADASS reported 83% of Councils operating at 'Substantial' and above eligibility level

¹²² Disability Discrimination Act 2005, inserting Part 5A (ss 49A-49F) into DDA1995

¹²³ Or 'anticipatory': see Lawson A, *Disability and Equality Law in Britain: the role of reasonable adjustment* (Hart 2008)

¹²⁴ DDA 1995 s49A(1) required the authority to 'have due regard' to the need to:

- eliminate discrimination and harassment;
- promote equality of opportunity, including more favourable treatment;
- promote positive attitudes; and
- encourage disabled people's participation in public life.

'Public authorities' for this section are defined as 'any person certain of whose functions are functions of a public nature', a definition echoing that of the Human Rights Act 1998, s6. Enforcement of the 'specific' public sector duty was set out in the Disability Discrimination (Public Authorities)(Statutory Duties) Regulations 2005

¹²⁵ The following section focuses on cases relating to independent living. For discussion of the use of Public Sector Equality Duties to challenge funding decisions through judicial review more generally see Fredman S, 'The Public Sector Equality Duty' (2011) 40(4) *Industrial Law Journal* 405

¹²⁶ Now subsumed, with changes, into Equality Act 2010 s146

¹²⁷ Because this phrase is somewhat vague, 'both discrimination and administrative lawyers were initially sceptical about the duties' potential to make a difference for their clients': Halford J, 'Paying Attention to Inequality: the Development of the Positive Equality Duties' (2009) *Judicial Review* 21, para 2

¹²⁸ *R (Kaur & Shah) v London Borough of Ealing* [2008] EWHC Admin 2026 para 27; the specific equality duty could only be enforced by the Equality and Human Rights Commission, under Equality Act 2006, ss 20-24A, by means of compliance notice enforceable in the County Court, with ultimate sanction of contempt of court

purposive approach to its interpretation:¹²⁹ where a public body is found to be in breach of its statutory equality duties, the court may quash a decision or action.¹³⁰ This was the result in *Chavda*,¹³¹ where Harrow LBC decided to restrict provision of community care services to those in 'critical' need only: the Council's decision was unlawful as it had not drawn the particular legal duties imposed by DDA s49A to the attention of the decision-makers.

Two further aspects of the DED were identified in *Brown*.¹³² Public authorities must have due regard to both the need to take account of the fact of disabled people's impairments and the need to recognise that this might involve treating disabled people more favourably. The duty, however, was to have 'due regard', not to take steps or to achieve results. *Boyejo*¹³³ continued this line of reasoning in the context of challenge to Barnet's decision to replace sheltered accommodation on-site wardens with peripatetic support and alarm systems. Here, the Council did not have sufficient regard to the impact on disabled residents or to the possible need for more favourable treatment.¹³⁴

*Domb*¹³⁵ raised the question of whether or not a local authority could rely on a budgetary deficit to modify its level of service provision.¹³⁶ The issue came to the fore again as the public sector funding cuts in the 2010 Spending Review began to bite.¹³⁷ In 2011, Birmingham City Council¹³⁸ took the

¹²⁹ See Halford (2009)

¹³⁰ As in, for example, *R(C) v Secretary of State for Justice* [2008] EWCA Civ 882

¹³¹ *R (Chavda & Others) v Harrow LBC* [2007] EWHC 3064; *Chavda* also held that it could not be argued on this basis that withdrawal of services from people with substantial needs involved a breach of Article 8: the Council was 'clearly right that questions of violation of [European] Convention rights arise not when the Council takes its decision but when an applicant contends for a violation... So at this point there can be nothing in the claimants' ECHR claims.'

¹³² *R (Brown) v Secretary of State for Work and Pensions* [2008] EWCA 3158 (Admin)

¹³³ *R (Boyejo) v Barnet LBC* [2009] EWHC 3261 (Admin)

¹³⁴ *ibid* para 63

¹³⁵ *R (Domb and others) v Hammersmith & Fulham LBC* [2009] EWCA Civ 941

¹³⁶ The Court of Appeal considered the Council's decision to introduce charges for its domiciliary services, after it had decided for electoral purposes to reduce its Council tax by 3%. Here the Court found no evidence that the Council had failed to consider its equality duties, but Sedley J recognised 'a major question of public law: can a local authority, by tying its own fiscal hands for electoral ends, rely on the subsequent budgetary deficit to modify its performance of its statutory duty?' *ibid* para 80

¹³⁷ As we have seen, the Coalition Government's 2010 Spending Review cut local authority budgets by 26% over a four-year period, and funding is no longer ring-fenced, leaving local

decision to reduce eligibility for social care to those with 'critical' needs only.¹³⁹ Four disabled people, with assessed needs including 'substantial' and 'critical', challenged the Council's decision, arguing, *inter alia*, breach of the Council's public sector duty under s49A DDA.

In *Birmingham*,¹⁴⁰ Walker J described the move to funding for critical only as 'potentially devastating'.¹⁴¹ In a long and detailed judgement, he found that although the Council gave consideration to how to address disabled people's needs, they did not ask themselves whether the impact of the move to 'critical only' 'was so serious that an alternative which was not so draconian should be identified and funded to the extent necessary by savings elsewhere'.¹⁴² The challenge succeeded. Birmingham City Council chose not to appeal, instead welcoming the judgement as giving 'greater clarity' regarding the DDA. It proposed to re-run the consultation and decision-making process in line with s49A, at the same time warning that 'there is no new money' and that 'hard choices about meeting growing needs with fewer resources will have to be made'.¹⁴³

authorities free to cut their social care budgets in real terms as part of their search for savings. With social care spending constituting a significant proportion of local authority expenditure, a number of authorities have considered either increasing charges or reducing services by tightening eligibility criteria, or both.

¹³⁸ Under pressure from unexpectedly deep funding cuts: a reduction in grant to the authority as a whole of £330 million, as opposed to the expected £57.9 million; *Birmingham*, *infra*, paras 49-51

¹³⁹ It proposed to use the 'new' social care funding to 'smooth' the reductions by new approaches, to build capacity in community and third sectors, and to increase productivity by 'doing things very differently'. *Birmingham*, *infra*, para 64

¹⁴⁰ *R (on the application of W) v Birmingham City Council; R (on the application of M, G and H) v Birmingham City Council* [2011] EWHC 1147 (Admin). Similar challenges to 'critical only' decisions were lodged against Lancashire County Council, the Isle of Wight, and at least one London Borough.

¹⁴¹ *Birmingham* para 183

¹⁴² *Ibid*

¹⁴³ BBC News, 'Birmingham City Council care funding cuts unlawful'

<http://www.bbc.co.uk/news/uk-england-birmingham-13455068> accessed 20.5.2011. At 7 August 2012, Birmingham City Council was continuing to provide at substantial and critical levels.

<http://www.birmingham.gov.uk/cs/Satellite/EligibilityCriteria?packedargs=website%3D4&rendermode=%27> accessed 7.8.12

Here we see a graphic example of judicial review used

by the most marginalised groups against some of the most hard-pressed local authorities in relation to some of the most intractable resource allocation issues.¹⁴⁴

We also see one of the weaknesses of judicial review as a means of enforcing socio-economic rights. However 'potentially devastating' the judge considers a decision to move to 'critical only' provision would be, the Council remains free to reconsider its decision in line with s49A procedures and reach the same decision. A case such as *Birmingham* may help to protect some existing services,¹⁴⁵ but, as the Council highlights, the underlying problem remains. Furthermore, the DDA equality duty under which Birmingham¹⁴⁶ failed to act has now been overtaken by the new, less taxing, general equality duty under the Equality Act 2010.¹⁴⁷ From April 2011, public authorities must 'have due regard' to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations across all 'protected characteristics'.¹⁴⁸ There is nothing in these new duties requiring 'due regard' to be taken of the fact of disabled people's impairments, or to recognise that this might involve treating disabled people more favourably. It remains to be seen how Councils and courts will respond to that change.

Neither *Chavda* nor *Birmingham* considered human rights to be relevant in the context of the authorities' s49A decision-making.¹⁴⁹ However, other

¹⁴⁴ Sunkin M, Calvo K, Platt L and Landman T, 'Mapping the Use of Judicial Review to Challenge Local Authorities in England and Wales' [2007] Public Law 545

¹⁴⁵ There have been several further successful challenges to decisions to cut social care funding, including *R(JM & NT) v Isle of Wight Council* [2011] EWHC 2911; *R on the application of (1) The Sefton Care Association (2) Melton Health Care Limited (3) Westcliffe Manor Nursing Home (4) Benbridge Care Homes Limited (5) Craignare Care Home v Sefton Council* [2011] EWHC 2676 (Admin). A case brought against Lancashire County Council - *R (JG and MB) v. Lancashire County Council* [2011] EWHC 2295 (Admin) - was unsuccessful, but that Council reportedly responded by undertaking a full and positive review, involving disabled people, of its service provision

¹⁴⁶ And the respondent councils in the cases discussed here

¹⁴⁷ Equality Act 2010 s149, in force 1 April 2011; see Chapter 7 above.

¹⁴⁸ Age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. Equality Act 2010 s4

¹⁴⁹ In *Chavda*, the claimants raised both Articles 3 and 8 ECHR, arguing on the basis of dignity, supported by *Botta* and *East Sussex*. However, Mackie J held that questions of violation of Convention rights arise not when the Council takes its decision but when rights

cases have allowed the courts to develop domestic human rights law in the context of independent living services, particularly under ECHR Articles 3 (prohibition of torture, inhuman and degrading treatment), and 8 (right to respect for private and family life).

Human rights law

An early case following HRA implementation¹⁵⁰ concerned allocation of suitable housing by the local authority. The *Bernard*¹⁵¹ family lost their fully-adapted property, and were re-housed by the local authority in inaccessible accommodation.¹⁵² Despite repeated assessments, the family's requests for rehousing in suitable adapted property went unanswered.¹⁵³ The family argued that their ECHR Articles 3 and 8 rights had been breached and sought damages.¹⁵⁴ Because Article 3 is an absolute right, allowing no qualification or exception, the European Court of Human Rights has established that, for the right to be engaged, ill-treatment must attain a minimum level of severity.¹⁵⁵ One issue in *Bernard* was therefore whether or not the treatment of the claimants had reached that level. Although Sullivan

are allegedly breached as a result of that decision. The human rights arguments, in that case, were held to be 'premature'. In *Birmingham*, Walker J agreed with the claimants that 'relevant articles in the European Convention on Human Rights did not add in substance to the heads of challenge already advanced.' para 190

¹⁵⁰ The judges began to consider individuals' ECHR rights before the HRA came into force. For instance, see *Coughlan (R v North East Devon Health Authority ex parte Coughlan)*, QB 47 BMLR 11 Dec 1998) where High Court and Court of Appeal considered the residents' rights to a home under Article 8 ECHR. The Appeal Court further recognised that a purpose-built environment may mean even more to a disabled person than a home does to most people, and that an enforced move would be emotionally devastating and seriously anti-therapeutic. In doing so, they confirmed both the lowering of the *Wednesbury* bar on interference with delegated discretion in human rights cases and its particular application in the context of disability.

¹⁵¹ *R (on the application of Bernard and another) v Enfield London Borough Council*. [2002] All ER (D) 383 (Oct)

¹⁵² Mrs Bernard was unable to use her wheelchair, and was confined to a downstairs lounge in which she lived, ate and slept, sharing it with her husband and two youngest children. She was unable to go out, to access the kitchen or upper floor to help care for the family, or to get to the bathroom without assistance, with the result that she frequently soiled herself. The front door of the property opened directly into the lounge, which also contained the stairway to the upper floor, depriving her of any privacy.

¹⁵³ As Sullivan J reports, '[f]or some unexplained reason the recommendation of the defendant's Social Services Department was not acted on by the defendant's Housing Department,' which at one point threatened the family with eviction, a threat withdrawn only after initiation of judicial review proceedings

¹⁵⁴ Under s8 of the Human Rights Act

¹⁵⁵ *A v UK* [1998] 27 EHRR 661, para 20

J found the issue to be ‘finely balanced’, he was not satisfied that the threshold had been met. The issue under Article 8, by contrast, was not finely balanced. Article 8 imposes positive as well as negative duties: to refrain from unwarranted interference, but also to take positive action, including the provision of suitably adapted accommodation. Therefore, not only was the Council in breach of its statutory housing duty under s21NAA48,¹⁵⁶ its failure to act on assessments was also incompatible with the claimants’ rights under Article 8 ECHR. Although Article 3 was not engaged in this case, it was not excluded from consideration; and *Bernard* confirmed that Article 8 could be relied on to give rise to a substantive right to community care services.

*East Sussex*¹⁵⁷ further developed Article 8 jurisprudence. Here, two sisters in their twenties challenged their local authority’s handling policy, which banned manual lifting¹⁵⁸ and thereby curtailed the sisters’ ability to take part in all but the most basic activities. The judge had to balance the local authority’s Article 8 duty towards the sisters against its responsibility for the health, safety and welfare of their carers.¹⁵⁹ Munby J held that the Article 8 guarantee of ‘physical and psychological integrity’¹⁶⁰ embraced two important concepts: human dignity and the right to participate in community life. He describes human dignity as the core value of our society, of the common law,¹⁶¹ and of the European Convention.¹⁶² When someone is so disabled as to be critically dependent on the help of others for the basic tasks of daily living, there is a positive obligation¹⁶³ to try to ameliorate and

¹⁵⁶ See Chapter 7 above

¹⁵⁷ *R (A,B, X and Y) v East Sussex County Council (No 2)* [2003] EWHC 167 (Admin)

¹⁵⁸ Requiring a hoist to be used at all times

¹⁵⁹ Under the Health and Safety at Work Act 1974

¹⁶⁰ Intended to ‘ensure the development, without outside interference, of the personality of each individual in his relations with other human beings’. *Botta v Italy* (1998) 26 EHRR 241 para 32. Munby J considers not only the ECHR, but also the EU Charter of Fundamental Rights. This Charter had been adopted by the EU in 2000, but at the time of *East Sussex* was not binding on Member States. It became binding insofar as it gives effect to EU law with the Lisbon Treaty in 2007

¹⁶¹ Munby J quotes, inter alia, the Bible (Matthew chapter 7, verse 12), Lord Chesterfield, and the Universal Declaration of Human Rights.

¹⁶² As confirmed in *A v UK* (1998) 27 EHRR 661, *Keenan v UK* (2001) 33 EHRR 913 and *Price v UK* (2001) 34 EHRR 1285; see also McCrudden C ‘Human Dignity and Judicial Interpretation of Human Rights’ (2008) 19(4) *European Journal of International Law* 655

¹⁶³ *Marckx v Belgium* (1979) 2 EHRR 330 PC

compensate for such disabilities; and as protection of human rights improves, increasingly high standards are required in provision for disabled people if their human dignity is not to be impaired.¹⁶⁴ Positive obligations towards disabled people also 'require appropriate measures to be taken' to ensure access to

essential economic and social activities and to an appropriate range of recreational and cultural activities... the crucial factor is the extent to which a particular individual is so circumscribed and so isolated as to be deprived of the possibility of developing his personality.¹⁶⁵

Therefore, protection of the health and safety¹⁶⁶ of the carer must be

commensurate with the best interests of the disabled person, their dignity and the promotion of their independence and their [European] Convention rights.¹⁶⁷

That balance must be struck in a way that is proportionate. Introduction of the principle of proportionality¹⁶⁸ enables Munby J to focus not only on the rationality of the local authority's actions but also on the rights of the sisters and the extent to which restriction of those rights is justified. This change in focus in effect repositions disabled people and rebalances relations between them and the authority. Moreover, Munby J's focus on dignity and participation complies with the subsequent requirements of CRPD Article 19 and the Convention's wider purpose.

¹⁶⁴ Relying on Lord Hoffman in *Birmingham City Council v Oakley* [2001] 1 AC 617 at 631G; *R (ota Smeaton) v Sec of State for health* [2002] EWHC 610 (Admin)

¹⁶⁵ Munby J's arguments for access and participation are drawn from *Botta v Italy* (1998) 26 EHRR 241, where a physically disabled man was claiming breach of his Article 8 rights because he was unable to gain access to a beach. Although the European Court of Human Rights held in *Botta* that Article 8 was not engaged, the European Commission on Human Rights had also considered his case. This quote is from the opinion of Mr N Bratza.

¹⁶⁶ Health and Safety at Work Act 1974, s 2: employer's duty to protect the health and safety of employees 'as far as reasonably practicable'

¹⁶⁷ *East Sussex* para 127

¹⁶⁸ The principle of proportionality was introduced into English common law through the Human Rights Act s2 requirement that domestic courts take into account Strasbourg jurisprudence when considering human rights cases. That jurisprudence holds that 'inherent in the whole of the Convention is a search for a fair balance between the demands of the general interest of the community and the requirements of the protection of the individual's fundamental rights.' (*Soering v UK*, 11 EHRR 439 para 89; see also Harris, O'Boyle & Warbrick, *Law of the European Convention on Human Rights*, 2nd ed (Oxford University Press 2009) 10). Proportionality is particularly germane to interpretation of qualified rights, such as Article 8.

However, this initial expansion of CRPD-compatible discourse was curtailed in *Anufrijeva v Southwark LB*.¹⁶⁹ Here, the Court of Appeal argued that Article 8 positive duties to provide welfare support such as those found in *Bernard* and *East Sussex* should only be imposed in extreme circumstances, such as those which engage Article 3.¹⁷⁰ As King comments,¹⁷¹ this suggests a stricter approach by the domestic courts than that taken by the European Court of Human Rights, which does not equate the level of severity required to engage Article 8 with the high level required to engage Article 3.¹⁷² The result is imposition of a high bar to engagement of Article 8 which threatens to side-line many human rights arguments in CRPD Article 19 cases,¹⁷³ as was the outcome in *MacDonald*.

*MacDonald*¹⁷⁴ concerned a dispute over whether to meet assessed night-time care needs through provision of a night-time carer or through the use of incontinence pads. The Council argued that the latter would provide the claimant with greater safety, independence and privacy, besides reducing the cost of her care by some £22,000 per annum. Ms MacDonald was not incontinent, her needs had not changed, and she considered the Council's proposal to be 'an intolerable affront to her dignity'.¹⁷⁵ In the Supreme Court, Lord Brown refers to *Gloucestershire*,¹⁷⁶ taking it as read that the local authority can take into account its resources both in making eligibility decisions and in deciding how to meet eligible needs.¹⁷⁷ Moreover, citing the high bar to engagement in *Anufrijeva*,¹⁷⁸ he concludes that there has been no

¹⁶⁹ [2004] QB 1124

¹⁷⁰ By this criterion, *Bernard* would have been wrongly decided, as Article 3 was found not to have been engaged.

¹⁷¹ King (2008)

¹⁷² In *Mazari v Italy* ((1999) 28 EHRR CD 175, 179-180) the ECtHR held that 'a refusal of the authorities to provide assistance... to an individual suffering from a severe disease might in certain circumstances raise an issue under article 8 of the Convention because of the impact of such a refusal on the private life of the individual'. The European Court makes no reference to Article 3. Langford (2008) 179-180

¹⁷³ See also *R (Kiana) v SSHD* [2010] EWHC 1002 (Admin), and *R (MS) v Oldham BC* [2010] EWCA 802 (Admin)

¹⁷⁴ *R (on the application of MacDonald) v Royal Borough of Kensington and Chelsea CA*: [2010] EWCA Civ 1109; SC: [2011] UKSC 33 6 July 2011

¹⁷⁵ *Ibid*, Lord Brown, Para 1

¹⁷⁶ See above

¹⁷⁷ *MacDonald*, para 8

¹⁷⁸ See above

interference with Ms MacDonald's Article 8 rights. Arguments under equality legislation¹⁷⁹ are also dismissed as 'hopeless'.¹⁸⁰ Baroness Hale dissents. Relying on *Sefton*,¹⁸¹ she argues that as NAAs21 gives rise to individual entitlement to residential care,¹⁸² it follows that NAA s29 (welfare provision) should also, logically, give rise to individual rights.¹⁸³ *Gloucestershire* was therefore wrongly decided: resources should not be relevant to the Council's considerations. Baroness Hale also raises issues of dignity,¹⁸⁴ but without reference to ECHR Articles 3 or 8. However, concerns about dignity are brushed aside,¹⁸⁵ Baroness Hale's *Gloucestershire* argument is not addressed, and Ms MacDonald's appeal is dismissed by a majority of four to one.

Both the collapse of the CSPDA s2 duty into a power in *Gloucestershire*, and the high bar to breach of Article 8 in *Anufrijeva* are thus reaffirmed in a judgement binding on the lower courts. Resource arguments may still justify denial of all but a 'core minimum' of service provision; and the incipient development of links between socio-economic entitlements, dignity and participation and positive obligations under ECHR Articles 3 and 8 in *Bernard* and *East Sussex* are side-lined, to reappear in future only in the most extreme cases.¹⁸⁶

MacDonald was decided in 2011, two years after UK ratification of the CRPD. As we have seen in Part 1, respect for inherent dignity is a fundamental requirement of the Convention, featuring in its purpose, in its Preamble, in

¹⁷⁹ DDA s21 (duty of providers of services to make adjustments), and s 49A (public sector equality duty)

¹⁸⁰ *MacDonald*, paras 22 and 24

¹⁸¹ See above

¹⁸² *MacDonald*, para 64

¹⁸³ Lady Hale refers to the Law Commission's 2011 review of adult social care as recommending that there should be an enforceable right to all the community care services required to meet the individual's eligible needs. *MacDonald*, para 65. What is more, she argues, s2 CSPDA was intended to create an individual right to services if its criteria were met; and NHSCCA s47 and the 1986 Disabled Persons (Services, Consultation and Representation) Act provide a right to assessment.

¹⁸⁴ *MacDonald*, para 78

¹⁸⁵ Lord Walker: 'the Council is well aware of Ms MacDonald's right to have her dignity respected...' (not mentioning Art 8) *MacDonald*, para 29

¹⁸⁶ See contributions of Munby LJ and Richard Gordon QC at Legal Action Group 'What Price Dignity' Conference, November 2011

<http://www.lag.org.uk/Templates/Internal.asp?NodeID=94024> accessed 5.3.12

individual articles and as the first of its general principles under Article 3. The services required under Article 19(b) are designed to enable disabled people to exercise autonomy and participation without which all other Convention rights are compromised. Despite CRPD Article 3(a)¹⁸⁷ being raised in argument by Ms MacDonald's advocate,¹⁸⁸ the Convention and Article 19 feature nowhere in the Supreme Court's judgement.¹⁸⁹

Moreover, the future of judicial review itself as channel for redress in independent living disputes seems uncertain, given the current marketisation of Article 19(b) provision.¹⁹⁰ Under the Human Rights Act s6(1), it is unlawful for a public authority to act in a way which is incompatible with a European Convention right. 'Public authority' is defined under s6(3)(b) as including 'any person certain of whose functions are functions of a public nature'.¹⁹¹ When this definition was debated in 1998, the government stated clearly that s6 was intended to include

private bodies, such as companies or charities [that] have come to exercise public functions that were previously exercised by public authorities.¹⁹²

The courts, however, have not always supported that view.

Over 90% of residential care places in England and Wales are currently provided by private, voluntary or charitable sector organisations,¹⁹³ raising

¹⁸⁷ Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

¹⁸⁸ At the Court of Appeal, [2010] EWCA Civ 1109, para 63

¹⁸⁹ Article 19 was cited, prior to ratification, by Silber J in *R (Harrison) v Secretary of State for Health* [2009] EWCA 574 (Admin) (a case about cash payments from the NHS); and by the European Court of Human Rights in *Glor v Switzerland* (Application no 13444/04), 30 April 2009 – and see Postscript below

¹⁹⁰ See Chapter 6 above

¹⁹¹ Other than either House of Parliament or persons exercising functions in connection with proceedings in Parliament.

¹⁹² The wording of s6 was described as 'a statement of principle to which the courts could give effect', as it was not possible to list all of the bodies to which it might apply. HC Debates, 16 Feb 1998, col 773

¹⁹³ Since the 1980s, s26 NAA has allowed local authorities to arrange residential care 'with a voluntary organisation or with any other person who is not a local authority...'. The number of adults in residential care in 2009-10 was 215,000, of which 78 per cent were aged 65 and over. <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-social-services-activity-england-2009-10-further-release> accessed 1.9.11. For discussion of the potential applications of European Union law in this area, see Hervey T, Stark A, Dawson A, Fernandez J-L, Matosevic T and McDaid

the question of protection of residents' rights under the HRA.¹⁹⁴ *YL v Birmingham City Council*¹⁹⁵ was the latest in a line of cases¹⁹⁶ addressing the definition of 'public authority' under HRA s6 in this context, and the first such case to reach the House of Lords

The action in *YL* was brought by an 84-year-old woman placed by her local authority in a home run by a private provider, Southern Cross Healthcare (SCH). The preliminary question was whether or not SCH was fulfilling public functions for the purposes of HRAs6(3). The five Law Lords split three to two, their various legal arguments drawn variously from 'welfare', ECHR and free market neo-liberal understandings. Lord Bingham considers that the state's 'last resort' social welfare responsibility for accommodation and care of 'the poor, the elderly and the infirm... can hardly be a matter of debate'.¹⁹⁷ Baroness Hale agrees, arguing also that care home providers must be covered by Article 6 HRA under the state's ECHR Article 13 duty to provide a domestic remedy for breach of human rights.¹⁹⁸ The opposite view, however, prevails, with the majority holding that SCH is not exercising public functions. Their reasoning is summed up by Lord Scott:¹⁹⁹

D, 'Long-term care for older people and EU law: the position in England and Scotland' (2012) 34(1) *Journal of Social Welfare and Family Law* 105

¹⁹⁴ See Collingbourne T, 'Collision and Fall-out? The legal position of publicly-funded residents in private residential/nursing care', Masters Dissertation, University of Essex, 2001; Joint Committee on Human Rights 'The Meaning of Public Authority under the Human Rights Act', Seventh Report of Session 2003-04 HL Paper 39, HC382; DIAL UK 'The: evidence of DIAL UK to the Joint Committee on Human Rights' April 2003, appended to JCHR Seventh Report, *ibid*

¹⁹⁵ *YL (by her litigation friend the Official Solicitor) v Birmingham City Council* [2007] UKHL 27

¹⁹⁶ *R v Servite Houses and London Borough of Wandsworth Council ex p Goldsmith and Chatting* [2001] LGR 55; *R v Leonard Cheshire Foundation and HM Attorney General ex p Heather and others* [2001] QBD CO/4727/00, 15 June 2001; *Donoghue v Poplar Housing and Regeneration Community Association Ltd* [2001] EWCA Civ 595, 27 April 2001; *R (Heather) v Leonard Cheshire Foundation* [2002] EWCA Civ 366; for further discussion see Collingbourne (2001); DIAL UK 'The: evidence of DIAL UK to the Joint Committee on Human Rights' April 2003, *supra*; Donnelly CM, 'Leonard Cheshire Again and Beyond: Private Contractors, Contract and section 6(3)(b) of the Human Rights Act' [2005] Public Law 785; Oliver D, 'Functions of a Public Nature under the Human Rights Act' [2004] Public Law 329; Sunkin M 'Pushing Forward the Frontiers of Human Rights Protection: The Meaning of Public Authority under the Human Rights Act' [2004] Public Law 643; Landau J, 'Functional public authorities after *YL*' [2007] Public Law 630

¹⁹⁷ *YL* para15

¹⁹⁸ ECHR Article 13

¹⁹⁹ *YL* para 26

Southern Cross is a company carrying out a socially useful business for profit. It is neither a charity nor a philanthropist. It enters into private law contracts with the residents in its care homes and the local authorities with whom it does business. It receives no public funding, enjoys no special statutory powers, and is at liberty to accept or reject residents as it chooses...and to charge whatever fees in its commercial judgement it thinks suitable. It is operating in a commercial market with commercial competitors.

Lord Neuberger suggests that if the legislature considers it desirable for residents in privately owned care homes to be given Convention rights against the proprietors, it should 'spell it out in terms'.²⁰⁰ The legislature obliged, enacting s145 of the 2008 Health and Social Care Act.²⁰¹ However, s145 constitutes only partial resolution of the problem. It provides no protection for those receiving domiciliary, as opposed to residential, care from private or voluntary sector providers,²⁰² or for those using their personal budgets to purchase services in a 'thriving social market'.²⁰³ While *YL* remains as precedent, their ECHR Article 13 right to an effective remedy in the courts for breach of their European Convention rights remains in question.²⁰⁴

Furthermore, judicial review itself has developed as a mechanism for redress against the State: its remit is limited to review of the actions of public

²⁰⁰ *YL* para 171

²⁰¹ (1) A person... who provides accommodation, together with nursing or personal care, in a care home for an individual under arrangements made... under the relevant statutory provisions [(2)(a) in relation to England and Wales, section 21(1)(a) and 26 of the National Assistance Act 1948] is to be taken for the purposes of subsection (3)(b) of section 6 of the Human Rights Act 1998... to be exercising a function of a public nature in doing so.

²⁰² 1.46 million in 2009-10 [though not all would be receiving services from private or voluntary sector providers]. Of those service users receiving community based services, 65 per cent were aged 65 and over. In 2009-10, 557,000 service users received home care, 512,000 service users received equipment and adaptations, 445,000 service users received professional support, 195,000 service users received day care services and 100,000 service users received meals. There were 166,000 service users in receipt of new/ existing direct payments and or personal budgets. <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-social-services-activity-england-2009-10-further-release> accessed 1.9.11

²⁰³ The number of service users receiving direct payments has continued to rise steadily since 2004-05, with only 24,000 users receiving direct payments in 2004-05, compared to 107,000 in 2009-10. <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-social-services-activity-england-2009-10-further-release> accessed 1.9.11; and see Chapter 6 above

²⁰⁴ See below for discussion of the Ombudsman's role in this context

bodies.²⁰⁵ Its role in the context of Article 19(b) thus seems likely to diminish in the context of the Coalition's free-market vision of social care unless the government accepts the Law Commission's proposal²⁰⁶ that 'community care entitlements' should be enforced by this means.

It would seem, then, that despite some initial expansion following introduction of the Human Rights Act, and some purposive application of equality duties, the capacity of judicial review to influence independent living policy, law or practice towards more CRPD-compatible understandings is at best limited, and is currently in retreat.²⁰⁷ Whilst common law, equality duties or ECHR rights may provide minimal protection,²⁰⁸ the overall trend following *MacDonald* and *Anufrijeva* is one of retraction from any rights-based understanding of independent living service provision. Even in this 'legal' setting, the CRPD, Article 19 and economic, social and cultural rights remain invisible; equality protections are reduced; the 'socio-economic' potential of civil and political rights under the European Convention on Human Rights is confined to the most extreme cases; and the future of judicial review itself as a redress mechanism in the context of the 'social market' is uncertain. Indeed, successful use of judicial review as a redress mechanism in Article 19 cases is set to become even less likely following enactment of the Legal Aid, Sentencing and Punishment of Offenders Act 2012. This Act removes availability of legal aid for advice, assistance or representation in the majority of 'community care' cases.²⁰⁹

²⁰⁵ See for instance Wade W and Forsyth C, *Administrative Law* 10th ed (Oxford University Press 2009); Carroll A, *Constitutional and Administrative Law*, 5th ed (Pearson-Longman 2009) part 5; Bailey SH, Jones B and Mowbray AR, *Bailey, Jones and Mowbray: Cases, Materials and Commentary on Administrative Law*, 4th Rev ed (Sweet & Maxwell 2005) part 2; Le Sueur A, Sunkin M and Murkens J, *Public Law: texts, cases and materials* (Oxford University Press 2010)

²⁰⁶ See Chapter 7 above

²⁰⁷ Palmer identifies an 'untutored allegiance of senior judges to the ascendancy of private economic power over fundamental human rights values.' Palmer E, *Judicial Review, Socio-Economic Rights and the Human Rights Act* (Hart 2009) Preface to the paperback edition, x. See also Palmer's conclusions at pp240 and 254, 274-6 and Afterword

²⁰⁸ Such as the 'core minimum' recognised by McCowan J in *Gloucestershire*, or delay in restriction of services to critical needs only in *Birmingham*

²⁰⁹ Legal Aid, Sentencing and Punishment of Offenders Act 2012, ss 8 and 9 and Schedule 1

Van Beuren insists that 'both the symbolism and the practical potential of courts ought not to be underestimated.'²¹⁰ However, as O'Conneide concludes,

it is obvious that the UK legal system still lacks a set of legal tools and an adequate legal or policy language to address issues of socio-economic rights deprivation. The polycentric nature of litigation involving socio-economic issues means that courts will often only be prepared to intervene where a definitive and distinct state actor has clearly denied basic support. Outside such cases... alternative methods of upholding socio-economic rights should be sought.²¹¹

Lord Woolf in *Anufrijeva* agrees that alternative methods should be sought, but on grounds of cost and proportionality.²¹² In an apparent reversal of the established presumption that Ombudsmen should not investigate where the complainant has a legal remedy,²¹³ Lord Woolf refers prospective claimants to the complaint procedures of the Parliamentary or Local Government Ombudsmen, 'at least in the first instance',²¹⁴ as they 'are designed to deal economically... and expeditiously with claims for compensation for maladministration.'²¹⁵ Importantly, he also recognises that the 'maladministration' the Ombudsmen are empowered to address, depending

²¹⁰ Beuren G van, 'Including the Excluded: the Case for an Economic, Social and Cultural Human Rights Act' [2002] Public Law 465; see also Gearty C and Mantouvalou V, *Debating Social Rights* (Hart 2011); Platt *et al* (2010) also argue that judicial review litigation can act as an incentive to change.

²¹¹ O'Conneide (2005) 17; see also King (2008) 292: 'Until Britain adopts or incorporates social rights, courts will feel restrained in reviewing resource allocation decisions for lack of a clear constitutional mandate.' Also Clements L, 'Winners and Losers' (2005) 32 *Journal of Law and Society* 34; Gearty C, 'Putting the Lawyers in their Place: the Role of Human Rights in the Struggle against Poverty' (undated)

http://www.conorgearty.co.uk/pdfs/Poverty_and_the_struggle_for_human_rights.pdf accessed 10.9.11; Genn H, 'Judging Civil Justice' (2008) The Hamlyn Lectures 2008, London and Edinburgh, 27 November, 2 December and 4 December 2008

²¹² *Anufrijeva*, para 80: 'a claim for damages under the HRA in respect of maladministration, whether brought as a free-standing claim or ancillary to a claim for other substantive relief, if pursued in court by adversarial proceedings, is likely to cost substantially more to try than the amount of any damages that are likely to be awarded. Furthermore,... there will often be no certainty that an entitlement to damages will be established at all.' For discussion of mediation and judicial review see Bondy V and Mulcahy L, 'Mediation and Judicial Review: an empirical research study' (Public Law Project 2009); also Genn (2008) *supra* and Lord Woolf's response, follow-up seminar 2009.

²¹³ The so-called 'statutory bar': Law Commission report on Public Service Ombudsmen 2011 <http://www.justice.gov.uk/lawcommission/publications/ombudsmen.htm> Summary, 3 The Law Commission supports a lowering of this statutory bar, as does Tom Mullen in 'A Holistic Approach to Administrative Justice?' in Adler M (ed) *Administrative Justice* (Hart 2010). Regarding Public Services Ombudsmen, see Local Government Act 1974 s26(6); regarding Parliamentary Ombudsman see Parliamentary Commissioner Act 1967

²¹⁴ *Anufrijeva*, para 81(iii)

²¹⁵ *Ibid*

on its extent and the severity of its impact, might constitute infringement of human rights.²¹⁶

So can the Ombudsman 'enterprise'²¹⁷ contribute to a more CRPD-compatible approach to Article 19 socio-economic rights?

The Ombudsman

The role of Ombudsman was introduced to England in the 1960s,²¹⁸ as a means of countering State abuse or misuse of power at the expense of the individual.²¹⁹ It was designed to be

impartial, open, informal, and of high reputation, guided by principles not rules and committed to norms based on what is fair and reasonable rather than a strict test of legality.²²⁰

Today, the Ombudsman concept has penetrated a variety of public and private fields.²²¹ Most relevant to Article 19 services is the Commission for Local Administration comprising two Local Government Ombudsmen (LGOs) each covering different areas of England, and the Parliamentary and Health Service Ombudsman (PHSO).²²² Whilst each has their distinct remit, they conduct joint investigations when appropriate.²²³ All are Crown appointees,

²¹⁶ Anufrijeva, para 48

²¹⁷ Buck T, Kirkham R and Thompson B, *The Ombudsman Enterprise and Administrative Justice* (Ashgate 2011)

²¹⁸ Following the Whyatt Report: Whyatt J, *The Citizen and Administration: The redress of grievance* (JUSTICE 1961)

²¹⁹ Abraham A, 'The Parliamentary Ombudsman and Administrative Justice: shaping the next 50 years' (2011) Tom Sargant lecture, <http://www.ombudsman.org.uk/about-us/media-centre/ombudsmans-speeches/2011/the-parliamentary-ombudsman-and-administrative-justice-shaping-the-next-50-years2/1> accessed 11.3.12

²²⁰ Following the Danish model: *ibid*, 5

²²¹ See Buck *et al* (2011)

²²² The members of the Commission are the two Local Government Ombudsmen and the Parliamentary Ombudsman. This latter role is currently combined with that of Health Service Ombudsman, held by Ann Abraham until 2011, from January 2012 by Dame Julie Mellor. There are also now a number of other private and public service Ombudsmen – see Buck *et al* (2011)

²²³ Regulatory Reform (Collaboration etc between Ombudsmen) Order 2007; St Helens case, 4 July 2011: "The Ombudsmen's power to investigate complaints jointly is particularly important when health and local government join together to provide a combined 'seamless' service - joint services mean joint accountability if things go wrong." Ann Abraham, Tom Sargant lecture (2011): 'This arrangement was put in place some years ago by way of a Regulatory Reform Order - which my Local Government Ombudsman colleagues and I try

independent of central and local government. They focus on individual dispute resolution, whilst also providing advice and guidance on complaint handling to public bodies, and reporting on wider issues²²⁴ as a means of driving improvement in public service provision.²²⁵ They thus serve both ‘consumer’²²⁶ and ‘managerial/bureaucratic’ models of administrative justice.

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Although the Ombudsmen have some powers equivalent to those of the courts,²²⁸ their approach to dispute resolution is fundamentally different. As the PHSO describes, ‘[t]he Ombudsman asks different questions from those asked in court and looks at different issues.’²²⁹ Their emphasis is on being open and accessible, and their service is free. Their investigations are inquisitorial and flexible in contrast to the courts’ formal and adversarial proceedings. They make non-binding recommendations²³⁰ rather than enforceable legal judgments, and may recommend individual remedies or systemic changes which are not available through the legal process.

womanfully to operate in the best interests of our mutual complainants – but which I can only describe in polite company as ‘challenging’.

²²⁴ For example the PHSO Report on Complaints about Disability Issues, 12 October 2011

²²⁵ See Abraham (2011), and Buck *et al* (2011) for discussion of the ‘novel techniques’ (ibid 125) being developed in this area

²²⁶ ‘Understanding expectations: customer satisfaction research for the LGO 2010’ Ipsos Mori Social Research Institute, October 2010

²²⁷ See Chapter 8 above. Buck *et al* identify a dual focus for the Ombudsman enterprise within the overarching purpose of ‘setting it right’ underlying the wider administrative justice system. That dual focus spans both the resolution of individual disputes where failures in administration have been identified (‘putting it right’), and contribution to the process of ‘getting it right’ first time by feeding back to public authorities knowledge and advice on good administration.

²²⁸ Such as a power to summon witnesses, and to obtain information and documents in the course of their investigation: for instance under the Local Government Act s29

²²⁹ PHSO ‘Report by the Parliamentary and Health Service Ombudsman on complaints about disability issues’, HC1512, 11 October 2011, 7

²³⁰ It is unusual for these recommendations not to be complied with: the Ombudsman’s findings of fact are binding on the authorities being investigated: *R v Local Commissioner for Administration ex p Eastleigh BC* [1988] 1 QB 855, see Birkinshaw P, ‘Grievances, Remedies and the State – Revisited and Re-appraised’ in Adler M (ed) *Administrative Justice in Context* (Hart 2010) 362; and the status of Ombudsman recommendations was enhanced following *R (Bradley and Others) v Secretary of State for Work and Pensions* [2007] EWCA 242 (Admin), where the Court of Appeal held that their findings should not be dismissed without good reason. The Law Commission sees recommendations as ‘essentially part of the political process’: Law Commission Report on Public Services Ombudsmen 2011, Summary, 5

The Ombudsmen investigate complaints about ‘maladministration’ and/or alleged ‘failure of service’.²³¹ ‘Maladministration’ is interpreted broadly and flexibly, to include delay, failure to follow procedures, inadequate consultation or record-keeping, or misleading or inaccurate statements.²³² For an investigation to result in a Report and/or remedy, maladministration by the public body must have caused ‘injustice’, such as hurt feelings, distress, worry or inconvenience, loss of right or amenity, not receiving a service, or financial loss.²³³ Like internal complaints and judicial review, complaint to the Ombudsman is not an appeal on the merits of a substantive decision: the closest the complainant may get to overturning a decision would be a finding of ‘failure of service’. However, the Ombudsman ‘enterprise’ is increasingly recognised as a developing constitutional alternative to the courts.²³⁴

While the PHSO investigates complaints against government departments and the NHS, the LGOs investigate local authority action, including their provision of adult social care. As ‘last resort’ redress mechanisms²³⁵ in health and social care, disability-related complaints make up a substantial proportion of the Ombudsmen’s workload;²³⁶ and in this context, they increasingly work together. For instance, ‘Six Lives: the provision of public services to people with learning disabilities’²³⁷ was a joint investigation by LGO and PHSO in response to complaints brought by MENCAP²³⁸ on behalf of the families of six people with learning disabilities who died while in NHS or local authority care. This was a high-profile investigation, which concluded that at least one, possibly two of the deaths resulted from ‘significant and distressing failures in service across health and social care’, some of which

²³¹ Local Government Act 1974 s26(1)(b) and (c); Health Service Commissioners Act 1993 s3; Parliamentary Commissioner Act 1967, s10

²³² <http://www.lgo.org.uk/about-us/> accessed 14.1.12

²³³ Ibid

²³⁴ See Buck *et al* (2011); Abraham (2011); O’Brien N, ‘Ombudsmen and Social Rights Adjudication’ [2009] Public Law 466; and contributions of Mullen, Dunleavy *et al* and Gulland in Adler M (ed) *Administrative Justice in Context* (Hart 2010)

²³⁵ A dis-satisfied complainant may request a further internal review or, if appropriate, apply for judicial review of the Ombudsman’s decision.

²³⁶ Around a third of the PHSO’s workload

²³⁷ Report on complaints 07B06309, 07B06077 & 07B09453 issued jointly with the Parliamentary and Health Service Ombudsman: laid before Parliament on 23 March 2009

²³⁸ MENCAP is an independent organisation which supports people with a learning disability, and their families and carers. <http://www.mencap.org.uk/about-us> last accessed 10.3.12

were for disability-related reasons; and that ‘many organisations responded inadequately to the complaints made against them, leaving family members feeling drained and demoralised.’²³⁹ Remedies included apology, financial compensation, recommendations to the bodies concerned to put in place service improvements, and ringing calls from both LGO and HSO for stronger leadership in health and social care professions to improve quality of care for people with learning disabilities.²⁴⁰

Since October 2010,²⁴¹ the LGOs’ social care remit has expanded to consider complaints from people who arrange and fund their own care, thus bringing the independent care sector²⁴² also under the LGOs’ scrutiny. This gives the LGOs currently a wider remit than the human rights jurisdiction of the courts,²⁴³ although awareness of this new role is as yet low.²⁴⁴ The PHSO similarly has power to address complaints relating to private

²³⁹ LGO Digest of Cases 2008-2009, Section L Social Care, p 12; these complaints followed on the heels of Joint Committee on Human Rights, ‘A Life Like Any Other? Human Rights of Adults with Learning Disabilities’. Seventh Report of Session 2007-08, HL Paper 40 HC 73, 6 March 2008. See also PHSO Report, ‘Responsive and Accountable? The Ombudsman’s review of complaint handling by government departments and public bodies 2010-11’, 25 October 2011

²⁴⁰ LGO Digest of Cases 2008-09, 12; for a more recent example, see ‘A report by the Health Service Ombudsman and the Local Government Ombudsman about the care and support provided to a person with Down’s syndrome’, HC 1644, 23 November 2011; see also Disability Rights Commission, ‘Equal Treatment: Closing the Gap: A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems’, (DRC 2006)

²⁴¹ Under Health Act 2009 s35 and Schedule 5

²⁴² Defined as all care providers registered with the Care Quality Commission.

²⁴³ See Human Rights Act coverage, above. While s145 Health and Social Care Act 2008 provides HRA protection for residents *in care homes*, the remit of the LGO now includes all care providers registered with the Care Quality Commission (CQC), including those providing *domiciliary* personal care services. (Health & Social Care Act 2008 s1). Indeed, the LGOs’ new remit may go wider even than that of the CQC. The CQC does not require registration ‘[w]here a person makes their own arrangement for nursing care or personal care, and the nurse or carer works directly for them without an agency or employer involved in managing or directing the care provided’ (CQC ‘Scope of Registration’, December 2011,12) as, for instance, where an individual directly employs a personal care assistant from their own funds or using Direct Payments. On the other hand, ‘[t]he LGO’s new role includes those who ‘self-fund’ from their own resources or have a personalised budget.’ (<http://www.lgo.org.uk/adult-social-care/> accessed 14.1.12)

²⁴⁴ LGO research in 2011 reports that ‘none of the users, relatives and advocates we spoke to had been aware of the change in LGO jurisdiction. This included paid staff at advocacy organisations.’ Once aware, however, participants were ‘overwhelmingly positive about the LGO’s new remit.’ LGO ‘Complaints about privately funded and arranged adult social care’ 2011, Executive Summary, 6. The issue of ‘self-funders’ and access to/quality of care had been highlighted by CSCI in its 2008 report ‘Lost to the System? The Impact of Fair Access to Care’

contractors in the NHS.²⁴⁵ As Buck *et al* comment, these Ombudsmen - unlike the courts - are 'well placed to deal with the practice of transferring public functions to the private sector'.²⁴⁶

As public authorities, the Ombudsmen must act compatibly with European Convention rights,²⁴⁷ although, unlike the courts, they are not required to 'take into account' Strasbourg jurisprudence.²⁴⁸ Nor do they create or follow precedent. Instead, they have developed overarching principles relating to good administration, complaint handling and remedy against which to assess the actions and decisions of public bodies.²⁴⁹ According to these Principles, good administration requires the authority to be customer-focused, open and accountable, to act fairly and proportionately, to put things right when they go wrong, and to seek continuous improvement. It also requires them to 'get it right' in the first place by complying with law and guidance, including human rights and equality law, and having regard for the rights of those concerned. However, the Ombudsmen are careful to distance themselves from the court-based legal process:

[t]he Ombudsman is not empowered to determine whether the law has been breached. The Ombudsman system of justice provides an alternative to taking a case to court but it is not a surrogate court... Although the Ombudsman does not determine or enforce the law she is nevertheless helping to *give force to the principles* that underpin the law as they affect the circumstances of the individual concerned.²⁵⁰ (emphasis added)

As O'Brien comments, this distinction between enforcing the law and 'giving force to' the principles that underlie it demonstrates a measure of ambivalence.

On the one hand, there is clear and understandable intention to distance the role of the ombudsman from overt determination of matters

²⁴⁵ 'Investigate any action taken by *or on behalf of* a government department' Parliamentary Commissioner Act 1967, s5(1) (emphasis added): Buck *et al* (2011) 108

²⁴⁶ *ibid*

²⁴⁷ HRA s6

²⁴⁸ Birkinshaw P, 'Grievances, Remedies and the State – Revisited and Re-appraised' in Adler M (ed) *Administrative Justice in Context* (Hart 2010) 364

²⁴⁹ <http://www.ombudsman.org.uk/improving-public-service/ombudsmansprinciples> accessed 11.4.12

²⁵⁰ PHSO 'Report by the Parliamentary and Health Service Ombudsman on complaints about disability issues', HC1512, 11 October 2011, 7-8

of human rights law. On the other hand, the reports themselves come very close to making findings that effectively depend upon the sort of human rights adjudication that is in principle being banished. To say, for example, that the “basic human rights” of dignity and privacy have been “denied” or that there has been “a failure to live up to human rights principles” is to come very close to active adjudication of the human rights issues at hand.²⁵¹

Nevertheless, this conceptual sleight of hand allows the Ombudsmen to take a much broader and more flexible approach to human rights and equality than that we have seen above in the context of judicial review. This approach can be seen in the 2011 ‘Report by the Parliamentary and Health Service Ombudsman on complaints about disability issues’ (the 2011 Report).²⁵²

The 2011 Report suggests that the three Principles of Good Administration most likely to come into play in relation to complaints about unfair treatment or poor services provided to disabled people are: ‘getting it right’, being customer focussed, and acting fairly and proportionately.

‘Getting it right’ includes

acting in accordance with the law and with regard for the rights of those concerned.... In this context... the *Disability Discrimination and Equality Acts*, together with the *Human Rights Act*, are of particular relevance, forming a specific element of the overall standard...²⁵³
(original emphasis)

Where rights under that legislation are engaged, the public body is expected to take account of those rights in their decision-making and in carrying out its functions throughout provision of services to the complainant. The 2011 Report illustrates this principle through the case of Miss W, a 40-year-old woman with learning disabilities and epilepsy, whose (mis)treatment in hospital included medication without consent and lack of basic nursing care. Here, the Ombudsman found

²⁵¹ O’Brien (2009) 474

²⁵² PHSO ‘Report by the Parliamentary and Health Service Ombudsman on complaints about disability issues’, HC1512, 11 October 2011

²⁵³ *Ibid* 8

minimal evidence which demonstrated that either doctors or nurses had regard to the law or any guidance relating to the provision of services for people with disabilities when they planned and delivered Miss W's care, or that Miss W's rights under disability discrimination law were a relevant consideration in their decision making about Miss W's care or the way that care was provided. Therefore we concluded that in providing care to Miss W, the Trust did not have regard to its obligations to her under disability discrimination law. The Trust's failing in this respect was so serious as to constitute service failure.²⁵⁴

The public body is also expected to have

had regard to and have taken account of core human rights principles of fairness, respect, equality, dignity and autonomy.²⁵⁵

These 'FREDA' principles have been central to the development in England of a 'human-rights-based approach' to public service provision:²⁵⁶ they supported the New Labour government's objective of creating a 'human rights culture' in the UK.²⁵⁷ Under the Ombudsman Principle of 'getting it right', failure to demonstrate compliance not only with the law but also with FREDA principles may contribute to maladministration or service failure. For instance, in the *Six Lives* case, as well as focusing on Articles 2, 3 and 14 ECHR, the Disability Discrimination Act,²⁵⁸ and relevant policy, the Ombudsmen found that eight of the public bodies investigated failed to live up to human rights principles, including equality, dignity and autonomy.²⁵⁹

'Being customer focused' requires the public body to ensure ease of access to its services, and to treat each individual with sensitivity bearing in mind their individual needs and responding flexibly to the circumstances of the

²⁵⁴ Ibid 24

²⁵⁵ Ibid

²⁵⁶ promoted by, amongst others, the British Institute of Human Rights in its work with the health care sector, <http://www.bih.org.uk/projects/human-rights-in-healthcare> accessed 11.4.12; see for instance Butler F, *Human Rights: Who Needs Them?* (Institute for Public Policy Research 2004)

²⁵⁷ 'What I mean ... when I talk about a culture of human rights is to create a society in which our public institutions are habitually, automatically responsive to human rights considerations in relation to every procedure they follow, in relation to every practice they follow, in relation to every decision they take, in relation to every piece of legislation they sponsor.' Lord Irvine, Lord Chancellor, 2001

²⁵⁸ 'Equality for people with disabilities does not mean treating them in the same way as everyone else. Sometimes alternative methods of making services available to them have to be found in order to achieve equality in the outcomes for them. The focus is on those outcomes.' *Six Lives*, Part 1

²⁵⁹ *Six lives*, part 1, 3

case;²⁶⁰ while ‘acting fairly and proportionately’ means understanding and respecting diversity, treating people equally regardless of their background or circumstances, and ensuring that decisions and actions are proportionate, appropriate and fair.²⁶¹ The aim is to ensure equality of outcome.²⁶² Again, where such standards have not been met, this may contribute to a finding of maladministration or service failure. The 2011 Report refers to the case of Mr L, a 21-year-old man with severe learning disabilities, whose hospital consultant blamed the failures in his treatment which led to his death on his ‘being a poor historian... [He] was mentally subnormal...’²⁶³ Here, the Ombudsman found it ‘extraordinarily inappropriate’ that the consultant should use such language, and ‘astonishing’ that he expected Mr L to be capable of providing the relevant history. ‘Mr L’s rights under discrimination law were engaged and should have been a relevant consideration in the Trust’s decision-making,’²⁶⁴ but they failed to ‘get it right,’ resulting in service failure.

Rights under the HRA and Equality Act, however, are limited to European Convention rights and non-discrimination. Here, as in the Courts - and despite the clearly disability-related and socio-economic nature of these complaints - economic, social and cultural rights, the CRPD and Article 19 remain invisible. However, as Abraham argues,

[t]he greater subtlety and persuasive nature of the ombudsman technique make it ideally placed to deal with disputes that touch upon the most sensitive areas of social and economic rights.... The orthodoxy is that such rights are not areas suitable for court-based adjudication. Yet internationally agreed commitments to social and economic rights still remain, and citizens will regularly feel let down by the actions or lack of action by public authorities in areas such as the provision of social housing, health care, disability and social services. Precisely because ombudsmen already deal with complaints that touch upon dignity and rights in a range of public services, they are well placed to develop these themes as matters of good administrative standards, flexibly applied and improved over time, rather than enshrined in hard-edged legal standards.²⁶⁵

²⁶⁰ PHSO ‘Report by the Parliamentary and Health Service Ombudsman on complaints about disability issues’, HC1512, 11 October 2011, 9

²⁶¹ Ibid

²⁶² Ibid

²⁶³ Ibid 21

²⁶⁴ Ibid 22

²⁶⁵ Abraham A, ‘The Ombudsman and the Executive: the Road to Accountability’, (2008) 61(3) Parliamentary Affairs 535, cited in Buck *et al* (2011) 38

In practice, then, the Ombudsmen recognise their role in the progressive implementation of economic, social and cultural rights. Moreover, scrutiny of the Ombudsman Principles as applied to complaints about disability issues reveals parallels between the Ombudsmen's approach and that of the CRPD. Both emphasise respect for dignity, autonomy and equality; and the continuous application of these principles throughout the provision of services to the disabled person.²⁶⁶ Both require planning, design and delivery of services to ensure that disabled people can access them easily; and that individuals be treated with sensitivity, 'bearing in mind their individual needs and responding flexibly to the circumstances of the case'.²⁶⁷ Both require respect for difference and acceptance of people with disabilities as part of human diversity, with equal access and treatment regardless of their background or circumstances to ensure equality of outcome.²⁶⁸

Furthermore, Ombudsman investigations frequently prompt actions conforming to CRPD requirements. For instance, in Miss W's case, the NHS Trust agreed to prepare an action plan to share lessons learnt with its clinical teams and to avoid a recurrence, in line with CRPD Article 4(d). In Mr L's case, the Trust set up a Learning Disabilities Focus and Task Group, in line with CRPD Article 4(3),²⁶⁹ undertook training programmes in line with CRPD Article 4(i),²⁷⁰ and commissioned an external review of their care for people with learning disabilities in line with CRPD Article 4(c). Recommendations from the *Six Lives* Report include not only remedial action by the relevant public bodies,²⁷¹ but also that all NHS and social care organisations in England urgently review the effectiveness of their systems for understanding

²⁶⁶ CRPD Article 3, general principles/Ombudsman Principle 'getting it right'

²⁶⁷ CRPD Articles 9, accessibility and 19(c) equal access to services, responsive to needs/Ombudsman Principle 'being customer focused', PHSO (2011) 9

²⁶⁸ CRPD Articles 1, purpose and 3(d) respect for difference/Ombudsman Principle 'acting fairly and proportionately' PHSO (2011) 9

²⁶⁹ Consisting of care providers, relatives and hospital staff

²⁷⁰ Such as study days for Trust staff using specific case examples

²⁷¹ Including senior level personal apology and offer of meetings, offer to involve family in planning services, actions to address failings and to minimise risk of reoccurrence, action plan notified at Board level and to the regulator, commitment to learn lessons from the investigations, and to work openly and collaboratively with local and central bodies, and identification of lessons learnt: see *Six Lives* supra

and meeting the needs of people with learning disabilities; that those responsible for the regulation of health and social care services check that their frameworks and monitoring systems ensure effective protection; and that the Department of Health 'promote and support the implementation of these recommendations, monitor progress against them and publish a progress report within 18 months of the publication of this report'.²⁷² The Department of Health duly produced a progress report in October 2010, setting out (including in accessible format) a range of improvements and remaining problems, with priorities for further work. The Ombudsmen's recommendations have thus – at least potentially - influenced not only the outcomes for the complainants, but also the awareness and actions of the individual public bodies, of those who work in them, and of the wider health and social care system, in line with CRPD Article 3, general principles; Article 4, States' general obligations; Article 8, awareness-raising; Article 9, accessibility; Article 19(b) & (c) services to support independent living; and Article 25, right to health. They thus help to influence understandings, systems and identities at all levels towards a more rights-based understanding of the economic, social and cultural rights required for the exercise of Article 19 and other CRPD rights. The Ombudsmen's stated objective is 'to change underlying attitudes and behaviour on a lasting basis',²⁷³ though they 'do not underestimate the challenges involved'.²⁷⁴

In a domestic setting which excludes economic, social and cultural rights, there are thus at least six aspects of the Ombudsman 'enterprise' that make it particularly apt as a forum for Article 19 socio-economic rights adjudication in line with CRPD understandings. Its accessibility, its distancing from the 'legal' forum of the courts, its focus on 'giving force to' principles rather than enforcing the law, its flexibility of remit and of process, the persuasive nature of its recommendations and the wide scope of available remedies all allow for a 'softer' approach to implementation of Article 19 socio-economic rights. However, these developments constitute a move away from a 'legal' model of

²⁷² *Six lives* Part 1 conclusions and recommendations

²⁷³ *Ibid*

²⁷⁴ *Ibid*

administrative justice towards a 'consumer'(giving people a voice)/ 'managerial'(improving public services)²⁷⁵ approach which, though potentially more acceptable in dominant domestic discourse, runs counter to the international economic, social and cultural rights discourse promoted by the UN Committee on Economic, Social and Cultural Rights.²⁷⁶

Moreover, opportunities to exercise the Ombudsman approach are limited. The complaint must first have exhausted available internal complaint mechanisms:²⁷⁷ as we have seen, complaints reaching this level of the administrative redress hierarchy represent the tip of the iceberg.²⁷⁸ Whether or not the Ombudsmen's developing confidence has an impact on the effectiveness of first tier complaints remains to be seen.²⁷⁹ Resource constraints dictate that the Ombudsmen concentrate on the more difficult and time-consuming cases, referring others back to the public body concerned for more 'proportionate dispute resolution',²⁸⁰ where they may or may not receive adequate consideration.²⁸¹ Furthermore, there is no statutory recognition of

²⁷⁵ See Adler models of administrative justice, Chapter 8 above

²⁷⁶ See constructive dialogue, Chapter 5 above

²⁷⁷ With some exceptions, at the discretion of the Ombudsman

²⁷⁸ In 2006-07, 1.75 million adults received one or more directly provided or commissioned social care services from their local authority. Those authorities received an estimated 17,100 complaints about adult social care services, of which around 95% were concluded at the first local stage, 900 complaints were investigated under Stage 2 (formal complaint), and 200 went to the third stage Review Panel. In the process, local authorities chose to spend an estimated total of £1.3 million on advocacy support for complainants, compared with £10.7 million spent on national statutory advocacy support for Health Service complainants. In that year, the LGO received 795 complaints relating to adult social care services that had not been resolved by local authorities. National Audit Office (2008) Executive Summary, 6, Table 2. In Sheffield, out of 211 complaints received in 2009-10, 5 were withdrawn, 116 remained live on 31 March 2010, and 90 had been completed. Sheffield City Council Annual Report on Complaints, 2009-10, 4

²⁷⁹ Gulland (2010) 477-8: 'We can only hope that the ombudsmen's confidence in their role, up to a point, supported by policy makers, will have an impact on the effectiveness of first tier complaints in public services. However, taking into account the variety of services concerned, the complexities of modern governance and the fact that complaining means different things to different people, this is quite a challenge.'

²⁸⁰ Buck *et al* (2011) 113

²⁸¹ For instance, although the number of LGO complaints about adult social services has been rising sharply, a high proportion of those subsequently reach remedy or settlement at local level, with only a very small number resulting in an LGO report of maladministration causing injustice. Between 2009/10 and 2010/11 complaints about care arranged or funded by councils doubled from 657 to 1,351, and in the six months to April 2011 the LGO received 141 and investigated 75 complaints under its new adult social care powers: LGO Annual Review letter to Doncaster Council, April 2011. LGO Annual Report figures for 2010-11 show a rise of 73% in complaints about adult social care, from 1052 to 1820: LGO detailed complaint statistics 2010-11, Table 1. <http://www.lgo.org.uk/publications/annual-report/>

the Ombudsman's role in the implementation of economic, social and cultural rights,²⁸² and visibility of the service remains low. Nevertheless, while the courts are retreating from involvement in this field, the Ombudsmen are expanding their role in a way that may contribute, however incrementally, to a more CRPD-compatible understanding of socio-economic rights in the context of Article 19. Some observers call for current restraints to be eased through introduction of an 'own initiative' power of investigation,²⁸³ and through more formal recognition of the Ombudsman's constitutional place as part of an integrated and coherent administrative justice system.²⁸⁴

The development of such a system, however, seems far from assured. The Administrative Justice and Tribunals Council (AJTC) set up in 2007²⁸⁵ to further that goal looks set to be abolished. According to Abraham, the AJTC

seemed at last to reaffirm Whyatt's vision of an integrated administrative justice system. If it is abolished, any such hope can only evaporate. The supposition that the Ministry of Justice, with its historic emphasis on civil justice and its current preoccupation with criminal justice, might fill the gap is surely fanciful. The reality sadly is that with the disappearance of the AJTC the prospect of an administrative justice system worthy of the name is as remote as ever.²⁸⁶

accessed 15.1.12. During 2010-11, 212 adult social care Ombudsman cases were remedied or settled at local level; maladministration causing injustice was found and reported in 3 adult social care cases. <http://www.lgo.org.uk/publications/analysis-complaints-2010-11/> accessed 4.3.12; for discussion, see Buck *et al* (2011) 112. In the same year, the PHSO received 15,066 health-related complaints, and accepted 351 for formal investigation. 79% of these investigated complaints were upheld or partly upheld. PHSO 'Listening and Learning: the Ombudsman's review of complaint handling by the NHS in England 2010-2011', <http://www.ombudsman.org.uk/healthchp/statistics/year-at-a-glance> accessed 10.4.12

²⁸² O'Brien (2009) 475; Buck *et al* (2011) 'do not believe that it is necessary to clarify this development in legislation', 239

²⁸³ 'the time has finally come to acknowledge the power of own initiative investigation, to accept that, in the absence of a specific individual complaint, the Ombudsman should not stand idly by. The ability from time to time, not all the time, to seize the initiative, to catch the whiff of a scandal and run with it, is now a necessity not a luxury, especially if social justice is to reach some of the most vulnerable and marginalised people in society.' Abraham (2011) 28

²⁸⁴ See Abraham (2011), Buck *et al* (2011); Birkinshaw (2010) 361-363; Law Commission Report on Public Service Ombudsmen (2011); House of Commons Select Committee on Public Administration, 'When Citizens Complain' Fifth Report, Session 2007-08, 24 March 2008

²⁸⁵ In response to the 2004 White Paper *Transforming Public Services: Complaints, Redress and Tribunals*, July 2004, Cm 6243

²⁸⁶ Abraham (2011)

Conclusion

This Chapter concludes Part 2 of the thesis, which has explored the potential for expansion of the CRPD-drafters' project in England. It has examined the UK's international dialogue with the UN Committee on Economic, Social and Cultural Rights and domestic implementation of CRPD Article 19. Chapter 5 concluded that the UK has not yet made the transition in understanding from 'welfare' to 'rights' that the CRPD requires. Chapters 6 to 8 have explored some effects of this mis-understanding on implementation through policy, law and practice in England of CRPD Article 19, the right to live independently and be included in the community. Alongside a strong and expanding civil and political discourse built on concepts of individual autonomy and choice, these Chapters found continuing invisibility of the economic, social and cultural rights essential for their exercise. With the CRPD and Article 19 also invisible, the lack of any international human rights framework to guide implementation of the socio-economic rights involved provides opportunities for regression, instability, and continuing oppression in 'welfare' policy, law and administration.

Chapter 9 has investigated the potential of internal complaints procedures, judicial review and complaint to the Ombudsman to counter this imbalance in domestic human rights protection. It has found that the capacity of internal complaints procedures to influence wider policy, law or administration towards more CRPD-compatible understandings remains negligible. Interpreted positively, new regulations allow for a more flexible and outcome-focussed approach. However, that interpretation will depend on the discursive struggles within each institution and on the subject positions of the various actors. Economic, social and cultural rights, the CRPD and Article 19, which might offer guidance and coherence, remain invisible. Moreover, the 'consumer'/'managerial' focus on procedure rather than substance means that even the most positive interpretation of the new regulations may leave the complainant's substantive problem unresolved and the complainant frustrated and exhausted, with judicial review or complaint to the Ombudsman as their potential 'last resort' options for redress.

Exploration of judicial review has examined the judges' application of common law, disability equality law and European Convention jurisprudence in the context of Article 19 service provision. Whilst a 'core minimum' of provision is recognised in common law, the courts' insistence that public resources may be taken into account effectively reduces any incipient individual 'right' to service provision to a discretionary power. Application of disability equality law has, in some cases,²⁸⁷ challenged the raising of eligibility for services to those with 'critical' need only. However, the public authorities challenged remain free to reconsider their decision in a procedurally correct manner and reach the same decision. With consolidation of the disability equality duty into the Equality Act's new, less stringent, public sector duty, such cases may become less effective. Introduction of the Human Rights Act prompted some judges to interpret Strasbourg jurisprudence expansively, in line with subsequent CRPD Article 19 requirements, particularly in relation to ECHR Article 8 rights to suitably adapted accommodation, dignity and participation. However, such expansion was swiftly reversed, with the imposition of a higher bar to engagement of Article 8 than that imposed in Strasbourg.

As a result, resource arguments may still justify refusal of all but a 'core minimum' of provision; arguments relating to dignity, participation and positive human rights obligations are confined to the most extreme cases. Here too, the CRPD and Article 19 remain invisible. Case law thus reflects rather than alters dominant exclusionary understandings: the capacity of judicial review to influence policy, law or administration towards more CRPD-compatible understandings appears remote.²⁸⁸ Moreover, the future of judicial review itself as a redress mechanism in the context of Article 19 looks uncertain in the context of increasing privatisation of the 'social market', and of Lord Woolf's signposting of such cases to the Ombudsman.

²⁸⁷ But not in others, for instance *R (JG and MB) v. Lancashire County Council* [2011] EWHC 2295 (Admin)

²⁸⁸ But see discussion of *Burnip v Birmingham City Council* [2012] EWCA Civ 629 in Postscript, below

Examination of the Ombudsmen's role reveals potentially more promising developments for expansion of a CRPD-compatible discourse. Unlike the courts, the service of PHSO and LGOs is free and accessible, their investigations inquisitorial and flexible, their brief to counter public sector 'maladministration' broad and unfettered by precedent, and their remit inclusive of private sector providers. As public bodies themselves, they must act compatibly with the European Convention. The principles they have developed to guide their work reflect this duty, requiring the public authorities concerned to comply both with European Convention and disability equality law as 'standards', and with human rights principles of fairness, respect, equality, dignity and autonomy. Whilst not 'enforcing' the law itself, they see themselves as 'giving force to' the principles that underpin the law. This conceptual sleight of hand enables the Ombudsmen to take a much broader and more flexible approach to human rights and equality than the courts, while the non-binding (though influential) nature of their recommendations encourages co-operation and incremental change on the part of the public bodies concerned at both local and national levels. Although the CRPD and Article 19 so far remain invisible here, in practice the Ombudsmen recognise their role in the progressive implementation of economic, social and cultural rights. The capacity of LGOs and PHSO to influence policy, law and practice relating to Article 19 services towards a more CRPD-compatible approach is therefore promising. However, such promise is not without its challenges, including reliance on exhaustion of internal complaints procedures, resource constraints, lack of visibility and lack of statutory recognition of the Ombudsmen's constitutional role in the implementation of all human rights.

Rather than countering the imbalance in domestic human rights protection to encourage a more CRPD-compatible discourse, available redress systems generally engage complex and labyrinthine systems of social relations which reflect dominant exclusionary understandings and may intensify rather than counter oppression. As O'Grady *et al* conclude,

[t]he disabling nature of society as it is currently structured places disabled people in a particularly vulnerable situation as regards the experience of justiciable problems. This vulnerability is, we argue, yet another facet of the social exclusion of disabled people from society. Disabled respondents to the [Legal Services Commission Civil and

Social Justice] survey demonstrated their action-orientated approach to dealing with justiciable problems. It is highly problematic however, that disabled people should have to rely primarily on their own actions and strategies to combat the disabling outcomes of society. Legal and advice services are important means through which social injustices can be addressed. However, increasing access to legal and advice services cannot, on its own, bring about social justice for the disabled population. Only concerted action to address the ways in which society disables people can do this.²⁸⁹

Chapter 10 brings the thesis to a close, and offers recommendations towards development of more CRPD-compliant understandings, and thus applications, of the law.

²⁸⁹ O'Grady *et al* (2004) 271. Note subsequent withdrawal of legal aid from many of these justiciable problem areas under the Legal Aid, Sentencing and Punishment of Offenders Act 2012; and see Postscript below

Chapter 10

Conclusion and Recommendations

Introduction

As noted in Chapter 1, this research project springs from the writer's long standing engagement in the field of disability rights, combined with an interest in the capacity of administrative and human rights law to bring about emancipatory change. The international disability/human rights discourse, with the hegemonic project it has spawned, is one with which the writer identifies. It is also one that has been encapsulated in international human rights law to which the UK government is committed. Both aspects are reflected in the thesis: it is positioned within both the discipline of law and the discipline of disability studies. Whilst its focus has been firmly on the law, its ethos has been that of emancipation.

In examining international treaties, national legislation and case law, the thesis has employed classical legal doctrinal methods, reflecting its basis in the discipline of law. The text of the CRPD has been discussed in the light of its context, object and purpose, its preamble and travaux préparatoires, and the circumstances of its conclusion, in line with the Vienna Convention on the Law of Treaties.¹ Domestic legislation, case law and administration relating to Article 19 have been described and analysed employing standard administrative law techniques.

¹ Vienna Convention on the Law of Treaties 1969, Articles 31 and 32

However, in the world of political discourse theory, everything has meaning: it is not possible to stand outside the social space to take a 'neutral' position. On that basis, this thesis has argued that law is not neutral. Legal cartographers choose to project their multi-dimensional political social reality into a two-dimensional legal map not only according to technical factors, the map's purpose and its cultural context but also according to their own ideologies. Their projection decisions inevitably distort reality, and because choices need to be made, that distortion will never be neutral.² Equally, it is argued here, academic research functions within a complex and dynamic socio-political context, influenced by a multitude of discursive understandings, systems and identities,³ including those of the researcher.⁴ The planning, research and writing of a thesis constantly require choices to be made, and those choices will never be neutral.⁵

In the field of disability, the 'positioning' of the researcher becomes particularly crucial. As we have seen throughout the thesis, here too everything has meaning: it is not possible to take a neutral position. While much mainstream disability research founded in the discourse of 'normality' has contributed to the objectification of disabled people, researchers identifying with the academic discourse of disability studies attempt to counter such objectification and to contribute to inclusive understandings and practices.⁶ Just as Laclau describes his work as a 'viewpoint from which to think politics',⁷ so disability studies perspectives can be understood as

² See Santos (2002) and discussion of 'projection' in Chapter 1 above

³ See, for instance, discussion of disability statistics in Chapter 1 above

⁴ See references under Chapter 1, footnote 39 above. Also Beresford P, *It's Our Lives: a short theory of knowledge, distance and experience* (Citizen Press in association with Shaping Our Lives, 2003): 'much social research, including social policy research is concerned with people facing discrimination, disadvantage and exclusions. By emphasising the value of neutrality we are downgrading the value and validity of their direct experience. We are adding to oppression and discrimination by routinely treating their knowledge as less valid and less reliable.'

⁵ 'Ways of viewing disability, of developing research questions, of interpreting research results, of justifying research methodology, and of putting policies and programmes in place are as much about ideology as they are about fact...' Rioux MH 'Disability: the place of judgement in a world of fact' (1997) 41(2) *Journal of Intellectual Disability Research* 102, abstract

⁶ See Chapter 1 above

⁷ Laclau (1990) and see Chapter 1 above

‘particular knowledge positions from which to address and refute disablism.’⁸ The choice of these discursive understandings as basis for the projection decisions taken in the course of planning, researching and writing this thesis inevitably reflects the ideological identity, practical experience and interests of the writer. However, it is the law as entrenched in the CRPD by its drafters that binds the UK government and demands paradigm change. Whilst it is hoped that the analyses set out in the thesis contribute to understanding that process of change, the recommendations below offer more concrete suggestions for overcoming some of the current obstacles to realisation of disability rights in England in conformity with the legal requirements of the CRPD.

This Chapter brings the thesis to its conclusion. It summarises the thesis’ approach, findings and conclusions before making recommendations to help engender a more CRPD-compliant discourse in domestic policy, law and practice. Recommendations are directed to government,⁹ as it is there that international legal obligations rest. Finally, it suggests further related areas for research from a political discourse theory perspective.

Summary and conclusions

To recapitulate, this thesis is about understandings, about how those understandings shape the law, and about how the law helps to shape those understandings. Its first premise is that law is formed and functions within a complex and dynamic socio-political context from which it is inseparable.¹⁰ The argument has been made through the prism of political discourse theory, enabling analysis of the processes by which such understandings come about, how they ‘shift’, and how they become sedimented in social structures and norms and in the realities of people’s lives. The social world is understood as consisting of ever-changing and dynamic discourses, forming and attempting to expand themselves by incorporating some discursive

⁸ Goodley (2010) 10

⁹ Of any political persuasion

¹⁰ See for instance O’Cinneide, C (2009) 168

elements and excluding others. The negation of identity essential for expansion of a discourse gives rise to social antagonism, whereby those excluded challenge and seek to undermine the discourse(s) from which they have been excluded. There is no possible 'final' resolution of these dynamic tensions, but that does not prevent us from wishing, and working, for such resolution through promotion of the hegemony of those discourses with which we identify.¹¹ The laying down of ideas and practices in legal text, the interpretation and implementation of those legal texts through legal and administrative systems, is one collection of social practices through which a political discourse may seek to dominate the field of meaning. As the law reflects and influences social understandings, structures and identities, it may contain and regulate a dominant social order or contribute to development of emancipatory social change.¹²

From this perspective, Part 1 of the thesis traced some discursive elements whose partial convergence gave rise to a new international disability/human rights discourse; and the hegemonic project to sediment that discourse in the text of a new legal order. It described the unique participatory drafting process which gave rise to the CRPD; the reshaping of the human rights framework to reflect and embrace the experience of disability; and the Convention's provisions for continuation of the international hegemonic project to drive implementation. The myth embedded in the CRPD pictures an accessible and welcoming world, where impairment is accepted as universal human variation, and disabled people are no longer excluded recipients of welfare, but active, valued and equal rights-holders. Key to this 'paradigm change' from welfare to rights is the full and equal enjoyment of all human rights: the CRPD text melds together civil, cultural, economic, political and social rights into an integral legal order which highlights new angles of the human rights framework and challenges basic human rights assumptions. Through this 'revolving door', the drafters' hegemonic project seeks to circulate its forms of power and knowledge so as to redefine the terms of the

¹¹ For instance, this thesis has been situated within both the discipline of law and the emancipatory ethos of disability studies (see above and Chapter 1)

¹² Chapter 1 above, and see Santos (2002)

political debate and set a new, transformative agenda within national settings around the world.

Whether, or to what extent, that project succeeds will depend not only on the power of the CRPD itself to drive implementation, but also on the reception, antagonisms or dislocations it encounters in the domestic sphere. Part 2 of the thesis turned to the UK to assess potential for expansion of the CRPD-drafters' project here. Chapter 5 highlighted the reluctance of successive UK governments to recognise and implement international economic, social and cultural rights standards. It concluded that UK governments have not yet fully made – indeed that they resist - the transformation in understanding from 'welfare' to 'rights' that the CRPD demands. The remainder of Part 2 explored the impact of this mis-understanding on implementation in England of Article 19, the right to live independently and be included in the community.

With continuing invisibility of economic, social and cultural rights, of the CRPD and of Article 19 in domestic independent living discourse, and thus with no recourse to the international human rights framework which might provide stability and coherence, Chapters 6 to 8 identified re-articulation, antagonism and regression in the policy field, partial and unstable legislative development, and an administrative system in flux, prey to conflicting logics and oppressive dynamics for decision-makers and service users alike. The CRPD-drafters' hegemonic project faces considerable challenges in this English domestic setting - in the field of meaning, in systems of social relations and in the formation of actor identities. Chapter 9 explored the capacity of available redress systems to influence independent living discourse towards more CRPD-compatible understandings. It concluded that, rather than advancing the CRPD drafters' emancipatory project, redress systems generally reflect dominant exclusionary understandings, and may intensify rather than countering oppression.

Article 19 is a hybrid right: realisation of its socio-economic provisions is a pre-requisite for exercise of its civil and political rights to autonomy and

participation. How these socio-economic provisions are implemented therefore has a determinative effect on its implementation. Part 2 of the thesis has argued that the UK's reluctance to acknowledge economic, social and cultural rights results in mis- and partial understandings, and thus in mis- or partial application, of Article 19. Article 19 is also an 'enabling' right: without the actual choice, control and freedom it requires, the exercise of all other rights is compromised. Part 2 of the thesis argues that mis- and partial application of Article 19 in turn undermines implementation of the Convention as a whole.

Moreover, Article 19 is emancipatory law *par excellence*. It is designed to contest oppression by bringing about a 'new political relationship'¹³ between the experiences and expectations of both disabled and 'non-disabled' people, and to stabilise those expectations on a new and more demanding level. For this reason, Article 19 was chosen in Part 2 of the thesis as a 'barometer' for progress – or otherwise - of the CRPD drafters' hegemonic project in England. Examination of implementation of Article 19 in England through policy, law and administration has identified re-articulation and dislocation in the field of meaning, instability and regression in systems of social relations, and continuing oppression in some areas of practice, demonstrating frustration of the CRPD drafters' hegemonic project in the English domestic sphere.

The UK states that it 'will not ratify a treaty unless the Government is satisfied that domestic law and practice comply.'¹⁴ On ratifying the CRPD, the UK undertook to 'ensure and promote the full realisation of all human rights'¹⁵ – civil, cultural, economic, political and social – for all disabled people in its jurisdiction. At the same time, successive governments continue to insist that economic, social and cultural rights cannot be incorporated in a meaningful

¹³ Santos (2002) and see Chapter 2 above

¹⁴ UK Report to UN Periodic Review 2008; see also Anne McGuire, Minister for Disabled People, Statement to Parliament Tuesday 6 May 2008

¹⁵ CRPD Art 4(1)

way within the British legal system,¹⁶ with the result that such rights remain invisible in domestic social, legal and political discourse. This thesis has argued that this contradiction in terms results in key elements of international disability/human rights discourse not being absorbed into the domestic sphere. In consequence, the UK has not made the transition from welfare to rights thinking that the CRPD requires, understanding and realisation of Article 19 in England are partial, realisation of other Convention rights is compromised, and expansion of the CRPD drafters' hegemonic project is undermined. For international disability/human rights discourse to be translated from myth to imaginary in England – to represent a 'default' system of meanings that underlies and structures our society – and for domestic law and practice to comply with international requirements, domestic discourse must absorb those key elements of international disability/human rights understandings which so far remain excluded. Some such elements have been identified in Chapters 5 – 9, and are discussed, with recommendations for government,¹⁷ below.

Discussion and recommendations

Nothing about us without us

From the earliest days of the international disabled people's movement, the demand not only to be heard but to be actively involved in decision-making, to share power, has formed a strong discursive element.¹⁸ It may be understood as antagonistic response to the 'dependency born of powerlessness, poverty, degradation and institutionalisation' described by Charlton¹⁹ which has resulted from the dominance of the ableist, exclusionary liberal discourse of 'normality'.²⁰ Chapter 2 traced the growing influence of disabled people at international level: in establishing the question

¹⁶ United Kingdom of Great Britain and Northern Ireland, Fifth Periodic Report to the Economic, Social and Cultural Rights Committee, July 2007, para 74

¹⁷ As noted above, these recommendations are directed to government (regardless of political persuasion) as it is there that international legal obligations lie

¹⁸ See Hurst's account of the 1981 RI conference in Winnipeg in Chapter 2 above: 'we are the people you are talking about, we must have a substantial voice in what you're saying.'

¹⁹ Charlton (2000) 3

²⁰ See Chapter 1 above

of disability as a human rights issue, in shaping the ten-year UN World Programme of Action and in drafting and monitoring the Standard Rules. Growing acknowledgement of their expertise in issues of identity, survival and dignity is further reflected in the hegemonic practice of negotiating the CRPD, as it adopts a holistic and participatory approach that takes the views and lived experience of disabled people as its principal point of departure. Relations of difference prevail to enable stable compromise and discursive expansion. This participatory approach is reflected not only in the text of the CRPD²¹ but also in the emphasis placed there on the ongoing participation of disabled people and their organisations throughout its implementation and monitoring at all levels.

In the English domestic sphere, however, Chapter 6 has found a very different social space. English disabled people's organisations have often struggled to survive and to have their voices heard.²² Current government policies²³ present such organisations both with opportunities to assert disabled people's rights and with threats of serving merely to legitimise budget-driven reforms. Moreover, respect for disabled people's experience and expertise regarding identity, survival and dignity cannot be assumed here. Incipient systems of coproduction²⁴ and involvement²⁵ have been re-articulated or dismantled, resulting in reversal of earlier moves towards hegemonic expansion of disabled people's discourse. Relations of difference are replaced by relations of equivalence,²⁶ and the hegemony of exclusionary liberal discourse is strengthened.

²¹ For example in Articles 4(3) and 33(3)

²² Disability LIB 'Thriving or Surviving: Challenges and Opportunities for Disabled People's Organisations in the 21st Century' (Scope 2008)

²³ Coalition government, 2012

²⁴ As understood in New Labour policy: see Chapter 6 above

²⁵ Such as the requirement for involvement of disabled people and their organisations in the formulation and monitoring of the Disability Equality Duty: see Chapter 6 above

²⁶ Such as media hype against disabled people and consequent harassment. See for instance Strathclyde Centre for Disability research and Glasgow Media Unit, in association with Inclusion London, 'Bad News for Disabled People: How the newspapers are reporting disability', University of Glasgow, 2011; and Walker P, 'Benefit cuts are fuelling abuse of disabled people, say charities' Guardian 5 February 2012, <http://www.guardian.co.uk/society/2012/feb/05/benefit-cuts-fuelling-abuse-disabled-people> accessed 27.3.12

Recommendation

All activities recommended below should be planned, executed and monitored with the full and active involvement of disabled people and their representative organisations at all levels.²⁷

Economic, social and cultural rights and CRPD implementation

The UN Committee on Economic, Social and Cultural Rights has worked over several decades to clarify the norms contained in the ICESCR. Economic, social and cultural rights have now been incorporated in most countries through a variety of legal systems,²⁸ and they are increasingly adjudicated around the world.²⁹ The Committee's General Comments and other supporting declarations³⁰ provide internationally agreed and developing standards which form a framework within which States Parties, law-makers, practitioners and individuals can undertake and measure progress in their implementation.

In England, that framework is invisible. Examination of the 'constructive' dialogue between the UK and the UN Economic, Social and Cultural Rights Committee reveals disagreement on incorporation, progressive realisation, justiciability, the Optional Protocol, the content of Bills of Rights, and awareness-raising/visibility – that is, on all key aspects of Covenant implementation. The rights themselves continue to be understood in England as principles and guidelines, not as rights but as welfare entitlements subject to the gift (or denial) of the State. Lack of recognition by successive UK governments of international economic, social and cultural rights standards, and the consequent absence of those standards from domestic discourse, impact in many ways on the understandings, systems and identities essential for implementation in England of the CRPD.

²⁷ CRPD Article 4(3) and Article 33(3)

²⁸ See Chapter 5 above

²⁹ Langford (2008); INTERIGHTS Commonwealth and International Human Rights database, <http://www.interights.org/commonwealth-and-international-law-database/index.html> last accessed 30.8.12

³⁰ Such as the Limburg Principles and Maastricht Guidelines

Understandings

The interdependence of civil and political rights with economic, social and cultural rights has been a key element in development of the disability/human rights discourse encapsulated in the Convention. In 1993, Leandro Despouy identified that '[d]isability is perhaps the area in which the importance of recognizing the indivisibility and interdependence of human rights...is most evident and sharp.'³¹ The 2002 Quinn Report which helped to trigger the Convention drafting project advised that

[t]he need for a holistic approach to disability is consonant with the postulate that civil and political rights, on the one hand, and economic, social and cultural rights, on the other, are interdependent and interrelated. Tangible material support is necessary to convert formal freedoms into real freedoms for people with disabilities. *This is not the freedom of welfare, which places people with disabilities in gilded cages and locks them into cycles of dependency and despondency. It is economic, social and cultural justice, which liberates people with disabilities so that they can play their part in – and contribute their share to – inclusive societies...* the drafting of a convention relating to disability without thinking creatively about marrying the two sets of rights is inconceivable.³² (emphasis added)

Hegemony 'involves the expansion of a particular discourse of norms, values, views and perceptions through persuasive re-descriptions of the world'.³³ UK governments' resistance to acknowledgement of economic, social and cultural rights and of their importance in the context of disability fatally undermines the Convention drafters' hegemonic purpose. Without that acknowledgement, the drafters' particular discourse of norms, values, views and perceptions cannot expand in the domestic sphere; the transition in **the field of meaning** from welfare to rights understandings that is their goal cannot begin to take place.

Recommendations

- **acknowledge economic, social and cultural rights as rights, and their equal importance to, interdependence with and indivisibility from civil and political rights**

³¹ Despouy L, 'Human Rights and Disabled Persons', Human Rights Studies Series, number 6 (UN Centre for Human Rights 1993) para 31

³² Quinn and Degner (2000) para 13.5

³³ Torfing (1999) 302

- **incorporate international economic, social and cultural rights understandings into domestic social, legal and political discourse**
- **acknowledge the particular importance of interdependence and indivisibility of civil, cultural, economic, political and social rights in the context of disability**

Systems

Law is one method of articulating and regulating systems of social relations. Disability/human rights discourse has been sedimented into the text of the CRPD. Economic, social and cultural rights as rights are integrated throughout, including, for instance, in the Convention's preamble,³⁴ its purpose,³⁵ its definition of discrimination,³⁶ the obligations of ratifying States,³⁷ and projection of the rights themselves.³⁸ The particular routes to realisation mapped in through larger-scale drafting emphasise the key function these rights play in enabling and driving the realisation of the Convention's purpose. They are a central element in the repositioning of disabled people in the new world of disability/human rights discourse, and in the all-permeating **change in systems of social relations** that entails. Yet, as Ms Bras Gomes noted in Geneva, despite UK governments' protestations in the international arena that 'economic, social and cultural rights are as important as civil and political rights',³⁹ within the UK they are not indivisible at *practical* level.

³⁴ (c) *Reaffirming* the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms...

³⁵ 'The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all fundamental rights and freedoms...' Article 1

³⁶ '... any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field...' Article 2

³⁷ '... to take measures to the maximum of its available resources.... With a view to achieving progressively the full realisation of [economic, social and cultural rights], without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.' Article 4(2). See Chapters 3 and 5 above for further discussion. See also, for example Article 9

³⁸ See discussion in Chapter 3 above

³⁹ For instance, UK Fifth Periodic Report to the Economic, Social and Cultural Rights Committee, July 2007, para 75

Political projects attempt to ‘weave together different strands of discourse in an effort to dominate or organise a field of meaning so as to fix the identities of objects and practices in a particular way’.⁴⁰ Economic, social and cultural rights as rights are integrated into the Convention text to help to bring about the change in social relations necessary to fix identities of objects and practices in line with the CRPD drafters’ vision. Failure to acknowledge that role in practice prevents the realisation of that vision through the social structures and practices of everyday life. Without recourse to the international human rights framework to provide meaning, stability and coherence, domestic policy, law and administration fail to comply with CRPD requirements; the repositioning of disabled people in the real world at *practical* level cannot begin to take place.

Recommendations

- **incorporate economic, social and cultural rights into domestic law**
- **ensure that they are justiciable, and provide effective remedies for breach**⁴¹
- **adopt all appropriate legislative, administrative and other measures for the implementation of all – civil, cultural, economic, political and social - CRPD rights**⁴²

Identities

Understandings, structures and identities are dynamic and interwoven components of any discursive process: as understandings shape structures and practices, so the **identities** of all concerned are both formed by and reflected in those understandings and structures. For the CRPD-drafters’ re-description of the world to be realised, domestic actors must be ‘socialised’ to adopt its beliefs and behavioural patterns, to align law, policy and administration with Convention values and bring about meaningful change.⁴³

⁴⁰ Howarth *et al* (2000) 2, and see Chapter 1 above

⁴¹ See Concluding Observations of the Committee on Economic, Social and Cultural Rights, E/C.12/GBR/CO/5, 22 May 2009

⁴² CRPD Article 4(1)(a)

⁴³ Quinn (2009) 219

The UK argues that raising awareness of economic, social and cultural rights would not be of 'practical benefit' to lawyers, to service providers or to the general public.⁴⁴ However, where economic, social and cultural rights are rendered invisible, law-drafters, policy-makers, administrators and individuals alike are unaware of their rights. Individual beliefs and behaviours remain unchanged, unable to reflect or to influence the structures within which they function towards more CRPD-compatible practice. The 'socialisation' of individuals cannot begin to take place, and the opportunity to make the 'paradigm change' from welfare to rights which is the fundamental goal of the Convention is lost.

Recommendations

- **Take all effective measures to increase awareness of economic, social and cultural rights – as justiciable rights and not merely rights as part of the Welfare State⁴⁵ - among politicians, public servants, lawyers, service providers and the general public, including disabled people**
- **Take all effective measures to increase understanding of the equal importance, indivisibility and interdependence of civil, cultural, economic, political and social rights in the context of disability among politicians, public servants, lawyers, service providers and the general public, including disabled people**

Flóvens suggests that

in those States in which economic, social and cultural rights have not been sufficiently implemented until now, there may arise some problems in implementing the Convention as a whole.⁴⁶

Mis-understanding of international economic, social and cultural rights standards by successive UK governments, and their consequent mis-application in domestic law and practice, frustrates expansion of the CRPD myth in England at all levels.

⁴⁴ See constructive dialogue, chapter 5 above

⁴⁵ Concluding Observations of the Committee on Economic, Social and Cultural Rights, E/C.12/GBR/CO/5, 22 May 2009, para 15

⁴⁶ Flóvens (2009) 26

Moreover, this thesis has argued that the CRPD is expressive/emancipatory law: a hegemonic formation, seeking to function as a 'revolving door' through which the various elements of international disability/human rights discourse can circulate around the world to redefine the terms of the political debate. In England, however, not only does the key discursive element of economic, social and cultural rights remain invisible, leading to mis- and partial understandings and application of the law, but the CRPD itself has received minimal attention. Here, as yet, the revolving door is barely open, the opportunity for the CRPD to influence the political debate negligible: the drafters' re-description of the world has yet to find a foothold in domestic social, legal or political discourse.⁴⁷

Recommendations

- **Take all effective measures to increase awareness of the CRPD among politicians, public servants, lawyers, service providers and the general public, including disabled people**
- **Adopt immediate, effective and appropriate measures to raise awareness and to foster respect throughout society for all of the rights – civil, cultural, economic, political and social – of disabled people⁴⁸**

Implementation of Article 19

Part 2 of the thesis has examined some effects of the situation discussed above on implementation in England of CRPD Article 19. Although some CRPD drafters were keen to distance themselves from disabled people's independent living movement, it has been argued in Chapter 4 that the concept of independent living as understood by that movement is so deeply ingrained that it is impossible to extract it from the Convention myth. Changing the perception by others that disabled people need to be segregated from society, to be institutionalised - with the systems of knowledge, power and identities that perception has established - is central to the drafters' hegemonic project. For many disabled people, to exercise

⁴⁷ But see Postscript below

⁴⁸ CRPD Article 8(1)(a)

their autonomy and to participate on an equal basis as full members of humanity requires more than the limited positive obligations of standard human rights law: it requires fundamental transformation – a re-description of the world. Anti-dependence and non-institutionalisation featured strongly throughout the Convention negotiations: they are encapsulated in Article 19 together with the economic, social and cultural rights required to translate them into the reality of people’s lives.

In English domestic rhetoric, however, whilst individual civil and political rights to autonomy, choice and participation ride high, the economic, social and cultural rights essential for their exercise continue to be excluded. Indeed, during CRPD negotiations, the UK argued against inclusion of Article 19(b), which provides for the social support to function autonomously in one’s chosen home and to participate in community life, to prevent isolation and segregation. Moreover, as the CRPD and Article 19 have also remained invisible in domestic discourse, independent living itself has continued to be (mis-)understood not as a right but as a welfare entitlement to be granted or denied by the State. The concept of independent living remains open to mis-understanding and to mis-appropriation by other, more powerful, discourses. The result, as described in Chapters 6 to 8 above, has been re-articulation and regression in the policy field, partial and unstable legislative development and an administrative system prey to conflicting logics and oppressive dynamics for decision-makers and service users alike: mis- and partial understandings of the context in which the law has been formed results in mis- and partial application of the law itself.

Article 19 is a hybrid right, an enabling right and an emancipatory right. It is fundamental to the Convention’s goal of paradigm change,⁴⁹ and to the exercise of all other Convention rights. Mis- or partial application of Article 19 results in failure to implement the Convention as a whole, and frustration of the drafters’ hegemonic project. ‘For a State which took part in drafting and

⁴⁹ Don McKay, Chair of the ad hoc negotiating committee, Daily Summary 7th session, 19 January 2006 afternoon session

has ratified the UN Convention on the Rights of Persons with Disabilities, a human-rights based approach to all of the rights set out in Article 19 should be the starting point for promoting, protecting and ensuring the full and equal enjoyment by all disabled people of their Article 19 right to independent living.⁵⁰

Recommendations

Policy

- **understand the right to live independently and be included in the community as set out in CRPD Article 19, in line with its context, object and purpose, its travaux préparatoires and the circumstances of its drafting⁵¹**
- **explain and disseminate government strategy for realisation of Article 19, with benchmarks for progressive realisation of the economic, social and cultural rights involved to the maximum of available resources**
- **raise awareness of all of the above among politicians, public servants, lawyers, service providers and the general public, including disabled people**

Law

- **acknowledge the basis of the right to live independently and be included in the community in international human rights law, including the law and jurisprudence relating to economic, social and cultural rights**
- **enact rights-based independent living legislation, including its economic, social and cultural elements, in conformity with CRPD and ICESCR requirements⁵²**

⁵⁰ Collingbourne T, 'Protecting the right of disabled people to independent living', Memorandum to Joint Committee on Human Rights, April 2011

⁵¹ As required by the Vienna Convention on the Law of Treaties 1969 Articles 31 and 32. If in doubt ask/listen to disabled people (Article 4(3))

⁵² CRPD Article 4(1)(a) and (b); ICESCR Article 2(1) and Committee on Economic, Social and Cultural Rights, General Comment 9; and see discussion of Independent Living Bill, Chapter 7 above

- raise awareness of all of the above among politicians, public servants, judges, lawyers, service providers and the general public, including disabled people

Administration

- provide clear and consistent rights-based guidance to those tasked with delivering independent living law and policy to individuals
- promote the training of all those working in the administrative justice system in the right to independent living, including its economic, social and cultural elements⁵³
- foster a rights-based culture in the administrative justice system: promote the socialisation of all involved to adopt CRPD-compatible beliefs and behavioural patterns to bring about meaningful change

Redress

As Ms Riera observed in Geneva,⁵⁴ a right which cannot come to court is not a right. Chapter 9 of the thesis has argued that available redress systems in England provide little remedy for the individual complainant, and generally resist rather than support the expansion of disability/human rights discourse. The capacity of internal complaints procedures to influence wider policy, law or administration towards more CRPD-compatible understandings remains negligible. Judicial review precedent reflects dominant exclusionary understandings,⁵⁵ and its future as a redress mechanism in this field looks increasingly uncertain. The work of the Ombudsman service offers potentially more fertile ground for expansion of the CRPD myth, but lacks visibility, statutory recognition and resources.

Recommendations

⁵³ CRPD Article 4(1)(i)

⁵⁴ See Chapter 5 above

⁵⁵ But see *Burnip v Birmingham*, Postscript, below

- **put in place accessible, affordable, impartial and effective legal remedies for those whose Article 19 rights, including their economic, social and cultural elements, have been breached⁵⁶**
- **ensure availability of a range of accessible and affordable information, advice and representation through standard independent legal and advice channels and Disabled People's User-Led Organisations**
- **raise awareness of such remedies and support services among disabled people, service providers, lawyers, advice workers, advocates, and the general public through publicity, guidance and training**

Conclusion

In 2009, the UN Committee on Economic, Social and Cultural Rights strongly reminded the UK of its legal obligation to fully realise the international treaties it ratifies, to give economic, social and cultural rights full domestic legal effect, to ensure that Covenant rights are justiciable, and to provide effective remedies for breach.⁵⁷ This thesis has argued that the UK is not meeting those obligations. The UK's reluctance to fully understand, acknowledge or implement international economic, social and cultural rights standards in domestic law goes to the heart of CRPD implementation. It undermines expansion of the Convention drafters' hegemonic project in the English domestic sphere, and leads to mis-understanding and mis- or partial application of the Convention's terms. The Article 19 right to live independently and be included in the community does not have full domestic legal effect, its terms are not justiciable and effective remedies for breach are not available. Moreover, reluctance to fully implement economic, social and cultural rights, with consequent mis- and partial implementation of Article 19, undermines realisation of all Convention rights, calling into question the UK's Article 4(1) undertaking as State Party to the Convention to 'ensure and

⁵⁶ CRPD Articles 12 and 13

⁵⁷ Concluding Observations of the Committee on Economic, Social and Cultural Rights, E/C.12/GBR/CO/5, 22 May 2009

promote the full realisation of all human rights and fundamental freedoms for all disabled people’.

Further areas for research from a political discourse theory perspective

For reasons of manageability, this thesis has concentrated on the dynamics between international and UK/English understandings. The UK, however, is a member of the European Union, and the EU helped to negotiate and, as a ‘regional integration organisation’, acceded to the CRPD in 2010. Chapter 4 above described how the Convention’s implementation and monitoring provisions are designed in such a way as to promote the continuation of the drafters’ hegemonic project. As noted there, the presence of regional integration organisations as Parties to the Convention brings new perspectives to the discussion, including their history and experience as a regional body, their institutional, legal and political relationships with their Member States, and, in the case of the EU, their established role in the international development field. Legal and political dynamics relating to the CRPD abound within and between Member States,⁵⁸ between Member States and the EU,⁵⁹ and between Europe, its Members and the UN,⁶⁰ providing rich fields of interlegality for political discourse analysis at both European and international levels.⁶¹

A further interesting topic for political and legal discourse analysis might be found in the relationship between the English Ombudsmen and their European counterparts. Chapter 9 above described the English

⁵⁸ Not all of which have ratified the Convention at the time of writing

⁵⁹ See, for instance, Hervey T, Stark A, Dawson A, Fernandez J-L, Matosevic T and McDaid D, ‘Long-term care for older people and EU law: the position in England and Scotland’ (2012) 34(1) *Journal of Social Welfare and Family Law* 105

⁶⁰ See, for instance, Ferri, D, ‘The Implication of the UNCRPD for EU Law’, presentation to ERA (Academy of European Law) Seminar on the UN Convention on the Rights of Persons with Disabilities, Madrid, 15-16 December 2011. Also Waddington L, ‘Breaking New Ground: The Implications of Ratification of the UN Convention on the Rights of Persons with Disabilities for the European Community’ in Arnandotir and Quinn (2009)

⁶¹ See, for instance, Howarth D and Torfing J, *Discourse Theory in European Politics* (Palgrave Macmillan 2005)

Ombudsmen's approach to resolving disputes, including those that touch on 'the most sensitive areas of social and economic rights'.⁶² In the absence of domestic economic, social and cultural rights protection, their work in this area relies on a conceptual sleight of hand, distancing itself from the courts as 'giving force to' human rights principles rather than 'enforcing' human rights law. At European level, the picture appears to be very different. Here, the European Social Charter and the socio-economic rights set out in the EU Charter of Fundamental Rights⁶³ are visible, and European Ombudsmen (including their English colleagues) are encouraged by the Council of Europe to cooperate with human rights institutions and to get involved in human rights disputes.⁶⁴ The interplay between these two discursive settings for the Ombudsmen's enterprise might yield interesting legal and political discourse analyses.

⁶² Abraham (2008) cited in Buck *et al* (2011) 38

⁶³ Chapter IV – solidarity. See Chapter 5 above for application in United Kingdom law

⁶⁴ O'Brien (2009)

Postscript

Subsequent developments

This thesis has covered developments to April 2012. The following section considers subsequent developments relating to implementation of Article 19 in England. These include the Government Response to the Joint Committee on Human Rights (JCHR) Report on Implementation of the Right of Disabled People to Independent Living; the long-awaited White Paper on social care reform; a draft Care and Support Bill; and a 'progress report' on social care funding.

Government Response to JCHR Report

Chapter 6 of the thesis identified elements of resistance to the invisibility of economic, social and cultural rights and of the CRPD itself, including Article 19, in domestic policy discussion. This resistance was bolstered in March 2012 by a strong JCHR Report on Implementation of the Right of Disabled People to Independent Living.¹ The Report regrets that the Convention has not been incorporated into UK law and notes the lack of domestic legislative underpinning of Article 19. It suggests recognition of the right to independent living in any Bill of Rights for the UK, and argues for free-standing, rights-based legislation, as the existing matrix of human rights, equality and community care legislation is not sufficient. It concludes, *inter alia*, that

[t]he CRPD is hard law, not soft law. The Government should fulfil their obligations under the Convention on that basis...²

¹ Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living', Twenty-third Report of Session 2010-12, HL Paper 257, HC 1074, 1 March 2012; see Chapter 6

² *Ibid* Conclusions and Recommendations, para 1

The Government, by contrast, holds that the existing matrix of legislation helps deliver independent living. Its Response³ echoes the UK's stance in the constructive dialogue with the ESCR Committee:⁴

the Convention imposes legal obligations on the UK Government. The UK fulfils these obligations through existing domestic legislation, such as the Equality Act 2010, and through policy and programmes that impact upon the lives of disabled people. In this way, the rights in the Convention have practical effect.⁵

The JCHR is also concerned that the CRPD, and Article 19 in particular, 'does not appear to have played a central role in the development of policy'.⁶ The Government's forthcoming Disability Strategy should cover all aspects of the Convention, including the right to independent living; and include clear milestones, monitored by an independent body to aid measurement and transparency.⁷ The Government promises that its Strategy will 'reflect what disabled people themselves have said are the important issues'.⁸ Importantly, the Government promises that its Disability Strategy will be based on the Convention.

The JCHR Report then focuses on the impact of a range of current reforms which, in the Committee's view, present individually and together a serious risk of retrogression in the realisation of Article 19. They include cuts in local authority funding,⁹ restrictions in eligibility criteria to critical-only,¹⁰ a range of reforms to housing benefit and social security benefits¹¹ and the closure of the Independent Living Fund. The Government merely promises to monitor disabled people's experience of the impact of these reforms and ensure that mechanisms are in place to address any issues arising.

³ Joint Committee on Human Rights, 'Second Report, Implementation of the Right of Disabled People to Independent Living: Government Response to the Twenty-third Report of Session 2010-12' HL Paper 23/ HC429, 2 July 2012

⁴ See Chapter 5 above

⁵ Government Response, 6

⁶ JCHR (2012) para 19

⁷ Ibid para 12

⁸ The ODI will consult disabled people on how the Strategy should be monitored, and will, 'for example, capture first hand the lived experiences of disabled people to inform an understanding of what impact the Strategy is having.' Government Response, 10

⁹ JCHR (2012) para 30

¹⁰ Giving rise to individual breaches of Art 19(b): *ibid*, para 32

¹¹ Secretary of State for Work and Pensions '21st Century Welfare' (Cm 7913, 2010); Welfare Reform Act 2012

Where adult social care is concerned, the JCHR welcomes the government's espousal of personalisation. However, it states that further monitoring and regulation is needed to ensure that the goal of increasing choice and control is in fact realised in both domiciliary and residential settings.¹² The Government, however, shifts primary responsibility for outcomes from central to local government:

Local authorities are not performance managed on a national basis, and are primarily accountable to their own population for the performance of services and the outcomes achieved for local people.¹³

Access to information, advice and advocacy, including that provided by Disabled People's User Led Organisations, is recognised by the JCHR as being critical for all disabled people to benefit from personalisation. Moreover, it recommends that the Disability Strategy should include action to ensure disabled people's access to redress and justice.¹⁴ The impact on the right to independent living of withdrawal of legal aid from many key areas of welfare law under the Legal Aid, Sentencing and Punishment of Offenders Bill¹⁵ should be monitored. In response, proposals to improve availability of information and advice are promised in the forthcoming White Paper.¹⁶ The Government is also 'developing a range of approaches to improve its evidence base on legal aid clients, including those with a disability'.¹⁷

The Government thus maintains its dualist approach to implementation of international treaties.¹⁸ Whilst it promises to base its Disability Strategy on the CRPD, there is no evidence at this stage of any specific benchmarks or independent monitoring, or of any recognition of the role of economic, social and cultural rights. The Government expresses satisfaction with the current legislation as a means of delivering independent living, and distances itself from responsibility, delegating to local authorities primary accountability for

¹² JCHR (2012) paras 40 and 45

¹³ Government response, 23

¹⁴ Ibid para 52

¹⁵ Royal Assent 1 May 2012; for potential effects on disabled people's access to specialist advice see for example <http://www.disability-equality.org.uk/news/a-message-from-our-ceo--/n69> accessed 11.8.12

¹⁶ See discussion below: this consists of advice in developing a support plan, online national and local information

¹⁷ Government response, 29

¹⁸ See Chapter 5 of the thesis

services and outcomes. Faced with allegations of a serious risk of retrogression, it merely offers to monitor the impact of reforms and address any issues.

On 11 July 2012, the government published three further documents: the long-awaited White Paper on social care, a draft Care and Support Bill and a 'progress report' on funding reform.

Social care reform

The White Paper

Chapter 6 of the thesis examined independent living policy in England for signs of re-organisation of the field of meaning in line with the CRD myth. It found widely varied understandings of independent living circulating in the policy field, where the CRPD drafters' hegemonic project faced re-articulation, dislocation and regression. Despite strong emphasis on individual civil and political rights to autonomy and choice, the economic, social and cultural rights essential for their exercise remain contested, putting the hegemonic project at serious risk.

The 2012 White Paper¹⁹ recognises that '[o]ur system of care and support is broken and in desperate need of reform'.²⁰ The Paper presents a myth²¹ to fill this 'lack', describing a world where people have 'far better support' and are in control; where they are treated with respect, their independence and wellbeing promoted, and their potential fulfilled.²²

¹⁹ Department of Health, 'Caring for our future: reforming care and support' (Cm 8378, 2012)

²⁰ Ibid, Foreword, 3

²¹ 'Myth is defined as a principle of reading of a given situation. The condition of emergence of myth is structural dislocation, and the function of myth is to suture the dislocated space by means of constructing a new space of representation.' Torfing (1999) 303; and see Chapter 1 above.

²² Executive Summary, 9

This myth is to be realised through two ‘core principles’: prevention²³ and control. Additionally, society needs to understand that ‘people with care needs very much have something to offer. Care and support should not just be about making people comfortable but about helping them to fulfil their potential, whatever their circumstances.’²⁴ Like the New Labour Government before it, the Coalition proposes ‘ambitious transformation’²⁵ through ‘a genuinely collaborative endeavour’.²⁶ This time, ‘transformation’ involves dissolving the boundaries between the third sector, private organisations, local authorities and individuals;²⁷ and listening, particularly to ‘the voices of those using care and support, their carers, their families and their friends.’²⁸ Although the CRPD remains invisible here, these ambitions appear compatible with its purpose: expansion of a discourse which, though not rights-based, recognises and respects the autonomy and contributions of disabled people and is encouraged through relations of difference and paradigm change.²⁹

When it comes to the practicalities, however, the Government’s proposals seem less sure. The project will happen in stages over the next ten years. There is additional funding for specialised housing to increase housing options in line with Article 19(a).³⁰ Beyond this, the Paper suggests encouraging better support in communities through ‘time banks, time credits and other approaches that help people share their time, talents and skills with others in the community’;³¹ involving communities in commissioning

²³ ‘The first is that we should do everything we can – as individuals, as communities and as a Government - to prevent, postpone and minimise people’s need for formal care and support.’ Executive Summary, 9

²⁴ *ibid*

²⁵ New Labour’s ‘transformation’ agenda is technically still running to 2013, and see Think Local, Act Personal <http://www.thinklocalactpersonal.org.uk/> accessed 23.9.12

²⁶ *ibid*

²⁷ *Ibid*, 3-4; according to the Paper, thousands of people who use or work in care and support took part in the Government’s consultation ‘engagement’ which shaped its plans. Executive Summary, 7

²⁸ *Ibid*

²⁹ Transformation of the system requires ‘a real shift in the way that everyone – the Government, local authorities, the NHS, care users and their families, care providers, voluntary organisations, care workers, and communities – approaches care and support. Change will be the shared responsibility of leaders at every level of the system, from chief executives to registered managers to personal assistants.... Together with our partners, we will now make this ambitious reform a reality.’ Executive Summary, 11

³⁰ Worth £200 million over 5 years

³¹ Executive Summary, 10

decisions; and developing new ways of investing in services, such as Social Impact Bonds. Entitlement to a personal budget will be enshrined in legislation, access to independent advice in developing a support plan improved, and direct payments will continue.³² A new national website is proposed, and local authorities will develop online information. This, with new feedback websites, will empower people to make informed decisions with their personal budget, and ensure development of a diverse range of high quality care services through market forces. The 'care workforce' will be provided with increased training; 'dignity and respect' will be 'at the heart' of a new code of conduct; and a Chief Social Worker will be appointed to provide leadership and to 'drive forward social work reform'.³³

As described in Chapter 6 of the thesis, New Labour's transformation agenda continues, re-articulated through the individualistic and market-driven discourse of the Coalition government. The myth put forward in the White Paper appears compatible with the Convention-drafters' purpose, emphasising respect for disabled people and holistic paradigm change. However, it offers little in the way of practical implementation or of central government accountability, and fails to mention redress. In the absence of a rights agenda, the concept of independent living remains open to further re-articulation and dislocation.

The Coalition's Disability Strategy, however, is still to come, and the Minister for Disabled People has promised the JCHR that it will be based on the CRPD. The first papers are expected in September 2012, with an action plan in early 2013.³⁴

³² And be piloted in residential care settings

³³ Executive Summary, 11

³⁴ Minutes from Joint APPG meeting on the Disability Strategy (APPG = All-Party Parliamentary Group), 12 June 2012, Action plan early 2013 (Maria Miller, Minister for disabled people) accessed via Disability Rights UK e-Newsletter, issue 4, July 2012

The Draft Care and Support Bill

One way of bringing about paradigm change is through law. The draft Care and Support Bill³⁵ published alongside the White Paper promises ‘an historic reform of care and support legislation’.³⁶

The Law Commission’s Report on Adult Social Care, the basis for this Bill, was discussed in Chapter 7 of the thesis, where it was contrasted with the 2006-2009 Health and Social Care (Independent Living) Bill. Unlike the CRPD-compatible Independent Living Bill, the Law Commission’s proposals were found to offer a ‘neutral’ centre based on a qualified principle of ‘well-being’. Its narrow boundaries reflect the status quo and its projections consolidate and strengthen aspects of the existing ‘community care’ regime whilst leaving the underlying oppressive ‘welfare’ discourse unchanged. It was suggested in Chapter 7 that the Government might favour an approach between the two, focusing on individual autonomy and supporting a change in social relations towards co-production and holistic assessment, while at the same time ruling out both rights-based and strategic approaches to rebalance responsibility for ‘welfare’ outcomes from the State to the individual.

The Government’s Response to the Law Commission’s proposals (the Response)³⁷ was published at the same time as the Draft Care and Support Bill.³⁸ They are discussed together here.

The Government accepts the Law Commission’s recommended structure of primary legislation, regulations and statutory guidance.³⁹ It also accepts the proposal for a statement of principles, and that the single overarching

³⁵ Cm 8386, July 2012

³⁶ Foreword to the Bill, 4; ‘[u]nderpinning many of our proposals will be the comprehensive modernisation of care and support law. By changing the law, we will place people’s needs and goals at the centre of how care and support will work in the future, and will ensure that local authorities work for the wellbeing of everyone in their area, not just the few.’ Executive Summary, 11

³⁷ ‘Reforming the law for adult care and support: the Government’s response to Law Commission report 326 on adult social care’, Cm 8379, July 2012

³⁸ Draft Care and Support Bill, Cm 8386, July 2012

³⁹ Though not repeal of the additional ability for Ministers to respond on occasion with proportionate, binding requirements on local authorities, under Local Authority Social Services Act 1970, s7A; or the Law Commission’s proposal for a Code of Practice. Government response para 2.9

principle should be that of individual 'well-being', undefined, but supported by a list of outcomes and a list of 'factors to be considered'.⁴⁰

Outcomes listed in the Draft Bill include

- (a) physical and mental health and emotional well-being;
- (b) protection from abuse and neglect;
- (c) control by the adult over day-to-day life (including over the care and support provided to the adult and the way in which it is provided);
- (d) participation in work, education, training or recreation;
- (e) social and economic well-being;
- (f) domestic, family and personal relationships;
- (g) the adult's contribution to society.⁴¹

Factors to which a local authority must 'have regard' include:

- (a) the importance of beginning with the assumption that the adult is best placed to judge the adult's well-being;
- (b) the adult's views, wishes and feelings;
- (c) the need to ensure that decisions about the adult are made having regard to all the adult's circumstances (and are not based only on the adult's age or appearance or any condition of the adult's or aspect of the adult's behaviour which might lead others to make unjustified assumptions about the adult's well-being);
- (d) the importance of the adult participating as fully as possible in decisions relating to the exercise of the function concerned and being provided with the information and support necessary to enable the adult to participate;
- (e) the importance of achieving a balance between the adult's well-being and that of any friends or relatives who are involved in caring for the adult;
- (f) the need to protect people from abuse and neglect;
- (g) the need to ensure that any restriction on the adult's rights or freedom of action that is involved in the exercise of the function is kept to the minimum necessary for achieving the purpose for which the function is being exercised.

⁴⁰ Government Response, section 3: Statutory Principles

⁴¹ Clause 2

Although independent living is not chosen as the ‘over-arching principle’, these outcomes and factors resonate compatibly with CRPD discourse and Article 19. In particular, there is much emphasis on mental and physical integrity, on individual control of services, on participation and on changing traditional assumptions of dependency. However, the Response makes it clear that neither the well-being principle nor the supporting outcomes or factors are intended to be directly enforceable or individual rights.⁴² Instead, the principle ‘should carry indirect legal weight, as a general duty where a local authority’s failure to have regard may be challenged through judicial review’.⁴³

The Draft Bill contains no definition of disability or disabled person. Instead, a person is eligible for services if they have an assessed eligible need determined through the assessment process.⁴⁴ Services are defined through a short, open list of categories, designed to act as a guide without restricting innovation.⁴⁵ This list⁴⁶ reflects the services covered by existing legislation, although the wording of the Draft Bill⁴⁷ suggests that other, ‘innovative’ examples are possible.⁴⁸

In the Draft Bill, local authorities have two levels of duty.⁴⁹ At the ‘universal’ level, they must provide information and advice;⁵⁰ shape the market of care and support providers;⁵¹ prevent, reduce or delay the onset of needs for care and support;⁵² and cooperate with local partners in the integration of services.⁵³ At the level of individual ‘targeted’ provision, a single ‘duty to

⁴² Ibid para 3.9, 3.13

⁴³ Ibid para 3.9

⁴⁴ Including carers, to give them ‘a right to support for the first time to put them on the same footing as the people for whom they care.’ Draft Bill Summary para 2.6

⁴⁵ Government Response 8.10

⁴⁶ Like that of the Law Commission, see Chapter 7 of the thesis, but with ‘goods and facilities’ substituted for ‘financial or any other assistance’, and information added to advice

⁴⁷ Clause 8 (1): ‘The following are examples of what may be provided to meet needs...’

⁴⁸ Services are further defined negatively by exclusion of those provided by health or housing authorities: Draft Bill clauses 21 and 22

⁴⁹ In line with Law Commission recommendations

⁵⁰ Draft Bill Clause 2

⁵¹ Draft Bill Clause 3

⁵² Draft Bill Clause 7

⁵³ Draft Bill Clauses 4, 5 and 6

assess' offers the sole means by which eligibility for services is determined.⁵⁴ The low qualifying threshold for assessment remains, regardless of the authority's view of the level of the person's needs or of their financial resources.⁵⁵ The assessment must include the outcomes the person wishes to achieve and how the care and support will contribute to those outcomes.⁵⁶ Regulations will set out in more detail how assessment should be carried out.⁵⁷

Allocation of services will be supported by a national eligibility framework⁵⁸ set out in regulations and supported by statutory guidance. This framework is not yet fully developed:⁵⁹ Clause 13 of the Draft Bill promises regulations here too. Once eligibility is determined, the local authority must prepare a care and support plan, tell the individual which eligible needs may be met by direct payments, and help them to decide how the needs should be met.⁶⁰ The Government's approach to care and support plans is non-directive: it prefers to set out 'the few, high-level items'⁶¹ relating to care and support plans in legislation without defining further in regulations.⁶² However, the basic assessment framework remains unchanged.

Personal budgets are a 'critical element'⁶³ of Government policy. Here, the Response goes further than the Law Commission, proposing to set out in primary legislation entitlement to a personal budget for all who qualify for services.⁶⁴ Clause 25 of the Draft Bill, however, merely defines a personal budget as a statement specifying the assessed cost of meeting the person's

⁵⁴ 'This duty would have a similar effect to s47(1)(b) of the NHS and Community Care Act 1990': Government Response to Law Commission, para 6.11

⁵⁵ an effort to counter some local authorities' current excuses for unlawful (under NHSCCA90 s47, see Chapter 7 of the thesis) delay or refusal of assessment

⁵⁶ Draft Bill Clause 9

⁵⁷ Draft Bill Clause 12

⁵⁸ As the Law Commission recommends; also recommended by the Dilnot Report, July 2011, and promised in the White Paper

⁵⁹ Government Response para 6.14

⁶⁰ Draft Bill Clause 23; if no eligible needs are identified, the individual should receive a copy of the assessment and any financial assessment, and advice on action to prevent development of any needs in the future.

⁶¹ Government Response para 8.17

⁶² Nevertheless, Clause 24 of the Draft Bill contains 12 quite specific sub-clauses and promises further regulations: Clause 24(12)

⁶³ Government Response para 8.19

⁶⁴ With limited exceptions, specified in regulations see Government Response para 8.22

needs, and where that money is to come from⁶⁵ – it says nothing about control.

Apart from the promise of a national eligibility framework, and a change in focus for local authorities at universal level, the Draft Bill, pending regulations, changes little on a practical individual level. While the outcomes and factors supporting the ‘well-being’ principle resonate with CRPD discourse, the Draft Bill’s projections simply confirm the current legal map of needs assessment, eligibility decision and care plan, with only minor adjustments such as entitlement to a personal budget statement.

In its White Paper and legislative plans, the Government has gone further than the Law Commission in its focus on individual autonomy and on wider change in social relations towards co-production and holistic assessment at individual level. At the same time, it has failed to follow the CRPD-compatible Independent Living Bill, ruling out both rights-based and strategic approaches.⁶⁶ Nothing in the Draft Bill is intended to constitute an individual right, or to be directly enforceable,⁶⁷ hence the principle of well-being merely carries ‘indirect legal weight’ in judicial review.⁶⁸ Despite ratification and the JCHR Report,⁶⁹ there is no mention of the CRPD or of Article 19. The right to live independently and be included in the community remains invisible here, together with the economic, social and cultural rights essential for its exercise. The opportunity to enact Convention-compatible legislation in line with Article 4(1) and Article 19(b) appears to have been missed.⁷⁰

The courts, however, may take a different view. In *Burnip v Birmingham City Council*,⁷¹ Kay LJ, considered a challenge to changes in Housing Benefit

⁶⁵ i.e. the person themselves (25(1)(b)), the local authority (25(1)(c)) or other public sources (25(2))

⁶⁶ See Chapter 7 of the thesis for comparison

⁶⁷ White Paper, para 3.9, 3.13

⁶⁸ Ibid para 3.9

⁶⁹ See above

⁷⁰ So far: at the time of writing (August 2012) the Bill has yet to be debated

⁷¹ *Burnip v Birmingham City Council*, *Trengrove v Walsall Metropolitan Council*, *Gorry v Wiltshire Council* [2012] EWCA Civ 629, 15 May 2012; see also *AH v West London MHT* [2011] UKUT 74 (AAC): ‘it seems to us that once the threshold tests...for establishing a right to a public hearing have been satisfied, article 6 of the European Convention on Human Rights (re-enforced by article 13 of the CRPD) requires that a patient should have the same or substantially equivalent right of access to a public hearing as a non-disabled person who

(HB) rules affecting disabled people. The claimants relied on ECHR Article 14 in connection with Article 1, Protocol 1 (protection of property), and on Articles 5(3)⁷² and 19 of the CRPD. Kay LJ agreed that the CRPD provisions, including Article 19, ‘resonate in the present case, even though they do not refer specifically to the provision of a state subsidy such as HB’.⁷³ He remarked (obiter) that

[i]f the correct legal analysis of the meaning of [ECHR] Article 14 discrimination in the circumstances of these appeals had been elusive or uncertain (and I have held that it is not), I would have resorted to the CRPD and it would have resolved the uncertainty in favour of the appellants. It seems to me that it has the potential to illuminate our approach to both discrimination and justification.⁷⁴

It may thus be that, in the absence of Government interest, it is the courts that draw the terms of CRPD and Article 19 into domestic legal discourse, including in socio-economic contexts.

The ‘progress report’ on funding reform

This thesis has been about understandings. It has consciously avoided discussion of resources,⁷⁵ which is a major topic worthy of a separate, different study. However, the understandings discussed here also shape the resource decisions relating to the socio-economic rights set out in CRPD Article 19(b).

As noted in the thesis,⁷⁶ at international level, both ICESCR and CRPD require progressive realisation of Article 19(b) to the maximum of available resources.⁷⁷ In international law, the UK has given unqualified undertakings

has been deprived of his or her liberty, if this article 6 right to a public hearing is to be given proper effect.’ para 22

⁷² Article 5(3) ‘In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

⁷³ *Burnip* para 20

⁷⁴ *Ibid* para 22

⁷⁵ Although see Chapter 6 ‘dislocation’

⁷⁶ Chapters 2, 3 and 5 above

⁷⁷ ICESCR Article 2; CRPD Article 4(2)

to take deliberate, concrete and targeted steps⁷⁸ towards meeting such socio-economic rights obligations. To avoid breach of these undertakings, at least minimum essential levels of each right must be met;⁷⁹ and failure to progressively respect, protect and fulfil each right constitutes violation. The Government is expected to act in a way reasonably calculated to achieve specific targets to satisfy a detailed substantive standard.⁸⁰ Any retrogressive measures must be fully justified.⁸¹

In England, this international framework is unavailable to guide implementation. Article 19(b) is not recognised as a right, and no specific government targets exist for its realisation against which to measure progression or retrogression.⁸² However, there is ample evidence that social care funding has been increasingly inadequate for a number of years, and that the system is in crisis as a result.⁸³ For instance, in June 2012, the Association of Directors of Social Services (ADASS) reported a £890 million shortfall in adult social care funding,⁸⁴ constituting a cumulative reduction in adult social care budgets of £1.89 billion over two years, at a time when pressure from the number of older and disabled adults is growing at 3 per

⁷⁸ General Comment 3 ‘The Nature of States Parties Obligations (Art. 2, par.1)’ CESCR 14/12/90

⁷⁹ General Comment 9 ‘The Domestic Application of the Covenant’ 03/12/98, E/C.12/1998/24, CESCR, para 10

⁸⁰ Maastricht Guidelines, para 7

⁸¹ General Comment 3, supra, para 9

⁸² The closest is the Office for Disability ‘Roadmap 2025’

(<http://odi.dwp.gov.uk/docs/res/annual-report/roadmap-full.pdf> accessed 23.9.12) and work of the ODI Independent Living Scrutiny Group, both of which have been on the back burner since 2010, awaiting the Coalition government’s forthcoming Disability Strategy. Neither is rights-based.

⁸³ For example Disability Rights Commission ‘Policy Statement on Social Care and Independent Living’ 2002; Council for Social Care Inspection, ‘Lost to the System? The Impact of Fair Access to care’, CSCI 2008; Campbell, J, ‘Social Care as an Equality and Human Rights Issue’, National Centre for Independent Living, ‘Independently’ Newsletter, Feb 2008; Learning Disability Coalition ‘Social care – the continuing crisis: from the perspective of local authorities in England’ (The Learning Disability Coalition Local Authority Survey 2011); Age UK ‘Care in Crisis 2012’ <http://www.ageuk.org.uk/get-involved/campaign/poor-quality-care-services-big-q/care-in-crisis-2012-report> accessed 30.7.12

⁸⁴ ADASS Adult Social Care Budget Survey 2012-13 http://www.adass.org.uk/images/stories/Press12/ADASS_BudgetSurvey2012Summary.pdf accessed 30.7.12

cent per year.⁸⁵ The majority of those reductions⁸⁶ have been met from service re-design, efficiency or increased charges,⁸⁷ but front-line services have also been cut.⁸⁸ ADASS predicts that, unless a new, sustainable funding system is put in place, the percentage of overall savings made by directly reducing services will increase.⁸⁹ This situation also impacts more widely. A recent NHS Confederation survey⁹⁰ found that funding shortfalls in local authority spending had resulted in more delayed discharges from hospital;⁹¹ greater demand for community services;⁹² more demand for mental health services;⁹³ more acute admissions to hospital;⁹⁴ more A&E attendances,⁹⁵ and more emergency readmission,⁹⁶ with all the concomitant negative impacts on those people's lives and their rights to independent living.

The debate surrounding the funding of social care has been underway in England for a number of years.⁹⁷ Most recently,⁹⁸ the Coalition launched a

⁸⁵ ADASS 'A new system for care funding: "now is the time to act" '

http://www.adass.org.uk/index.php?option=com_content&view=article&id=813&Itemid=470
accessed 30.7.12

⁸⁶ Over 85 per cent - £688 million

⁸⁷ £77 million

⁸⁸ Saving £113 million – 12.7%; ADASS reports 83% of Councils operating at 'Substantial' and above eligibility level

⁸⁹ Sarah Pickup, President of ADASS, 12 June 2012,

http://www.adass.org.uk/index.php?option=com_content&view=article&id=813&Itemid=470
accessed 30.7.12. 'This balancing between budget reductions and significant growing demographic pressure is not sustainable and reiterates the urgent message calling for a long term funding solution for adult social care.' ADASS Adult social care budget 2012-13

⁹⁰ 'Social care funding crisis impacting on NHS patients now, says head of the NHS Confederation', <http://www.nhsconfed.org/PressReleases/Archive/2012/Pages/Social-care-funding-crisis-impacting-on-NHS-patients-now.aspx> accessed 3.8.12

⁹¹ 92% of respondents

⁹² 87% of respondents

⁹³ 76% of respondents

⁹⁴ 57% of respondents

⁹⁵ 55% of respondents

⁹⁶ 50% of respondents

⁹⁷ A Royal Commission on Long Term Care reported in 1999 ('With respect to old age: long term care - rights and responsibilities', Cm 4912-1, 1 March 1999). It recommended that the costs of long-term care should be split between living costs, housing costs and personal care, with free personal care paid for from general taxation and the rest means-tested. The New Labour government rejected this proposal, though it was implemented in Scotland through the Community Care and Health (Scotland) Act 2002. See also Robinson JE (ed) *Towards a New Social Compact for Care in Old Age* (King's Fund 2001)

⁹⁸ 20 July 2010

Commission on Funding of Care and Support, which reported in July 2011.⁹⁹ The Dilnot Report recommended a cap on individuals' contribution to their social care,¹⁰⁰ beyond which they would be eligible for full state support; an increase in the means-test threshold;¹⁰¹ and free state support without means-test for all those entering adulthood with care and support needs.

Rather than responding directly to these recommendations, the Government issued a 'progress report' on funding reform,¹⁰² published alongside the White Paper and Draft Bill. Here, the Government supports the Dilnot Commission's approach and intends to base a new funding model on them. However, it states there are 'important questions' about how the Commission's approach could be applied, which need further consultation.¹⁰³ Because of the current economic situation, the government is 'unable to commit to introducing the new system at this stage'.¹⁰⁴ Rather, it will wait until the next Spending Review,¹⁰⁵ as yet undated. Many commentators echoed the response of the NHS Confederation:

We can no longer afford the political debates and academic discussions about social care funding. This is a real issue that is having a detrimental impact on people's lives, now, today. This is the time for action.¹⁰⁶

It seems, however, that action will not take place until at least 2015. In the meantime, local authorities continue to implement the cumulative 2010 Spending Review cuts¹⁰⁷ while facing rising demand for services combined with heightened expectations of prevention and 'personalisation' raised by the myth set out in the White Paper. As we have seen in Chapter 8 of the

⁹⁹ The Dilnot Report: Department of Health, 'Fairer Care Funding', 4 July 2011, <http://www.dilnotcommission.dh.gov.uk/2011/07/04/commission-report/> accessed 12.8.11; see also Wanless D, 'Securing Good Care for Older People: taking a long-term view' (King's Fund 2006); Care Quality Commission *The quality and capacity of adult social care services: an overview of the adult social care market in England 2008/09*, (CQC 2009)

¹⁰⁰ Of £35,000

¹⁰¹ From £23,250 to £100,000

¹⁰² 'Caring for our future: progress report on funding reform', Cm 8381, July 2012

¹⁰³ These include the level of the cap on individuals' contribution, elements of the means-test and who might benefit. Progress Report on Funding, 37

¹⁰⁴ Ibid 37; although a universal system for deferred payments for residential care, and a national minimum eligibility threshold will be in place from April 2015.

¹⁰⁵ Health Minister Andrew Lansley, 11 July 2012

¹⁰⁶ Mike Farrar, NHS Confederation chief executive, 11.7.12

¹⁰⁷ See Chapter 6 of the thesis

thesis, such tensions give rise to frustration for service users and further instabilities and dilemmas for service providers. Further delay raises the imminent risk of continuing and compounding retrogression in the implementation of Article 19.

In its report,¹⁰⁸ the JCHR recognises the exceptional economic circumstances facing the UK and the challenges involved in implementing 'stringent' spending cuts, but reminds the Government that it must nevertheless 'give due attention to [its] obligations under international law'.¹⁰⁹ Those obligations, as argued in this thesis, include full implementation of CRPD Article 19, including both civil and political rights, and the economic, social and cultural rights essential to their exercise.

¹⁰⁸ See above

¹⁰⁹ JCHR Report Recommendation 29

References

References are grouped alphabetically under the following headings:

1. Books and book chapters
2. Journal articles
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5. International human rights documents
 - a. UN Economic, Social and Cultural Rights Committee and constructive dialogue
6. United Kingdom Government documents
7. Hansard
8. Non-governmental research reports
9. Media/online resources
10. Cases
11. Legislation

1. Books and book chapters

Adler M (ed) *Administrative Justice in Context* (Hart 2010)

Alston P, 'Economic, Social and Cultural Rights' in Henkin L and Hargrove JL (eds), *Human Rights: an Agenda for the Next Century* (1994) cited in Hunt P, *Reclaiming Social Rights: International and Comparative Perspectives* (Dartmouth Publishing Co Ltd 1996)

Alston P, 'The Committee on Economic, Social and Cultural Rights' in Eide A, Krause C and Rosas A, *Economic, Social and Cultural Rights: A Textbook* (Brill 2001)

Alston P, Goodman R and Steiner H, *International Human Rights in Context: Law, Politics, Morals*, 3rd ed (Oxford University Press 2007)

American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed (APA 2010)

Andenas M and Fairgrieve D (eds) *Judicial Review in International Perspective*, Liber Amicorum in Honour of Lord Slynn of Hadley, vol II (Kluwer Law International 2000)

An-Naim AA, *Human Rights in Cross-Cultural Perspectives: A Quest for Consensus* (University of Pennsylvania Press 1995)

Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

Arnadóttir OM, 'A Future of Multidimensional Disadvantage Equality?' in Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

Baderin M, *International Human Rights and Islamic Law* (Oxford University Press 2005)

Bailey SH, Jones B and Mowbray AR, *Bailey, Jones and Mowbray: Cases, Materials and Commentary on Administrative Law*, 4th Rev ed (Sweet & Maxwell 2005)

Bamforth N, Malik M and O'Connell C, *Discrimination Law: Theory and Context*, 1st ed (Sweet & Maxwell 2008)

Barak-Erez D and Gross AM (eds) *Exploring Social Rights: between theory and practice* (Hart 2011)

Barnes C and Mercer G (eds) *Disability Policy and Practice: Applying the Social Model* (The Disability Press 2004)

Barnes C and Mercer G (eds) *Doing Disability Research* (The Disability Press 1997) out of print, full text available on Leeds Disability Archive

Barnes C and Mercer G, *Independent Futures: creating user-led disability services in a disabling society* (Policy Press 2006)

Barnes C, 'A Legacy of Oppression' in Barton L, Oliver M, *Disability Studies: Past Present and Future* (The Disability Press 1997)

Barnes C, 'Independent Living, Politics and Implications for the 21st Century' in Alonso JVC (ed) *El Movimiento de Vida Independiente, Experiencias Internacionales* (Luis Vives 2003)

Barnes C, *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation* (Hurst in association with the British Council of Organisations of Disabled People 1991)

Barnes C, Morgan H and Mercer G, *Creating Independent Futures* (The Disability Press (2001)

Barton L and Oliver M (eds) *Disability Studies: Past, Present and Future* (The Disability Press 1997)

Basser LA, 'Human Dignity' in Rioux M, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011)

Bates E, 'The United Kingdom and the International Covenant on Economic, Social and Cultural Rights' in McCorquodale R and Baderin M (eds) *Economic, Social and Cultural Rights in Action* (Oxford University Press 2007)

Batmanghelidj C, 'The Gateless Wall: a discourse on participation' in Griffiths S (ed) *The Politics of Aspiration* (Social Market Foundation 2007)

Beresford P, Fleming J, Glynn M, Bewley C, Croft S, Branfield F and Postle K, *Supporting People: towards a person-centred approach* (Policy Press 2011)

Beresford P, Green D, Lister R and Woodard K, *Poverty First Hand: Poor people speak for themselves* (Child Poverty Action Group 1999)

Berlin I, *The Age of Enlightenment* (Mentor 1956)

Bingham T, *Widening Horizons: the influence of comparative law and international law on domestic law*, The Hamlyn Lectures 61st series (Cambridge University Press 2010)

Birkinshaw P, 'Grievances, Remedies and the State – Revisited and Re-appraised' in Adler M (ed) *Administrative Justice in Context* (Hart 2010)

- Birkinshaw P, *Grievances, Remedies and the State* (Sweet & Maxwell 1985)
- Borsay A, *Disability and Social Policy in Britain since 1750: a History of Exclusion* (Palgrave Macmillan 2005)
- Buck T, Kirkham R and Thompson B, *The Ombudsman Enterprise and Administrative Justice* (Ashgate 2011)
- Butler F, 'Building a Human Rights Culture' in Harvey C (ed) *Human Rights in the Community: Rights as Agents for Change* (Hart 2005)
- Butler F, *Human Rights: Who Needs Them?* (Institute for Public Policy Research 2004)
- Campbell FK, 'Legislating Disability' in Tremain S, *Foucault and the Government of Disability* (The University of Michigan Press, 2005)
- Campbell J and Oliver M, *Disability Politics: Understanding Our Past, Changing Our Future* (Routledge 1996)
- Campbell J, "Growing Pains": Disability Politics The Journey Explained and Described' in Barton L and Oliver M (eds) *Disability Studies: Past, Present and Future* (The Disability Press 1997)
- Campbell T, Ewing KD and Tomkins A (eds) *Sceptical Essays on Human Rights* (Oxford University Press 2001)
- Caplan AL (ed) *When Medicine Went Mad: Bioethics and the Holocaust* (Humana Press 1992)
- Carroll A, *Constitutional and Administrative Law*, 5th ed (Pearson-Longman 2009)
- Charlton JI, *Nothing About Us Without Us: Disability Oppression and Empowerment* (University of California Press 2000)
- Clarke J, McDermont M and Newman J, 'Delivering Choice and Administering Justice: Contested Logics of Public Services' in Adler M (ed) *Administrative Justice in Context* (Hart 2010)
- Clements L and Morris R 'The Millennium Blip: The Human Rights Act 1998 and Local Government' in Halliday S and Schmidt P (eds) *Human Rights Brought Home: Socio-Legal Perspectives on Human Rights in the national Context* (Hart 2004)
- Clements L, *Community Care and the Law*, 3rd, 4th and 5th eds (Legal Action Group 2004, 2007, 2011)
- Corker M and French S (eds) *Disability Discourse* (Open University Press 1999)
- Corker M and Shakespeare T (eds) *Disability/Postmodernity: embodying disability theory* (Continuum 2002)
- Corker M, 'Disability Discourse in a Postmodern World' in Shakespeare T (ed) *The Disability Reader* (Cassell 1998)
- Craig PP, 'Competing Models of Judicial Review', in Forsyth C (ed) *Judicial Review and the Constitution* (Hart 2000)
- Craig PP, 'Ultra Vires and the Foundations of Judicial Review' in Forsyth C (ed) *Judicial Review and the Constitution* (Hart 2000)

- Craig PP, *Administrative Law*, 6th ed (Sweet & Maxwell 2008)
- Critchley S and Marchart O (eds), *Laclau: a critical reader* (Routledge 2004)
- Davis KC, *Discretionary Justice: A Preliminary Inquiry* (University of Illinois Press 1969)
- Dembour M-B, 'Critiques' in Moeckli D, Shah S and Sivakumaran S, *International Human Rights Law* (Oxford University Press 2010)
- Derrida J, *Writing and Difference* (Routledge & Kegan Paul 1987 [1967]) cited in Torfing J, *New Theories of Discourse: Laclau, Mouffe and Žižek* (Blackwell 1999)
- Devlin R and Pothier D, 'Introduction: Toward a Critical Theory of Dis-Citizenship' in Pothier D and Devlin R, *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (UBC Press 2006)
- Donnelly J, *Universal Human Rights in Theory and Practice* (Cornell paperbacks) 2nd ed (Cornell University Press 2002)
- Doyle B, *Disability Discrimination: law and practice*, 6th ed (Jordans 2008)
- Dworkin R, *Sovereign Virtue: the theory and practice of equality* (Harvard University Press 2000)
- Dworkin R. *A Matter of Principle* (Clarendon Press 1986)
- Eide A, Krause C and Rosas A, *Economic, Social and Cultural Rights: A Textbook* (Brill 2001)
- Evans J, 'The Independent Living Movement in the UK' in Alonso JVC (ed) *El Movimiento de Vida Independiente, Experiencias Internacionales* (Luis Vives 2003)
- Fennell P, *Treatment Without Consent: Law, Psychiatry and the Treatment of Mentally Disordered People since 1845* (Routledge 1996) cited in Borsay A, *Disability and Social Policy in Britain since 1750* (Palgrave Macmillan 2005)
- Fenwick H, *Civil Liberties and Human Rights* (Routledge-Cavendish 2010)
- Finkelstein V, *Attitudes and Disabled People* (World Health Organisation 1980)
- Flóvenz BG, 'The Implementation of the UN Convention and the Development of Economic and Social Rights as Human Rights', in Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)
- Forsyth C (ed) *Judicial Review and the Constitution* (Hart 2000)
- Foucault M, 'The Subject and Power' appended to Dreyfus HL and Rabinov P, *Michel Foucault: Beyond Structuralism and Hermeneutics* (University of Chicago Press 1982)
- Fredman S, 'Disability Equality: a Challenge to the Existing Anti-discrimination Paradigm?' in Lawson A and Gooding C, *Disability Rights in Europe* (Hart 2005)
- Fredman S, *Human Rights Transformed* (Oxford University Press 2008)
- Gamble A and Thomas R, 'The Changing Context of Governance: Implications for Administrative Justice' in Adler, M, (ed) *Administrative Justice in Context*, Oxford and Portland, Oregon (Hart Publishing 2010) Chapter 1

- Gearty C and Mantouvalou V, *Debating Social Rights* (Hart 2011)
- Gearty C, *Can Human Rights Survive?* (Cambridge University Press 2006)
- Genn H, *Paths to Justice: what people do and think about going to law* (Hart 1999)
- Ghai Y and Cottrell J (eds) *Economic, Social and Cultural Rights in Practice: the Role of Judges in Implementing Economic, Social and Cultural Rights* (Interights 2004)
- Goodley D, *Disability Studies: An Interdisciplinary Introduction* (Sage 2010)
- Greaves I, *Disability Rights Handbook: April 2011-April 2012* (Disability Alliance 2011)
- Griffith JAG, *The Politics of the Judiciary*, 2nd ed (Fontana 1981)
- Griffiths S (ed) *The Politics of Aspiration* (Social Market Foundation 2007)
- Gulland J, 'Complaints Procedures and Ombudsmen' in Adler, M, ed, *Administrative Justice in Context* (Hart 2010)
- Halliday S and Schmidt P(eds) *Human Rights Brought Home: Socio-Legal Perspectives on Human Rights in the national Context* (Hart 2004)
- Harris D, O'Boyle M, Bates E, and Buckley C, *Harris, O'Boyle & Warbrick Law of the European Convention on Human Rights*, 2nd ed (Oxford University Press 2009)
- Harvey C (ed) *Human Rights in the Community: Rights as Agents for Change* (Hart 2005)
- Hayek FA, *Law, Legislation and Liberty: a new statement of the liberal principles of justice and political economy* (Routledge & Kegan Paul 1982)
- Hepple B, Coussey M and Choudhury T, *Equality, A New Framework: Report of the independent review of the enforcement of UK anti-discrimination law* (Hart 2000)
- Hepple B, *Equality: the new legal framework* (Hart 2011)
- Higgins R, 'Dualism in the Face of a Changing Legal Culture' in Andenas M and Fairgrieve D (eds) *Judicial Review in International Perspective*, Liber Amicorum in Honour of Lord Slynn of Hadley, vol II (Kluwer Law International 2000)
- Hill TE, *Autonomy and Self-Respect* (Cambridge University Press 1991) cited in Bamforth N, Malik M and O'Conneide C, *Discrimination Law: Theory and Context*, 1st ed (Sweet & Maxwell 2008)
- Howard M, Garnham A, Finnister G and Veit-Wilson J, *Poverty: the Facts* (Child Poverty Action Group 2001)
- Howarth D and Stavrakakis Y, 'Introducing discourse theory and political analysis' in Howarth D, Norval AJ and Stavrakakis Y, *Discourse Theory and Political Analysis: Identities, Hegemonies and Social Change* (Manchester University Press 2000)
- Howarth D and Torfing J, *Discourse Theory in European Politics* (Palgrave Macmillan 2005)
- Howarth D, *Discourse* (Open University Press 2000)

Howarth D, Norval AJ and Stavrakakis Y (eds), *Discourse Theory and Political Analysis: identities, hegemonies and social change* (Manchester University Press, 2000)

Hunt P (ed) *Stigma: The Experience of Disability* (Geoffrey Chapman 1966) University of Leeds Centre for Disability Studies Archive

Hunt P, 'A Critical Condition' in Hunt P (ed) *Stigma: The Experience of Disability* (Geoffrey Chapman 1966) University of Leeds Centre for Disability Studies Archive

Hunt P, 'The Right to Health: A Way Forward at the International Level' in Hunt P, *Reclaiming Social Rights: International and Comparative Perspectives* (Dartmouth Publishing 1996)

Hunt P, *Reclaiming Social Rights: International and Comparative Perspectives* (Dartmouth Publishing 1996)

International Disability Rights Monitor, *IDRM International Disability Rights Compendium*, (Centre for International Rehabilitation 2003)

Jayawickrama N, *The Judicial Application of Human Rights Law* (Cambridge University Press 2002)

Jones M, 'Inclusion, Social Inclusion and Participation' in Rioux MH, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011)

Kennedy D, *The Dark Sides of Virtue: reassessing international humanitarianism* (Princeton University Press 2004)

Kesey K, *One Flew over the Cuckoo's Nest* (Penguin 1962)

King JA, 'United Kingdom: Asserting Social Rights in a Multi-layered System' in Langford M (ed) *Social Rights Jurisprudence: emerging trends in international and comparative law* (Cambridge University Press 2008)

Laclau E and Mouffe C, *Hegemony and Socialist Strategy* (Verso 1985)

Laclau E, *New Reflections on the Revolution of our Time* (Verso 1990)

Langford M (ed) *Social Rights Jurisprudence: emerging trends in international and comparative law* (Cambridge University Press 2008)

Langford M and Nolan A, *Litigating Economic, Social and Cultural Rights: Legal Practitioners Dossier* (Centre on Housing Rights and Evictions 2006)

Langford M, 'The Justiciability of Social Rights: from Practice to Theory' in Langford M (ed) *Social Rights Jurisprudence: emerging trends in international and comparative law* (Cambridge University Press 2008)

Lawson A and Gooding C, *Disability Rights in Europe* (Hart 2005)

Lawson A, *Disability and Equality Law in Britain: the role of reasonable adjustment* (Hart 2008)

Le Sueur A, Sunkin M and Murkens J, *Public Law: texts, cases and materials* (Oxford University Press 2010)

Liachovitz C, *Disability as a Social Construct: legislative roots* (University of Pennsylvania Press 1988)

- Lord JE and Brown R, 'The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: the UN Convention on the Rights of Persons with Disabilities' in Rioux MH, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011)
- Loughlin M, 'Restructuring of Central-Local Government Relations' in Oliver D and Jowell JL (eds) *The Changing Constitution* (Oxford University Press 2000)
- Maiman R 'We've Had To Raise Our Game': Liberty's Litigation Strategy Under the Human Rights Act 1998' in Halliday S and Schmidt P(eds) *Human Rights Brought Home: Socio-Legal Perspectives on Human Rights in the National Context* (Hart 2004)
- Marks D, *Disability: Controversial Debates and Psychological Perspectives* (Routledge 1999) cited in Goodley D, *Disability Studies: An Interdisciplinary Introduction* (Sage 2010)
- Marshall TH (ed) *Citizenship and Social Class and Other Essays*, (Cambridge University Press 1950)
- Marshall TH, 'Citizenship and Social Class' in Marshall TH (ed) *Citizenship and Social Class and Other Essays*, (Cambridge University Press 1950)
- Mashaw JL, *Bureaucratic Justice: Managing Social Security Disability Claims* (Yale University Press 1983)
- McCorquodale R and Baderin M (eds) *Economic, Social and Cultural Rights in Action* (Oxford University Press 2007)
- McFarlane A, *The Origins of English Individualism* (Blackwell 1978)
- McHoul AW and Grace W, *A Foucault Primer: Discourse, Power and the Subject* (Melbourne University Press 1993)
- Merrills JG, *Human Rights in Europe: a study of the European Convention on Human Rights*, 4th ed (Manchester University Press 2001)
- Mill JS, *On Liberty* (1859)
- Miller P, Parker S and Gillinson S, *Disablism: how to tackle the last prejudice* (Demos 2004)
- Moeckli D, Shah S and Sivakumaran S, *International Human Rights Law* (Oxford University Press 2010)
- Monmonier M, *Maps Distortion and Meaning* (Association of American Geographers 1981) cited by Santos (2002)
- Morris J, *Independent Lives: Community Care and Disabled People* (Macmillan 1993)
- Mouffe C, *The Return of the Political* (Verso 1993)
- Mowbray AR, *The Development of Positive Obligations Under the European Convention on Human Rights by the European Court of Human Rights* (Hart Publishing 2004)
- O'Conneide C, 'Disability Discrimination' in Bamforth N, Malik M and O'Conneide C, *Discrimination Law: Theory and Context*, 1st ed (Sweet & Maxwell 2008)

O’Cinneide C, ‘Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and New Possibilities’ in Arnardóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

Oliver D and Jowell JL (eds) *The Changing Constitution* (Oxford University Press 2000)

Oliver M and Barnes C, *The New Politics of Disablement* (Palgrave 2012)

Oliver M, *The Politics of Disablement* (Palgrave Macmillan 1990)

Oliver M, *Understanding Disability: from Theory to Practice* (MacMillan 1996)

Palmer E, *Judicial Review, Socio-Economic Rights and the Human Rights Act* (Hart 2009)

Peters S, Wolbers K and Dimling L, ‘Reframing global education from a disability rights movement perspective’ in Gabel S and Danforth (eds) *Disability and the International Politics of Education* (Peter Lang 2008) cited in Goodley D, *Disability Studies: an interdisciplinary introduction* (Sage 2010)

Pinto PC, ‘Monitoring Human Rights: a Holistic Approach’ in Rioux MH, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011)

Pleasence P, Balmer N and Buck A, *Causes of Action: Civil Law and Social Justice* 2nd ed (Legal Services Research Centre 2006)

Pleasence P, Buck A, Balmer N (eds) *Transforming Lives: law and social process* (Legal Services Commission 2007)

Pleasence P, Buck A, Balmer N, O’Grady A, Genn H and Smith M, *Causes of Action: Civil Law and Social Justice* (Legal Services Research Centre 2004)

Potheir D and Devlin R, *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (UBC Press 2006)

Quinn G and Arnardóttir OM, ‘Introduction’ in Arnardóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

Quinn G, ‘Resisting the Temptation of Elegance’: Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?’ in Arnardóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

Rawls JB, *A Theory of Justice Revised* (Harvard University Press 1999)

Rioux MH and Riddle CA, ‘Values in Disability Policy and Law: Equality’ in Rioux MH, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011)

Rioux MH, Basser L and Jones M (eds) *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhof 2011)

Robinson JE (ed) *Towards a New Social Compact for Care in Old Age* (King’s Fund 2001)

Rosas A and Helgesen J, 'Introduction' in Rosas A and Helgesen J (eds) *Human Rights in a Changing East-West Perspective* (1990) cited in Hunt P, *Reclaiming Social Rights: International and Comparative Perspectives* (Dartmouth Publishing Co Ltd 1996)

Sachs A, *Social and Economic Rights: Can They Be Made Justiciable?* (Southern Methodist University School of Law 1999) cited in Langford M (ed) *Social Rights Jurisprudence: Emerging Trends in International and Comparative Law* (Cambridge University Press 2008), frontispiece

Santos BS, 'Toward a Multicultural Conception of Human Rights' in Hernandez-Truyol B (ed) *Moral Imperialism: A Critical Anthology* (York University Press 2002)

Santos BS, *Toward a New Legal Common Sense*, 2nd ed (Butterworths 2002)

Scheinin M, 'Human Rights Committee: not only a committee on civil and political rights' in Langford M (ed) *Social Rights Jurisprudence: emerging trends in international and comparative law* (Cambridge University Press 2008)

Sedley S, 'Governments, Constitutions and Judges' in Richardson G and Genn H (eds) *Administrative Law and Government Action* (Oxford University Press 1994)

Sedley S, *Ashes and Sparks* (Cambridge University Press 2011)

Shah S and Priestley M, *Disability and Social Change: Private Lives and Public Policies* (Policy Press 2011)

Shakespeare T (ed) *The Disability Reader* (Cassell 1998)

Shakespeare T, *Disability Rights and Wrongs* (Routledge 2006)

Sherry M, *Disability Hate Crimes: Does Anyone Really Hate Disabled People?* (Ashgate 2010)

Shue H, *Basic Rights: Subsistence, Affluence, and US Foreign Policy* (Princeton University Press 1980)

Smith A, *An Inquiry into the Nature and Causes of the Wealth Of Nations* (1776)

Soanes C, *Oxford Compact English Dictionary*, 2nd ed (Oxford University Press 2000)

Stein MA and Lord JE, 'Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities' in Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

Stone D, *The Disabled State* (MacMillan 1984)

Stone R, *Civil Liberties and Human Rights* (Oxford University Press 2010)

Striker HJ, *A History of Disability* (Michigan University Press 1999) cited in Borsay A, *Disability and Social Policy in Britain since 1750* (Palgrave Macmillan 2005)

Sullivan M, 'Subjected Bodies: Paraplegia, Rehabilitation and the Politics of Movement' in Tremain S (ed) *Foucault and the Government of Disability* (University of Michigan Press 2005)

Taylor-Gooby P (ed) *Welfare States Under Pressure* (Sage 2001)

Taylor-Gooby P, 'Welfare Reform in the UK: the Construction of a Liberal Consensus' in Taylor-Gooby P, *Reframing Social Citizenship* (Oxford University Press 2009)

Taylor-Gooby P, *Reframing Social Citizenship* (Oxford University Press 2009)

Teubner G, 'Juridification: Concepts, Aspects, Limits, Solutions' in Teubner G (ed) *Juridification of Social Spheres: A Comparative Analysis in the Areas of Labour, Corporate, Antitrust and Social Welfare Law* (de Gruyter 1987) 3–48, discussed in Hepple B, 'Enforcing Equality Law: Two Steps Forward and Two Steps Backwards for Reflexive Regulation' (2011)

Thane P, *Old Age in English History: Past Experiences, Present Issues* (Oxford University Press, 2000) cited in Borsay A, *Disability and Social Policy in Britain since 1750* (Palgrave Macmillan 2005)

Thomas C, *Sociologies of Disability, 'Impairment' and Chronic Illness: Ideas in Disability Studies and Medical Sociology* (Palgrave 2007)

Tom Mullen, 'A Holistic Approach to Administrative Justice?' in Adler M (ed) *Administrative Justice in Context* (Hart 2010)

Torring J, *New Theories of Discourse: Laclau, Mouffe and Žižek* (Blackwell 1999)

Tregaskis C, *Constructions of Disability: researching the interface between disabled and non-disabled people* (Routledge 2004)

Tremain S (ed) *Foucault and the Government of Disability* (University of Michigan Press 2005)

Tremain S, 'Foucault, Governmentality and Critical Disability Theory' in Tremain S (ed) *Foucault and the Government of Disability* (The University of Michigan Press, 2005)

Tremain S, 'On the Subject of Impairment' in Corker M and Shakespeare T (eds) *Disability/Postmodernity: embodying disability theory* (Continuum 2002)

Waddington L, 'Breaking New Ground: The Implications of Ratification of the UN Convention on the Rights of Persons with Disabilities for the European Community' in Arnadóttir OM and Quinn G (eds) *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009)

Wade W and Forsyth C, *Administrative Law* 10th ed (Oxford University Press 2009)

Wadham J, Robinson A, Ruebain D and Uppal S, *Blackstone's Guide to the Equality Act 2010* (Oxford University Press 2010)

Williams C and Ferris K, *Complaints Panels in Social Care* (Russell House Publishing 2010)

Wittgenstein L, *Tractatus Logico-Philosophicus* (London 1981) cited in Laclau E, *New Reflections on the Revolution of our Time* (Verso 1990)

Wright D, *Mental Disability in Victorian England: the Earleswood Asylum 1847-1901* (Clarendon Press 2001)

Young IM, *Justice and the Politics of Difference* (Princeton University Press 1990)

Zarb G, 'Independent Living and the Road to Inclusion' in Barnes C and Mercer G (eds) *Disability Policy and Practice: Applying the Social Model* (The Disability Press 2004)

Ziv N, 'The Social Rights of People with Disabilities: reconciling care and justice' in Barak-Erez D and Gross AM (eds) *Exploring Social Rights: between theory and practice* (Hart 2011)

2. Journal articles

Abraham A, 'The Ombudsman and the Executive: the Road to Accountability', (2008) 61(3) *Parliamentary Affairs* 535

Adler M, 'A Socio-Legal Approach to Administrative Justice' (2003) 25(4) *Law & Policy* 323

Ashtiany S, 'The Equality Act 2010: Main Concepts' (2010) 5 *Equal Rights Review* 25

Baldwin R and Hawkins K, 'Discretionary Justice: Davis Reconsidered' [1984] *Public Law* 570

Baldwin R and Houghton J, 'Circular Arguments: the Status and Legitimacy of Administrative Rules' [1986] *Public Law* 239

Barnes C, 'Disability Activism and the Price of Success: A British Experience' (2007) 1(2) *Intersticios: Revista Sociológica de Pensamiento Crítico* 15

Barnes C, 'Disability Rights: Rhetoric and Reality in the UK' (1995) 10(1) *Disability & Society* 111

Barriga SR and Young K, 'CRPD: An Overview of the Conference of States Parties and Committee of Experts' (2007) 56(4), *Rehabilitation International Review*

Beresford P 'Poverty and Disabled people: challenging dominant debates and policies' (1996) 11(4) *Disability & Society* 553

Beresford P, 'What Future for Care?' (2008) *Joseph Rowntree Foundation Viewpoint*, September 2008

Beuren G van, 'Including the Excluded: the Case for an Economic, Social and Cultural Human Rights Act' [2002] *Public Law* 465

Bindman G, 'Interaction between equality and human rights principles' (2007) *Disability Rights Commission Legal Bulletin* 12 *Legacy Edition* 78

Birkenbach JE, Charrerji S, Badley E M and Ustun T B, 'Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps' (1999) 48 *Social Science & Medicine* 1173, cited in O'Conneide C, 'Disability Discrimination' in Bamforth N, Malik M and O'Conneide C, *Discrimination Law: Theory and Context*, 1st ed (Sweet & Maxwell 2008)

Blyth C and Gardner A "We're not asking for anything special': direct payments and the carers of disabled children' (2007) 22(3) *Disability & Society* 235

Burca G de, 'The European Union in the Negotiation of the UN Disability Convention' (2010) 35(2) *European Law Review* 174

Burchardt T, 'Capabilities and Disability: the capabilities framework and the social model of disability' (2004) 19(7) *Disability & Society* 735

Butlin S F, 'The UN Convention on the Rights of Persons with Disabilities: Does the Equality Act 2010 Measure up to UK International Commitments?' (2011) 40(4) *Industrial Law Journal* 428

Campbell J, 'Social Care as an Equality and Human Rights Issue' (2008) 'Independently' Newsletter, National Centre for Independent Living, February 2008

Clark M, Glasby J and Lester H, 'Cases for Change: User Involvement in Mental Health Services and Research' (2004) 22(2) *Research Policy and Planning*, 31

Clarke J, Smith N and Vidler E, 'The Indeterminacy of Choice: Political, Policy and Organisational Implications' (2006) 5(2) *Social Policy & Society* 327

Clements L, 'The Collapsing Duty' (1997) 2(3) *Judicial Review* 162

Clements L, 'The disability rights convention and the right to independent living' (2008) *Nov Legal Action* 27

Clements L, 'Winners and Losers' (2005) 32 *Journal of Law and Society* 34

Diesfeld K, 'International Ethical Safeguards: genetics and people with learning disabilities, (1999) 14(1) *Disability & Society* 21

Donnelly CM '*Leonard Cheshire* Again and Beyond: Private Contractors, Contract and section 6(3)(b) of the Human Rights Act' [2005] *Public Law*, 785

Doyle B, 'Enabling Legislation or Dissembling Law? The Disability Discrimination Act 1995', (1997) 60(1) *Modern Law Review* 64

Ellis K, 'Disability rights in practice: the relationship between human rights and social rights in contemporary social care' (2005) 7 *Disability & Society* 691

Ewing KD, 'Social Rights and Constitutional Law' [1999] *Public Law* 104

Feldman D, 'Human Dignity as a Legal Value' Part I [1999] *Public Law* 682 & Part II [2000] *Public Law* 61

Fletcher A and O'Brien N, 'Disability Rights Commission: From Civil Rights to Social Rights' (2008) 35(4) *Journal of Law and Society* 520

Foster S, 'Finally: a Bill of Rights for the UK?' (2008) 13(2) *Coventry Law Review* 8

Fredman S, 'The Public Sector Equality Duty' (2011) 40(4) *Industrial Law Journal* 405

Gabel S and Peters S, 'Presage of a Paradigm Shift? Beyond the social model of disability toward resistance theories of disability' (2004) 19(6) *Disability & Society* 585

Geisinger A and Stein MA, 'A Theory of Expressive International Law' (2007) 60 *Vanderbilt Law Rev* 77

Gibbs D, 'Public Policy and Organisations of Disabled People' (2005) Seminar presentation to University of Leeds Centre for Disability Studies, 22 April 2005

- Glasby J and Beresford P, 'Who knows best? Evidence-based practice and the service user contribution' (2006) 26 *Critical Social Policy* 268
- Gulland J, 'Independence in complaints procedures: lessons from community care' (2009) 31(1) *Journal of Social Welfare and Family Law* 59
- Gulland J, 'Second-tier reviews of complaints in health and social care' (2006) 14(3) *Health and Social Care* 206
- Gulland J, 'Taking complaints seriously: the role of informality in complaints about public services' (2011) 10(4) *Social Policy and Society* 483
- Guttmann L, 'History of the Stoke Mandeville Hospital, Aylesbury', (1967) 34 *Paraplegia* 115
- Halford J, 'Paying Attention to Inequality: the Development of the Positive Equality Duties' (2009) *Judicial Review* 21
- Hemingway L and Priestley M, 'Natural hazards, human vulnerability and disabling societies: a disaster for disabled people?' (2006) 2(3) *Review of Disability Studies* 57
- Hendriks A, 'UN Convention on the Rights of Persons with Disabilities' (2007) 14(3) *European Journal of Health Law* 273
- Hepple B, 'Enforcing Equality Law: Two Steps Forward and Two Steps Backwards for Reflexive Regulation' (2011) 40(4) *Industrial Law Journal* 315
- Hepple B, 'The new Single Equality Act in Britain' (2010) 5 *Equal Rights Review* 11
- Hervey T, Stark A, Dawson A, Fernandez J-L, Matosevic T and McDaid D, 'Long-term care for older people and EU law: the position in England and Scotland' (2012) 34(1) *Journal of Social Welfare and Family Law* 105
- Hodge N, 'Evaluating Lifeworld as an emancipatory methodology' (2008) 23(1) *Disability & Society* 29
- Horejes T and Lauderdale P, 'Disablism Reflected in Law and Policy: The Social Construction and Perpetuation of Prejudice' (2007) 3(3) *The Review of Disability Studies: an International Journal* 13
- Hughes B, 'Bauman's Strangers: Impairment and the invalidation of disabled people in modern and post-modern cultures' (2002) 17(5) *Disability & Society* 571
- Hvinden B, 'Nordic Disability Policies in a Changing Europe: Is There Still a Distinct Nordic Model?' (2004) 38(2) *Social Policy & Administration* 170
- In Control, 'Research on Person-centred Planning' (2006) 14(2) *Journal of Integrated Care*
- Irvine H, 'Judges and Decision-makers: the Theory and Practice of *Wednesbury* Review' [1996] *Public Law* 59
- Jolly D, 'The Government of Disability: economics and power in welfare and work' (2003) 18(4) *Disability & Society* 509
- Jowell J, 'The Legal Control of Administrative Justice' [1973] *Public Law* 178
- Kayess R and French P, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 *Human Rights Law Review* 1

Kirkham R, 'A Complainant's View of the Local Government Ombudsman' (2005) 27(3-4) *Journal of Social Welfare and Family Law* 383

Klug F, 'A Bill of Rights: Do We need One or Do We Already Have One?' (2007) Winter, *Public Law* 701

Landau J, 'Functional public authorities after YL' (2007) Winter, *Public Law*, 630

Lawson A, 'Disability and Employment in the Equality Act 2010: Opportunities Seized, Lost and Generated' (2011) 40(4) *Industrial Law Journal* 359

Lawson A, 'The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?' (2006-2007) 34 *Syracuse Journal of International Law and Commerce* 563

Lester A and Beattie K, 'The New Commission for Equality and Human Rights' [2006] *Public Law* 197

Liebenberg S, 'Adjudicating the Positive Duties Imposed by Economic, Social and Cultural Rights' (2006) 15 *INTERIGHTS Bulletin* 109

Liebowitz T, Minkowitz T, Trommel S and Barriga SH, 'How the Conference of States Parties Can Serve as an Essential Forum for CRPD Implementation' (2008) 57(1) *International Rehabilitation Review* 8

Lindqvist B, 'UN Standard Rules on Disability Pave the Way for Human Rights' (2004) 14(3) *INTERIGHTS Bulletin* 95

Linton S, 'Disability studies/not disability studies' (1998) 13(4) *Disability & Society* 525

McCrudden C, 'A Common Law of Human Rights?: Transnational Judicial Conversations on Constitutional Rights' (2000) 20(4) *Oxford Journal of Legal Studies* 499

McCrudden C, 'Human Dignity and Judicial Interpretation of Human Rights' (2008) 19(4) *European Journal of International Law* 655

McKay D, 'The Convention on the Rights of Persons with Disabilities: A Benchmark for Action' (2007) 56(1) *International Rehabilitation Review* 1

McKay D, 'The United Nations Convention on the Rights of Persons with Disabilities' (2006-2007) 34 *Syracuse Journal of International Law and Commerce* 323

Mégret F, 'The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?' (2008a) 30(2) *Human Rights Quarterly* 493

Mégret F, 'The Disabilities Convention: Towards a Holistic Concept of Rights' (2008b) 12(261) *International Journal of Human Rights* 3

Melish T, 'The UN Disability Convention: Historic Process, Strong Prospects, and Why the U.S. Should Ratify' (2007) 14 *Human Rights Brief* 37

Minkowitz T, 'The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from Non-consensual Psychiatric Interventions' (2006-2007) 34 *Syracuse Journal of International Law and Commerce* 405

Morris J 'Rethinking Disability Policy' (2011) *Viewpoint* , Joseph Rowntree Foundation

- Morris J, 'Independent Living and community care: a disempowering framework' (2004) 19(5) *Disability & Society* 429
- O'Brien N, 'Ombudsmen and Social Rights Adjudication' [2009] *Public Law* 466
- O'Connell C, 'The Commission for Equality and Human Rights: A New Institution for New and Uncertain Times' (2007) 36(2) *Industrial Law Journal* 141
- O'Connell C, 'The Right to Equality: A Substantive Legal Norm or Vacuous Rhetoric?' (2008) 1 *Human Rights Review* 81
- O'Connell P, 'On Reconciling Irreconcilables: Neo-Liberal Globalisation and Human Rights' (2007) 7(3) *Human Rights Law Review* 483
- O'Grady A, Pleasence P, Balmer NJ, Buck A and Genn H, 'Disability, social exclusion and the consequential experience of justiciable problems' (2004) 19(3) *Disability & Society* 259
- Oliver D, 'Functions of a Public Nature under the Human Rights Act' [2004] *Public Law* 329
- Oliver M, 're-Defining Disability: A Challenge to research' (1987) 5 *Research, Policy and Planning*
- Otto D, 'Everything is Dangerous: Some Post-structural Tools for Rethinking the Universal Knowledge Claims of Human Rights Law' (1999) 1 *Australian Journal of Human Rights* 22
- Palmer E and Sunkin M, 'Needs: Resources and Abhorrent Choices' (1998) 61(3) *Modern Law Review* 401
- Palmer E, 'Resource Allocation, Welfare Rights – Mapping the Boundaries of Judicial Control in Public Administrative Law' (2000) 20(1) *Oxford Journal of Legal Studies* 63
- Parker C and Clements L, 'The UN Convention on the Rights of Persons with Disabilities: a new right to independent living?' (2008) 4 *European Human Rights Law Review* 508
- Parton N, 'Reconsidering professional practice' (2003) 33(1) *British Journal Of Social Work* 1 cited in Beresford P, Fleming J, Glynn M, Bewley C, Croft S, Branfield F and Postle K, *Supporting People: towards a person-centred approach* (Policy Press 2011) 227
- Pillay N, 'Human rights in United Nations action: norms, institutions and leadership' (2009) 1 *European Human Rights Law Review* 1
- Platt, L, Sunkin M, and Calvo K, 'Judicial Review Litigation as an Incentive to Change in Local Authority Public Services in England and Wales' (2010) 20(3) *Journal of Public Administration Research and Theory*, 243
- Pleasence P and Balmer N, 'Mental health and the experience of housing problems involving rights' (2007) 2(1) *People, Place and Policy Online* 4
- Pleasence P, Genn H, Balmer NJ, Buck A and O'Grady A, 'Causes of Action: First Findings of the LSRC Periodic Survey' (2003) 30(1) *Journal of Law and Society* 11
- Poole T, 'The Reformation of English Administrative Law' (2009) 1 *Cambridge Law Journal* 142

Preston-Shoot M, 'A Triumph of Hope over Experience? Accountability: the Case of Complaints Procedures in Community Care' (2001) 35(6) *Social Policy and Administration* 701

Priestley M and Hemingway L 'Disabled People and Disaster Recovery: a tale of two cities?' (2006) 5(3/4) *Journal of Social Work in Disability and Rehabilitation* 23

Priestley M, Waddington L and Bessozi C, 'Towards an agenda for disability research in Europe: learning from disabled people's organisations' (2010) 25(6) *Disability & Society* 731

Pring J, 'The frequency and potential consequences of the failure to visit learning-disabled adults in out of area placements' (2004) 9(2) *Learning Disability Review* 35

Rayment B, '*Ex parte Barry* in the House of Lords' (1997) 2(3) *Judicial Review* 158

Rioux MH, 'Disability: the place of judgement in a world of fact' (1997) 41(2) *Journal of Intellectual Disability Research* 102

Runswick-Cole, K 'The Tribunal was the most stressful thing: more stressful than my son's diagnosis or behaviour': the experiences of families who go to the Special Educational Needs and Disability Tribunal (SENDIST) (2007) 22(3) *Disability & Society* 315

Sapey B and Pearson J, 'Do Disabled People Need Social Workers?' (2004) 11(3) *Social Work and Social Sciences Review* 52

Sbaraini S and Carpenter J, 'Barriers to complaints: a survey of mental health service users' (1996) 10(6) *Journal of Management in Medicine* 36

Scourfield P 'What matters is what works'? How discourses of modernization have both silenced and limited debate on domiciliary care for older people' (2006) 26(1) *Critical Social Policy* 5

Sedley S, 'Judicial Politics: Stephen Sedley on the separation of powers' (2012) 34(4) *London Review of Books*

Seneviratne M, Cracknell S, 'Consumer Complaints in Public Sector Services' (1988) 66(2) *Public Administration* 181

Sherry M, '(Post)Colonising disability' 4 (Summer) *Wagadu, Journal of Transnational Women's and Gender Studies* 10 cited in Goodley D, *Disability Studies: An Interdisciplinary Introduction* (Sage 2010) 8

Shildrick M and Price J, 'Breaking the Boundaries of the Broken Body' (1996) 2(4) *Body & Society* 93

Smith B and Sparkes AC, 'Narrative and its potential contribution to disability studies' (2008) 23(1) *Disability & Society* 17

Speed E, 'Patients, consumers and survivors: A case study of mental health service users discourses' (2006) 62 *Social Science and Medicine* 28

Stein MA and Lord JE, 'Jacobus tenBroek, Participatory Justice, and the UN Convention on the Rights of Persons with Disabilities' (2007) 13 *Texas Journal on Civil Liberties & Civil Rights* 167

Stein MA and Stein PJS, 'Beyond Disability Civil Rights' (2006-2007) 58 *Hastings Law Journal* 1203

- Stein MA, 'Disability Human Rights' (2007) 95(1) California Law Review 75
- Stevens M, Glendinning C, Jacobs S, Moran N, Challis D, Manthorpe J, Fernandez J-L, Jones K, Knapp M, Netten A and Wilberforce M, 'Assessing the Role of Increased Choice in English Social Care Services' (2011) 40(2) Journal of Social Policy 257
- Sunkin M 'Pushing Forward the Frontiers of Human Rights Protection: The Meaning of Public Authority under the Human Rights Act' [2004] Public Law 643
- Sunkin M, 'Keep Up the Momentum' (2006) Autumn, Tribunals 9
- Sunkin M, Calvo K, Platt L and Landman T, 'Mapping the Use of Judicial Review to Challenge Local Authorities in England and Wales' [2007] Public Law 545
- Syrett K 'Of resources, rationality and rights: emerging trends in the judicial review of allocative decisions' (2000) 1 Web Journal of Current Legal Issues 1
- Townsend P, 'Policies for the aged in the 21st century: more "structured dependency" or the realisation of human rights?' (2006) 26 Ageing & Society 161
- Twining W, 'Have concepts, will travel: analytical jurisprudence in a global context' (2005) 1(1) International Journal of Law in Context 5
- Van Beuren G, 'Including the Excluded: the Case for an Economic, Social and Cultural Human Rights Act' [2002] Public Law 456
- Williams C and Ferris K, 'Proposals to Transfer Complaints Panels to the Commission for Social Care Inspection – Throwing the Baby out with the Bath Water?' (2005) 27 Journal of Social Welfare and Family Law 199
- Wood D, 'Acting on complaints about mental health service: implications of power imbalances' (1996) 10(3) Journal of Management in Medicine 31

3. Academic papers and presentations

- Abberley P, 'The Concept of Oppression and the Development of a Social Theory of Disability' (1997) available on Leeds Disability Archive
- Abraham A, 'The Parliamentary Ombudsman and Administrative Justice: shaping the next 50 years' (2011) Tom Sargent lecture, JUSTICE, 13 October 2011
- Arbour L, Statement to General Assembly Ad Hoc Committee, 7th session, New York 27 January 2006
- Arnardóttir OM, 'A Future of Substantive and Multidimensional Equality?' (2007) presentation to The Human Rights of Persons with Disabilities – from Social Policy to Equal Rights Conference, Reykjavik, 27 September 2007
- Barnes C ' 'Emancipatory' Disability research: project or process?' Public lecture at City Chambers, Glasgow on 24 October 2001
- Barnes C, 'Independent Futures: policies, practices and the illusion of inclusion' (2006) Background notes to a verbal presentation to the European Network for Independent Living, 3 November 2006, available on Leeds Disability Archive

Beresford P, 'User Involvement in Research: connecting lives, experience and theory' (University of Warwick 2003)

Bondy V and Mulcahy L, 'Mediation and Judicial Review: an empirical research study' (Public Law Project 2009)

Carter P, 'Polemics & Persuasion – the Use of International Law by NGOs' (2006) presentation to British Institute of International and Comparative Law lecture Series International Law in the Domestic Courts, 8 May 2006

Choudhury T, 'Discrimination in Economic and Social Rights' Paper for Democratic Audit, 2003

Clements L 'Honoured in the breach: statutory and policy impediments to realising the right to independent living' (2007) Paper for Session 1 of the joint Disability Rights Commission and British Institute of Human Rights seminar 'A Right to Independent Living – Rhetoric or Reality?' 3 September 2007

Collingbourne T, 'Administrative Justice? Realising the Right to Independent Living' (2010) Disability Studies Conference, Lancaster University, 9 September 2010

Collingbourne T, 'The Disability Rights Convention: first human rights treaty of the 21st century' (2007) Summer BIHR Brief 14

Collingbourne T, 'The UN Convention on the Rights of Persons with Disabilities and the Right to Independent Living', (2009) Paper for the European Network on Independent Living, July 2009

Dean H, 'From Poverty Reduction to Welfare Rights: A Social Policy Perspective on Human Rights' (2006) Crossing the Boundaries: The Place of Human Rights in Contemporary Scholarship conference, London School of Economics and Political Science, 24 March 2006

Ellis K, 'Human Rights, professional practice and social care: the findings of a small scale research study' (2004) presentation to 'Disability Studies: from theory to practice' conference, University of Lancaster 26-28 July 2004

Ferri D, 'The Implication of the UNCRPD for EU Law' (2011) presentation to ERA (Academy of European Law) Seminar on the UN Convention on the Rights of Persons with Disabilities, Madrid, 15-16 December 2011

Finkelstein V, 'The 'Social Model of Disability' and the Disability Movement' (2007) Leeds Disability Archive

Fraser M, 'Doing the Duty: the role for disability organisations' Paper for RADAR conference Doing the Duty – the Disability Equality Duty – impact so far and legal enforcement, London, 7 January 2009

Gearty C, 'Can Human Rights Deliver Real Equality?' (2007) 5th Annual Legal Action Group conference, 19 November 2007

Gearty C, 'Equality of Esteem: the Ethical basis for human rights' (2004) Presentation to Discrimination Law Association conference 'Understanding Equality: the Need for Discrimination' 13 December 2004

Gearty C, 'Putting Lawyers in their Place: the Role of Human Rights in the Struggle against Poverty', undated, available at www.conorgearty.co.uk

- Genn H, 'Judging Civil Justice' (2008) The Hamlyn Lectures 2008, London and Edinburgh, 27 November, 2 December & 4 December 2008
- Gibbs D, 'Disabled People and the Research Community' (1999) Paper for ESRC-funded seminar 'Who Owns the research process?' Belfast September 1999, available at Leeds Disability Archive
- Gordon R, 'I am a mental health lawyer – how is the Human Rights Act helping my practice? Human Rights developments in mental health law' (Human Rights Lawyers Association 2005)
- Gordon R, 'The Impact of the HRA on English Public Law – a practitioner's view' (2005) British Institute of International and Comparative Law conference, London
- Gordon R, 'What Price Dignity' (2011) keynote address, Legal Action Group Community Care Conference: What Price Dignity? London, 30 November 2011
- Harding T, 'The Long and Winding Road – towards dignity and equality in old age' Help the Aged lecture, 25 October 2006
- Hasler F 'Philosophy of Independent Living' (Independent Living Institute 2003)
- Hunt P, 'Settling Accounts with the Parasite People: a Critique of 'A Life Apart' by E. J. Miller and G. V. Gwynne' (1981)
- Hunt P, 'Taking Economic, Social and Cultural Rights Seriously' (2006) Human Rights Law Resource Centre 2006 Human Rights Dinner, Melbourne, Australia, 29 April 2006
- Hunt P, Novak M and Osmani S, 'Human Rights and Poverty Reduction Strategies: a discussion paper' available at <http://www.fao.org/righttofood/kc/downloads/vl/docs/AH177.doc>
- Hurst, R, 'The International Disability Rights Movement' (2000) text of a public lecture, given as part of the 'New Directions in Disability Studies' seminar series, Centre for Disability Studies, University of Leeds, 11 October 2000 available at Leeds Disability Archive
- Jefferson M, 'Discrimination Law to Equality Law' (2010) Association of Law Teachers conference, April 2010
- Jolly D, 'Personal Assistance and Independent Living: Article 19 of the UN Convention on the Rights of Persons with Disabilities' (undated) Paper for European Network on Independent Living
- Klug F, 'Establishment of the Commission for Equality and Human Rights: implications for the public sector' (2004) Westminster Explained 36: An assessment of the impact of the HRA, 7 December 2004
- Laclau E, 'Philosophical Roots of Discourse Theory' (undated) Essex University Centre for Theoretical Studies available at <http://www.essex.ac.uk/centres/TheoStud/onlinepapers.asp>
- Lawson A, 'The UN Draft International Convention on the Rights of Persons with Disabilities: Purpose, Progress and Potential' (2006) Delivered at London School of Economics, 9 March 2006
- Light R, 'Social Model or Unsociable Muddle?' (Disability Awareness in Action, undated)

Light R, speech to Scope, ECHR, DAA and UKDPC Making Rights a Reality – implementing the UN Convention on the Rights of Persons with Disabilities conference, London, 28 March 2008

Lindqvist B, speech to the Nineteenth Congress of Rehabilitation International, Rio de Janeiro, 25 – 30 August 2000

Lord Falconer of Thoroton, 'Human Rights and Common Sense' (2007) Harry Street lecture, Manchester University, 9 February 2007

Lord Falconer of Thoroton, 'Human Rights and Constitutional Reform' (2004) Law Society/Human Rights Lawyers Association conference, 17 February 2004

Massie B, 'Finding the Wormhole: Achieving equal citizenship for disabled people' (2006) 4th Annual Disability Lecture, St John's College, Cambridge University, 9 May 2006

Massie B, 'Reflections on the Role of the Judiciary in Enhancing or Restricting the Civil Rights of Disabled People' (2004) Disability Rights Commission, February 2004

Member of UK delegation to the CRPD negotiating Committee, 'Convention on the Rights of Persons with Disabilities' (2007) presentation to the Centre of Applied Disability Studies, University of Sheffield, 18 April 2007

Morris J, 'Citizenship and disabled people' (2005) Paper for Disability Rights Commission seminar 'Equal Rights... equal responsibilities?' February 2005

Morris J, 'Independent Living and Government Policy: Triumph or Tragedy?' (2011) Seminar for Leeds University Centre for Disability Studies, 23 March 2011

Morris J, 'Independent Living: the role of evidence and ideology in the development of government policy' (2005) Paper delivered at Cash and Care Conference, Social Policy Research Unit, University of York, 12-13th April 2005, available at Leeds Disability Archive

Munby LJ, 'What Price Dignity?' (2011) keynote address, Legal Action Group Community Care Conference: What Price Dignity? London, 30 November 2011

National Centre for Independent Living 'Independent Living Bill and Adult Care Reform: Making the Connections' (NCIL 2008)

Noronha N de, 'Assessing Equality and Human Rights in local public services' (2009) presentation to 'Equality, Human Rights and Good Relations: evidence based interventions and policy making' seminar, University of Liverpool, 21 May 2009

O'Conneide C, 'Socio-economic Entitlements and the UK Rights Framework' (2005) Irish Human Rights Commission Conference on Economic, Social and Cultural Rights: Model of Enforcement, Dublin, 9/10 December 2005

Oliver M and Barnes C, 'Disability Politics and the Disability Movement in Britain: where did it all go wrong?' (2006) Leeds Disability Archive

Oliver M, 'The Individual and Social Models of Disability' (1990) Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians, 23 July 1990

Oliver M, 'User Involvement in This Voluntary Sector – a View from the Disability Movement' (1996) Paper prepared for submission to the Commission on the Future of the Voluntary Sector, January 2006

Parker C, 'Is there a right to independent living?' (2007) Paper for Session 1 of the joint Disability Rights Commission and British Institute of Human Rights seminar 'A Right to Independent Living – Rhetoric or Reality?' 3 September 2007

Parker C, 'Independent Living and the Human Rights Act 1998' (2004) paper commissioned by the Disability Rights Commission, The Social Care Institute for Excellence and The National Centre for Independent Living, December 2004

Pridmore A 'Disability Activism, Independent Living and Direct Payments' Paper for 'Independent Living and Direct Payments: the National Picture' Conference, Leeds 22 March 2006

Quinn G and Bruce A, 'Toward Free and Inclusive Societies for People with Disabilities: Reflections on the Liberating Role of Economic, Social and Cultural Rights' (undated) Disability Law and Policy Research Unit, Faculty of Law, National University of Ireland, Galway, available at <http://www.nuigalway.ie/law/Common%20Files/Disability%20Research%20Unit/GQ/Quinn%20and%20Bruce%20Disability%20Paper.pdf>

Quinn G, 'Added value of the UN Convention on the Rights of Persons with Disabilities' (2008) presentation to Seminar of the European Coalition for Community Living, Drammen, Norway; printed in Newsletter of the European Coalition for Community Living, December 2008/January 2009, 2

Reiser R, 'Internalized Oppression: how it seems to me' in Rieser R and Mason M (eds) *Disability Equality in Education* (ILEA 1990)

Roosevelt FD, 'The Four Freedoms', speech delivered 6 January, 1941 available at <http://www.americanrhetoric.com/speeches/fdrthefourfreedoms.htm>

Santos BS, 'Toward a Multicultural Conception of Human Rights' (2000) World Social Forum Library of Alternatives, Version June 30, 2000

Scully JL, 'Reframing Disability in the UN Convention' (2011), presentation at Nordic Network on Disability Research Conference, Reykjavik, 28 May 2011

Simon J-L, 'Convention on the Rights of Persons with Disabilities' (2009) Address to UK Parliamentarians, Regional Seminar for the 12+ Group, London, 27-28 April 2009

Straw J, 'Human Rights Act 10 years on' (2008) Speech to the British Institute of Human Rights Annual Conference, London 21 October 2008

Straw J, 'The Future of British Human Rights Legislation' (2007) Mackenzie Stuart Lecture, University of Cambridge Faculty of Law, 25 October 2007

Sumption J, 'Judicial and Political Decision-making: the uncertain boundary' (2011) The F.A. Mann Lecture, London, 9 November 2011

Turner W, 'Human Rights, Royal Rights and the Mentally Disabled in Late Medieval England' (2009) Compass Interdisciplinary Virtual Conference, 19-30 October 2009

4. Theses

Clark L, 'A comparative study on the effects of community care charging policies for personal assistance users' submitted for degree of Master of Arts in Disability Studies, University of Leeds 2006

Collingbourne T 'Collision and fall-out? The legal position of publicly-funded residents in private residential/nursing care' Masters Dissertation, School of Law, University of Essex, 2001

Ferris, K, 'An analysis of the complaints review panel under part III of the Children Act 1989 and NHS & Community Care Act 1990.' PhD thesis, University of Sheffield, 2006

Gulland , J, 'Complaining, Appealing or Just Getting It Sorted Out: complaints procedures for community care service users', PhD thesis, University of Edinburgh, 2007

Hodgkins, S.L., 'Discoursing Disability: the Personal and Political Positioning of Disabled People in Talk and Textwork' PhD thesis, University of Northampton, September 2008

Reeve, D, 'Negotiation disability in everyday life: the experience of psycho-emotional disablism', unpublished PhD thesis, Lancaster, 2008, cited in Goodley (2010) 86

5. International human rights documents

Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 'Views submitted by Governments, intergovernmental organizations and United Nations bodies concerning a comprehensive and integral international convention on the protection and promotion of the rights and dignity of persons with disabilities', note by the Secretary-General, A/AC.265/2003/4+A/AC.265/2003/4/Corr.1, 2003

Ad Hoc Committee, 'Compilation of proposals for a Comprehensive and Integral Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities', Ad Hoc Committee 2nd session, A/AC.265/CRP.13, Add.1 & Add. 2, 2003

Ad Hoc Committee, 'Report of the Working Group to the Ad Hoc Committee', Ad Hoc Committee 3rd session, A/AC.265/2004/WG/1, 2004

Despouy L, 'Human Rights and Disabled Persons', Human Rights Studies Series number 6 (UN Centre for Human Rights 1993)

Economic and Social Council, 'Monitoring of the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities', E/CN.5/2007/4, 16 November 2006

Economic and Social Council, 'Monitoring of the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities', E/CN.5/2008/4, 26 October 2007

Economic and Social Council, 'Monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities', E/CN.5/2009/6, 17 November 2008

Office of the High Commissioner for Human Rights 'Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors' Professional training series no 17 (United Nations 2010)

Quinn G and Degener T, with Bruce A, Burke C, Castellino J, Kenna P, Kilkelly U, Quinlivan S, 'Human Rights and Disability: the current use and future potential of United Nations human rights instruments in the context of disability', HR/PUB/02/1 (United Nations 2002)

Report of the Secretary-General, 'Status of the Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto', UN General Assembly A/64/128, 7 July 2009

The Secretary-General, 'Note by the Secretary-General on the Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities', submitted following the conclusion of the deliberations of the Ad Hoc Committee, A/57/357, 27 August 2002

United Nations 'Disability Statistics Compendium', Statistics on Special Population Groups, Series Y number 4, ST/ESA/STAT/SER.Y/4 (United Nations, 1990) http://unstats.un.org/unsd/publication/seriesy/seriesy_4e.pdf last accessed 7.1.11

United Nations Enable Factsheet on Persons with Disabilities, <http://www.un.org/disabilities/documents/toolaction/pwdfs.pdf> accessed 2.1.11

United Nations General Assembly Resolution A/RES/36/77 of 8 December 1981

United Nations General Assembly Resolution A/RES/37/52 of 3 December 1982

United Nations General Assembly Resolution A/RES/48/96 of 20 December 1993

United Nations General Assembly Resolution A/RES/56/168 of 19 December 2001

United Nations General Assembly Resolution A/RES/63/150 of 18 December 2008

United Nations High Commissioner for Human Rights, 'Annual Report of the United Nations High Commissioner for Human Rights... Thematic Study... on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities', A/HRC/0/48, 26 January 2010

United Nations High Commissioner for Human Rights, 'Report of the United Nations High Commissioner for Human Rights and Follow-up to the World Conference on Human Rights: Human Rights of Persons with Disabilities', E/CN.4/2002/18/Add.1, 12 February 2002

United Nations High Commissioner for Human Rights, Address to the Human Rights Council, 6 March 2009

United Nations Human Rights Committee, 'United Kingdom of Great Britain and Northern Ireland, Sixth Periodic Report to the Human Rights Committee', CCPR/C/GBR/6, 18 May 2007

United Nations Human Rights Council, 'National report submitted in accordance with paragraph 15(a) of the annex to human rights council resolution 5/1 - United Kingdom of Great Britain and Northern Ireland', Universal Periodic Review, 1st session, 7-18 April 2008, A/HRC/WG.6/1/GBR/2, 2008

United Nations Secretary General 'Realizing the Millennium Goals for Persons with Disabilities through the Implementation of the World Programme of Action concerning Disabled Persons and the Convention on the Rights of Persons with Disabilities', Report of the Secretary General to 64th Session UN General Assembly, A/64/180, July 2009

United Nations, 'From Exclusion to Equality', UN Handbook for Parliamentarians number 14 (UN 2007)

World Health Organisation and World Bank, 'World Disability Report' (WHO 2011)

World Health Organisation, 'Global Programming Note 2006-2007: Call for Resource Mobilisation and Engagement Opportunities' (WHO 2006)

World Health Organisation, 'International Classification of Functioning, Disability and Health' (ICHD-2), (WHO 2001)

4.a United Nations Committee on Economic, Social and Cultural Rights and Constructive Dialogue

Economic, Social and Cultural Rights Protocol Open-ended Working Group, Third session, E/CN.4/2006/47 <<http://www2.ohchr.org/english/issues/escr/intro.htm>> accessed 21 January 2010

Equality and Human Rights Commission, 'Submission to the United Kingdom's Fifth Periodic Report under the International Covenant on Economic Social and Cultural Rights' (EHRC 2009)

United Nations Committee on Economic, Social and Cultural Rights, 'Replies by the Government of the United Kingdom of Great Britain and Northern Ireland to the list of issues (E/C.12/GBR/Q/5) to be taken up in connection with the consideration of the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland' E/C.12/GBR/5, E/C.12/GBR/Q/5/Add.1, 26 March 2009

United Nations Committee on Economic, Social and Cultural Rights, 'Concluding observations of the Committee on Economic, Social and Cultural Rights: United Kingdom of Great Britain and Northern Ireland', E/C.12/1/Add.79, 17 May 2002

United Nations Committee on Economic, Social and Cultural Rights, General Comment 3 'The Nature of States Parties Obligations (Art. 2, par.1)' 14 December 1990

United Nations Committee on Economic, Social and Cultural Rights, General Comment 5 'Persons with Disabilities', 9 December 1994

United Nations Committee on Economic, Social and Cultural Rights, General Comment 9, 'The Domestic Application of the Covenant', E/C.12/1998/24, 3 December 1998

United Nations Committee on Economic, Social and Cultural Rights, Seventeenth Session, 'Summary Record of the 36th meeting', E/C.12/1997/SR.36, 27 November 1997

United Nations Committee on Economic, Social and Cultural Rights, Twenty-eighth session, 'Summary Record of the 12th Meeting', E/C.12/2002/SR.12, 6 May 2002

United Nations Economic and Social Council, 'Implementation of the International Covenant on Economic, Social and Cultural Rights, Third Report of the United Kingdom of Great Britain and Northern Ireland', E/1994/104/Add.11, 17 June 1996

United Nations Economic and Social Council, 'Implementation of the International Covenant on Economic, Social and Cultural Rights, Fourth Report of the United Kingdom of Great Britain and Northern Ireland', E/C.12/4/Add.8, 28 February 2001

United Nations Economic and Social Council, 'Implementation of the International Covenant on Economic, Social and Cultural Rights, Fifth Report of the United Kingdom of Great Britain and Northern Ireland', E/C.12/GBR/5, 20 July 2007

United Nations Economic and Social Council, United Kingdom of Great Britain and Northern Ireland 'Core Document', HRI/CORE/1/Add.5, 1992

6. United Kingdom Government Documents

'Report of the Inter-Departmental Committee on Social Insurance and Allied Services' (The Beveridge Report) Cmnd 6404, November 1942

Association of Directors of Adult Social Services, 'Adult Social Care Budget Survey 2012-13' (ADASS 2012)

Association of Directors of Adult Social Services, 'Common Resource Allocation Framework' (ADASS, updated June 2010)

Association of Directors of Adult Social Services, 'People who pay for care' (ADASS 2011)

Association of Directors of Adult Social Services, 'Personal Budgets Survey March 2011: the results' (ADASS 2011)

Association of Directors of Adult Social Services, 'Putting People First: Workforce Study' (ADASS 2010)

Association of Directors of Adult Social Services, 'Report on Personalisation Survey September 2011' (ADASS 2011)

Association of Directors of Social Services, 'Putting People First: 2nd year progress' (ADASS 2010)

Cabinet Office, 'Open Public Services', Cm 8145, 11 July 2011

Commission on Funding of Care and Support, 'Fairer Care Funding: The Report of the Commission on Funding of Care and Support', (The Dilnot Report) July 2011

Department for Constitutional Affairs, 'A Guide to the Human Rights Act 1998', 3rd ed (DCA 2006)

Department for Constitutional Affairs, 'Human Rights Fact 'n' Fiction' (DCA undated)

Department for Constitutional Affairs, 'Interdepartmental Review of International Human Rights Instruments' (DCA 2004)

Department for Constitutional Affairs, 'International Human Rights Instruments: the UK's position' (DCA 2004)

Department for Work and Pensions, 'Fulfilling Potential: the discussions so far' (DWP 2012)

Department of Communities and Local Government, 'Discrimination Law Review: A Framework for Fairness: Proposals for a Single Equality Bill for Great Britain' (DCLG 2007)

Department of Health 'Vision for Adult Social Care: Capable Communities and Active Citizens', Gateway reference 14847, 16 November 2010

Department of Health 'Wave 1 Action and Learning Sites 2008-09 Final Report' (DH 2009)

Department of Health and British Institute of Human Rights, 'Human Rights in Health – A Framework for Action', Gateway reference 8022, 2007

Department of Health and Social Security, 'Growing Older' (DH 1981)

Department of Health, 'A Sign of the Times: Modernising mental health services for people who are deaf' (DH 2002)

Department of Health, 'Caring for Our Future: shared ambitions for care and support', consultation document (DH 2011)

Department of Health, 'Listening, Responding, Improving: a guide to better customer care', Gateway reference 11215, 26 Feb 2009

Department of Health, 'Putting People First: Working together with user-led organisations', Gateway reference 111018, 9 March 2009

Department of Health, 'The Government Response to Law Commission Consultation Paper 192: review of the law on adult social care' (DH 2010)

Department of Health, 'User-led Organisations (ULO) Project Policy', Gateway reference 8470, September 2007

Doncaster Metropolitan Borough Council Directorate of Adults & Communities, 'Complaint and Compliments, Annual Report 2010-2011', (DMBC 2011)

Enoch Powell, Minister for Health, 'Water tower' speech to Conservative Party conference, March 1961

Genn H, Lever B and Gray L, 'Tribunals for Diverse Users', Department for Constitutional Affairs Research series 1/06 (DCA 2006)

Government Equalities Office and Equality and Diversity Forum 'Equality Act 2010: What do I need to know? Disability Quick Start Guide' (2010)

Government Equalities Office, 'Public Sector Equality Duty consultation' Aug-Nov 2010

Her Majesty's Government, 'The Coalition: our programme for government', May 2010

Hurstfield, J, Parashar, U, Schofield, K and SQW Ltd, 'The Costs and Benefits of Independent Living' (Office for Disability Issues 2007)

Individual Budgets Evaluation Network, 'Evaluation of the Individual Budgets pilot programme: final report', Gateway reference 10741, 21 October 2008 (Department of Health 2008)

Joint Committee on Human Rights, 'Second Report, Implementation of the Right of Disabled People to Independent Living: Government Response to the Twenty-third Report of Session 2010-12' HL Paper 23/ HC429, 2 July 2012

Law Commission 'Adult Social Care Consultation Responses: Statutory Principles' <http://www.justice.gov.uk/lawcommission/350.htm> (ASCCR) accessed 1.5.11

Law Commission, 'Adult Social Care – a consultation paper', Consultation Paper 192 (LC 2010)

Law Commission, 'Adult Social Care Consultation Analysis', Consultation Paper 192 (Consultation analysis) (LC 2011)

Law Commission, 'Adult Social Care: Scoping Report' (LC 2008)

Law Commission, 'Adult Social Care', Law Com no 326, HC 941, 10 May 2011

Law Commission, 'Public Service Ombudsmen', Law Com no 329, HC1136, 13 July 2011

Law Commission, Adult Social Care: Outline of our proposed Adult Social Care Statute (Law Commission 2010)

Local Government Association Briefing, 'The Spending Review 2010', 20 October 2010 <http://www.lga.gov.uk/lga/aio/14462985> accessed 7.8.11

Lord Chancellor and Secretary of State for Justice, 'Rights and Responsibilities: developing our constitutional framework', Cm 7577, March 2009

Ministers, local government, NHS, social care, professional and regulatory organisations, 'Putting People First: a shared vision and commitment to the transformation of adult social care' (DH 2007)

Ministry of Justice, 'Human Rights Insight Project', Ministry of Justice Research Series 1/08, (MJ 2008)

Ministry of Justice, 'Human Rights Insight Report', Ministry of Justice Research Series 1/08 (MJ 2008)

Ministry of Justice, 'Human Rights: Common Values, Common Sense' (MJ undated)

Ministry of Justice, 'Making sense of human rights: a short introduction' (MJ 2006)

Ministry of Justice, 'Review of the Implementation of the Human Rights Act' (MJ 2006)

Murdoch J, 'The Optional Protocol to the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW): The Experience of the United Kingdom; an evaluation' (Ministry of Justice 2008)

Northern Ireland Human Rights Commission, 'Response to Government consultation on Northern Ireland Bill of Rights', 17 Feb 2010

Northern Ireland Office, 'A Bill of Rights for Northern Ireland: next steps', November 2009

Office for Disability Issues 'Review of Disability Estimates and Definitions' In-house Report 128, March 2004

Office for Disability Issues 'Roadmap 2025: achieving disability equality by 2025' (ODI 2009)

Office for Disability Issues, 'Independent Living: a cross-government strategy about independent living for disabled people' (ODI 2008)

Office of Disability Issues, 'Secretary of State Reports on Disability Equality: overview', (ODI 2008)

Office of Population, Censuses and Surveys, 'General Household Survey 1984' (OPCS 1986)

Office of the Deputy Prime Minister, 'The Drivers of Social Exclusion: a review of the literature for the Social Exclusion Unit in the breaking the Cycle series' (Social Exclusion Unit 2008)

Parliamentary Under-Secretary for Work and Pensions, 'The UN Convention on the Rights of Persons with Disabilities' and Explanatory Memorandum, Cm7564, 3 March 2009

Parliamentary Under-Secretary of State for Work and Pensions, 'Explanatory Memorandum on the United Nations Convention on the Rights of Persons with Disabilities', appended to Command Paper containing the text of the Convention, 3 March 2009, Cm7564

Prime Minister's Strategy Unit, 'Improving the Life Chances of Disabled People', (PMSU 2005)

Secretary of State for Constitutional Affairs, 'Transforming Public Services: Complaints, Redress and Tribunals', Cm 6243, July 2004

Secretary of State for Health, 'Building the National Care Service', Cm 7854, 30 March 2010

Secretary of State for Health, 'Building the National Care Service' Cm 7854, March 2010

Secretary of State for Health, 'Caring for our future: progress report on funding reform', Cm 8381, July 2012

Secretary of State for Health, 'Caring for our future: reforming care and support', Cm 8378, July 2012

Secretary of State for Health, 'Caring for Our Future: reforming care and support', Cm 8378, July 2012

Secretary of State for Health, 'Caring for People: Community Care in the Next Decade and Beyond...' (DH 1990)

Secretary of State for Health, 'Government Response to the Joint Committee on Human Rights: A Life Like Any Other? Human Rights of Adults with Learning Disabilities', Cm 7378, May 2008

Secretary of State for Health, 'Independence, Well-being and Choice', Cm 6499, 21 March 2005

Secretary of State for Health, 'Our health, our care, our say: a new direction for community services', Cm 6737, 30 January 2006

Secretary of State for Health, 'Reforming the law for adult care and support: the Government's response to Law Commission report 326 on adult social care', Cm 8379, July 2012

Secretary of State for Health, 'Shaping the Future of Care Together', Cm 7673, July 2009

Secretary of State for health, 'Shaping the Future of Care Together', Cm 7673, July 2009

Secretary of State for Justice and Lord Chancellor, 'The Governance of Britain', Cm 7170, July 2007

Secretary of State for Work and Pensions 'Raising expectations and increasing support: reforming welfare for the future', Cm 7506, December 2008

Secretary of State for Work and Pensions, '21st Century Welfare', Cm 7913, July 2010

Secretary of State for Work and Pensions, 'No one written off: reforming welfare to reward responsibility', Cm 7363, July 2008

Secretary of State for Work and Pensions, 'No one written off: reforming welfare to reward responsibility', Cm 7363, July 2008

Sheffield City Council Communities Portfolio, 'Annual Report of complaints received about Adult Social Care Services, 1 April 2009-31 March 2010' (SCC 2010)

Straw J, Evidence to Joint Committee on Human Rights inquiry into a Bill of Rights for the UK?, 21 May 2008

United Kingdom of Great Britain and Northern Ireland, 'UK Initial Report on the UN Convention on the Rights of Persons with Disabilities' (Office for Disability Issues, 2011)

7. Hansard

Anne McGuire, Minister for Disabled People, HC Deb 6 May 2008, vol 475, col 30WS

Baroness Royall of Blaisdon, HL Deb 15 Dec 2006, vol 687, col 1815

Baroness Verma of Leicester, HL Deb 28 June 2011, vol 728, col WS145

Jonathan Shaw, Parliamentary Under-Secretary of State for Work and Pensions, HC Deb 3 March 2009, vol 488 col 51WS

Lord Bingham, HL Deb 3 July 1996, vol 573 col 1465

Lord McKenzie of Luton, Parliamentary Under-Secretary of State for Work and Pensions, HL 12 Feb 2009, vol 707, col WA222

Lynne Featherstone, Parliamentary Under-Secretary of State for the Home Department, HC Deb 28 June 2011, vol 530, col 46WS

Mike O'Brien, Parliamentary Under-Secretary of State for the Home Department, HC Deb 21 October 1998, vol 317, col 1322

8. Non-governmental research reports

Abraham A, 'Responsive and Accountable? The Ombudsman's review of complaint handling by government departments and public bodies 2010-11' (PHSO 2011)

Adler M and Gulland J, 'Tribunal Users' Experiences, Perceptions and Expectations: a literature review' (Council on Tribunals 2003)

Advice UK, 'It's the System, Stupid! Radically Rethinking Advice' (Advice UK 2008)

Age UK 'Care in Crisis 2012' (Age UK 2012)

American Psychiatric Association, 'Diagnostic and Statistical Manual of Mental Disorders', 5th ed (2010)

Audit Commission, 'Human Rights: Improving Public Service Delivery' (Audit Commission 2003)

Benson/Waterhouse Consultancy with DIAL Waltham Forest, 'Hidden Benefits: the value of DIAL advice work' (DIAL UK 2003)

Beresford P and Turner M, 'It's Our Welfare' (1997)

Beresford P, 'It's Our Lives: a short theory of knowledge, distance and experience' (Citizen Press in association with Shaping Our Lives, 2003)

Blanck C, Scherman A and Sellin K 'The price of freedom of choice, self-determination and integrity: a report from the Knowledge Project' (JAG 2006)

Bott S, Sweeney A and Watts R, 'A Commissioner's Guide to Developing and Sustaining User-led Organisations', SCIE Guide 36 (Social Care Institute for Excellence 2010)

British Institute for Human Rights 'Something for Everyone: the impact of the Human Rights Act and the need for a Human Rights Commission' (BIHR 2002)

British Institute of Human Rights 'BIHR Response to the UK Government's draft 5th periodic report under the ICESCR to the UN Committee on Economic, Social and Cultural Rights' (BIHR 2007)

Burkhardt, T, 'The Dynamics of Being Disabled', CASE paper 036 (CASE 2000)

Burchardt T 'Being and Becoming: Social exclusion and the onset of disability', CASE Report 21 (ESRC Research Centre for Analysis of Social Exclusion (CASE 2003)

Butler F, 'Improving Public Services: Using a Human Rights Approach' (Institute for Public Policy Research 2005)

Butler F, 'Rights for Real: Older People, Human Rights and the CEHR' (Age Concern 2006)

Campbell J, 'Social Care as an Equality and Human Rights Issue', 'Independently' Newsletter, National Centre for Independent Living, February 2008

Care Quality Commission, 'The quality and capacity of adult social care services: an overview of the adult social care market in England 2008/09' (CQC 2009)

Centre for Public Scrutiny and Local Government Ombudsman, 'Aiming for the Best: using lessons from complaints to improve public services' (LGO 2011) <http://www.lgo.org.uk/publications/advice-and-guidance#focus> accessed 15.1.12

Coalition on Charging, 'Charging into Poverty? Charges for care services at home and the national debate on adult care reform in England' (Coalition on Charging 2008)

Collingbourne T, 'Protecting the right of disabled people to independent living', Memorandum to Joint Committee on Human Rights, April 2011

Commission for Social Care and Healthcare Commission, 'Joint Investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust', July 2006

Council for Social Care Inspection, 'Lost to the System? The Impact of Fair Access to Care' (CSCI 2008)

Daw R, 'The Impact of the Human Rights Act on Disabled People' (Disability Rights Commission 2004)

Democratic Audit, 'Economic and Social Rights for the UK' (DA 2003)

DIAL Barnsley 'Your Choice: an independent report looking at choice and control and disabled people' (DIAL Barnsley 2009)

DIAL UK 'The evidence of DIAL UK to the Joint Committee on Human Rights', April 2003, appended to JCHR Seventh Report of Session 2003-04 'The Meaning of Public Authority under the Human Rights Act' HL Paper 39, HC382

Disability Awareness in Action, 'Definitions of Disability – a Briefing Paper' (DAA 2005)

Disability Law Service, 'English Social Services Complaint Procedure' www.dls.org.uk accessed 15.3.12

Disability LIB Alliance, 'Thriving or Surviving: Challenges and Opportunities for Disabled People's Organisations in the 21st Century' (Scope on behalf of Disability LIB Alliance, 2008)

Disability LIB Alliance, "Less Courses, more conversations': Disabled People's Organisations (DPOs) and Mainstream Capacity Building', (DLA 2010)

Disability LIB Alliance, 'Comprehensive Spending Review: what it will mean for DPOs' (DLA 2010)

Disability Rights Commission, 'Policy Statement on Social Care and Independent Living' (DRC 2002)

Disability Rights Commission, 'Ten years of the DDA', Bulletin (DRC 2005)

Disability Rights Commission, 'A Briefing on Lord Ashley's Disabled Persons (Independent Living) Bill' (DRC 2006)

Disability Rights Commission, 'Consultation on definition of disability in anti-discrimination law' (DRC 2006)

Disability Rights Commission, 'Disability Briefing' (DRC 2006)

Disability Rights Commission, 'Doing the Duty: an overview of the Disability Equality Duty for the public sector' (DRC 2006)

Disability Rights Commission, 'Equal Treatment: Closing the Gap: A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems' (DRC 2006)

Disability Rights Commission, 'The Disability Equality Duty and Involvement: Guidance for public authorities on how to effectively involve disabled people' (DRC 2006)

Disability Rights Commission, Equal Opportunities Commission and Carers UK, 'The Future: Who Cares' (2006)

Disability Rights Commission, 'Involvement for real equality: the benefits for public services of involving disabled people' (DRC 2007)

Disability Rights Commission, Legal Bulletin issue 11 and issue 12 (Legacy Edition) 2007

Disability Rights Promotion International, 'Opportunities, Methodologies and Training Resources for Disability Rights Monitoring' (DRPI 2003)

Dyer L, 'Involving Service Users and Carers – the Mersey Care Way' (Mersey Care NHS Trust 2008)

Equality and Human Rights Commission 'EHRC's role in relation to UN Human Rights Treaties' (EHRC 2010)

Equality and Human Rights Commission, 'Developing the Equality Measurement Framework: selecting the indicators' (EHRC 2010)

Equality and Human Rights Commission 'Close to Home: an Inquiry into Older People and Human Rights in Home Care' (EHRC 2011)

Equality and Human Rights Commission, 'Hidden in Plain Sight: Inquiry into Disability-Related Harassment' (EHRC 2011)

Equality and Human Rights Commission, 'Human Rights Inquiry' (EHRC 2009)

Flynn M, 'Winterbourne View Hospital: a serious case review' (South Gloucestershire Council 2012)

Foundation for People with Learning Disabilities, 'Count Us In: The report of the Committee of Inquiry into meeting the mental health needs of young people with learning disabilities' (Mental Health Foundation 2002)

French P, 'Human Rights Indicators for People with Disability – a resource for disability activists and policy makers' (Queensland Advocacy Incorporated 2007)

Gee A and Holdsworth M (ed) 'Regeneration and Renewal: a good practice guide for London advice agencies' (London Advice Services Alliance 2002)

Glendinning C, Challis D, Fernandez J-L, Jacobs S, Jones K, Knapp M, Manthorpe L, Moran N, Netten A, Stevens M and Wilberforce M, 'Evaluation of the Individual Budgets Pilot Programme: final report' (the IBSEN study) (Social Policy Research Unit, University of York 2008)

Glynn M, Beresford P, Bewley C, Banfield F, Butt J, Croft S, Pitt KD, Fleming J, Flynn R, Parmore C, Postle K and Turner M 'Person-centred Support: what service users and practitioners say' (Joseph Rowntree Foundation 2008)

Harding T, Felton M and Wigul H, 'Everyday Age Discrimination: what older people say' (Help the Aged 2004)

Healthcare Commission, 'Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust', January 2007

Heywood F and Turner L, 'Better Outcomes, Lower Costs: implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence' (Office for Disability Issues 2007)

House of Commons Health Committee, 'Social Care', Third Report, Session 2009-10, 12 March 2010, HC 22-1

House of Commons Select Committee on Public Administration, 'When Citizens Complain', Fifth Report, session 2007-08, 24 March 2008, HC409

House of Commons Select Committee on Public Administration, 'When Citizens Complain: Government Response to the Committee's Fifth Report of Session 2007-08', Seventh Special Report, session 2007-08, 23 July 2008, HC997

Human Rights Lawyers' Association, 'Human Rights – Home to Stay' (HRLA 2008)

Hurstfield J, Meager N, Aston J, Davies J, Mann K, Mitchell H, O'Reagan S and Sinclair A, 'Monitoring the Disability Discrimination Act (DDA) 1995 Phase 3' (Department of Work and Pensions and Disability Rights Commission 2004)

In Control, 'Response to the Law Commission's Consultation on the Future of Adult Social Care Law' (2010)

International Disability Alliance, 'Position Paper on the Convention on the Rights of Persons with Disabilities (CRPD) and Other Instruments' (IDA 2008)

International Disability Rights Monitor, 'IDRM: Regional Report of the Americas' (IDRM 2004)

International Disability Rights Monitor, 'IDRM: Disability and Early Tsunami Relief Efforts in India, Indonesia and Thailand' (IDRM 2005)

International Disability Rights Monitor, 'IDRM: Regional Report of Asia' (IDRM 2005)

International Disability Rights Monitor, 'The United Kingdom' in 'IDRM: Regional Report for Europe' (IDRM 2007)

Joint Committee on Human Rights, 'Implementation of the Human Rights Act', Second Special Report, session 2000-2001, 10 April 2001, HL 66/HC 332

Joint Committee on Human Rights 'The Meaning of Public Authority under the Human Rights Act', Seventh Report, session 2003-04, 3 March 2004, HL Paper 39, HC 382

Joint Committee on Human Rights, 'The International Covenant on Economic, Social and Cultural Rights', Twenty-first Report, session 2003-04, 2 November 2004, HL Paper 183, HC 1188

Joint Committee on Human Rights, 'A Life Like Any Other? Human Rights of Adults with Learning Disabilities', Seventh Report, session 2007-08, 6 March 2008, HL Paper 40 HC 73

Joint Committee on Human Rights, 'A Bill of Rights for the UK?', Twenty-Ninth Report, session 2007-08, 10 August 2008, HL 165-I/HC 150-I

Joint Committee on Human Rights 'UN Convention on the Rights of Persons with Disabilities: Reservations and Interpretative Declaration', Twelfth Report, session 2008-09, 17 April 2009, HL Paper 70 HC 397

Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living', Twenty-third Report, session 2010-12, 1 March 2012, HL Paper 257, HC 1074

Joseph Rowntree Foundation, 'Response to the Law Commission Consultation on Adult Social Care' (2010)

JUSTICE and 13 NGOs 'Poverty Undermines Rights in the UK', Joint submission to the United Nations Committee on Economic, Social and Cultural Rights, October 1997

JUSTICE and other NGOs, 'Joint NGO Report to the United Nations Committee on Economic Social and Cultural Rights: response to the UK Government's Fourth Report under the International Covenant on Economic, Social and Cultural Rights', April 2002

JUSTICE 'Inquiry into the Concluding Observations of the UN Committee on Economic, Social and Cultural Rights Joint Committee on Human Rights' (JUSTICE 2003)

Learning Disability Coalition, 'Social care – the continuing crisis: from the perspective of local authorities in England' (The Learning Disability Coalition Local Authority Survey 2011)

Liberty, 'The Human Rights Act: Exploding the Myths' (Liberty 2006)

Liberty, 'Common Sense: Reflections on the Human Rights Act' (Liberty 2010)

Light R, 'Review of Evidence contained on the DAA Human Rights Database' (DAA 2003)

Light R, 'Review of the Chair's Draft Text Prepared Subsequent to the Sixth Session of the UN Ad Hoc Committee', 2005

- Local Government Ombudsman, 'Response to Law Commission Consultation Paper No 192 Adult Social Care' (2010)
- Local Government Ombudsman, 'Complaints about privately funded and arranged adult social care', Executive Summary (LGO 2011)
- Lord Chancellor's Department and Law Centres Federation, 'Legal and Advice Services: a Pathway Out of Social Exclusion' (2001)
- Malhotra, R and Fasel, N (2005) 'Qualitative Human Rights Indicators – A Survey of Initiatives', Background Paper developed for a seminar conducted by the Institute for Human Rights Abo Akademi University, cited in French P, 'Human Rights Indicators for People with Disability - A resource for disability activists and policy makers' (Queensland Advocacy Incorporated 2007)
- Matthews L, Sceats S, Hosali S and Candler J, 'The Human Rights Act –Changing Lives', 2nd ed (British Institute of Human Rights 2008)
- Maynard-Campbell S, Maynard A and Winchcombe M, 'Mapping the Capacity and Potential for User-Led Organisations in England: a summary of the main findings from a national research study commissioned by the Department of Health' (Equal Ability CIC 2007)
- Maynard-Campbell S and Maynard-Lupton A, 'Bureaucratic Barriers to Normal Day-to-Day Activity', MusclePower! 2000, available on Leeds Disability Studies Archive <http://www.leeds.ac.uk/disability-studies/archiveuk/>
- Melanie Henwood Associates, 'Journeys without maps: The decisions and destinations of people who self-fund – a qualitative study' in Association of Directors of Adult Social Services, 'People who pay for care' (ADASS 2011)
- Morris J, '“One town for my body, another for my mind”: Services for people with physical impairments and mental health support needs' (Joseph Rowntree Foundation/York Publishing Services 2004)
- Morris J, 'Centres for Independent Living/Local user-led organisations: a discussion paper' (Valuing People Support Team 2006)
- Morris J, 'Rethinking Disability Policy' (Joseph Rowntree Foundation 2011)
- Murdoch J, 'The Optional Protocol to the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW): The Experience of the United Kingdom (Ministry of Justice 2008)
- National Audit Office, 'Feeding Back? Learning from complaints handling in health and social care', session 2007-2008, 10 October 2008, HC835
- National Centre for Independent Living and RADAR, 'Joint Response to the Law Commission Adult Social Care Consultation' (2010)
- National Institute for Social Work, 'Report of the Citizens' Commission on the Future of the Welfare State' (NISW 1997)
- Needham C, 'Co-production: an emerging evidence base for adult social care transformation' (Social Care Institute for Excellence 2009)
- O'Brien N and Gooding C, 'Final Reflections', DRC Legal Bulletin 12, Legacy Edition, 2007

Parliamentary and Health Service Ombudsman, 'Report by the Parliamentary and Health Service Ombudsman on complaints about disability issues', HC1512, 11 October 2011

Parliamentary and Health Service Ombudsman, 'Responsive and Accountable? The Ombudsman's review of complaint handling by government departments and public bodies 2010-11' (PHSO 2011)

People First, 'Outside but not Inside... Yet! Leaving hospital and living in the community: an evaluation by people with learning difficulties' (People First 1994)

Phelps L and Williams A, 'The Pain of Complaining: CAB ICAS Evidence of the NHS Complaints Procedure' (Heswell Citizens Advice Bureau 2005)

Putting People First Consortium, 'People Who Pay for Care: quantitative and qualitative analysis of self-funders in the social care market' (PPFC 2011)

Putting People First Consortium, 'Think Local, Act Personal: a sector-wide commitment to moving forward with personalisation and community-based support' (PPFC 2011)

Royal Commission for Long Term Care, 'With respect to old age: long term care - rights and responsibilities', Cm 4912-1, 1 March 1999

Schultze M, 'Understanding the UN Convention on the Rights of Persons with Disabilities: a handbook on the human rights of persons with disabilities' (Handicap International 2009)

Simons K, 'I'm Not Complaining, But... Complaints procedures in social services department' (Joseph Rowntree Foundation 1995)

Social Care Institute for Excellence, 'Response to Law Commission Consultation Paper on Adult Social Care' (SCIE 2010)

Social Care Institute for Excellence, 'Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers', SCIE Report 40, February 2011

Strathclyde Centre for Disability Research and Glasgow Media Unit, in association with Inclusion London, 'Bad News for Disabled People: How the newspapers are reporting disability' (University of Glasgow 2011)

The Children's Society, Citizens Advice and Disability Rights UK, 'Holes in the safety net: The impact of Universal Credit on disabled people and their families' (The Children's Society 2012)

Tibble M 'Review of existing research on the extra costs of disability' Department of Work and Pensions Working Paper 21 (DWP 2005)

Tozer R and Thornton P, 'A Meeting of Minds: older people as research advisers' (Social Policy Unit, University of York 1995)

Turner M, Brough P and Williams-Findlay RB, 'Our voice in our future: Service users debate the future of the welfare state' (Joseph Rowntree Foundation 2003)

Union of the Physically Impaired Against Segregation, 'Policy Statement' (UPIAS 1974/5)

Wanless D, 'Securing Good Care for Older People: taking a long-term view' (King's Fund 2006)

Whyatt J, 'The Citizen and Administration: The redress of grievance' (JUSTICE 1961)

Williams B, Copestake P, Eversley J and Stafford B, 'Experiences and Expectations of Disabled People' (Office for Disability Issues 2008)

Wood C, 'For disabled people, the worst is yet to come... Destination Unknown: Summer 2012' (Demos 2012)

Woodin S, 'Mapping User-Led Organisations: User-Led Services and Centres for Independent/Integrated/inclusive Living: A Literature Review Prepared for the Department of Health' (University of Leeds 2006)

Zarb G and Nadash P, 'Cashing in on Independence' (British Council of Organisations of Disabled People 1994)

Zarb G, Hasler F and Campbell J, 'Implementation of the Community Care (Direct Payments) Act: Findings' (Joseph Rowntree Foundation 2000)

9. Media/online resources

Alzheimers Society, 'Overprescription of antipsychotic drugs', <http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=389> accessed 28 September 2012

Association of Directors of Adult Social Services, 'A new system for care funding: "Now is the time to act"', Press release, 12 June 2012 <http://www.adass.org.uk/index.php?option=com_content&view=article&id=813&Itemid=470> accessed 30 July 2012

Association of Directors of Adult Social Services, 'Use of personal budgets leaps by nearly 40%', Press release, 20 June 2012 <http://www.adass.org.uk/index.php?option=com_content&view=article&id=816:personal-budget-survey&catid=156:press-releases-2012&Itemid=470> accessed 14 July 2012

BBC News, 'Birmingham City Council care funding cuts unlawful' <<http://www.bbc.co.uk/news/uk-england-birmingham-13455068>> accessed 20 May 2011

BBC Panorama, 'Undercover Care: the Abuse Exposed', BBC1, Tues May 31 2011

British Cartographic Society, 'What is a map projection?' <<http://www.cartography.org.uk/default.asp?contentID=748>> accessed 1 November 2009

British Institute of Human Rights, 'Human Rights in Healthcare' <<http://www.bihr.org.uk/projects/human-rights-in-healthcare>> accessed 11 April 2012

Butler P, 'Disabled people hit especially hard by cuts, finds report', *The Guardian*, 22 June 2012 <<http://www.guardian.co.uk/society/2012/jun/22/disabled-people-hit-hard-cuts>> accessed 17 July 2012

Care Quality Commission, 'Scope of Registration', December 2011 <http://www.cqc.org.uk/sites/default/files/media/documents/20120621_100001_v4.0_scope_of_registration_guidance_final_1.pdf> accessed 14 January 2012

Chapman J and Shipman T, 'Human rights cave-in: Cameron pledged to scrap Act... now Clegg champions it under ANOTHER coalition compromise', *The Daily Mail*, 20 May 2010 <<http://www.dailymail.co.uk/news/article-1279544/Nick-Clegg-champions-Human-Rights-Act-David-Cameron-pledged-scrap.html#ixzz0wya6yTMz>; > accessed 13 July 2012

Commission on a Bill of Rights, 'A Second Consultation', July 2012 <<http://www.justice.gov.uk/downloads/about/cbr/second-consultation/cbr-second-consultation.pdf> > accessed 30 July 2012

Crow L, 'Resistance: which way the future?' Film installation <http://www.manchestersfinest.com/arts/film-reviews/resistance-liz-crow/> accessed 31 August 2012

Cul-de-Sac Theatre Group, 'Telling Lives', Theatre production, Lancaster Disability Studies Conference, 13 September 2012

Department for Work and Pensions, '23 May 2012 – Over £500k of Government funding awarded to Disabled People's User-Led Organisations' <<http://www.dwp.gov.uk/newsroom/press-releases/2012/may-2012/dwp056-12.shtml>> accessed 30 July 2012

Department for Work and Pensions, 'Making Choice Real for Disabled People - Independent Living Fund, User Profile Analysis, Results up to quarter ending June 2010' < <http://www.dwp.gov.uk/docs/user-profiles-0610.pdf> > accessed 7 August 2011

Direct Gov, 'Independent Living Fund' <http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/OtherBenefitsAndSupport/DG_4019444> accessed 7 August 2011

Disability Awareness in Action, 'Uganda: Disabled people abandoned in refugee camps', *Our Rights* Newsletter, Issue 17, December 2009 <<http://www.daa.org.uk/?page=newsletter> > accessed 7 January 2010

Disability Now, 'Hate Crime Dossier' < <http://www.disabilitynow.org.uk/the-hate-crime-dossier?searchterm=hate+crime+dossier> > last accessed 12 October 2011

Disability Rights Commission, 'Policy Statement on Social Care and Independent Living', 2002

Disabled Peoples' International, 'Support to the India Workshop on the CRPD', 2008 <<http://v1.dpi.org/files/uploads/INDIA%20WORKSHOP%20-%20CRPD.PDF>> accessed 23 October 2009

Dunning J, 'Councils to deny social care support to all but most needy', *Community Care*, 15 September 2010 <<http://www.communitycare.co.uk/Articles/2010/09/15/115321/councils-to-deny-social-care-support-to-all-but-most-needy.htm> > accessed 7 August 2011

Encyclopædia Britannica, 'T4 programme' <<http://www.britannica.com/EBchecked/topic/714411/T4-Program> > accessed 7 January 2010

Equality and Human Rights Commission, 'Equality Act Codes of Practice' section 6 'Other Codes of Practice' <<http://www.equalityhumanrights.com/legal-and-policy/equality-act/equality-act-codes-of-practice/>> accessed 8 March 2012

Eriku J, 'Uganda: 'Don't Abandon Your Disabled Relatives in Camps'', All Africa, <<http://allafrica.com/stories/200911130128.html>> accessed 7 January 2010

European Disability Forum, 'Violence Against Women: Forced Sterilization Of Women With Disabilities Is A Reality In Europe', 9 November 2009 <http://www.edf-feph.org/Page_Generale.asp?DocID=13855&thebloc=23097> accessed 7 January 2010

Forced Migration Review, 'Disability and Displacement' FMR35, July 2010 <<http://www.fmreview.org/disability/>> accessed 26 June 2010

Ghose K, 'This human rights hysteria threatens every one of us', *The Guardian*, 22 August 2007, 28

Home Office, 'May: political correctness won't lead to equality', Press release, 17 November 2010, <<http://www.homeoffice.gov.uk/media-centre/press-releases/political-correctness>> accessed 16 February 2011

INTERIGHTS, 'Commonwealth and International Human Rights Case Law Databases' <<http://www.interights.org/database-search/index.htm>> last accessed 3 September 2012

International Service for Human Rights, Committee on Economic, Social and Cultural Rights, 42nd Session, United Kingdom of Great Britain and Northern Ireland, 4 – 5th Report, 12 – 13 May 2009' <<http://www.ishr.ch/treaty-body-monitor/cescr#42>> accessed 10 June 2011

Jenny Booth, 'David Askew collapsed and died after decade of attacks', *The Times*, 11 March 2010 <<http://www.thetimes.co.uk/tto/news/uk/crime/article2464295.ece>> accessed 12 October 2010

Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living, Oral Evidence HC 1074–i–vi', May - October 2011, <http://www.parliament.uk/documents/joint-committees/human-rights/Independent_Living_oral_evidence_HC1074_i_vi.pdf> last accessed 19 November 2011

Just Fair, 'Single Equality and Human Rights Commission facing a 60% cut in funding' <http://just-fair.co.uk/hub/single/equality_and_human_rights_commission_facing_a_60_cut_in_funding> accessed 11 August 2011

Liberty, 'The Human Rights Act – what's not to love?' <<http://liberty-human-rights.org.uk/whatsnottolove/index.htm>> accessed 15 February 2010

Local Government Ombudsman, 'About us: Key facts about the Ombudsmen' <<http://www.lgo.org.uk/about-us/>> accessed 14 January 2012

Local Government Ombudsman, 'Adult Social Care', <<http://www.lgo.org.uk/adult-social-care/>> accessed 14 January 2012

Local Government Ombudsman, 'Analysis of Complaints 2010-11' <<http://www.lgo.org.uk/publications/analysis-complaints-2010-11/>> accessed 4 March 2012

Local Government Ombudsman, 'Annual Reports' 'Detailed complaint statistics 2010-11', Table 1. < <http://www.lgo.org.uk/publications/annual-report/> > accessed 15 January 2012

Map Toaster, 'What is Projection?' <www.maptoaster.com/.../datum-projection.htm> accessed 9 November 2009

Ministry of Justice, 'Commission on a Bill of Rights' <<http://www.justice.gov.uk/about/cbr> > accessed 30 July 2012

Minutes from Joint All-Party Parliamentary Group meeting on the Disability Strategy, 12 June 2012, accessed via Disability Rights UK e-Newsletter, issue 4, July 2012 <<http://disabilityrightsuk.org>> accessed 4 July 2012

Mumford R, 'Former Top Judge hits back at current Top Judge', *UK Human Rights Blog*, 17 February 2012 <<http://ukhumanrightsblog.com/2012/02/17/former-top-judge-hits-back-at-current-top-judge/#more-12542> > accessed 17 February 2012

National Centre for Independent Living 'NCIL welcomes 'no one written off' welfare reform green paper', Press release, July 2008 <[Welfare reform draft NCIL release July 08.doc](#)> accessed 15 September 2008

National Fairground Archive, University of Sheffield, 'Freak Shows' <<http://www.nfa.dept.shef.ac.uk/history/shows/freaks.html> > accessed 10 January 2011

NHS Confederation, 'NHS Confederation comments on Government proposals for social care', Press release, 11 July 2012 <<http://www.nhsconfed.org/PressReleases/Archive/2012/Pages/NHS-Confederation-comments-on-Government-proposals-for-social-care.aspx> > accessed 25 July 2012

NHS Confederation, 'Social care funding crisis impacting on NHS patients now, says head of the NHS Confederation', Press release, 11 July 2012, <<http://www.nhsconfed.org/PressReleases/Archive/2012/Pages/Social-care-funding-crisis-impacting-on-NHS-patients-now.aspx> > accessed 3 August 2012

NHS Information Centre, 'Community Care Statistics: Social Services Activity, England 2009-10 (further release)', 20 April 2011 < <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-social-services-activity-england-2009-10-further-release> > accessed 1 September 2011

Nolan A, 'Don't believe everything you read – there is a case for socio-economic rights', *UK Human Rights Blog*, 17 July 2012 <<http://ukhumanrightsblog.com/2012/07/17/dont-believe-everything-you-read-there-is-a-case-for-socio-economic-rights-professor-aoife-nolan/> > accessed 17 July 2012

Not Dead Yet < <http://www.notdeadyetuk.org>> accessed 17 June 2010

Nuffield Foundation, 'Administrative Justice and Tribunals' < <http://www.nuffieldfoundation.org/administrative-justice-and-tribunals> > accessed 26 February 2008

Office for Disability Issues, 'Strengthening Disabled People's User-Led Organisations Programme' <<http://odi.dwp.gov.uk/odi-projects/user-led-organisations.php>> accessed 14 June 2012

Oxfordshire County Council, 'Taking control: helping you take control of your care and support', <<http://www.takingcontroloxon.org.uk/wps/wcm/connect/occ/Taking+control/Home/Video+library/>> accessed 16 September 2012

Parliamentary and Health Service Ombudsman (PHSO), 'Listening and Learning: the Ombudsman's review of complaint handling by the NHS in England 2010-2011' (PHSO 2011) 'Our Year at a Glance' <<http://www.ombudsman.org.uk/healthchp/statistics/year-at-a-glance>> accessed 10 April 2012

Parliamentary and Health Service Ombudsman, 'Ombudsman's Principles' <<http://www.ombudsman.org.uk/improving-public-service/ombudsmansprinciples>> accessed 11 April 2012

Public Interest Research Unit, 'Sex, Race and Disability Discrimination Laws not Enforced', Press release 30 August 2006 <www.piru.org.uk> accessed 30 August 2006

RADAR 'Briefing on the Health and Social Care (Independent Living) Bill', December 2009 <<http://www.radar.org.uk/radarwebsite/tabid/167/default.aspx>> accessed 17 January 2010

Red Tape Challenge, 'Equalities' <<http://www.redtapechallenge.cabinetoffice.gov.uk/themehome/equalities-act/>> accessed 5 August 2011

Samuel M, 'Lansley backs independent practices to support older people', *Community Care*, 5 November 2010 <<http://www.communitycare.co.uk/Articles/2010/11/05/115743>> accessed 14 March 2011

Social Care Institute for Excellence, 'Latest videos on Social Care TV', <<http://www.scie.org.uk/socialcaretv/latest.asp>> accessed 16 September 2012

Social Care Institute for Excellence, 'Personalisation for someone with a physical disability', Social Care TV video, <<http://www.scie.org.uk/socialcaretv/video-player.asp?guid=91834b9d-26ef-44ba-9055-c9720606edf9>> accessed 9 August 2011

Social Care Institute for Excellence, 'SCIE response to Law Commission adult social care consultation' <<http://www.scie.org.uk/news/mediareleases/2010/010710.pdf>> accessed 4 March 2011

The Stanley Burton Centre for Holocaust and Genocide Studies, <<http://www2.le.ac.uk/centres/stanley-burton-centre>> accessed 31 August 2012

The Willard Suitcase Exhibit Online, 'The Lives They Left Behind' <<http://www.suitcaseexhibit.org/indexhasflash.html>> last accessed 15 September 2012

Think Local, Act Personal <<http://www.thinklocalactpersonal.org.uk/>> accessed 23 September 2012

Topping A and Wintour P, 'London riots: Wandsworth council moves to evict mother of charged boy' *The Guardian*, 12 August 2011 <<http://www.guardian.co.uk/uk/2011/aug/12/london-riots-wandsworth-council-eviction?INTCMP=SRCH>> accessed 5 September 2012

UK Parliament, 'Health and Social Care (Independent Living) Bill [HL] 2009-10, Summary of the Bill' <<http://services.parliament.uk/bills/2009-10/healthandsocialcareindependentlivinghl.html>> accessed 4 March 2011

UN Enable, 'Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities', Negotiation archives, <<http://www.un.org/disabilities/default.asp?id=1423>> last accessed 20 October 2012

United Nations, 'Disability and Statistics' <<http://www.un.org/disabilities/default.asp?id=1515>> accessed 20 January 2011
United States Holocaust Museum, 'People with Disabilities' <http://www.ushmm.org/research/library/bibliography/?lang=en&content=people_with_disabilities#05-web_resources> accessed 7 January 2010

University of Leeds Centre for Disability Studies Archive <<http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>> last accessed 21 September 2012

Wagoner RG, 'Speaking for the "Unfit": A Commentary on Disability, the Holocaust and the Modern Eugenics Movement', Wagoner & Associates Inc, <<http://weradaexperts.com/kruppel.pdf>> accessed 14 June 2010

Walker P, 'Benefit cuts are fuelling abuse of disabled people, say charities', *The Guardian*, 5 February 2012 <<http://www.guardian.co.uk/society/2012/feb/05/benefit-cuts-fuelling-abuse-disabled-people>> accessed 27 March 2012

Wellcome Collection, 'Royal College of Physicians 'Reframing Disability' exhibition', London 2011 <<http://wellcomecollection.wordpress.com/2011/05/11/re-framing-disability>> accessed 19 October 2011

10. Cases

European Court of Human Rights

A v UK (1998) 27 EHRR 661

Botta v Italy (1998) 26 EHRR 241

Glor v Switzerland (Application no 13444/04) 30 April 2009

HL v United Kingdom 45508/99 (2004) EHRR 471

Keenan v UK (2001) 33 EHRR 913

Marckx v Belgium (1979) 2 EHRR 330 PC

Mazari v Italy (1999) 28 EHRR 175 CD

Price v UK (2001) 34 EHRR 1285

Soering v UK (1989) 11 EHRR 439

United Kingdom cases

AH v West London MHT [2011] UKUT 74 (AAC)

Anufrijeva [2003] EWCA Civ 1406

Archibald v Fife Council [2004] IRLR 651; [2004] ICR 954 (HL)

Associated Provincial Picture Houses Ltd v Wednesbury Corporation [1948] 1 KB 223

Birmingham City Council v Oakley [2001] 1 AC 617

Bugdaycay v Secretary of State for the Home Department [1987] 1 All ER 940

Burnip v Birmingham City Council, Trengrove v Walsall Metropolitan Council, Gorry v Wiltshire Council [2012] EWCA Civ 629, 15 May 2012

Coleman v Eastern Counties Railway [1846] 16 LJ Ch. 73

Coleman v Attridge Law C-303/06 [2008] IRLR 722 (ECJ)

Donoghue v Poplar Housing and Regeneration Community Association Ltd [2001] EWCA Civ 595, 27 April 2001

ex p Lain [1967] 2 QB 864

London Borough of Hillingdon v Steven Neary, Mark Neary and the Equality and Human Rights Commission [2011] EWHC 1377 (COP) 9 June 2011

NS and others v Secretary of State for the Home Department (C-411-10) ECJ

O'Reilly v Mackman [1983] 2 AC 237

R (A,B, X and Y) v East Sussex County Council (No 2) [2003] EWHC 167 (Admin)

R (BAPIO Action Ltd & Yousaf) v Secretary of State for the Home Department and Secretary of State for Health [2007] EWHC 199 (QB)

R (BAPIO Action Ltd) v Secretary of State for the Home Department [2007] EWCA Civ 1139

R (Boyejo) v Barnet LBC [2009] EWHC 3261 (Admin)

R (Bradley and Others) v Secretary of State for Work and Pensions [2007] EWCA 242 (Admin)

R (Brown) v Secretary of State for Work and Pensions [2008] EWCA 3158 (Admin)

R (C) v Secretary of State for Justice [2008] EWCA Civ 882

R (Chavda & Others) v Harrow LBC [2007] EWHC 3064

R (Domb and Others) v Hammersmith & Fulham LBC [2009] EWCA Civ 941

R (Eisai) v National Institute for Clinical Excellence & Others [2007] EWHC Admin 1941

R (F) v Wirral Borough Council [2009] EWHC 1626 (Admin)

R (Harrison) v SS for Health [2009] EWCA 574 (Admin)

R (Heather) v Leonard Cheshire Foundation [2002] EWCA Civ 366

R (JG and MB) v. Lancashire County Council [2011] EWHC 2295 (Admin)

R (JG and MB) v Lancashire County Council [2011] EWHC 2295 (Admin)

R (JM & NT) v Isle of Wight Council [2011] EWHC 2911

R (Kaur & Shah) v London Borough of Ealing [2008] EWHC Admin 2026

R (Kiana) v SSHD [2010] EWHC 1002 (Admin)

R (L) v Bournemouth Community and Mental Health NHS Trust (1998) UKHL 24

R (MS) v Oldham BC [2010] EWCA 802 (Admin)

R (NM) v London Borough of Islington & Northamptonshire County Council [2012] EWCA 414 (Admin), 29 Feb 2012

R (on the application of Bernard and another) v Enfield London Borough Council. [2002] All ER (D) 383 (Oct)

R (on the application of Burke) v General Medical Council [2005] EWCA Civ 1003; [2005] All ER (D) 445 (Jul)

R (on the application of Elias) v Secretary of State for Defence and another [2005] EWHC 1435 (Admin), CO/5181/2004

R (on the application of M, G and H) v Birmingham City Council [2011] EWHC 1147 (Admin),

R (on the application of MacDonald) v Royal Borough of Kensington and Chelsea CA: [2010] EWCA Civ 1109; SC: [2011] UKSC 33 6 July 2011

R (on the application of W) v Birmingham City Council; R (on the application of M, G and H) v Birmingham City Council [2011] EWHC 1147 (Admin)

R (Rogers) v Swindon NHS Primary Care Trust, Secretary of State for Health [2006] EWCA Civ 392

R (Smeaton) v Secretary of State for Health [2002] EWHC 610 (Admin)

R on the application of (1) The Sefton Care Association (2) Melton Health Care Limited (3) Westcliffe Manor Nursing Home (4) Benbridge Care Homes Limited (5) Craignare Care Home v Sefton Council [2011] EWHC 2676 (Admin)

R v Birmingham CC ex p Taj Mohammed [1998] 3 All ER 788

R v Bristol CC ex p Penfold (1998) 1 CCLR 315

R v Cambridge Health Authority ex parte B [1995] 2 All ER 129

R v Criminal Injuries Compensation Board ex p Lain [1967] 2 QB 864

R v East Sussex County Council ex p Tandy [1998] 2 All ER 769

R v Gloucestershire County Council ex parte Barry [1996] 4 ALL ER 421; 1 CCLR 19. HL: [1997] AC 584; [1997] All ER 1; (1997) 1 CCLR 40

R v Leonard Cheshire Foundation and HM Attorney General ex p Heather and Others [2001] QBD CO/4727/00, 15 June 2001

R v Local Commissioner for Administration ex p Eastleigh BC [1988] 1 QB 855

R v Ministry of Defence ex parte Smith [1996] QB 517

R v North East Devon Health Authority ex parte Coughlan [2001] QB 213; QB 47 BMLR 11 Dec 1998; (1999) 2 CCLR 285; (2000) 51 BMLR 1 CA

R v Northumberland Compensation Appeal Tribunal ex p Shaw [1952] 1 KB 338

R v Panel on Takeovers and Mergers ex p Datafin [1987] QB 815

R v Sefton MBC ex p Help the Aged [1997] EWCA Civ 2265 [1997] 4 All ER 532

R v Servite Houses and London Borough of Wandsworth Council ex p Goldsmith and Chatting [2001] LGR 55

Ridge v Baldwin [1964] AC40

Roy v Kensington & Chelsea Family Practitioner Committee [1992] 1 AC 624

Wandsworth LBC v Winder [1985] AC461

YL (by her litigation friend the Official Solicitor) v Birmingham City Council [2007] UKHL 27

Other jurisdictions

Chacón Navas v Eurest Colectividades (C-13/05) [2006] E.C.R. I-6467

Government of the Republic of South Africa and Others v Grootboom and Others 2000 (11) BCLR 1169 CC

Ombudsman reports

Local Government Ombudsman, 'Digest of Cases 2008-2009', Section L Social Care

Parliamentary and Health Service Ombudsman and Local Government Ombudsman, 'A report by the Health Service Ombudsman and the Local Government Ombudsman about the care and support provided to a person with Down's syndrome', Thirteenth Report, session 2010-2012, 22 November 2011, HC 1644

Parliamentary and Health Service Ombudsman and Local Government Ombudsman, 'Six Lives: the provision of public services to people with learning disabilities, Report on complaints 07B06309, 07B06077 & 07B09453', Second Report, session 2008-2009, 23 March 2009, HC 203-I

Parliamentary and Health Service Ombudsman and Local Government Ombudsman, 'A report by the Health Service Ombudsman and the Local Government Ombudsman about the care and support provided to a vulnerable person living independently in the community' (St Helen's case), Sixth Report, session 2010-2012, 4 July 2011, HC 1355

11. Legislation

International instruments

Bangalore Declaration and Plan of Action 1995

Charter of the United Nations 1945

Convention on the Elimination of All Forms of Discrimination against Women 1979

Convention on the Rights of Persons with Disabilities 2006

Declaration on the Rights of Disabled Persons 1975

Declaration on the Rights of Mentally Retarded Persons 1971

Geneva Conventions:

First Geneva Convention for the Amelioration of the Condition of the Wounded and Sick in Armed Forces in the Field 1864

Second Geneva Convention for the Amelioration of the Condition of Wounded, Sick and Shipwrecked Members of Armed Forces at Sea 1906

Third Geneva Convention relative to the Treatment of Prisoners of War 1929

International Convention on the Elimination of All Forms of Racial Discrimination 1966

International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families 1990

International Covenant on Civil and Political Rights 1966

International Covenant on Economic, Social and Cultural Rights 1966

Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights, E/CN.4/1987/17, Annex

Maastricht Guidelines on Violations of Economic, Social and Cultural Rights, Maastricht, January 22-26, 1997

Millennium Development Goals 2000

Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women 1999

Optional Protocol to the Convention on the Rights of Persons with Disabilities 2006

Optional Protocol to the International Covenant on Civil and Political Rights 1966

Optional Protocol to the International Covenant on Economic, Social and Cultural Rights 2008

Principles relating to the Status of National Institutions (The Paris Principles) 1993

Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1994

SUVA Declaration 2006

United Nations Principles for Older Persons 1991

United Nations Convention on the Rights of the Child 1989

Universal Declaration of Human Rights 1948

Vienna Convention on the Law of Treaties 1969

Vienna Declaration and Programme of Action 1993

European instruments

European Union Directive 2000/78

European Union Charter of Fundamental Rights 2000

European Social Rights Charter (revised) 1996

Protocol 'On the Application of the Charter of Fundamental Rights of the European Union to Poland and to the United Kingdom', C306/156, 17 December 2007

Other jurisdictions

American Declaration of Independence 4 July 1776

Americans with Disabilities Act 1990

Belfast Agreement 1998

Déclaration des Droits de l'Homme et du Citoyen 1789

United Kingdom legislation

Primary legislation

Children Act 1989

Chronically Sick and Disabled Persons Act 1970

Community Care (Direct Payments) Act 1996

Community Care and Health (Scotland) Act 2002

Disability Discrimination Act 1995

Disability Discrimination Act 2005

Disabled Persons (Services, Consultation and Representation) Act 1986

Equality Act 2006

Equality Act 2010

European Communities Act 1972

Health Act 1999

Health Act 2009

Health and Safety at Work Act 1974

Health and Social Care (Community Health and Standards) Act 2003

Health and Social Care Act 2001

Health and Social Care Act 2008

Health and Social Care Act of 2001

Health and Social Services and Social Security Adjudications Act 1983

Health Service Commissioners Act 1993

Health Services and Public Health Act 1968

Homelessness Act 2002

Housing Act 1996

Housing Grants, Construction and regeneration Act 1996

Human Rights Act 1998

Legal Aid, Sentencing and Punishment of Offenders Act 2012

Local Authority and Social Services Act 1970

Local Authority Social Services Act 1970

Local Government Act 1974

Local Government Act 1974

Magna Carta 1215

Mental Capacity Act 2005

Mental Health Act 1959

Mental Health Act 1983

Mental Health Act 2007

National Assistance Act 1948

National Health Service Act 1977

National Health Service and Community Care Act 1990

Parliamentary Commissioner Act 1967

Poor Law Act 1601

Welfare Reform Act 2012

Bills

Disabled Persons (Independent Living) Bill [HL] (2006-2007) 14

Draft Care and Support Bill, July 2012 Cm 8386

Health and Social Care (Independent Living) Bill [HL] (2009-2010) 19

Secondary legislation

Community Care (Direct Payments) Regulations 1997 SI 1997/734

Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003 SI 2003/762

Continuing Care (National Health Service Responsibilities) Directions 2004

Disability Discrimination (Public Authorities) (Statutory Duties) Regulations 2005 SI 2005/2966

Local Authority Social Services and National Health Service Complaints (England) Regulations 2009, SI 2009/309

Local Authority Social Services Complaints (England) Regulations 2006 SI 2006/1681

National Assistance (Assessment of Resources) Regulations 1992 SI 1992/2977

National Assistance Act 1948 (Choice of Accommodation) Directions 1992

Regulatory Reform (Collaboration etc between Ombudsmen) Order 2007 SI 2007/1889

The Equality Act 2010 (Specific Duties) Regulations 2011 SI 2011/2260

Circulars and guidance

Department of Health 'Fair Access to Care Services' LAC (2002) 13

Department of Health 'Fair Access to Care Services: guidance for eligibility criteria for adult social care' 2003

Department of Health 'Transforming Adult Social Care' LAC (DH)(2008)1

Department of Health 'Transforming Adult Social Care' LAC (DH)(2009) 1

Department of Health 'Prioritising Need in the Context of Putting People First: a whole system approach to eligibility for social care – guidance on eligibility criteria for adult social care, England 2010' (2010) Gateway ref 13729

Disability Rights Commission 'The Duty to Promote Disability Equality: Statutory Code of Practice, England and Wales' (DRC 2005)

Appendix 1

Observation Notes

UN Committee on Economic, Social and Cultural Rights: examination of United Kingdom of Great Britain and Northern Ireland, Session 42, Geneva, 12 – 14 May 2009, 14th meeting, 12 May

Examination of the United Kingdom of Great Britain and Northern Ireland by the UN Committee on Economic, Social and Cultural Rights took place at the Palais Wilson, Geneva on Tuesday 12 May and Wednesday 13 May 2009, as part of the Committee's 42nd session. There were three public meetings in all between the Committee and representatives of the UK government: one on Tuesday afternoon, and two on Wednesday (am and pm). Whilst a full official record of the public sessions on Wednesday is available on the Committee's website, at the time of researching and writing this thesis no official record of the Tuesday meeting was available.

The observation notes set out below are those taken during the Tuesday meeting by the writer. They form the basis for discussion of that meeting in Chapter 5 of the thesis.

Tuesday 12 May 2009, 3 – 6pm (14th meeting of 42nd session)

The 23 members of the UK delegation were welcomed by the Chair.¹ The Committee were impressed by the number and expertise of the delegation and by the UK's Fifth Periodic Report, which was described as specific, up-to-date, and 'outstanding'. However, a face-to-face dialogue was also needed.

Mr Vijay Rangarajan, Head of the UK delegation made an opening statement, a draft of which² reads as follows:

1. Mr Chairman, members of the Committee, ladies and gentlemen, good afternoon. I am Dr Vijay Rangarajan – leader of the UK delegation.
2. I am the Constitution Director in the United Kingdom Ministry of Justice. The Ministry of Justice leads the development of policy on human rights for the UK and has lead responsibility for the UK's obligations under the International Covenant on Economic, Social and Cultural Rights. We prepared the UK's 5th Periodic Report under the Covenant, which we submitted to you in July 2007.

¹ Mr Marchan Romero (Ecuador)

² Copy available on the day, in the writer's possession

3. On behalf of the UK delegation, I warmly welcome the opportunity to discuss with you the UK's fulfilment of its obligations under the Covenant, and the Government's achievements and ambitions.
4. I emphasise at the outset the high value which the United Kingdom places on the work of this Committee and of other UN treaty monitoring bodies. The UK views the monitoring process led by expert committees as an essential element in the promotion and protection of rights internationally, and a catalyst for achieving meaningful change. The UK Government respects your advice on the implementation of the Covenant and gives it serious consideration in the development of UK policy on matters concerning economic, social and cultural rights.
5. We gave careful consideration to the Committee's concluding observations and recommendations following the previous examinations in 2002. The action we have taken in response to the Committee's concerns and recommendations is summarised in our 5th Report. But of course, we continue to bear the Committee's recommendations in mind as we develop policies and monitor performance on delivery of the rights within the Covenant.
6. In preparing the Report, we consulted with members of civil society in the UK, including Non-Governmental Organisations, National Human Rights Institutions, academia and individuals concerned about rights. We took on board suggestions as to how the report could be improved and are confident that the process of consultation strengthened the report and continues to enhance the monitoring process more generally. We have noted a real appetite from NGOs for a more systematic and structured approach to collaboration for this and our other international commitments, and we will take action on this.
7. Mr Chairman, for this examination the Committee has raised an important range of issues on which we are pleased to respond. We sent you a preliminary written response addressing all these issues on 17 February this year. On these responses, too, we consulted with members of civil society.
8. Meanwhile, we have studied carefully the parallel reports submitted to you by UK NGOs. Within the NGO reports, there is positive recognition of steps the UK Government has taken since the previous examination in 2002. These include the recently launched consultation on a UK Bill of Rights and Responsibilities; the Equality Bill; progress in improving overall levels of health; action to reduce child poverty; flexible working reforms, and pension reform.
9. The UK is fully committed to a vigorous development of economic, social and cultural policy. It has consistently pursued a progressive agenda, largely through the 'Welfare State', and can point to sustained progress on social inclusion and increased funding for education and healthcare, as well as measures to eradicate child poverty, as evidence of its commitment to domestic realisation of the rights set out in the Covenant.
10. While there has been significant progress, we acknowledge that there is room for improvement. We continue to set challenging targets for improvement in those areas which still pose difficulties, and to pursue a range of measures including legislation, policies and programmes which advance the principles and objectives set out in the Covenant. The

Government believes that its progressive social policy ensures that the rights in the Covenant are being delivered.

11. The Government sees provision of these rights as a progressive endeavour. It notes that different jurisdictions take different approaches depending on their constitutions, their history and their social and economic conditions. It is the Government's clear view that, for the UK, democratically elected representatives are better placed than are the judiciary to make politically sensitive decisions on resource allocation. Parliamentary sovereignty remains the cornerstone of the UK constitution. Our approach to social and economic rights reflects the fact that although some rights require immediate realisation, the obligation under the Covenant is one of progressive realisation.
12. The Committee should be in no doubt about the UK's commitment both to meet this obligation, especially in the current economic climate. Indeed, the economic situation has heightened the need to ensure that people's basic economic and social needs are fulfilled. The UK is taking action internationally, nationally and locally to help people and businesses to cope with the financial downturn. In the recent Budget, the Chancellor announced that households and families are receiving support including increases in tax allowances and child benefits; pensioners have received one-off payments and increased pension credits; over £8 billion is being invested in social housing from 2008-11, including further support for homeowners with mortgage payments where they have lost their jobs. There is also a £1.6 billion per year 'Supporting People Programme', which funds housing related support for 1.2 million vulnerable people. When people are made redundant in the UK our flexible labour market allows for innovative measures to combat unemployment. Extra resources in job centres have helped to get 1.2m (75% of) people off benefits and back to work since last November and all 18-24 year olds who have been out of work beyond 12 months are now guaranteed jobs or training. In the international context, the UK remains committed to providing overseas aid and working towards its Millennium Development Goals, at a time when developing countries are more than ever in need of assistance.
13. In the domestic context, the UK has continued to make progress in key socio-economic areas since the last reporting session in 2007. Its commitment to the ICESCR objectives has been notably reinforced by the establishment of the Equality and Human Rights Commission, which came into operation on 1 October 2007. The Commission's brief is to eliminate discrimination, reduce inequality, protect human rights and build good relations, ensuring that everyone has a fair chance to participate in society. The new commission brings together the work of three previous equality commissions and takes on new equality responsibilities in relation to age, sexual orientation and religion or belief. Together with the Scottish Human Rights Commission, brought into operation 2008 with a mandate to promote all human rights – civil, political, economic, social and cultural – and the already established Northern Ireland Commission on Human Rights, the UK now enjoys a full complement of human rights Commissions for its various jurisdictions. This is in accordance with the Concluding Recommendations of the Committee in 2007.
14. The UK's record on addressing discrimination goes back 40 years to the first Race Relations Act in the 1960s. Our approach is tailored to the UK context. We have more to do and are taking our work forward in the Equality Bill, which was recently introduced to Parliament. This Bill will extend the

protection against discrimination from gender, race and disability considerations to age, sexual orientation, religion or belief, gender reassignment and pregnancy/maternity. It will also streamline the current, complex web of equality legislation, making it more accessible and understandable to those who will benefit from it and those who need to comply with it. The Bill reflects the Government's determination to prioritise equality issues. The Committee may wish to note a number of further initiatives in this field. A newly established Judicial Diversity Panel is working with the senior judiciary, Judicial Appointments Commission, legal professions and equality and diversity sector to produce recommendations for reform by November 2009. In Parliament, a Speaker's Conference is under way to consider, and make recommendations for rectifying, the disparity between the representation of women, ethnic minorities and disabled people in the House of Commons and their representation in the UK population at large. A Panel on Fair Access to Professions has also been set up to focus on identifying barriers to entering the professions for people from disadvantaged socio-economic backgrounds.

15. Meanwhile, the UK labour market is increasingly designed to encourage women, parents, older workers and those with disabilities to be economically active. Its flexibility enables businesses to respond quickly to changes in the market place, but also ensure that there are fair standards and support for people when they need to move between jobs. The UK Government works closely with trade unions, business organisations and other interested parties on employment law and policy issues and will continue to bring forward measures to ensure that the legal framework remains up to date, that the rights of employees are adequately protected and that all workers who should be aware of and benefitting from these rights are doing so. Since 2007, the minimum annual entitlement to paid leave has been increased to 28 days; working mothers' Statutory Maternity Pay, Statutory Adoption Pay and Maternity Allowance have been increased; since October 2008, over 1 million workers have benefitted from increases in National Minimum Wage rates, around two thirds of them women; the right to request flexible working has recently been extended to parents of children aged 16 and under. The UK Government is also taking action in relation to vulnerable workers, having embarked upon a programme to combat abuse of worker rights and ensure that all workers, including migrant workers, have access to their rights and an improved enforcement framework.
16. Clear progress is being made in health and education reforms across the UK. Education standards have risen at all levels and across all major ethnic groups since the last UK report. The achievement gaps are closing between most of the historically under-performing ethnic groups and the national average. While UK Governments continue to focus on those ethnic minority groups such as Gypsy, Roma and Traveller children who under-perform at school, there is also renewed focus on poor children, those with special educational needs and children looked after by a local authority. In health, there has been major progress in terms of the 12-month 'Next Stage Review', led by 2,000 clinicians and staff across the country and which involved 60,000 patients, public and staff. The policy plans which emerged from the Review are set to give patients more choice and information, reward hospitals and clinics that offer both the highest quality of care, and provide the most responsive services. Meanwhile, the new National Health Service Constitution brings together, for the first time, the principles, values, rights and responsibilities that underpin the NHS. It is designed to renew and secure commitment to the enduring principles of the NHS, making sure that

the NHS continues to be relevant to the needs of patients, the public and staff in the 21st century.

17. Of course, in all the UK Government's dealings with economic, social and cultural rights, it is important to bear in mind that we have multiple jurisdictions and the constitutional context with regard to the UK's Overseas Territories, Crown Dependencies and Devolved Administrations. Each is able to a great extent (whether through self-Government or wide legislative competence) to prioritise its various concerns in this field and tailor its legislation and practice accordingly. Devolution has been a major achievement and important constitutional reform. The degree of self-determination accorded to each administration allows for innovative measures to ensure progressive realisation of the Covenant rights in a way which reflects local culture and needs. My colleagues will be happy to advise on variations in areas such as the health service, education and child wellbeing as you proceed with your questioning.
18. The issue of cultural variance more generally is central to the UK Government's policy agenda. The United Kingdom is home to a rich diversity of communities, faith groups and cultures. The Government positively encourages the freedom of these communities to express themselves in a creative and free environment. The Olympic and Paralympic Games 2012 will present a unique opportunity to promote our cultural diversity and the value we attach to this as a society. As a delegation we also welcome any considerations the Committee wish to highlight as UK preparations continue for this major event on the world stage.
19. Finally, I wish to draw the Committee's attention to an initiative which we believe will enhance awareness of, and civic participation and engagement with, economic, social and cultural rights in the UK. The UK Government has recently launched a public consultation on a UK Bill of Rights and Responsibilities, following publication of its Green Paper *'Rights and Responsibilities: developing our constitutional framework'*. The Paper explores a range of entitlements which we enjoy as members of UK society and which go beyond the civil and political rights in the European Convention on Human Rights (as incorporated in the Human Rights Act 1998). These entitlements sit, as part of our well established welfare state, firmly in the sphere of social and economic rights. The Government proposes that including provisions in a new constitutional document which point to key aspects of our welfare state, such as NHS entitlements; victims' rights; equality; good administration; children's wellbeing and principles of sustainable development in relation to our environment, could help to paint a fuller picture of the rights and responsibilities we share in the UK. A formal public engagement exercise has begun, with the aim of involving all parts of UK society in discussions on what is potentially a major constitutional reform. Meanwhile, progress continues on a potential Bill of Rights for Northern Ireland. The Northern Ireland Human Rights Commission has provided statutory advice to the Secretary of State for Northern Ireland on the scope for defining in UK legislation, rights supplementary to those in the European Convention on Human Rihts to reflect the particular circumstances of Northern Ireland, drawing as appropriate on international instruments and experience. The advice is under consideration and the UK Government will ensure that the public debate around a UK instrument does not detract from the process relating to a potential Bill for Northern Ireland.
20. In advance of this examination the UK delegation has answered questions on issues covering the general overarching provisions [Articles 1-5] of the

Covenant and its specific substantive provisions [Articles 6-15], all of which raise questions of Government policy that continue to fuel debate in the UK. We value the opportunity to extend that debate today and my colleagues will now be pleased to answer your questions.

21. Mr Chairman, with that I conclude this brief overview of recent developments in the UK and look forward to hearing your views and advice.

The opening statement was followed by a number of questions and comments from Committee members:

Mr Riedel (Germany):

1. You mention there is appetite from NGOs for more collaboration. What action are you taking?
2. You have ratified [the ICESCR] but saying bound at international level only, not domestic, implementation progressive only, Parliament best... Role of Committee is not instead of Parliament (General Comment 3). You are misrepresenting the role of this Committee. When it comes to resources, it is about reasonableness, proportionality (see our Optional Protocol discussions)
3. The Equality and Human Rights Commission (EHRC) has commented on the Fifth Report, and Joint Committee on Human Rights (JCHR) has had an input. But your Bill of Rights and Responsibilities consultation is about civil and political rights, not economic, social and cultural rights.
4. Will the UK sign the ICESCR Optional Protocol?

Mr Pillay (Mauritius):

1. The JCHR has made proposals [in its report on a British Bill of Rights?³]. Have those proposals been implemented, or is their report a dead letter?
2. 'Very disappointed' with UK response to Committee's list of issues (issue 1 – increasing awareness of ESC rights) that 'awareness is already high'.
3. ESCR not justiciable? UK still holds on to inflexible approach – not seen as rights (see Bill of Rights Green Paper). JCHR says judicial review is not adequate for vulnerable groups.
4. Human Rights Commissions require a roadmap, holistic, indivisibility of rights. UK government has not changed at all: example of children and punishment, nothing done so far. Talking about Covenant obligations but not being implemented or taken seriously.
5. Northern Ireland Bill of Rights includes ESCR. NI Human Rights Commission has mandate in favour of ESCR being justiciable/enforceable. Will UK government enact this Bill of Rights and include ESCR also in UK Bill of Rights?

³ Joint Committee on Human Rights, 'A Bill of Rights for the UK?' Twenty-Ninth Report of session 2007-08, HL 165-I/HC 150-I. 10 August 2008

Mr Schrijver (Netherlands):

1. Impact of counter-terrorism measures on ESCR, e.g. non-discrimination, migrant workers, ethnic minorities etc – opportunity for judicial review/ effective remedy? If yes, comfortable to sign up to Optional Protocol?
2. Fifth Report section on action of companies operating overseas. What about asylum-seekers and healthcare: England denies healthcare, Wales, Scotland & N Ireland not denied.
3. Covenant Article 2: UK international development policy. To what are human rights embedded in your development policy? Please say something specific about ESCR.

Mr Kedzia (Poland):

1. Social rights are applicable in admin or courts only if spelled out in domestic legislation. Lack of direct applicability of international law to domestic law should not affect ratification of Optional Protocol or incorporation.
2. People in difficult situations have double bind: difficulty of situation and difficulty of getting redress. Access to legal remedies?

Speaker (female):

1. Revised European Charter: why not ratified? Are you going to ratify?
2. Jersey etc and employment: reservation? Discrimination? men and women?
3. Most countries apply and implement ESCR all over the world. Optional Protocol – a right which cannot come to court is not a right. UK reasons for non-incorporation in its Fifth Report don't make sense: you do not *wish* domestic courts to enforce, raises questions about ratification. Needs to change over time.

Mr Abdel-Moneim (Egypt):

1. What measures applied to rights of people who come under anti-terrorism laws?
2. ESCR of inhabitants of overseas territories: how reported here?
3. Table of reservations and declarations, Fifth Report pp30-31: still 6 reservations – in line with Vienna Declaration max number of reservations? Declaration re Art 1.3: any conflict between Covenant and UN Charter, UN Charter will prevail. How do you envisage such a conflict?...

Ms Bras Gomes (Portugal):

You disagree with the Committee on a number of issues.

1. Para 75 of Fifth Report: agree that rights are indivisible and interdependent. But ESCR part of Welfare State, not 'rights'. Bill of Rights consultation focusses on civil and political rights, not ESCR as rights. Why not indivisible at *practical* level?
2. How do you see ESC obligations? No reference to 'fulfilment'.

3. Housing in Belfast: meaningful consultation?
4. British companies re overseas activities – obligations to ‘protect’

Speaker (male):

1. Best report submitted by developed countries, but very long!
2. Report p 119: ILO Conventions 8, 9 & ? not ratified: why?

Mr Sadi (Jordan):

1. Introductory speech provocative: ‘we appreciate your *advice*’. Use stronger word? Recommendations of the Committee are not just ‘advice’.
2. What does consultation with civil society mean?
3. UK Bill of Rights and responsibilities? Is purpose to draw balance between individual and collective rights?
4. You accept some rights for immediate implementation, some progressive. Which are which?
5. You have various Human Rights Commissions. Do you need some kind of national one? What is the relationship between them?
6. Fifth Report para 14 re Equality Bill, list of ‘strands’ includes race, why not national/ethnic origin?

Ms Bondon-Dandan (Philippines):

1. Clarify protection of migrant agency workers such as Philippino sailors, hired by Philippino companies, working for UK companies
2. Where are Chagos islanders now, and how is UK government protecting their rights?

Ms Barahona Riera (Costa Rica):

1. Legal framework: Art 1 para 3 of Covenant, self-determination and declaration re UN Charter priority over Covenant? Non-ratification of Optional Protocol? Is there a legal problem related to international position of UK?
2. International development assistance: what resources, given credit crunch? Any changes?
3. What is UK position re ILO Convention 169? Indigenous population...
4. Equality Bill: why referring to maternity/pregnancy? What are provisions to address?

Speaker ??

1. Equality Bill: how presented from legal point of view? Mandatory or recommendations? Law or ‘Charter’?
2. Cultural diversity: can different people actually occupy high level posts in UK government?
3. ESCR in development policies? Commitment, not obligatory
4. What do you mean, ESCR not justiciable? Justiciability of ESCR contributes to good government. Do you see the State as Messiah? How can you do that?

Mr Martinov (Belarus):

1. Unfortunate insistence on reservations
2. Art 10: Bermuda/Falklands and maternity care

The UK delegation was given 10 minutes to group the questions, with option to defer some until the next day.

Dr Vijay Rangarajan (Ministry of Justice) (Head of UK delegation):

Mr Sadi's question about 'advice'. Maybe 'advice' doesn't carry the right connotations, but we take it extremely seriously.

Rosemary Davies (Ministry of Justice):

On incorporation: this is a common theme, and we did anticipate the questions. UK doesn't incorporate, ECHR is exception. EU law has some effect re some ESC rights. ICESCR = international commitment to progressive realisation. Committee's regret in 2002 and General Comment 9: some UK arguments against incorporation may have lost their force, such as vagueness of Covenant language.

Need to look at what UK has achieved, and the future. UK has been committed since foundation of welfare state, race discrimination since 1960s, also e.g. NHS, education... May not be expressed in terms of ICESCR. Accept we could do more to raise awareness.

Resources are matter for elected Parliaments not judges. Internationally, some judges have gone further than UK would feel acceptable, e.g. India, South Africa. Where do you draw the line re allocation of resources?

UK law does impose obligations on public authorities. System of Tribunals, e.g. social security, employment, mental health, asylum. Unifying Tribunal system. Also judicial review: significant public law challenges on ESCR including health, housing etc.

Bill of Rights and Responsibilities Green Paper is consultation only, might include some ESC rights. Government's view has been: don't see directly enforceable rights as appropriate – because we have so many already.

John Kissane (Ministry of Justice):

How we promote ESCR and Optional Protocol. Over last 6 years: how best to educate everyone about human rights, controversial, opposition to human rights. Programme in Ministry of Justice to educate officials: 150 copies of guidance. Trying to counteract myths in Press, with BIHR, Amnesty etc: new part of education syllabus partly about Rights of the Child.

Practical evidence of understanding their rights. General public doesn't know list of rights in this Covenant, but they do know, e.g. use of Tribunals. Social security: 240K cases, mental health 23K, employment 99K. Activity, cheaper, simpler than through Court. But more to be done. Not going to stop educating public, including putting response to ESCR Committee on

website. Please advise on how to publicise rights to allow everyone to know where to look for rights.

Three National Human Rights Institutions: major role, willing to work together, not a weakness.

Helen Nelthorpe and Louise Constantine (Foreign & Commonwealth Office)

Responses re overseas territories and reservations

Annette Warrick (Dept for Children, Schools and Families)

Corporal punishment. Banning smacking is not the way to achieve aim. Parenting classes to encourage other ways to discipline their children. Children Act 2004 increases protection: no 'reasonable punishment' defence.

John Luxton (Welsh Assembly)

Booklets for parents, also informing children of their rights, ways to avoid physical punishment.

Jeremy Oppenheim (Home Office)

Counter-terrorism. Committee has nothing to fear. Appeal rights, judicial review. Subject to detention: conditions independently monitored. Right to work: once accepted can work like anyone else. Seafarers: if employer based in UK, national and local powers to take decisive action.

Tony Strutt (Government Equalities Office)

Equality Bill. Separate to immigration law. Maternity rights extended to goods and services. Also public sector duty. Positive action extended, also to address imbalance in public life, e.g. women only shortlists. Bringing in proposals.

Status of the Bill: when enacted, force of law. Guidance will be provided, and enforcement channels.

Vijay Rangarajan (Ministry of Justice)

Supplementary points on Equality Bill. Other things happening too, e.g.

1. Speaker's conference in Parliament re minority representation (report by end 2009)
2. Judicial Appointments Commission, independent panel to change whole system to improve diversity

John Kissane (Ministry of Justice)

Optional Protocol. UK not against on principle, took part in drafting, but not convinced of practical use. Committees are not courts. Individuals can use courts and Tribunals. But UK wants to test out process: 2004 CEDAW OP ratification, 2 cases, both inadmissible. Reviewed process, report end 2008, very little take-up by civil society. Report concludes not enough empirical evidence, more needed. In meantime, will consider other OPs, including CRPD to provide database of evidence.

Not static/intransigent, just trying to work it out.

Consideration of remaining issues was adjourned until the following day. There is a full official record of the Wednesday morning meeting (E/C.12/2009/SR.15) at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G09/425/11/PDF/G0942511.pdf?OpenElement> last accessed 10.10.12; and of the public content of the Wednesday afternoon meeting (E/C.12/2009/SR.16) at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G09/423/73/PDF/G0942373.pdf?OpenElement> last accessed 10.10.12.

Appendix 2

Assessment Forms

1. Association of Directors of Adult Social Services,
Common resource allocation framework,
Personal Needs Questionnaire and Scoring Sheet
2. Local authority Community Care Assessment

Common resource allocation framework

Personal needs questionnaire

This is your personal needs questionnaire. It includes a number of questions for you to answer.

The aim of the questionnaire is to give an indication of how much money you may need to live your life as an equal citizen and achieve some or all of these general outcomes:

1. To stay healthy safe and well
2. To have the best possible quality of life, including life with other family members, if this is what you choose
3. To participate as an active citizen, increasing independence where possible
4. To have maximum choice and control
5. To live your life safely, free from discrimination or harassment
6. To achieve economic well-being and have access to work and/or benefits if you choose to do so
7. To keep your personal dignity and be respected by others

For each question a number of points will be allocated depending on your answer. These will be used to work out if, and how much, money you could be offered as part of your personal budget. Under some of the sections there are examples for you. Please tick the statement that best describes your situation. The exact support you may need will be discussed at the next stage, which is when you will plan your support.

This is only a guide. The aim is for you to work out what support you may need.

You can complete the questionnaire by yourself or with the support of someone else.

All information provided will be kept confidential.

1.1 Meeting Personal Care needs

This part is about the support / encouragement I need with things like personal hygiene, dressing, taking medication and moving around my home in order to do such tasks. This could also include supporting me to get in and out of bed.

Outcome: I am able to meet my personal care needs	My view	Assessors View
A) I do not need any support with my personal care		
B) I need occasional support / encouragement with my personal care (e.g. once or twice a week)		
C) I need some support / encouragement with my personal care (e.g. at least once a day)		
D) I often need support / encouragement with my personal care (e.g. at least twice a day)		
E) I need frequent support / encouragement with my personal care (e.g. several times a day)		

1.2 Meeting Personal Care needs (day and/or night and support)

If you answered B, C, D, or E above please indicate when you need support (day, and/or night) and how many people you may need to support you at these times. Please select either day or night, or both.

	My view		Assessors View	
	During the day	During the night	During the day	During the night
A) I need 1 person to support me with my personal care ...				
<i>OR</i>				
B) I need 2 people to support me with my personal care ...				

2.1 Keeping myself safe

This part is about keeping safe inside and outside of my home. Staying safe means different things to different people.

Outcome: I am able to keep safe	My view	Assessors View
A) I am able to keep myself safe all of the time		
B) I need occasional support to keep myself safe		
C) I often need support to keep myself safe		
D) I always need support to keep myself safe		

2.2 Keeping myself safe (day and/or night and support)

If you have answered B, C or D above, please indicate when you need support. Please select either day or night, or both.

	My view		Assessors View	
	During the day	During the night	During the day	During the night
A) I need support to help me keep safe ...				

3. Eating and drinking

This part is about the support / encouragement I need to eat, drink and prepare my meals.

Outcome: I am able to eat drink and prepare my meals	My view	Assessors View
A) I am able to eat, drink and prepare my meals without support		
B) I often need support to eat, drink and / or prepare my meals (e.g. at least once a day)		
C) I always need support to eat, drink and / or prepare my meals (e.g. several times a day)		

4. Making decisions and organising my life

This part is about who decides important things in my life. Things like where I live, who supports me, who decides how my money is spent.

Outcome: I am able to make decisions and organise my life	My view	Assessors View
A) I can make decisions and organise my life without support.		
B) I need occasional support to make decisions and organise my life.		
C) I often need support to make decisions and organise my life.		
D) Other people always make decisions and organise my life		

5. Being part of my community

This part is about doing things in my community, like using the library, going to the cinema, community centre, or place of worship, or meeting up with friends

Outcome: I am able to be part of my community	My view	Assessors View
A) I am able to participate in my local community as much as I want to		
B) I need occasional support to be part of my local community		
C) I often need support to be part of my local community (e.g. at least once a week)		
D) I frequently need support to be part of my local community (e.g. several times each week)		
E) I want to be part of my community and regularly need a lot of support to do this (e.g. daily or several times each day)		

6. My role as a parent or carer

This part is about the support I need to care for someone else e.g. child, parent, partner

Outcome: I am able to play my full role as a parent or carer	My view	Assessors View
<p>A) I am not a parent / carer</p> <p>Or</p> <p>I am able to fulfil my parenting / caring role without support</p>		
<p>B) I need occasional support with my parenting / caring role</p>		
<p>C) I need some support with my parenting / caring role (e.g. at least once a day)</p>		
<p>D) I often need support with my parenting / caring role (e.g. at least twice a day)</p>		
<p>E) I frequently need support with my parenting / caring role (e.g. several times a day)</p>		

7. Running and maintaining my home

This part is about the support I need to manage day to day tasks e.g. housework, shopping, gardening, routine maintenance and paying bills

Outcome: I am able to run and maintain my home	My view	Assessors View
A) I am able to run and maintain my home without support		
B) I need occasional support to run and maintain my home		
C) I often need support to run and maintain my home (e.g. at least once a week)		
D) I frequently need support to run and maintain my home (e.g. several times each week)		
E) I regularly need support in all aspects to do with running and maintaining my home		

8. Having work and learning opportunities

This part is about working and learning. The work may include voluntary work or paid work that I choose to do. This part is also about learning opportunities at a local college or community centre or anywhere else I choose to attend

Outcome: I am able to have work and learning opportunities if I choose to	My view	Assessors View
A) I do not require support with work or learning opportunities currently		
B) I need occasional support to work or learn or both (e.g. once a week)		
C) I often need support to work or learn or both (e.g. several times each week)		
D) I would like to work or learn or both and regularly need support to do this. (e.g. daily or several times each day)		

9.1 Managing my actions

This part is about how my actions may affect other people and the support I might need to manage this. It can be about forgetfulness, lack of understanding, or any other factors that may have an impact on the safety of others.

Outcome: I am able to manage my actions	My view	Assessors View
A) I do not need any support with this		
B) I need occasional support to help me to manage my actions		
C) I often need support to help me manage my actions		
D) I always need support to help me manage my actions		

9.2 Managing my actions (day and/or night and support)

If you have answered B, C or D above, please indicate when you need support. Please select either day or night, or both.

	My view		Assessors View	
	During the day	During the night	During the day	During the night
A) I need support to help me manage my actions ...				

10.1 Informal support

This part is about the support I get which is unpaid – for example from family, friends and neighbours

Outcome: I am able to draw on support from friends and family without placing an undue burden on them	My view	Assessors View
I have family members or friends who provide unpaid support	Yes / No	Yes / No

10.2 Informal support (continued)

If you answered yes above, please choose one of the following options:

	My view	Assessors View
A) My family and friends can provide all of the support I need		
B) I am able to get much of the support I need from family and friends and have or need occasional paid support		
C) I am able to get only some of the support I need from family and friends and need significant paid support.		
D) I get little support from family or friends		

11.1 Family carer and informal support

This part is for an unpaid carer (this is often a family member or close friend) who is currently providing informal support. Please tell us how providing this support affects your life.

	My view	Assessors View
A) It causes me no concern in my daily life		
B) It causes some concern and has some effect on my daily life		
C) It causes significant concern and has a significant impact on my daily life		
D) It has a critical impact on my daily life and affects my health and well-being.		

11.2 Family carer and social support (continued)

You have the right to a carer's assessment. This is a chance to talk about these issues and find out what support is available.

A) I would like to receive a carer's assessment.	
B) I don't want a carers assessment	
C) I have already had a carer's assessment	

12. Signatures

My comments	
My signature	

Assessors comments	
Assessors signature	

Common resource allocation framework
Questionnaire scoring sheet

<p><u>Question 1: Meeting Personal Care Needs</u></p> <p>A = 0, B = 3, C = 5, D = 8, E = 13</p> <p>A (During the day) = 0. A (During the night) = 3 B (During the day) = 6. B (During the night) = 9</p>	<p><u>Question 7: Running and maintaining my home</u></p> <p>A = 0, B = 1, C = 3, D = 4, E = 6</p>
<p><u>Question 2 Keeping Myself Safe</u></p> <p>A = 0, B = 4, C = 7, D = 13</p> <p>A (During the day) = 0. A (During the night) = 4</p>	<p><u>Question 8: Having work and learning opportunities</u></p> <p>A = 0, B = 1, C = 2, D = 5</p>
<p><u>Question 3 Eating and Drinking</u></p> <p>A = 0, B = 6, C = 10</p>	<p><u>Question 9: Managing my Actions</u></p> <p>A = 0, B = 3, C = 7, D = 12</p> <p>A (During the day) = 0. A (During the night) = 4</p>

<p><u>Question 4: Making Decisions and organising my life</u></p> <p>A = 0, B = 2, C = 4, D = 8</p>	<p><u>Questions 10 and 11 : Informal support</u></p> <p>Multiply the indicative allocation by the figure in the table below (0% = no allocation, 100% = full allocation)</p>																																										
<p><u>Question 5: Being part of my community</u></p> <p>A = 0, B = 2, C = 4, D = 5, E = 6</p>	<table border="1"> <thead> <tr> <th colspan="2"></th> <th>Q11:</th> <th>A</th> <th>B</th> <th>C</th> <th>D</th> </tr> </thead> <tbody> <tr> <td rowspan="5">Q10</td> <td>A</td> <td></td> <td>0%</td> <td>40%</td> <td>70%</td> <td>100%</td> </tr> <tr> <td>B</td> <td></td> <td>40%</td> <td>40%</td> <td>70%</td> <td>100%</td> </tr> <tr> <td>C</td> <td></td> <td>70%</td> <td>70%</td> <td>70%</td> <td>100%</td> </tr> <tr> <td>D</td> <td></td> <td>100%</td> <td>100%</td> <td>100%</td> <td>100%</td> </tr> <tr> <td>No unpaid support</td> <td></td> <td colspan="4">100%</td> </tr> </tbody> </table>							Q11:	A	B	C	D	Q10	A		0%	40%	70%	100%	B		40%	40%	70%	100%	C		70%	70%	70%	100%	D		100%	100%	100%	100%	No unpaid support		100%			
		Q11:	A	B	C	D																																					
Q10	A		0%	40%	70%	100%																																					
	B		40%	40%	70%	100%																																					
	C		70%	70%	70%	100%																																					
	D		100%	100%	100%	100%																																					
	No unpaid support		100%																																								
<p><u>Question 6: My role as a parent or carer</u></p> <p>A = 0, B = 2, C = 5, D = 7, E = 10</p>																																											

Community Care Assessment

Contact Details

Title First Name Middle Initial Last/Family Name

Name

NHS Number

Social Care Number

Date of Birth

Gender

Home Address

House No. and Street

Area

Town / City

Postcode

Telephone Number

Mobile Number

Emergency Contact

Tel. Number

Current Address (if different from above)

House No. and Street

Area

Town / City

Postcode

Telephone Number

Mobile Number

Emergency Contact

Tel. Number

Where person is living at time of referral

The person's permanent home at time of referral

Type of accommodation

Tenure of accommodation

Who person lived with at referral

Date of Contact

Date of Assessment

Version 1.1

Issue No2

Personal Details

Religion

Marital Status

Current / Previous Occupation

First Language

Age of leaving full time education

Employment status

Ethnic Origin

White Ethnic Group Asian or Asian British Ethnic Group Black or British Ethnic Group Chinese or other Ethnic Group

Other

Main Carer Details

Title	First Name	Middle Initial	Last/Family Name
-------	------------	----------------	------------------

Name

Address

House No. and Street

Area

Town / City

Postcode

Telephone Number

Mobile Number

GP Details

GP Name

House No. and Street

Area

Town / City

Postcode

Version 1.1

Issue No2

Telephone Number

Mobile Number

Your Current Situation

In your own words please tell us why you or your representative contacted social services

How does this matter impact on your life & that of others close to you?

How long has this been affecting you?

What do you think would help you &/or those close to you?

Do you have any other matters causing you difficulty at the moment?

Has anything in your life changed recently?

What do your family, or people who may care for you, think of your current situation?

Please give details of permanent or long-standing diagnosed physical and mental health conditions or disabilities.

[Redacted]

1. Memory and Making Decisions

B1.a I have problems with short-term memory – I can not remember to do important things or things that happened recently but I can usually remember things in the past Yes No

[Redacted]

B1.b I have problems doing things in the right order. This makes it difficult for me to undertake my daily activities in a safe way without assistance/prompting

[Redacted]

Please tick the phrase which best describes you. Select One

B2.a.0 I am able to make appropriate, safe & realistic decisions

B2.a.1 In new or unfamiliar situations I find it hard to make decisions

B2.a.2 I can make most day to day decisions but need periodic prompting throughout the day

B2.a.3 I need assistance to make even the simplest day to day decisions and plans. Decisions are consistently poor or unsafe & support is needed at all times

B2.a.4 I very rarely/never make decisions

If you, or your carers, have any additional comments please make a note here

[Redacted]

2. Communication

Please tick the phrase which best describes you

Select One

- C2.0 I can chat to people and express my ideas/thoughts easily
- C2.1 I sometimes have problems finding the right word, but given a bit of time I'm fine
- C2.2 I have difficulty finding the right words and need prompting
- C2.3 Expressing myself is difficult, but I can let people know my basic needs, I use gestures and signing to help with communication
- C2.4 I can not make myself understood &/ or use assistive technology to communicate with people

Please tick the phrase which best describes you

Select One

- C3.0 I can understand what people are saying to me
- C3.1 I can usually understand what is said to me
- C3.2 With help I can understand what is said to me
- C3.3 I can understand if sentences are kept short and simple
- C3.4 I do not understand what is said to me

If you, or your carers, have any additional information please make a note here

3. Vision (ability to see with glasses – if worn)

Please tick the phrase which best describes you during the past 3 days

Select One

- D1.0 I can see to read standard print in newspapers and books
- D1.1 I can see to read large print books and headlines in newspapers
- D1.2 I am not able to see newspaper headlines but I can identify objects
- D1.3 I struggle to make out objects but can follow movements
- D1.4 I can only distinguish light, colours & shapes

[Redacted]

4. Feelings & Behaviour

Please tick the phrases which best describe how you have felt & how often you felt like this

No Occasionaly Everyday

E1.a I feel sad or low in mood

E1.c I get easily annoyed/angry/cross with myself & other people

E1.b People think I can have unrealistic fears about things

E1.d I think I need more help from doctors & nurses than I am getting at the moment

E1.e I feel anxious & need reassurance. I have to keep asking when things are going to happen or what's happening next

E1.f People are concerned that I look unhappy or worried

E1.g I cry or feel tearful

[Redacted]

E1.j I have trouble sleeping &/ or have disturbed nights

[Redacted]

Please tick the phrases which best describes you have been behaving recently

No Yes Yes
 Easily Difficult
 Control Control

E3.a I have been found wandering about for no apparent reason, or, I can suddenly 'bolt' & run away

[Redacted]

E3.c I have been shouting at people

[Redacted]

E3.b I have been hitting out at people and aggressive towards others or harming myself

[Redacted]

E3.d I have been told my behaviour in public has been causing concern and is thought to be inappropriate

[Redacted]

E3.e I have been resisting care

[Redacted]

E4.0&1 My family & /or carers think that my behaviour is getting worse

[Redacted]

If you, or your carers, have any additional comments please make a note here

5. Social Functioning (includes work, voluntary and leisure activities)

Please tick the statement which best describes you

Select One

F2.0 I am taking part in my usual work/voluntary/religious and/or social activities

F2.2 I am not involved in as much work/voluntary/religious/social activity as I used to be but it doesn't bother me.

F2.1 I am not involved in as much work/voluntary/religious/social activity as I used to be and this upsets me.

Time by Yourself

Please tick the statements which best describe you

F3.0 I am hardly ever alone during the day

F3.a.1 I'm usually alone for about an hour during the day

F3.a.2 I'm often alone for long periods of time during the day

F3.a.3 I am alone all day

F3.b.0 I do not feel lonely

F3.b.1 I feel lonely

If you, or your carers, have any additional comments please make a note here

[Empty box]

6. Cooking and Preparing Food (e.g. how meals are prepared, planning meals, cooking, assembling ingredients, setting the table & serving food)

Please tick the phrase which best describes you

- H1.a.a.0 I prepared all my own meals Select One
- H1.a.a.1 I had help preparing some of my meals
- H1.a.a.2 someone helped me to prepare all my meals
- H1.a.a.3 someone else prepared my meals
- H1.a.a.8 No meals were prepared

If you had to prepare a meal by yourself how difficult would it be? Easy Some Great

 Difficulty Difficulty

H1.b.a.0 H1.b.a.1 H1.b.a.2

[Empty box]

Eating

- L1.a I have a normal diet & can swallow my food easily Yes No
- L1.c I eat food which is easy to chew and swallow
- L2.a My food is pureed and drinks are thickened to help me swallow them
- L2.b I take some food by mouth and some via a tube
- L2.c In the last 3 days, I have had very little to drink

[Empty box]

7. Housework (how day to day housework is performed, e.g. doing the dishes, dusting, vacuuming, making bed, tidying up, laundry)

Please tick the phrase which best describes you

- H1.a.b.0 I did all my own housework Select One
- H1.a.b.1 I had some help doing the housework

H1.a.b.2 I had a lot of help doing the housework

H1.a.b.3 someone else did all the housework

H1.a.b.8 No housework was done

If you had to do the housework by yourself how difficult would it be?

Easy

Some
Difficulty

Great
Difficulty

H1.b.b.0 H1.b.b.1 H1.b.b.2

8. Managing Money (how bills are paid and household bills and bank account balanced)

Please tick the phrase which best describes you

Select One

H1.a.c.0 I am able to manage my own money

H1.a.c.1 I had some help managing my money

H1.a.c.2 I had a lot of help managing my money

H1.a.c.3 someone else managed my money for me

H1.a.c.8 No money was used or household bills paid

If you had to manage money by yourself how difficult would it be?

Easy

Some
Difficulty

Great
Difficulty

H1.b.c.0 H1.b.c.1 H1.b.c.2

9. Shopping (how shopping is undertaken i.e. selecting and paying for items)

Please tick the phrase which best describes you

Select One

H1.a.f.0 I did all my own shopping

H1.a.f.1 I had some help doing the shopping

H1.a.f.2 I had a lot of help with the shopping

H1.a.f.3 someone else did the shopping

H1.a.f.8 No shopping was done

If you had to do the shopping by yourself how difficult would it be?

Easy

Some
Difficulty

Great
Difficulty

H1.b.f.0 H1.b.f.1 H1.b.f.2

10. Transport (how you get to places beyond walking distance)

Please tick the phrase which best describes you

Select One

- H1.a.g.0 I am able to get out and about by myself
- H1.a.g.1 I had some help to enable me to go out
- H1.a.g.2 I had help from someone every time I went out
- H1.a.g.3 other people organise my transport & getting from place to place
- H1.a.g.8 I did not go out

If you had to go out by yourself how difficult would it be?

Easy Some Difficulty Great Difficulty

H1.b.g.0 H1.b.g.1 H1.b.g.2

11. Managing your Medication (e.g. Opening Pill bottles and administering injections etc)

Please tick the phrase which best describes you

Select One

- H1.a.d.0 I am able to take my own medicine
- H1.a.d.1 I had some help with my medicine
- H1.a.d.2 I had a lot of help to prepare & take my medicine
- H1.a.d.3 someone else got my medicines ready for me and told me when to take them
- H1.a.d.8 I did not take any medicine

If you had to take your medicine by yourself how difficult would it be?

Easy Some Difficulty Great Difficulty

H1.b.d.0 H1.b.d.1 H1.b.d.2

12. Access to work, Education and Learning

Please select the phrase which best describes you

Select One

- I am unable to work / do not wish to work / I am retired
- I am able to work and / or learn if I choose without any support
- I need occasional support to work or learn or both
- I need support several times each week to work or learn or both
- I would like to work/learn regularly but without constant support I would not be able to do this

If you, or your carers, or your social worker have any additional comments please make a note here

--

13. Personal Care & mobility

The next section is probably the most detailed and hardest section to complete. Please take your time and consider your answers carefully.

Think about the activities below labelled A-J. Use one of the following 8 phrases (0 – 8) to describe how much support you were given to undertake the activity

0	Independent , I need minimal help occasionally
1	Set-up help only , for example, clothes laid out on the bed, equipment placed within easy reach
2	Supervision , encouragement and/or very little physical assistance
3	Some assistance , I can do most things by myself but I need some physical assistance from another person on a daily basis
4	Extensive assistance , I can do some things by myself but I need a lot of physical assistance on a daily basis
5	Maximum assistance , I can do a few things by myself but I need a lot of physical assistance from 2 people on a daily basis
6	Totally dependent on others
8	Activity did not occur

EXAMPLE: if you always need someone to put your trousers on for you but you can do up the zip then you would score as follows:

F	Dressing Lower body, i.e. below the waist	4
A	Moving about in bed, i.e. turning from side to side, sitting up and lying down	
B	Moving to and between places, i.e. bed, chair, wheelchair	
C	Moving about inside the house	
D	Moving about outside the house	
E	Dressing upper body, i.e. above the waist	
F	Dressing lower body, i.e. below the waist	

H	Using the toilet, commode or urinal	
I	Personal hygiene, including combing hair, brushing teeth, shaving, applying make-up, washing/drying face and hands	

14. Falls

K6 I am unsteady on my feet and in danger of falling over Yes No

If you, or your carers, have any additional comments please make a note here

15. Caring for Yourself

H3 I am finding it difficult to care for myself Yes No

Support you give to others

Please select the phrase which best describes you Select One

I am able to fulfil my parenting/caring role without support, or I am not a parent or carer	<input type="checkbox"/>
I need minimal help with my parenting/caring role	<input type="checkbox"/>
I need a moderate amount of help to fulfil my parenting/caring role	<input type="checkbox"/>
I need a substantial amount of help to fulfil my parenting/caring role	<input type="checkbox"/>

16. Support

Family carer and informal Support (i.e. help/support not paid for)

Please give details below of your two main carers. If you do not have any carers please tick the box 'no such carer'.

We also need to know if your carers would be able to increase the amount of support they give you. Tick the box below to indicate if they could give you more help.

My main carer is

G1.A.a&b Name Title First Name Middle Initial Last/Family Name

G1.ea.0 My main carer lives with me No Yes No Such Carer

G1.ka.0 My carer is able to increase the amount of help they No 1-2hrs 2hrs +

give me with day to day tasks such as preparing meals,
Housework, Shopping

G1.1a.0 My carer is able to increase the amount of help they
give me with my personal care, e.g. getting in & out of bed,
washing & dressing

My other important Carer is

G1.B.c&d Name Title First Name Middle Initial Last/Family Name

G1.eb.0 My main carer lives with me No Yes No Such Carer

G1.kb.0 My carer is able to increase the amount of help they
give me with day to day tasks such as preparing meals,
Housework, Shopping

No 1-2hrs 2hrs+

G1.lb.0 My carer is able to increase the amount of help they
give me with my personal care, e.g. getting in & out of bed,
washing & dressing

Carer Support

G2.a.0&1 My carer(s) is/are able to sustain the current levels of care Yes No

G2.b.0&1 My main carer is showing signs of exhaustion/distress/anger/frustration

G2.c.0&1 None of the above statements apply

G2.d.0&1 Would your carer like a Carers Assessment

The next section is to be completed by you & your main carer. This covers support which is not paid for and which can continue to be provided without placing an undue burden on family &/or friends.

	Help Provided?		Approximately how often?
	Yes	No	
Shopping	<input type="checkbox"/>	<input type="checkbox"/>	
Cooking & preparing food	<input type="checkbox"/>	<input type="checkbox"/>	
Eating	<input type="checkbox"/>	<input type="checkbox"/>	

Communicating	<input type="checkbox"/>	<input type="checkbox"/>	
Going out to social activities, work or study	<input type="checkbox"/>	<input type="checkbox"/>	
Making decisions	<input type="checkbox"/>	<input type="checkbox"/>	
Reminding/prompting the person to do things	<input type="checkbox"/>	<input type="checkbox"/>	
Personal care (washing, dressing, going to the toilet)	<input type="checkbox"/>	<input type="checkbox"/>	
Housework	<input type="checkbox"/>	<input type="checkbox"/>	
Managing Money	<input type="checkbox"/>	<input type="checkbox"/>	
Other activities (please give details)			

Taking in to consideration the information given above would you say the person will get:

- Nearly all the help needed (approx. 80%) from family and friends
- Most of the help needed (approx 60%) from family and friends
- Some of the help needed (approx 40%) family and friends
- Little or no help (less than 40%) from family and friends

Formal Care Services

Please tick if you have been visited by any of the professional staff listed below or used any of the services listed below



Number of Visits
Per Week

P1.a	Home Carers / P.A.'s	<input type="checkbox"/>	
P1.b	District Nurses / MacMillan Nurse	<input type="checkbox"/>	
P1.c	Community Mental Health Nurse / Community Learning Disabilities Nurse	<input type="checkbox"/>	
P1.f	Physiotherapists	<input type="checkbox"/>	
P1.g	Occupational Therapist	<input type="checkbox"/>	
P1.h	Speech & Language Therapists	<input type="checkbox"/>	
P1.j	Social Care Worker	<input type="checkbox"/>	
P1.i	Day Care Services	<input type="checkbox"/>	
P1.e	Voluntary Services	<input type="checkbox"/>	
P1.d	Hot Meals	<input type="checkbox"/>	

Professionals Involved

Name:

Title:

Organisation:

Tel no:

E-mail:

Name:

Title:

Organisation:

Tel no:

E-mail:

Name:

Title:

Organisation:

Tel no:

E-mail:

17. Recording Your Information

How did you complete this form? Please tick

- A. I completed it myself
- B. I answered the questions with the help of someone else
- C. Someone else filled in the form for me

If you ticked B or C, please state who helped you:

Signed

Date

Signature of person completing form (if appropriate)

Signed

Date

Signature of Social Worker

Signed

Date

18. Consent for Information Storage and Information Sharing

I understand the information that is recorded in this form. I understand that the information will be stored and used for the purpose of providing services to me.

I also understand that you may need to share this information with professionals in other organisations, such as health services, housing services or voluntary organisations, to make sure that I can get the help I need.

I am giving you my permission to share the information in this form for this purpose, and I understand that I can take away my permission at any time. I am aware that I can say if there is any particular organization, or person, that I do not want to see my information, and that you will not share this information without me knowing about this or agreeing to this.

Signed

Date

I have filled in this form on behalf of another person; I can confirm that they are aware that I have done so on their behalf and that they have agreed to this. They are also aware that you may share the information I have provided with other professionals, who may be involved in providing the help they need.

Signed

Print Name

Relationship to Person

Date

19 Statement of Eligibility

Whenever Community Services assess your needs they must provide you with a statement of whether your needs will be met, with your agreement, from other sources. Some needs cannot be met by the Council because they are the legal responsibility of others. 'Within those areas where it has the power to act, the Council has determined that 'critical' and 'substantial' needs are eligible to be met from Council resources (see table overleaf for more detail). If you have needs that are not 'eligible', the worker who carried out your assessment will try to assist you in finding help from other sources.

If you don't understand this, please talk to the worker who carried out your assessment of need.

Assessed Area of Need	FACS degree of risk	Eligibility	Description of Need & Action Taken

Any other comments

Assessed by

Date

If eligible Care Manager Contact Details:

House No. and Street

Area

Town / City

Postcode

Telephone Number

Mobile Number

Copy of Eligibility Statement sent to

Date Sent

Version 1.1

Issue No2

Eligibility Criteria

Community Services Eligibility Criteria. Social Care needs within the shaded boxes will normally be met by [redacted] within our legal powers and duties. A charge may be made for Services.

Definitions of Levels of Risk	Health and/or Safety Issues	Personal and Daily Routines	Family and Community Life	Carers
Critical Immediate risk of major harm / danger to yourself or others or major risks to independence now or in the next few days.	You have major health problems, which cause immediate life threatening harm or danger to yourself or others.	You are unable to carry out vital personal care or domestic routines.	You are unable to sustain vital family or social roles and responsibilities.	Your carer is unable to carry out vital or most aspects of your personal family or domestic routines due to major change in their personal circumstances.
	Serious abuse or neglect has occurred or is strongly suspected and you require intervention.	You have an extensive / complete loss of choice and control over vital aspects of your home environment.	You are unable to sustain vital involvement in work, education or learning.	
Substantial The risk of significant impairment to the health and well being of yourself or others or significant risk to independence now or within 3 months.	You have significant health problems which cause significant risks of harm or danger to yourself or others.	You are unable to carry out the majority of personal care or domestic routines.	You are unable to sustain the majority of family and other social roles and responsibilities.	Your carer is unable to carry out many aspects of personal, family or domestic routines.
	Abuse or neglect has occurred or is strongly suspected.	You have significant loss of choice and control managing your home environment.	You are unable to sustain many aspects of work, education or learning.	
Moderate The risk of some impairment to the health and well being of yourself or others, some risk to independence now or within 12 months.	You have some health problems, which may be intermittent indicating some risks to your independence.	You are unable to carry out some personal care or domestic routines.	You are unable to manage some aspects of family and social roles and responsibilities.	Your carer is unable to manage some aspects of the caring, family or domestic routines.
		You are unable to manage some aspects of your home environment.	You are unable to sustain some aspects of work, education or learning.	
Low There is little or low risk to independence.	You have a few health problems indicating low risks to your independence.	You have difficulty with one or two aspects of your personal care, domestic routines or home environment.	You have difficulty undertaking one or two aspects of family or social networks, work learning or education.	Your carer has difficulty undertaking one or two aspects of their caring or domestic role.