

**REALISING SUPPORTED DECISION-MAKING IN THE
CONTEXT OF DEMENTIA AND TREATMENT DECISIONS:
INTERNATIONAL PRINCIPLES AND INITIATIVES FROM
EUROPE**

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Abstract

The thesis analyses how to create better conditions for people living with dementia to exercise their right to choose on medical treatment. It starts from the numerous barriers faced by these individuals in deciding on healthcare matters and seeks to study how a legal, policy and practice approach to healthcare decision-making, characterised by a stronger focus on support and on accommodating contextual dynamics would better enable the person to decide for themselves.

In addressing such a question, this work adopts the perspective of the social model of disability and of Fineman's vulnerability theory. The social model looks at disability and chronic conditions as social, rather than just clinical problems, conceptualising them in terms of interaction between an impairment and societal barriers. In this regard, it focuses on removing the societal obstacles preventing the person from living their life to the fullest. Fineman's vulnerability theory supports and extends such claims in relation to legal personality and the role of the state. Starting from a vision of vulnerability as a universal characteristic, it argues that it makes no sense to distinguish between autonomous/nonautonomous or capable/incapable individuals and advocates for state and social institutions to take action in providing the services necessary for people to be more resilient to internal and external jeopardies. Starting from this perspective this work argues that the numerous obstacles faced by individuals living with dementia in choosing on medical treatment can be overcome or greatly attenuated if we adopt a model of healthcare decision-making which makes use of social institution's potential for building resilience and removing disabling barriers.

Such a model appears embodied by Article 12 UN Convention on the Rights of Persons with Disabilities. Indeed, this Article affirms that all disabled individuals must be recognised the right to legal capacity and decision-making, refusing the traditional distinction between capacity and incapacity and requiring State Parties to actively support disabled individuals in exercising their right to choose. The thesis analyses the implications of such provisions with regard to treatment decisions of people living with dementia, by studying how European regional organisations such as the Council of Europe and the European Union, can contribute to the practical realisation of such principles, and how promising initiatives developed in single European countries can provide an idea on how they can translate into concrete behaviours and practices.

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CHAPTER 1

Introduction

1. Research problem and its importance

This thesis aims to analyse how to create better conditions for people living with dementia to exercise their right to choose on medical treatment. It starts from the numerous barriers faced by these individuals in this area and seeks to study how a legal, policy and practice approach to healthcare decision-making, characterised by a stronger focus on support and accommodating contextual dynamics, would better enable the person to decide for themselves. Indeed, because of their impairment, individuals living with dementia are often judged as mentally incapable to make choices on medical treatment and thus deprived of their decisional power.¹ However, as shown by a number of studies and experiential accounts, often what really prevents them from expressing their will is not so much the conditions of their brain, but rather the fact that the current approach to consent to treatment does not take into account the needs of individuals living with dementia.² In order to explore how this system can be changed, this thesis analyses relevant initiatives put in place in the European continent and developed by international, regional and national actors.

The problem at the centre of this study is of increasing importance in today's health law and policy. The World Health Organisation (WHO) estimates that dementia currently affects round 50 million people worldwide,³ of which, according to Alzheimer's Disease International, around 10.5 million live in Europe,⁴ with 850.000 based in the UK.⁵ They are 90-98% older individuals (over 65 years of age) as there is

¹ L Pickering Francis, 'Decision-making at the End of Life: Patients with Alzheimer's or other Dementias' (2001) 35 *Georgia Law Review* 539, 542; T Mueller et al, 'Comparison of Three Different Assessments of Capacity to Consent in Dementia Patients' (2015) 28 *GeroPsych* 21. See further Section 3 of this Chapter and Chapter 2.

² TM Breden and J Vollman, 'The Cognitive Based approach of Capacity Assessment in Psychiatry: a philosophical critique of the MacCAT-T' (2004) 12 *Health Care Analysis* 273, 278-279; F Cowdell, 'The Care of Older People with Dementia in Acute Hospitals' (2010) 5 *International Journal of Older People Nursing* 83, 86-87 < <https://pdfs.semanticscholar.org/f2a7/f8e1ff4f0e8d012a6f79c87c203cc9c02c56.pdf>> accessed 24 April 2018.

³ WHO, 'Dementia. Key Facts' (12 December 2017) <www.who.int/news-room/fact-sheets/detail/dementia> accessed 31 May 2018.

⁴ M Prince et al, *World Alzheimer Report 2015. The Global Impact of Dementia* (Alzheimer's Disease International 2015), 24.

⁵ Alzheimer's Society, *Dementia UK Updated* (Alzheimer's Society 2014), 43-59.

a strong correlation between aging and dementia.⁶ Focusing on Europe, it is calculated that the condition affects around 1.5-2.5% of the population aged 60-69, 3-7% of that aged 70-79, around 8.5-20.5% of that aged 80-89, and about 30-40% of that aged above 90, with a consistently lower prevalence in Eastern Europe compared to Western Europe.⁷ Also due to their advanced age, these individuals are constantly in need of medical procedures, therefore collecting their consent to treatment is a frequent task for many medical professionals and carers.⁸ Therefore, the questions of how to manage the healthcare arrangements of people living with dementia and of how to guarantee their dignity and autonomy in this context is increasingly at the centre of the attention of scholars, professionals and governments in the western world.⁹

This introductory chapter provides basic information necessary to put the research problem in context, such as basic medical, epidemiological and demographic notions relating to dementia and background information with regard to consent to treatment of people living with cognitive impairments. Moreover, it provides an explanation of the aim, scope, methodology, and structure of the study. Section 2 contains an overview of what dementia is and its main subtypes and symptoms, while section 3 sets the scene of the research, explaining the relevance and scope of questions regarding consent on medical treatment for people living with dementia. Section 4 summarises the aims and research question of this work and clarifies its theoretical premises, evaluative framework, and methodology. Section 5 details the structure of the work and provides a brief outline of the thesis chapters.

2. Dementia: subtypes and symptoms

Before considering the specific issues at the centre of this thesis, it is useful to have an overview of the main subtypes and the specific symptoms of dementia. The clinical nature of dementia and its impact on the cognitive abilities and behaviour of the person play a significant role in determining how society reacts to such dynamics and how decision-making on medical treatment is performed in this area.

⁶ OECD, *Addressing Dementia: The OECD Response* (OECD Publishing 2015), 20.

⁷ Prince et al, *World Alzheimer Report 2015*, above, 20.

⁸ For more information on the relevance of the problem see section 3 of this Chapter.

⁹ A sign of this centrality in the public debate is that nearly all European governments and both the two major regional organisations of the continent (the EU and the Council of Europe) have established multi-year dementia strategies. I will refer to some of these plans in Chapter 7.

Dementia is an umbrella term which refers to several types of conditions that affect the cognitive functioning of an individual. Such conditions are characterised by a significant decline in one or multiple cognitive domains such as learning and memory, language, executive functioning, complex attention, perceptual-motor, and social cognition. The deficit must interfere with independence in everyday activities, not occur exclusively in the context of delirium, and cannot be explained by the presence of other mental health disorders.¹⁰ Moreover, dementia may provoke changes of personality and opinions and challenging behaviour such as agitation, restlessness, aggressiveness, non-cooperative attitude, or apathy.¹¹

According to Kaufer and DeKosky, the various subtypes of dementia can broadly be divided into two categories: degenerative and non-degenerative dementias.¹² While non-degenerative dementias represent a heterogeneous group of conditions, with aetiologies varying from vascular and endocrine to inflammatory and nutritional,¹³ the processes involved in degenerative dementias are intrinsic to the nervous system and dependent on chemical alterations, the deterioration of synaptic processes, and atrophic phenomena.¹⁴ Examples of non-degenerative dementias include vascular dementia, infectious dementia, posttraumatic dementia, and demyelinating disorders,¹⁵ while the main examples of degenerative dementia are Alzheimer's disease and Dementia with Lewy bodies.¹⁶ So, under the common umbrella term various pathologies can be included with combinations of symptoms quite different from one another and the way in which the condition is experienced varies from person to person. For this reason, in the latest edition of the American Psychiatric Association Diagnostic Statistical Manual (DSM-5) the expression 'dementia' has been substituted by 'major neurocognitive disorder'.¹⁷ However, the term is still widely used both in medical and public discourse, generally designating an acquired, persistent syndrome

¹⁰ American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders* (5th ed, APA 2013), 602-605.

¹¹ Ash, EL Ash, 'What is Dementia?' in C Foster, J Herring and I Doron (eds), *The Law and Ethics of Dementia* (Hart 2014), 4.

¹² D Kaufer and S DeKosky, 'Diagnostic Classifications: relationships to the Neurobiology of Dementia' in EJ Nestler (ed), *Neurobiology of Mental Illness* (Oxford University Press 1999).

¹³ EP Flanagan, 'Nondegenerative Dementias and Encephalopathies' in KD Flemming and LK Jones (eds), *Mayo Clinic Neurology Board Review: Clinical Neurology for Initial Certification and MOC* (Oxford University Press 2015).

¹⁴ American Psychiatric Association, *above*, 608-609.

¹⁵ Flanagan, *above*.

¹⁶ See further below.

¹⁷ American Psychiatric Association, *above*, 602.

or cognitive impairment often but not always linked to increasing age and generally referring to widespread forms such as Alzheimer's disease, vascular dementia or dementia with Lewy-bodies.¹⁸ Also in this study the term dementia is used in this sense.

Alzheimer's disease and Dementia with Lewy bodies are the most prominent examples of degenerative dementia conditions.¹⁹ Alzheimer's is supposedly caused by the production of a toxic protein in the brain (amyloid β or τ protein), which creates fibrous masses impeding synapses among neurons.²⁰ The onset of Alzheimer's disease is most commonly characterised by an impaired ability to form new memories (which includes short term memory loss, difficulties with learning, and episodic memory) and decreasing visual memory.²¹ A person with these problems may struggle with remembering tasks and decisions in everyday life, forget appointments, and be confused by planning changes.²² The presence of these symptoms alone, however, is not sufficient. For the diagnosis of Alzheimer's disease to be defined in practice, the person has to have additional deficiencies in several functional domains, such as language, executive function, praxis, visuospatial, or constructional capacities.²³ One of the most frequent secondary deficiencies in people living with Alzheimer's Disease is difficulty in word-finding.²⁴ Regarding the onset and progression of the condition, each case is relatively unique, though it is usual to speak about two types of Alzheimer's: early and late onset.²⁵ The former type affects people under the age of 60-65 while the second and most prevalent affects people above that age. They are not only different in the time of the first symptoms appearing, but also have a distinct progression, with early onset having a stronger negative impact on attention and executive functioning as well as a quicker deterioration of short-term memory.²⁶ The

¹⁸ See Ash, *above*, 8-10.

¹⁹ American Psychiatric Association, *above*, 602.

²⁰ See CL Masters, 'The Neuropathology of Alzheimer's Disease' and CW Ritchie and CL Masters, 'The Central role of A β amyloid and tau in the Pathogenesis of Alzheimer's Disease' both in D Ames, JT O'Brien and A. Burns (eds), *Dementia* (5th ed, CRC Press 2016).

²¹ American Psychiatric Association, *above*, 607-608.

²² *Ibid.*

²³ *Ibid.*

²⁴ A Martin and P Fedio, 'Word Production and Comprehension in Alzheimer's Disease: The breakdown of semantic knowledge' (1983) 19 *Brain and Language* 124.

²⁵ MN Rossor et al, 'Neurochemical Characteristics of Early and Late onset types of Alzheimer's Disease' (1984) 288 *British Medical Journal* 961.

²⁶ Martin and Fedio, *above*.

late onset individuals show worse outcomes regarding their long-term memory and semantic abilities.²⁷

According to some sources, Dementia with Lewy bodies (DLB) can account for as much as 4.6% of all dementia cases.²⁸ It is caused by abnormal masses of alpha-synuclein protein in neurons, which impede synapses.²⁹ The principal areas of cognition affected by DLB include attention, executive functioning, and visual perception, the latter specifically including colour vision impairment.³⁰ The last aspect is the defining characteristic of Dementia with Lewy bodies in comparison with similar conditions such as Alzheimer's.³¹ Other differences between these two conditions include gender prevalence (with Dementia with Lewy bodies being more prevalent and aggressive in men), significantly shorter course of the diseases and prominent presence of other neurological signs such as Parkinsonism (tremors).³²

The other major category of dementias is vascular dementia. The term is used to describe a broad range of problems including reasoning, attention, planning, and general judgement due to obstructed flow of blood to the brain.³³ One of the more prominent examples of the group is Binswanger's disease, a small vessel vascular dementia caused by damages to the white matter areas (responsible for the transmission of impulses and communication between the various areas of the brain).³⁴ Despite the fact that the condition is classified under the dementia umbrella, mood changes and neurological signs are the earliest symptoms of the condition rather than cognitive deficits.³⁵ Binswanger's Disease is characterised by manic phenomena, obsessions, and fixation on ritualistic behaviours which severely impact everyday functioning and eventually result in significant levels of personal neglect.³⁶ Aphasia

²⁷ *Ibid.*

²⁸ JP Kane et al, 'Clinical Prevalence of Lewy Body Dementia' (2018) 10 *Alzheimer's research and Therapy* 19.

²⁹ IG McKeith, 'Dementia with Lewy Bodies' (2007) 84 *Handbook of Clinical Neurology* 531.

³⁰ IG McKeith et al, 'Consensus Guidelines for the Clinical and Pathologic Diagnosis of Dementia with Lewy Bodies (DLB)' (2006) 47 *Neurology* 1113.

³¹ PM Flanigan, 'Color Vision Impairment in Dementia with Lewy Bodies: A Novel and Highly Specific Distinguishing Feature from Alzheimer Dementia' (2017) 13 *Alzheimer's and Dementia* 1460.

³² WW Barker et al, 'Relative Frequencies of Alzheimer Disease, Lewy Body, Vascular and Frontotemporal Dementia, and Hippocampal Sclerosis in the State of Florida Brain Bank' (2002) 16 *Alzheimer Disease and Associated Disorders*, 203.

³³ *Ibid.*

³⁴ V Babikian and AH Ropper, 'Binswanger's Disease: A Review' (1987) 18 *Stroke* 2.

³⁵ Barker et al, *above*.

³⁶ RM Lawrence, 'Is the Finding of Obsessional Behaviour Relevant to the Differential Diagnosis of Vascular Dementia of the Binswanger Type?' (2000) 12 *Behavioural Neurology* 149.

and psychomotor problems are also often observed in people living with Binswanger's Disease, while memory impairments are not very prominent.³⁷

3. Dementia and decisions on medical treatment

People living with dementia and medical treatment

People living with dementia are frequently in need of a number of medications and healthcare procedures.³⁸ One could say that medical treatment is an everyday component of their lives, having a considerable impact on their habits, daily activities, and management of relationships with others. Statistics on various western countries show that individuals living with this condition use healthcare services significantly more than others, generating even two or three times greater healthcare expenditure than the average individual in the same age category.³⁹ Also, according to the World Alzheimer's Report 2016, people living with dementia face a significantly higher probability of being admitted to the hospital than other individuals of similar age and medical infirmity.⁴⁰

This increased use of medications and health services is primarily related to the management of symptoms directly deriving from dementia. Many people living with this condition and in particular with Alzheimer's take anti-cholinesterase drugs such as Donepezil, Rivastigmine and Galantamine daily.⁴¹ These pharmacological treatments have the effect of attenuating memory loss or confusion but may cause nausea, diarrhoea, vomiting, anorexia, and weight loss.⁴² Moreover, individuals living with dementia may also be administered other medicines for the control of behavioural

³⁷ Barker et al, *above*.

³⁸ M Prince et al, *World Alzheimer Report 2016. Improving Healthcare for People Living with Dementia* (Alzheimer's Disease International 2016).

³⁹ RL Kane and A Atherly, 'Medicare Expenditures associated with Alzheimer Disease' (2000) 14 *Alzheimer Disease and Associated Disorders* 187; A Sicras et al, 'Prevalence, Resource Utilization and Costs of Vascular Dementia compared to Alzheimer's Dementia in a Population Setting' (2005) 19 *Dementia and Geriatric Cognitive Disorders* 305; TC Kuo, 'Implications of Comorbidity on Costs for Patients with Alzheimer Disease' (2008) 46 *Medical Care* 839, 841-845; L Schwarzkopf et al, 'Excess Costs of Dementia Disorders and the role of Age and Gender - an analysis of German Health and Long-Term Care Insurance Claims Data' (2012) 12 *BMC Health Services Research* 165.

⁴⁰ Prince et al, *World Alzheimer Report 2016, above*, 58-60.

⁴¹ For a brief summary see N Bregman and O Moore, 'Clinical Management of Dementia: an Overview (1)' and C Fox et al, 'Clinical Management of Dementia: an Overview (2)' both in Foster, Herring and Doron (eds), *above*, 46-50 and 69-73.

⁴² *Ibid.*

symptoms, such as antipsychotics,⁴³ which may again have significant side effects including drowsiness, tremors, accelerated cognitive decline, stroke, and increasing risk of death.⁴⁴ Both behavioural problems and cognitive deterioration can also be addressed through non-pharmacological interventions. These may consist of physical therapy or exercise, face-to-face or group psychotherapy, and various techniques of cognitive rehabilitation such as reminiscence therapy (i.e. triggering the recall of memories through a variety of stimuli), validation therapy (focusing on building sense confidence and self-respect), multi-sensory stimulation, speech therapy, music therapy, and support groups.⁴⁵ These interventions are less controversial and do not have the side effects of drugs, but still have an influence on the everyday life of people with dementia - occupying part of their time, putting them in potentially uncomfortable situations, imposing them to create human relationships they would not have cultivated otherwise, or to do activities they would have otherwise not done. Therefore, all forms of treatment cited so far can impact the personal freedom, lifestyle, or physical and mental integrity of the person, which are all fundamental interests which cannot be touched without authorisation of the person.

Also, dementia appears associated with a significant number of comorbidities (other physical or mental health conditions arising in coincidence with it).⁴⁶ In particular, the physical illnesses most frequently coinciding with dementia appear to be cardiovascular and cerebrovascular diseases, diabetes, fractures often related to falls, osteoporosis, various visual and auditory impairments, cancer, Parkinson's disease, renal conditions, prostatic hypertrophy, and skin ulcers; while the most prevalent psychiatric conditions are depression, bipolar, and delusional disorders.⁴⁷ The data on the prevalence rate of the various pathologies tend to vary from study to

⁴³ S Banerjee, 'The use of Antipsychotic Medication for People with Dementia: Time for action' (UK Department of Health 2009), available at <<http://psychrights.org/research/digest/nlps/banerjeereportongeriaticneurolepticuse.pdf>> accessed 27 May 2018.

⁴⁴ C Ballard and A Corbett, 'Management of Neuropsychiatric Symptoms in People with Dementia' (2010) 24 *CNS Drugs* 729; Bregman and Moore, *above*, 49-50; Fox et al, *above*, 74-75.

⁴⁵ Bregman and Moore, *above*, 50-56; Fox et al, *above*, 75-78.

⁴⁶ M Sanderson et al, 'Co-Morbidity associated with Dementia' (2002) 17 *American Journal of Alzheimer Disease and Other Dementias* 73; CC Schubert et al, 'Comorbidity Profile of Dementia Patients in Primary Care: are they Sicker?' (2006) 54 *Journal of American Geriatric Society* 104; F Bunn et al, 'Comorbidity and Dementia: a Scoping Review of the Literature' (2014) 12 *BMC Medicine* 192.

⁴⁷ Schubert et al, *above*, 106-108; Kuo, *above*, 843-844; B Poblador-Plou et al, 'Comorbidity of Dementia: a Cross-Sectional Study of Primary Care Older Patients' (2014) 14 *BMC Psychiatry* 84, 86-89.

study and in consideration of the different types of dementia and the social and geographical context of the survey. Nonetheless, they depict a landscape characterised by rather large numbers. Therefore, people with dementia are very likely to face at least one serious surgical intervention such as a heart operation, cancer surgery, hip replacement, removal of compromised organs such as kidneys, or eye surgery. Moreover, they may have to take medications such as chemotherapy, drugs for preventing high pressure, angina, blood clots, arrhythmia, and heart failure, insulin, diuretics, or again antipsychotic medications. These are all treatments that can be invasive or present significant side effects, ranging from confusion, blurred vision, dizziness, or fainting to fatigue, anaemia, appetite changes, nausea and vomiting, increased risk of falls, difficulty urinating, or diminished cognition.⁴⁸ Such adverse effects may also be due to the interaction of different medications.⁴⁹ Finally, also given the high incidence of falls or strokes, people living with dementia appear to be among the most frequently admitted to Accident and Emergency⁵⁰

In addition to this, because of the prevalence of dementia, a relatively significant amount of resources is being invested in research and innovation to try to cure this condition or to manage its symptoms.⁵¹ Therefore, people living with it may be requested to participate in clinical trials or undertake experimental treatments, which of course requires an evaluation of the risks and benefits of taking part in the research.⁵²

⁴⁸ JD Curb, 'Effect of Diuretic-Based Antihypertensive Treatment on Cardiovascular Disease Risk in Older Diabetic Patients with Isolated Systolic Hypertension' (1996) 276 *Journal of American Medical Association* 1886; I Olver, 'Chemotherapy for Elderly Patients with Advanced Cancer: is it worth it?' (2000) 23 *Australian Prescriber* 80; Banerjee, *above*; M Ayan et al, 'Cardiac Drug Therapy—Considerations in the Elderly' (2016) 13 *Journal of Geriatric Cardiology* 992.

⁴⁹ C Mueller et al, 'Polypharmacy in People with Dementia: associations with Adverse Health Outcomes' (2018) 106 *Experimental Gerontology* 240.

⁵⁰ KE Sleeman, 'Predictors of Emergency Department Attendance by People with Dementia in their Last Year of Life: retrospective Cohort Study using Linked Clinical and Administrative Data' (2018) 14 *Alzheimer's and Dementia* 20.

⁵¹ Alzheimer's Research UK, *Annual Review* (AlzUK 2015), 16 available at <www.alzheimersresearchuk.org/wp-content/uploads/2015/01/ARUK_AnnualReview2015_web.pdf> accessed 31 May 2018. See also Alzheimer's Association, 'Congress Prioritizes Alzheimer's and Dementia Research Funding in 2018 Budget' (2018) <https://alz.org/news_and_events_105707.asp> accessed 31 May 2018.

⁵² E Bettie, 'Research Participation of Individuals with Dementia: Decisional Capacity, Informed Consent, and Considerations for Nurse Investigators' (2009) 2 *Research in Gerontological Nursing* 94; H Helmchen, 'Forschung mit Menschen, die an Demenz erkrankt sind?' (2015) 86 *Nervenarzt* 1140; M Lepore et al, 'Challenges in Involving People with Dementia as Study Participants in Research on Care and Services. Background Paper' (Research Summit on Dementia Care, Bethesda, March 2017), 2-4 available at <<https://aspe.hhs.gov/system/files/pdf/256696/Session%20%20Background.pdf>> accessed 31 May 2018.

Finally, we have to consider that presently there is no cure for dementia so this condition is always fatal, either because of the natural course of the condition or because of other causes that occur earlier (e.g. a stroke or a fall). Because of dementia's long development and degenerative nature, the person in the final phases of their life is often almost totally paralysed, incontinent, and unable to eat and speak.⁵³ In these situations, the question arises of whether to administer artificial nutrition, hydration, and ventilation or to apply a number of palliative treatments and end-of-life procedures.⁵⁴

Dementia and consent to treatment

All medical treatments and procedures require the previous approval of the person on which they are performed. All western legal systems recognise the fundamental right of every person to not undergo a therapeutic procedure without their prior consent.⁵⁵ This is generally seen as the way in which the law recognises the principles of dignity and autonomy in relation to medical treatment.⁵⁶ In this regard, Faden and Beauchamp affirm that 'informed consent is rooted in concerns about protecting and enabling autonomous or self-determining choice by patients'.⁵⁷ Equally, Randall and Downie maintain: 'it is not difficult to see the connections between the general concept of dignity and autonomy and the more specific concept of consent. [...] Given that people are mind-body unities it follows from the ideas of autonomy and dignity that they should have a right to determine what is done to their bodies'.⁵⁸

⁵³ Alzheimer Society of Ireland, 'Understanding Late Stage Dementia' (2015) < www.alzheimer.ie/Alzheimer/media/SiteMedia/HelpLine%20and%20Information%20Resources/Info%20Pack%20PDF%27s/Understanding-late-stage-dementia_Section-A6.pdf> 31 May 2018.

⁵⁴ See M Gordon, 'Ethical Perspectives on End-of-Life Care: Euthanasia, Assisted Suicide and the Refusal or Withdrawal of Life-Sustaining Treatments in those Living with Dementia' in Foster, Herring and Doron (eds), *above*.

⁵⁵ See for example I Kennedy and A Grubb, *Medical Law*, (3rd ed, Butterworths 2002), 575; M Brazier and E Cave, *Medicine Patients and the Law* (6th ed, Penguin 2011), 67; N Eyal, 'Informed Consent', *Stanford Encyclopedia of Philosophy* (2011) < <https://plato.stanford.edu/entries/informed-consent/>> accessed 25 September 2018.

⁵⁶ Kennedy and Grubb, *above*, 575; B Ademola Bello, 'Dignity and Informed Consent in the Treatment of Mature Minors' (2010) 21 *Journal International de Bioéthique* 103; Brazier and Cave, *above*, 67; C Foster, *Human Dignity in Bioethics and Law* (Hart 2011), 111.

⁵⁷ RR Faden and TL Beauchamp, *History and Theory of Informed Consent* (Oxford University Press 1986), 235.

⁵⁸ F Randall and RS Downie, *The Philosophy of Palliative Care: Critique and Reconstruction* (Oxford University Press 2006), 59. See also CB Fisher and M Oransky, 'Informed Consent to Psychotherapy: Protecting the Dignity and Respecting the Autonomy of Patients' (2008) 64 *Journal of Clinical Psychology* 576.

In order to consider consent or refusal of medical treatment or other health interventions valid, medical law traditionally requires that:

- the person has the *capacity* (or *competency*) *to consent*, meaning they are able to understand the nature and purpose of the medical treatment or procedure and to appreciate the implications and consequences of their decision;
- the person has been appropriately *informed* of the treatment before consenting or refusing it;
- the consent or refusal has been *voluntarily expressed* and the decision is not the product of others' undue influence.⁵⁹
-

On a practical level, the first prerequisite appears to be the most important in the case of people living with dementia. Because of their cognitive impairment, these individuals may often be seen as lacking the level of intellectual abilities required to grasp the nature and implications of their treatment and make conscious choices.⁶⁰ This may also have an impact on how informed they are about a certain treatment or on their vulnerability to undue influence. Individuals living with dementia could appear to struggle to understand information given in conventional ways and to remember their doctor's explanations, or, because of disorientation in space and time, they could be more prone to surrender to the self-interested 'advice' of a relative or friend. Therefore, as noted by Donnelly, all the problems regarding decisions of individuals living with this condition, including those on medical treatment, tend to be seen through the lens of capacity.⁶¹ As Grisso and Appelbaum note, if the person is judged as capable of consenting they are allowed to autonomously decide on their medical treatment but if judged as incapable they are stripped of this right and alternative decisional mechanisms are sought, such as appointing a third person (doctor, relative, deputy or guardian) who will decide for them.⁶² For this reason, capacity is defined also as the 'gatekeeping concept for informed consent'.⁶³

Here the concept displays all its legal weight. It is the framework under which a person is conferred or denied the power to make decisions regarding their care. In this regard, capacity to consent to medical treatment is a subtype of the more general

⁵⁹ Faden and Beauchamp, *above*, 274; Grisso and Appelbaum, *Assessing Competence*, *above*, 7.

⁶⁰ Pickering Francis, *above*, 542; T Mueller et al, 'Comparison', *above*. See further Chapter 2.

⁶¹ M Donnelly, 'A Legal Overview' in Foster, Herring and Doron (eds), *above*, 271.

⁶² Grisso and Appelbaum, *Assessing Competence*, *above*, 1.

⁶³ Faden and Beauchamp, *History and Theory*, *above*, 286.

category of legal capacity, which, according to the definition given by Lewis, is the construct through which the law recognises and validates people's decisions and transactions such as contracts, wills and indeed healthcare choices.⁶⁴ In medical law, as in all other areas of legislation, this recognition and validation is subordinated to the presence of mental capacity in the decision-maker, which is the possession of the necessary cognitive abilities to 'reasonably' make a certain decision.⁶⁵ Therefore, the term 'capacity to consent' refers both to the ability to understand and weigh the nature and consequences of a clinical procedure and to the fact that, traditionally, this ability is legally necessary for the validity of an individual's choice.⁶⁶ The rationale under this construction is explained by Faden and Beauchamp, who affirm that if a person is autonomous and able to make conscious decisions, it is morally justifiable that they should autonomously decide on the medical treatment. However, if the person is 'non-autonomous', thus unable to make a thoughtful decision, it is morally preferable that the power of deciding is transferred to other people as otherwise it may lead to potential self-harm for the person.⁶⁷

This approach is grounded on the classical-liberal conception of the individual which has strongly influenced the modern approach to consent to treatment.⁶⁸ This view starts from the Cartesian and Enlightenment idea of rationality as the necessary and distinctive characteristic of human nature.⁶⁹ As such, it advocates that every individual of 'sound mind' is entitled to plan and shape their own life according to

⁶⁴ O Lewis, 'Advancing Legal Capacity Jurisprudence' (2011) 6 *European Human Rights Law Review* 700, 700.

⁶⁵ On the distinction between legal and mental capacity see N Devi, J Bickenbach and G Stucki, 'Moving towards Substituted or Supported Decision-Making? Article 12 of the Convention on the Rights of Persons with Disabilities' (2011) 5 *ALTER* 249, 252; A Arstein-Kerslake and E Flynn, 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law' (2015) 20 *The International Journal of Human Rights* 471, 474-475.

⁶⁶ In legislations and academic discourse, the two categories of legal and mental capacity are normally conflated and tend to coincide. P Bielby, 'The Conflation of Competence and Capacity in English Medical Law: A Philosophical Critique' (2005) 8 *Medicine, Health Care and Philosophy* 357. See also Committee on the Rights of Persons with Disabilities, 'General Comment', *above*, 4.

⁶⁷ *Ibid*, 288. See also Grisso and Appelbaum, *Assessing Competence*, *above*, 12.

⁶⁸ For an analysis on the influence exerted by liberal thought on the modern concept of consent to treatment see M Donnelly, *Healthcare Decision-Making and the Law. Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press 2010), 16-22.

⁶⁹ Such a position is formulated in R Descartes, *Discourse sur le Methode* (Leiden 1637) and was supported by philosophers of the age of Enlightenment such as Kant (see I Kant, *Beantwortung der Frage: was ist Aufklärung?*, 1784). For a general *excursus* see M Mori, 'Intelletto e ragione da Cartesio a Hegel' (lecture series University of Turin 2003) <<http://www.filosofico.net/inteellettoearagione.htm>> accessed 29th January 2015; W Bristow, 'Enlightenment', *Stanford Encyclopedia of Philosophy* (2011) <<http://plato.stanford.edu/archives/sum2011/entries/enlightenment/>> accessed 28 January 2015.

their own personal values,⁷⁰ having to be let free to choose without pressures from the outside.⁷¹ As noted by McLean, here the individual is seen as supreme - but on condition that they are rational and mentally capable.⁷²

Literature in medical ethics and national legislations has developed criteria which a person needs to meet in order to be considered mentally capable of deciding on medical treatment (so-called capacity tests). One of the earliest tests in this area is the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), developed in the late 1980s-1990s by American psychiatrists Thomas Grisso and Paul S Appelbaum, which demands that, in order to decide on medical treatment, a person possesses (1) the ability to understand information about the treatment, (2) manipulate the information rationally, (3) appreciate the significance of the decision for their own situation and (4) express a choice.⁷³ Similar criteria are also contained in European legislations on consent to treatment and mental capacity. For example, section 3 of the English Mental Capacity Act 2005 states that a person is incapable of making any decision (including one on medical treatment) when they are unable '(a) to understand the information relevant to the decision, (b) to retain that information, (c) to use or weigh that information as part of the process of making the decision, or (d) to communicate [the] decision'. Similar criteria have been developed, for example, by German case law and legal scholars which require that a person is able to understand '*Art/Wesen, Bedeutung und Tragweite*' (type/nature, significance and implications) of a medical procedure and to weigh the pros and cons of the decision.⁷⁴

As already noted, people living with dementia may be judged as not satisfying such prerequisites. Doctors and carers may often assume the person incapable only on the basis of their diagnosis.⁷⁵ Moreover, they may find it difficult to understand the statements of the individual, judging them as the senseless utterances of an 'unsound'

⁷⁰ See JS Mill, *On Liberty* (London 1859), 21-23. See also R. Dworkin, *Life's Dominion. An Argument about Abortion and Euthanasia* (Harper Collins 1993), 224-225; M. Bratman, *Structures of Agency* (Oxford University Press 2007), 3-12 and 21-45.

⁷¹ Mill, *above*, 14.

⁷² SAM McLean, *Autonomy Consent and the Law* (Routledge 2009), 19-20.

⁷³ See PS Appelbaum and T Grisso, 'Assessing Patient's Capacity to Consent to Treatment' (1988) 319 *The New England Journal of Medicine* 1635; T Grisso, PS Appelbaum and C Hill-Fotouhi, 'The MacCAT-T: a Clinical Tool to Assess Patients' Capacities to make Treatment Decisions' (1997) 48 *Psychiatric Services* 1415; T Grisso and PS Appelbaum, *MacArthur Competence Assessment Tool for Treatment (MacCAT-T)* (Professional Resource Press 1998).

⁷⁴ See for example BGH, 16.11.1971 - VI ZR 76/70 NJW 1972, 335. For an overview see U Golbs, *Das Vetorecht eines einwilligungsunfähigen Patienten* (Nomos, 2006), 56.

⁷⁵ A Derse, 'Making Decisions about Life-Sustaining Medical Treatment in Patients with Dementia' (1999) 20 *Theoretical Medicine* 55, 55-56 and 61-63, but see further Chapter 2.

mind.⁷⁶ The idea that people with dementia are individuals devoid of their self and true human qualities who are inevitably and constitutively incapable of understanding what is going on around them is still widespread in our society.⁷⁷ As a result, even people with mild or moderate dementia are assessed as lacking the capacity to make healthcare decisions.⁷⁸

However, an increasing number of scholars, professionals, carers and people living with dementia are critical of this situation. Studies and experiential accounts show that individuals in the early stages of dementia, but also many of those in the advanced phases of the condition, are often able to articulate consistent and motivated preferences on their care.⁷⁹ Many statements which may seem incomprehensible at first sight, do appear to make sense in relation to the particular life situation of the person after more careful consideration. Therefore, it seems often unjust to disregard the statements by individuals with dementia. According to some legal scholars, the way in which the law on legal capacity and capacity to consent is framed also bears a significant responsibility here. In assessing capacity, the law tends to concentrate only on cognitive abilities, requiring absolute rationality in the decision-making.⁸⁰

The present work tries to address these concerns, showing how they can be avoided through a different approach to capacity to consent and a vision of the person living with dementia and of healthcare decision-making which is alternative to the apparent basis of current health law. In order to do so, it focuses on the theme of decisions of people living with dementia, specifically regarding the administration of traditionally designed medical treatments such as drugs, surgical operations or other smaller interventions performed, for example, by GPs, dentists, opticians, or nurses in the context of everyday healthcare of the person. It does not refer only to the strictly medical aspects of these treatments, but focuses on the full process of delivering healthcare, including the action of non-medical professionals such as informal carers.

⁷⁶ See chapter 2.

⁷⁷ PJ Fox, 'From senility to Alzheimer's disease: The rise of the Alzheimer's Disease Movement' (1989) 67 *Milbank Quarterly* 58, 58.

⁷⁸ T Mueller, *above*.

⁷⁹ See for example L Barth, 'Chronologie eines rechts- und verfahrensförmigen Sterbeprozesses' (2008) *Zeitschrift zum Altenpflegerecht* 1; J Gather and J Vollmann, 'Physician-Assisted Suicide of Patients with Dementia. A Medical Ethical Analysis with a special focus on Patient Autonomy' (2013) 36 *International Journal of Law and Psychiatry* 444, 446; C Emmett et al, 'Homeward Bound or Bound for a Home? Assessing the Capacity of Dementia Patients to Make Decisions about Hospital Discharge: Comparing Practice with Legal Standards' (2013) 36 *International Journal of Law and Psychiatry* 73.

⁸⁰ See Donnelly, 'A legal', *above*, 271.

For this reason, in this thesis the term ‘decision/choice on medical treatment’ is used as a synonym of ‘healthcare decision/choice’.

4. Scope of the research, theoretical premises and methodology

Scope of the research

As already discussed, the focus of this work is on creating better conditions for people living with dementia to exercise their right to choose on medical treatment. Its thesis is that, in order to achieve this goal, legislation, professionals, and carers need to embrace a new approach based on an alternative vision of the person living with dementia. Many scholars, doctors, nurses, lawyers, judges, social workers, and relatives still tend to look at dementia only as a dreadful malfunctioning of the brain, leading to an inevitable loss of reasoning ability, and about which one can provide basic care to the person and prevent them from harming themselves.⁸¹ Moreover, regulations of healthcare decision-making still appear underpinned by an individualistic conception which sees personal choices as something that needs to be done in isolation and recognises the right to decide only for those who have a sufficient mental capacity/capacity to consent, thus risking the exclusion of people living with impairments such as dementia.⁸² Such a system also creates a series of practical challenges in the dialogue with the person and the collection of their consent.⁸³

This research seeks to identify a legal, policy and practice approach which avoids or at least attenuates these problems. In doing so it proposes a vision of dementia which recognises that the concrete impact of such a brain condition depends, at least to some extent, on how society reacts to it or accommodates the needs of the person concerned.⁸⁴ In this vision, an individual’s ability to make decisions is determined not so much by the integrity of their brains but rather by the possibility of getting adequate opportunities to make decisions for themselves.⁸⁵ This study explores how adopting

⁸¹ See for example RL Beard, J Knauss and D Moyer, ‘Managing Disability and Enjoying Life: How we Reframe Dementia through Personal Narratives’ (2009) 23 *Journal of Aging Studies* 227, 228 and then further Chapter 2 section 2.

⁸² See for example the reflection done by L Series, ‘Relationships, autonomy and legal capacity: Mental Capacity and Support Paradigms’ (2015) 40 *International Journal of Law and Psychiatry* 80, 80-84. But see further Chapter 2.

⁸³ See further Chapter 2 section 4.

⁸⁴ See on this point M Oliver, *The Politics of Disablement* (Macmillan 1990), 46-49; T Kitwood, *Dementia Reconsidered. The Person Comes First* (Open University 1997).

⁸⁵ Series, *above*, 83-84.

this perspective could lead to a more inclusive decision-making system for people living with dementia, as the point would not be to prevent them from deciding because of their incapacity to consent, but rather to create the necessary conditions for them to exercise their power of choice. In doing so it focuses on decisions on medical treatment, as this is the kind of health choices that directly and extensively impact the life and care of people living with dementia. This focus makes it possible, on the one hand, to analyse the whole spectrum of questions arising in this area, and on the other hand, to discuss proposals which can really make a difference in the life of people.

Theoretical framework: an alternative view of dementia

In order to conceptualise the vision of dementia underpinning this thesis, I refer to the social model of disability and to Martha Fineman's vulnerability theory. These accounts are analysed in more detail in chapter 3.

The social model sees disability primarily as a social dynamic rather than solely as a medical problem.⁸⁶ It defines disability in terms of interaction between an impairment, such as dementia, and societal barriers disabling and excluding the person living with the impairment.⁸⁷ It advocates for the removal of obstacles preventing the person from being included in society and living their life to the fullest.⁸⁸ With regard to treatment decisions of individuals living with dementia, the social model of disability can be the conceptual basis for an approach which does not just focus on the person's diminished mental capacity, but rather concentrates on removing the external barriers to the exercise of their decisional power and on creating the conditions for them to express their will on care.

Fineman's vulnerability theory, developed in the context of legal studies, supports and extends such claims by putting them in relation to human condition and legal personality and providing a more articulate message with regard to the need for state and social institutions to engage in removing barriers such as those faced by people living with dementia. This account identifies vulnerability as a universal characteristic shared by all individuals and advocates for putting the 'vulnerable subject' at the centre

⁸⁶ Oliver, *above*, 17-20. See also M Priestley, 'Constructions and Creations: Idealism, Materialism and Disability Theory' (1998) 13 *Disability & Society* 75.

⁸⁷ Oliver, *above*, 22; SJ Williams, 'Is Anybody there? Critical Realism, Chronic Illness and the Disability Debate', (1999) 21 *Sociology of Health and Illness* 797, 810.

⁸⁸ T Shakespeare, 'The Social Model of Disability' in LJ Davis (ed), *The Disability Studies Reader* (4th ed, Routledge 2013).

of legal and policy discourse.⁸⁹ Similar to the social model, it claims that vulnerability inevitably derives from the interaction between our body, which exposes us to injuries and illnesses, and the social structures in which we are all embedded that may accommodate or enhance our dependency and vulnerability.⁹⁰ It emphasises how frailty, dependency, or incompetence are not social pathologies or exceptions, but an essential and natural part of the human condition. On one hand, this assumption leads to challenge the artificial binary distinction between capable individuals and incapable individuals that still characterises regulations on consent to treatment.⁹¹ On the other hand, adopting the vulnerable subject as the paradigm at the centre of legal and policy discourse leads to advocate that state and social institutions take responsibility to attenuate the various forms of vulnerability experienced by their members.⁹² Therefore, in relation to healthcare decision-making, it provides a basis to claim that institutions at all levels should actively support the person and create the conditions for them to exercise their right to decide.

Realising a new legal approach

The ideas of the social model and of vulnerability theory have also been circulating for several years in the legal debate on the rights and healthcare decisions of disabled people and individuals living with cognitive impairments. Moreover, they appear to be echoed in the recent UN Convention on the Rights of Persons with Disabilities (CRPD).⁹³ Based on its text and negotiation reports, the Convention is strongly underpinned by the social model of disability.⁹⁴ In addition, though vulnerability theory does not appear to be among the direct sources of inspiration of the CRPD, some of the Convention's provisions seem in line with Fineman's vision. For example,

⁸⁹ M Fineman, 'The Vulnerable Subject: anchoring Equality in the Human Condition' (2008) 20 *Yale Journal of Law and Feminism* 1, 8-12; M Fineman, 'The Vulnerable Subject and the Responsive State' (2010) 60 *Emory Law Journal* 251, 266-269.

⁹⁰ Fineman, 'The Vulnerable Subject and the Responsive State', *above*, 8-10; M Fineman, 'Vulnerability and Inevitable Inequality' (2017) 4 *Oslo Law Review* 133, 143-145.

⁹¹ See also B Clough, 'Disability and Vulnerability: Challenging the Capacity/Incapacity Binary' (2017) 16 *Social Policy and Society* 469, 473-479.

⁹² Fineman, 'Vulnerability', *above*, 146-149.

⁹³ UN Convention on the Rights of Persons with Disabilities (adopted 13 December 2006 UN General Assembly Res 61/106 (2006) UN Doc A/RES/61/106, opened for signatures 30 March 2007, entered into force 3 May 2008) 2515 UNTS 3 (CRPD).

⁹⁴ Statement of the European Disability Forum in Ad Hoc Committee, 'Compilation of Comments on Articles of the Draft Text of the Working Group' (3rd session 2004). See also R Kayess and P French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 *Human Rights Law Review* 1, 7.

in Article 12(2) the CRPD affirms that all disabled individuals must be recognised the right to legal capacity and to make autonomous decisions, refuting the traditional binary division between capacity and incapacity on the basis of the mental abilities of the person. In addition, Article 12(3) states that disabled individuals have the right to receive support in exercising their decisional power and in overcoming the difficulties that they may face because of their condition.⁹⁵ Scholars and practitioners have not yet extensively analysed the possible implications of this norm in relation to the case of people living with dementia. For this reason, this thesis will investigate how Article 12 CRPD can offer a normative model which addresses the issues emerging from literature and practice on healthcare decision-making of such individuals. In doing this, it will mainly refer to the interpretation of the Article given in General Comment No 1⁹⁶ by the UN Committee on the Rights of Persons with Disabilities, to which the Convention has given the task of monitoring the correct interpretation and implementation of the CRPD.⁹⁷

However, because of its innovative content and its nature of provision of principles, the Article has triggered many controversies with regard to its correct interpretation.⁹⁸ Moreover, it is necessary to establish how its sometimes vague norms can be translated into concrete behaviours. Also, as with all international human rights provisions, it requires the identification of normative and policy mechanisms to guide its implementation. In order to explore what these potential mechanisms could be, I will focus on the developments emerging in the European continent.

This is a particularly interesting context for my topic. First, due to the relevance of the phenomenon of dementia, a series of national governments, authorities, care structures, research teams, professionals, and NGOs are establishing initiatives regarding healthcare decision-making of individuals living with this condition.⁹⁹ Moreover, the continent is home to two authoritative regional organisations, the Council of Europe (CoE) and the European Union (EU), which have made strong official commitments towards the promotion of CRPD principles.¹⁰⁰ Therefore, by

⁹⁵ For an analysis of Article 12 CRPD see Chapter 4.

⁹⁶ Committee on the Rights of Persons with Disabilities (11th session), 'General Comment No. 1 Article 12: Equal recognition before the law' (2014) UN Doc CRPD/C/GC/1.

⁹⁷ General information on the Committee can be found in <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>> accessed 17 January 2018.

⁹⁸ See Chapter 4.

⁹⁹ See Chapter 7.

¹⁰⁰ See Chapters 5 and 6.

looking at this area it will be possible both to study the channels available at a continental level to advance the implementation of the Convention and to gain a vision of how an Article 12-compliant approach to capacity to decide on medical treatment of people living with dementia could look like.

The original contribution of the thesis

This work aims to address the problems emerging in decision-making on medical treatment of people living with dementia by insisting on three points: a more inclusive vision of dementia, the application of a set of legal principles embodying such a vision (i.e. Article 12 CRPD) and the use of the transformative potential of CoE and EU legal and policy mechanisms as well as initiatives developed in national jurisdictions. Its original contribution consists of bringing together theoretical accounts such as the social model of disability and vulnerability theory, which developed following different routes and in relation to other problems, and explore their potential in relation to the case of people living with dementia. It also shows how legal principles and policy initiatives which have not yet been fully applied to healthcare choices of individuals living with dementia have the potential to solve or attenuate the dilemmas that scholars, activists, and practitioners have been facing for several decades. Finally, it provides an analysis of possible initiatives and practices which could be put in place in order to empower people living with this condition.

In doing so, this work does not have the ambition to analyse all the possible nuances of regulations in its field or to give detailed instructions on what carers, professionals and policy makers should do. Rather, it aims to provide a pathway for change. This choice is due to the fact that the link between the problems this work focuses on and the principles it uses has not yet been clearly highlighted by scholars or activists, a gap which needs to be filled before proceeding to more specific issues. Once this gap is bridged it will be possible to further explore how my proposed approach can be implemented in the various concrete situations of decision-making practice, a plan which I would like to accomplish in the next stages of my career as a researcher.

Terminology

The particular view of dementia and treatment decisions underpinning this study promotes a use of language which does not stigmatise people living with this condition.

For this reason, I will avoid terms such as ‘the demented’, ‘dementia sufferer’, or ‘dementia victim’, preferring instead, ‘person living with dementia’, which poses more emphasis on the existential, relational aspect of the condition and does not reduce the person to just their condition or diagnosis.

As this work is based on the social model of disability, I will also adopt a terminology which is in line with its vision of this phenomenon as essentially produced by society. Some activists and public bodies maintain that the phrase ‘people with disabilities’ is the most appropriate one in this context.¹⁰¹ Indeed, it puts the word ‘person’ before the word ‘disability’, signalling the prominence of the human component on that of ‘(in)ableness’.¹⁰² However, I will adhere to another school of thought, which endorses the use of the locution ‘disabled people’. Indeed, I believe that such a phrase transmits more clearly the idea according to which the person is ‘made disabled’ by society, instead of having a body or a mind ‘with’ a disability.¹⁰³

In keeping with the principles of the social model I will also avoid referring to individuals living with this condition as ‘patients’ as this risks excessively medicalising the discourse and presupposes a subordination to doctors or carers. Instead, I will use the more neutral term of ‘person’ or ‘individual’. For the same reasons, I will also refrain from defining dementia as an ‘illness’ or ‘disease’, both words which refer to something intrinsically negative and pathological, preferring instead the term ‘condition’.

Methodology

As already explained, the aim of this study is to explore how values such as those affirmed by the social model and vulnerability theory along with legal principles such as those affirmed in Article 12 CRPD and in a series of European legal sources and policy documents can contribute to better addressing the issues related to healthcare decision-making of people living with dementia. It will also clarify how these values can be translated into initiatives and behaviours which facilitate the exercise of these

¹⁰¹ See, for example United Spinal Association, ‘Disability Etiquette. Tips on interacting with People with Disabilities’, 6 available at <<http://www.unitedspinal.org/pdf/DisabilityEtiquette.pdf> California>; Canadian Courts, ‘Disability Terminology Chart’ available at <<http://www.courts.ca.gov/partners/documents/7-terminology.pdf>> both accessed 25 July 2018. This choice characterises also the UN Convention on the Rights of Persons with Disabilities.

¹⁰² A Lawson, ‘The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?’ (2007) 34 *Syracuse Journal of International Law and Commerce* 563, 572.

¹⁰³ This point is also explained by Lawson, *above*, 572.

individuals' legal capacity. This first requires clarification of the normative content of the analysed provisions and, relating it to the context, problems and dynamics emerging from practice. For this reason, this study relies on a combination of doctrinal and socio-legal research methods.

In particular, in order to accomplish the first task, I will employ the classical criteria for the exegesis of legal texts widely accepted in legal scholarship and practice, and codified in documents such as the Vienna Convention on the Law of the Treaties or specific national and European guidelines. In doing this, I will consider primary legislative sources (e.g. international conventions, laws, EU directives and regulations, and policy documents), case law, and reports of International and European monitoring bodies in addition to the opinions of legal scholars.

I will use document analysis to explore the practical problems emerging in the field of treatment decisions of people living with dementia and of how the legal principles and policies at the centre of this work can be realised through promising practices.¹⁰⁴ In particular, I will rely on empirical studies, reports, personal accounts of people living with dementia and their carers, official documents, webpages of governments and NGOs, blogs, posters, and audio or video material which reports the experiences and difficulties of people with dementia in deciding on medical treatment and/or describes promising initiatives. I will give particular attention to sources in which the voice of people living with the condition is more central (e.g. personal testimonies or interviews with individuals living with the condition) or reports of organisations in which such individuals are extensively involved. These materials, which have been released in increasing number in recent decades throughout and beyond Europe, offer an extensive and detailed picture of the situation in the field of healthcare decision-making of people living with dementia. The documents are all published and have been collected through a series of channels. The first type of channel consists of scientific databases such as Google Scholar, PubMed, PsychNet, and Heinonline. These sources have been selected in order to guarantee the inclusion of studies produced both in the fields of medicine or psychology and of social sciences. For the collection of promising practices I have also used repositories managed by

¹⁰⁴ P Atkinson and A Coffey 'Analysing Documentary Realities' in D Silverman (ed), *Qualitative Research. Theory, Method and Practice* (2nd ed Sage 2004); I Dobinson and F Johns, 'Qualitative Legal Research' in M McConville and WH Chui (eds), *Research Methods for Law* (Edinburgh University Press 2007), 32-40 GA Bowen, 'Document Analysis as a Qualitative Research Method' (2009) 9 *Qualitative Research Journal* 27.

public authorities, NGOs, and research institutions, such as the portals of Alzheimer Europe¹⁰⁵ and the European Foundations' Initiative on Dementia (EFID),¹⁰⁶ the practices database of the ZERO Project,¹⁰⁷ the supported decision-making resource library of the American Civil Liberties Union (ACLU),¹⁰⁸ and the reports released in the context of the EU ALCOVE project¹⁰⁹ and by the Academic Network of European Disability Experts (ANED).¹¹⁰ This sample has been supplemented by excerpts from autobiographies of people living with dementia and other white and grey literature collected through snowballing from the material of the database search.

In analysing this material I will mainly rely on classical content analysis, focusing on the facts, events, and behaviours narrated, although I will also take into account the language used as a possible indicator of attitudinal barriers such as stigma and prejudice or as an element through which it is possible to identify the spirit and true intentions of a certain practice.

5. Structure

This thesis starts from the barriers faced by people living with dementia in making decisions on medical treatment and by embracing an alternative view of the person living with this condition, echoed in Article 12 CRPD, proposes a framework which avoids or attenuates such difficulties. Then it turns to CoE, EU and single national initiatives to explore how such a model can be realised in practice.

Chapter 2 begins by presenting an overview of the barriers preventing individuals living with dementia from exercising their legal capacity and their right to decide on medical treatment. It claims that, though the person's impairment plays a role, difficulties arising in this context are often due to external barriers such as the prejudice of carers and medical or legal professionals as well as the way in which conversations on healthcare choices are normally conducted. It also draws attention to how

¹⁰⁵ <www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies> and <www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons> accessed 23 October 2016.

¹⁰⁶ See <www.efid.info/eng/awards/> and <www.efid.info/eng/resources/mapping-dfcs/> accessed 16 February 2017.

¹⁰⁷ <<https://zeroproject.org/innovative-practices/>> accessed 16 February 2016.

¹⁰⁸ <www.aclu.org/other/supported-decision-making-resource-library?redirect=supported-decision-making-resource-library> accessed 16 February 2017.

¹⁰⁹ See <www.alcove-project.eu/index.php?option=com_content&view=article&id=9&Itemid=118> accessed 23 October 2016.

¹¹⁰ <www.disability-europe.net/> accessed 6 November 2014.

legislation on capacity to consent is often not helpful as it demands that the person satisfies a utopian and discriminatory standard of mental capacity. The information supporting the chapter has been collected through document analysis of qualitative and quantitative studies, personal accounts of people living with dementia and their carers, and grey literature by NGOs and governmental bodies, and is complemented with reflections of scholars in the field.

Chapter 3 analyses the main ideas of the social model of disability and vulnerability theory, clarifying their implications with regard to treatment decisions of people living with dementia. In particular, it shows how the combination of these two accounts provides a conceptual basis on which to ground an approach to healthcare decision-making where the person is not stigmatised, is recognised the right to decide for themselves, and is supported in expressing their will on care through adequate services provided by the state and by the action of their network of relationships. To do this, I refer to the texts of the main theorists of the two conceptions, setting their claims in relation to the case of treatment decisions of people living with dementia.

Chapter 4 focuses on the CRPD and Article 12, identifying it as the legal channel through which such a model can be realised in normative terms. First, it aims to study how the Convention is underpinned by many of the values discussed in Chapter 3. Then, it analyses the normative content of Article 12, shedding light on its possible interpretations. In doing so it adopts a doctrinal methodology and refers to the opinions of legal experts and monitoring bodies as interpretive aids. It puts particular attention to General Comment No. 1 by the UN Committee on the Right of Persons with Disability.

Chapter 5 explores how the powers, institutions, and initiatives of the Council of Europe can contribute to the promotion of the principles of the CRPD with regard to treatment decisions of people living with dementia. In particular, it looks at the potential of CoE policies, case law of the European Court of Human Rights, and the action of various monitoring bodies to promote the values of the Convention, help Member States translate them into specific regulations and practices, and create the necessary conditions for supported decision-making. To do this, the chapter relies on both the doctrinal analysis of CoE legal and policy documents and on the content analysis of reports describing awareness-raising, practice-spreading or rights-monitoring initiatives.

Chapter 6 turns to EU institutions, powers, and law-policy making mechanisms, studying how they can also contribute to the realisation of the CRPD and Article 12 in relation to healthcare decisions of people living with dementia. It mainly focuses on policies in the competence areas of health and equality, the possible use of EU regulatory powers in this area, and the potential of EU funding programmes. It uses doctrinal analysis to shed light on the possible interpretation of legal and policy provisions and document analysis to gather information on field initiatives and their implications.

Finally, Chapter 7 looks at initiatives and promising practices established in different European countries which can give an idea of how a CRPD-oriented approach to treatment decisions of people living with dementia could look like in reality. It concentrates on actions that aim to fight dementia-related prejudice, training programmes for professionals and carers, specific practices of support during care decisional processes, and mechanisms to avoid abuses and undue influence. To do this, it relies on document analysis of reports describing the specific initiatives and collected through scientific databases and repositories.

The Conclusion chapter summarises the main messages of the thesis. In particular, it emphasises how an approach to treatment decisions based on a more inclusive vision of dementia, the centrality of the person, and supported decision-making permits to better promote the right to choose of individuals living with this condition. The initial positive effects of initiatives already undertaken at the UN, European, and national levels, show their potential for producing change in the field of healthcare decision-making. However, I will suggest that many of the opportunities available in this context are still vastly unexploited. As a result, I try to propose future steps in terms of policies, practices, and research to further promote the right of individuals living with dementia to decide on medical treatment within the European context.

CHAPTER 2

People with Dementia and Treatment Decisions: challenges and barriers

1. Introduction

Living with dementia can impact on an individual's capacity to consent or refuse medical treatment.¹ Indeed, as noted in Chapter 1, people living with this condition are often judged as not meeting mental capacity standards for valid treatment decisions. This chapter analyses the reasons why this happens and the specific barriers faced by individuals living with dementia in exercising their right to choose. Therefore, it makes a first step towards addressing the research question at the centre of this work, as it identifies the concrete problems to which the following chapters aim to propose a solution.

The central claim of this part is that, though the person's impairment plays a role, many of the obstacles arising in the area of treatment decisions derive from contextual factors such as prejudice, organisational problems, lack of training of carers or medical professionals, and the inadequacy of the current approach to legal capacity.² Therefore, the focus is on the societal barriers hindering the capacity to consent of individuals living with dementia. In order to analyse these barriers, the chapter relies on personal accounts and empirical studies published in books, journals, newspapers or grey literature reporting the experiences and opinions of people living with dementia, their doctors and formal or informal carers, complemented with the analyses of scholars in the field.

The exposition is structured as follows. Section 2 starts by examining how prejudice is often the first obstacle preventing people living with dementia from exercising their decisional power in healthcare matters. Indeed, because of this, their wishes on medical treatment tend to be automatically disregarded, and decisions are made on the basis of previous statements or by a surrogate who decides in their best

¹ R Jacoby, 'Ethical and Legal Issues in Dementia' (2006) 2 *The Foundation Years* 15, 15.

² Such a position also emerges from Nuffield Council on Bioethics, *Dementia: Ethical Issues* (Nuffield 2009), 79; NL Batsch and MS Mittelman (eds), *World Alzheimer Report 2012. Overcoming the Stigma of Dementia* (Alzheimer's Disease International 2012), 24-31 and 37.

interests.³ However, people living with dementia are often able to express articulate opinions on their medical treatment,⁴ making it ethically and legally problematic not to listen to what they say. These concerns emerge particularly clearly in the scholarly debate on the traditional mechanisms of advance directives and decisions on best interests, which is analysed in Section 3. Here it is further shown how the significant theoretical and practical problems posed by the application of these legal instruments to the case of people living with dementia confirm the necessity of a decisive change of approach in this area. Section 4 investigates the practical issues faced by individuals living with this condition in developing and communicating their medical decisions and the challenges confronted by medical professionals, carers and relatives in understanding, interpreting and enacting the person's wishes. Here I note how many of such difficulties arise or are aggravated by contextual factors such as the absence of support mechanisms and professionals' lack of training. Section 5 argues that most of the issues described in this chapter can be linked to the inadequacy of legal approaches to decision-making in dementia care and to the current concept of capacity to consent. Finally, the Conclusion further emphasises that, though the person's impairment has an influence, many of the barriers faced by individuals living with dementia come from external factors such as prejudice, organisational problems, lack of preparation of medical professionals and carers, and the inadequateness of regulations on capacity to consent. In this regard, it is pointed out how in causing or fuelling these dynamics a determinant role is played by the vision of dementia and mental disability currently underpinning law and practice in this area.

³ See L Pickering Francis, 'Decision-Making at the End of Life: Patients with Alzheimer's or other Dementias' (2001) 35 *Georgia Law Review* 539, 542; Nuffield Council of Bioethics, *above*, 79; ME De Boer, 'Advance Directives in Dementia: issues of Validity and Effectiveness' (2009) *International Psychogeriatrics* 1, 2-3.

⁴ See for example J Gather and J Vollmann, 'Physician-Assisted Suicide of Patients with Dementia. A Medical Ethical Analysis with a special focus on Patient Autonomy' (2013) 36 *International Journal of Law and Psychiatry* 444, 446; T Mueller et al, 'Assessing Capacity to Consent to Treatment with Cholinesterase Inhibitors in Dementia using a Specific and Standardized version of the MacArthur Competence Assessment Tool (MacCAT-T)' (2017) 29 *International Psychogeriatrics* 333.

2. Dementia, prejudice and the label of incapacity

The word dementia derives from the Latin *dementia* (adj *demens*), which literally means ‘without mind’.⁵ So, from the outset it emerges what, in common perception, is regarded as the main characteristic of this disease: the loss of self and mental ability.

Swinton notes how various works in academic literature acknowledge that having dementia is often regarded as the same as ‘losing one’s mind’.⁶ Moreover, Fox lists a series of terms used by doctors, researchers and journalists in order to refer to dementia, such as ‘mind robber’, ‘never ending funeral’ or ‘slow death of the mind’.⁷ Cohen and Eisdorfer note how this condition may often be seen as causing a ‘dissolution of the self’.⁸ Beard, Knauss and Moyer, observe that ‘the dominant story told about people living with dementia has historically been one where their talk is deemed meaningless, their memories defective, and their recollections are of little importance’.⁹ So general attitudes towards these individuals tend to be characterised by negative assumptions and preconceptions on their capacity to think and have meaningful interactions with the world around them.¹⁰

This perception is also reflected in the field of healthcare decision-making. In this regard, prejudice is the first barrier hindering the right to choose of the person, as it leads to almost automatically ignore the individual’s statements, assuming they do not know what they are saying.¹¹ Indeed, doctors and carers still frequently equate a

⁵ See GJ Sterin, ‘Essay on a Word. A Lived Experience of Alzheimer’s Disease’ (2002) 1 *Dementia* 7.

⁶ J Swinton, *Dementia: Living in the Memories of God* (Eerdmans Publishing Company 2012), 54.

⁷ PJ Fox, ‘From Senility to Alzheimer’s Disease: The rise of the Alzheimer’s Disease Movement’ (1989) 67 *Milbank Quarterly* 58, 58. As examples see also M Clark et al, ‘A Slow Death of the Mind’ *Newsweek* (New York 3rd December 1984) 56; W Froelich, ‘Family’s Fate Turns on a Biological Roll of the Dice’, *San Diego Union* (San Diego 23rd June 1986); N Cutler, ‘Public Response: The National Politics of Alzheimer’s Disease’ in M Gilhooly, S Zarit, and J Birren (ed), *The Dementias: Policy and Management* (Prentice Hall 1986), 161.

⁸ D Cohen and C Eisdorfer, *The Loss of Self: A Family Resource for Care of Alzheimer’s disease and Related Disorders* (Norton 1986). See also A Fontana and RW Smith, ‘Alzheimer’s Disease Victims: The “Unbecoming” of Self and the Normalization of Competence’ (1989) 32 *Sociological Perspectives* 35.

⁹ RL Beard, J Knauss and D Moyer, ‘Managing Disability and Enjoying Life: How we Reframe Dementia through Personal Narratives’ (2009) 23 *Journal of Aging Studies* 227, 228.

¹⁰ RM Tappen, ‘Persistence of Self in Advance Alzheimer’s Disease’ (1999) 31 *Image, the Journal of Nursing Scholarship* 1, 1-2; L Snyder, ‘The Lived Experience of Alzheimer’s – Understanding the Feelings and Subjective Accounts of Persons with the Disease’ (2001) 2 *Alzheimer’s Care Today* 8, 9 and 11; NL Batsch and MS Mittelman (eds), *World Alzheimer Report 2012. Overcoming the Stigma of Dementia* (Alzheimer’s Disease International 2012), 7-29.

¹¹ KA Lyman, ‘Bringing the Social Back: a critique of the Biomedicalization of Dementia’ (1989) 29 *The Gerontologist* 597, 601.

diagnosis of dementia with incapacity to decide on care¹² and it is not rare to find, in the literature, statements simplistically affirming that people living with this condition cannot participate in choices about their care.¹³ Indeed, quantitative studies show how more than 50% of individuals with mild to moderate dementia tend to be judged as incapable to consent by their doctors.¹⁴ In fairness, a growing number of physicians are adopting a more nuanced and positive approach but they seem still far from the majority.¹⁵

This situation is criticised by organisations involved in dementia care. The Leeds Christian Council on Ageing states:

We have noticed that it is too easily assumed by the decision makers in providing care (as well as generally) that people with dementia are incapable of making choices and taking decisions [...] thereby ‘de-humanising’ them.¹⁶

Derse reports cases in which a surgical operation had to be performed on individuals with early stage Alzheimer’s Disease and the surgeon avoided talking to the person, considering more appropriate to discuss the details of the procedure only with the relatives.¹⁷ Indeed, as noted by Gillies, because of difficulties in comprehension and communication, the person with dementia tends to be assumed incompetent and unreliable.¹⁸ Also spouses and relatives often have prejudices against

¹² L Pickering Francis, *above*, 542; F Muije et al, ‘Mental Capacity Assessments among General Hospital Inpatients referred to a Specialist Liaison Psychiatry Service for Older People’ (2009) 21 *International Psychogeriatrics* 729, 732.

¹³ See for example EG DeRenzo, ‘Decisionally Impaired Persons in Research: Refining the Proposed Refinements’ (1997) 25 *Journal of Law Medicine and Ethics* 139; L Volicer, *End-of-Life Care for People with Dementia in Residential Care Settings* (Alzheimer’s Association 2005), 16; MR Gillick, ‘Doing the Right Thing: A Geriatrician’s Perspective on Medical Care for the Person with Advanced Dementia’ (2012) 40 *Journal of Law Medicine & Ethics* 51, 51.

¹⁴ DC Marson et al, ‘Consistency of Physician Judgments of Capacity to Consent in Mild Alzheimer’s Disease’ (1997) 45 *Journal of the American Geriatric Society* 453, 455-456; T Mueller et al, ‘Comparison of Three Different Assessments of Capacity to Consent in Dementia Patients’ (2015) 28 *GeroPsych* 21. Such results are mirrored in studies on consent to experimental treatments as shown by J Warner et al, ‘Participation in Dementia Research: Rates and Correlates of Capacity to give Informed Consent’ (2008) 34 *Journal of Medical Ethics* 167.

¹⁵ See among others K Hirschman et al, ‘Do Alzheimer’s Disease Patients Want to Participate in Treatment Decision, and would their Caregivers Let Them?’ (2005) 45 *The Gerontologist* 381.

¹⁶ Reported in Nuffield Council on Bioethics, *above*, 79; LM Miller, CJ Whitlatch and KS Lyons, ‘Shared Decision-Making in Dementia: a review of Patient and Family Carer Involvement’ (2016) 15 *Dementia* 1141, 1144–1146 and 1151-1153.

¹⁷ A Derse, ‘Making Decisions about Life-Sustaining Medical Treatment in Patients with Dementia’ (1999) 20 *Theoretical Medicine* 55, 55-56 and 61-63.

¹⁸ B Gillies, ‘The Experience of Living through Dementia’ (2001) 16 *International Journal of Geriatric Psychiatry* 111, 111. As shown by surveys like those by the English Care Quality Commission (CQC), there are hospitals and care structures in which staff is keen to listen to the person, but this does not happen everywhere. See CQC, *Time to Listen. In NHS Hospitals. Dignity and Nutrition Inspection*

their relatives living with dementia. In a study by Manthorpe, Samsi and Rapaport a nurse reports that ‘usually when we start having that conversation [carers] will say things like, “well [my mum] doesn’t know what she’s doing, she can’t make decisions”, even though this sort of scenario rather occurs only in the very late stages of the illness.¹⁹ Policy documents and reports by various European governments and NGOs affirm how, though there are signs of improvement, prejudice against people with dementia still largely characterises interactions between these individuals and professionals or lay persons.²⁰ For example, according to the French Government *Plan Maladies Dégeneratives 2014-2019* ‘the impairment of the brain and its consequences on the motor and cognitive functions creates particularly negative images, distant from the reality of the people affected and their carers’.²¹ The Norwegian Dementia Plan 2020 states that ‘social barriers can result in prejudice and needless isolation, and add to the impact of dementia’.²² Nonetheless, in various countries there are (few) cases of hospitals, care structures or health services in which there is, generally, a stronger openness to listen to the person without preconception, but also in such situations individuals living with dementia and care staff report difficulties in countering the scepticism and negative attitude of relatives or colleagues.²³

People living with dementia express frustration for such negative attitudes, confirming how they are really limit their possibility to make choices and shape their life. A person in the early stages of this condition, cited by Phillips, remarked: ‘the reality is that when diagnosed with Alzheimer’s, we are immediately discounted; our views are discredited because of the disease’.²⁴ Taylor, in the memoir of his experience

Programme 2012 (CQC 2013), 14-18 and CQC, *Time to Listen. In Nursing Homes. Dignity and Nutrition Inspection Programme 2012* (CQC 2013), 14-19.

¹⁹ J Manthorpe, K Samsi and J Rapaport, ‘Dementia Nurses’ Experience of the Mental Capacity Act 2005: a follow-up study’ (2014) 13 *Dementia* 131, 136.

²⁰ For a general overview see Batsch and Mittelman, *above*, 24-32.

²¹ Ministère des Affaires Sociales, de la Santé et des Droits des Femmes, *Plan Maladies Neuro-Dégénératives 2014-2019* (Dicom 2014), 56 <www.cnsa.fr/documentation/plan_maladies_neuro_degeneratives2014.pdf> accessed 5 July 2018.

²² Norwegian Ministry of Health and Social Care Services, *Dementia Plan 2020* (Ministry of Health and Care Services 2015), 17 <https://www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/dementia_plan_2020_long.pdf> accessed 5 July 2018.

²³ See for example KL Smebye, M Kirkevold and K Engedal, ‘How do Persons with Dementia Participate in Decision Making related to Health and Daily care? A multi-case study’ (2012) 12 *BMC Health Services Research* 1, 8-10; O St-Amant et al, ‘Making Care Decisions in Home-Based Dementia Care: why context matters’ (2012) 31 *Canadian Journal on Aging* 423, 428-431; Manthorpe, Samsi and Rapaport, *above*, 136.

²⁴ Opinion of a person with Alzheimer Disease taken from JM Phillips, ‘A Personal View of Living with Early-Onset Alzheimer’s’ (2000) 6 *Perspectives – A Newsletter for Individuals with Alzheimer’s Disease* 1, 2.

with Alzheimer Disease laments that he is often not taken seriously: ‘my behaviour is treated as something apart from me. “It’s not him, it’s the disease”’.²⁵ Davis, in his personal account, denounces the risks others’ attitudes pose for his autonomy: ‘I live with the imminent dread that one mistake in my daily life will mean another freedom will be taken from me’.²⁶ In a study by Cowdell, a woman with dementia, complains that she is consistently ignored by doctors and nurses during her hospital stay:

‘Don’t know what’s happening to me...do I stay here forever?...People never look and they never speak, the doctors and that they come in, there’s a reason for it but it’s not very satisfying’.²⁷

However, such prejudices do not seem to be experienced in the same way by all individuals living with dementia. Some authors maintain that the personal and social context in which a person living with dementia is embedded may impact on how they are perceived and perceive themselves.²⁸ Research in this area is still limited, so it is not possible to formulate general conclusions with regard to the precise impact of various social structures on treatment choices of people with dementia. However, elements emerging within the literature allow some tentative considerations.

The first variable cited by researchers is age.²⁹ As already noted in Chapter 1, the vast majority of individuals living with dementia are above 65.³⁰ These people might be subject not only to the stigma related to their condition but also to ageist attitudes according to which an older person is to be seen as less worthy of consideration or less capable than others.³¹ This might increase the risk that older individuals living with dementia are ignored in their opinions on treatment.

²⁵ R Taylor, *Alzheimer’s form the Inside Out* (Health Professions 2007), 150-151.

²⁶ R Davis, *My Journey into Alzheimer’s Disease* (Tyndale House 1989), 91.

²⁷ F Cowdell, ‘The Care of Older People with Dementia in Acute Hospitals’ (Alzheimer Society 2007), 10 < <https://pdfs.semanticscholar.org/f2a7/f8e1ff4f0e8d012a6f79c87c203cc9c02c56.pdf>> accessed 24 April 2018.

²⁸ See among others Snyder, *above*; D O’Connor, B Purves and M Down, ‘Decision Making and Dementia: toward a Social Model of Understanding’ in D O’Connor and B Purves (eds), *Decision Making, Personhood and Dementia. Exploring the interface* (Jessica Kinsley 2009); D O’Connor, A Phinney and W Hulko, ‘Dementia at the Intersections: A unique case study exploring Social Location’ (2010) 24 *Journal of Aging Studies* 30.

²⁹ R Cheston, ‘Stories and Metaphors: Talking about the Past in a Psychotherapy group for People with Dementia’, (1996) 16 *Ageing and Society* 579, 595; Snyder, *above*, 101.

³⁰ See *above* Chapter 1.

³¹ School of Nursing and Midwifery Trinity College Dublin, ‘Perceptions of Stigma in Dementia: An Exploratory Study’ (Alzheimer Society of Ireland 2006) 23-27; S Chester Evans, ‘Ageism and Dementia’ in L Ayalon and C Tesch-Römer (eds), *Contemporary Perspectives on Ageism* (Springer 2018).

In relation to gender, Bamford maintains that women living with dementia could be more subject to exclusion than men as, on top of age and dementia stigma, they have also to cope with the effects of gender discrimination, suffering a ‘triple jeopardy’.³² In their survey Mielke, Vemuri and Rocca show that many older women have still lower education and socialisation levels than men because of the gender role in which they used to be constricted in the past.³³ This could make them less well equipped to make sense and cope with dementia and to oppose biased behaviours.³⁴ Moreover, some maintain that women can be more inclined to hide their condition. For example Borley, Sixsmith, and Church report the experience of an older woman living with dementia expressing denial and struggling to accept to have passed from being the carer of the family, role traditionally given to women,³⁵ to someone who is cared for.³⁶ Also with regard to decisions on medical treatment, all these dynamics can make the person less resilient to stigmatizing behaviours and so more prone to hold back their opinions or to accept that others take control of the situation. However, men living with dementia may also feel under pressure to hide their problems and not accept help, even in decision-making, sticking to an idea of masculinity that demands strength in the face of adversities.³⁷

In a study involving eight older people with dementia of different social background and nationality, Hulko suggests that in families from the working class there could be a less negative view of dementia and the person could be less subject to disempowering prejudice with regard to care decisions.³⁸ This would happen both because the sense of social blame and conventions is less strong in such contexts and because here people face more difficulties in coping with practical issues, having less time to think about the existential implications of their condition.³⁹ However, on the

³² SM Bamford, *Women and Dementia - Not forgotten* (ILCUK 2011), 4 and 27 in <http://www.ilcuk.org.uk/files/pdf_pdf_191.pdf> accessed 10th June 2016.

³³ MM Mielke, P Vemuri P and WA Rocca, ‘Clinical Epidemiology of Alzheimer’s Disease: Assessing Sex and Gender Differences’ (2014) 6 *Journal of Clinical Epidemiology*, 37, 38-41.

³⁴ *Ibid*, 42.

³⁵ On this aspect see R Erol, D Brooker and E Peel, *Women and Dementia. A global research review* (Alzheimer’s Disease International 2015), 23-33.

³⁶ G Borley, J Sixsmith and S Church, ‘How does a Woman with Alzheimer’s Disease make sense of becoming Cared for?’ (2014) 15 *Dementia* 1405.

³⁷ See for example the personal account reported in S Wiedersehn, ‘Dementia challenges Idea of Masculinity’ *The Guardian (Australia)* (Sydney 15 Jun 2018) <www.theguardian.com.au/story/5471135/dementia-challenges-idea-of-masculinity/?cs=12> accessed 5 July 2018.

³⁸ W Hulko, ‘From “Not a Big Deal” to “Hellish”’: Experiences of Older People with Dementia’ (2009) 23 *Journal of Aging Studies* 132, 135-139.

³⁹ *Ibid*, 139-142.

other hand, people with low income might receive healthcare of lower quality, in which overburdened and poorly trained staff may ignore their wishes just because they do not have time to stop and listen or because they are unable to effectively communicate with the person.⁴⁰ Moreover, the cultural environment in which the person with dementia lives plays a role in their social consideration and the prejudice they face.⁴¹ In this regard, an empirical study by Hulko et al, on the self-perception of indigenous people living with dementia in Canada, shows how the approach of this community is more focused on understanding the positive animistic and metaphysical value of dementia, rather than on the problems relating to this condition.⁴² Also, because of their stronger sense of community, these people may react to these illness experiences by putting the person even more at the centre of attention giving to them a surplus of support and dialogue space.⁴³ As already pointed out, more research is needed to shed light on the exact impact of these factors, and a thorough analysis of these complex dynamics goes beyond the scope of this work. What is important here is to remark that the label of incapacity is not attached to everyone in the same way and it does not only depend on the cognitive abilities of the person, but also on a series of social structures in which the life of the individual with dementia is embedded.

One of the social structures which may contribute to create a negative prejudice towards people living with dementia and hence be a barrier to their ability to make treatment choices is the law. The fact that legal capacity legislation provides that if a person is not 'autonomous' or 'mentally capable', they can be deprived of the power to choose, puts people with dementia at risk of being ignored when they try to express their views. Indeed, it encourages people to think that it is acceptable and even right to consider meaningless the wishes of people showing difficulties in expressing themselves. Moreover, Harding, in her analysis of decisions by English courts on cases regarding people living with dementia, shows how judges tend to embrace a rather stigmatising attitude.⁴⁴ Indeed, their judgements often contain phrases such as '[the

⁴⁰ Department of Health, 'Dementia. A state of the Nation report on Dementia Care and Support in England' (Department of Health 2013) <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf> accessed 12 June 2016.

⁴¹ JN Henderson, 'The Experience and Interpretation of Dementia: Cross-Cultural Perspectives' (2002) 17 *Journal of Cross Cultural Gerontology* 195.

⁴² W Hulko et al, 'Views of First Nation Elders on Memory Loss and Memory Care in Later Life' (2010) 25 *Journal of Cross Cultural Gerontology* 317.

⁴³ *Ibid.*

⁴⁴ R Harding, 'Legal Constructions of Dementia: Discourse of Autonomy at the Margins of Capacity' (2012) 34 *Journal of Social Welfare and Family Law* 425, 437-440.

person's] present beliefs are not based in reality'⁴⁵ or 'many of her actions are not volitional',⁴⁶ without showing any efforts to understand what the person wants to say, maybe in 'uncommon ways'.⁴⁷ Because of this sometimes biased tendency of judges also people with mild dementia may end up being declared incapable to make healthcare choices. At that point the person is deprived of their power to directly decide on treatment, while choices will be made for them on the basis of previous statements (advance directives) or of their 'best interests' or 'hypothetical will' by a surrogate,⁴⁸ as it is explained in Section 3.

However, medical practitioners, scholars and people that have been close to individuals living with dementia affirm that they are often able to understand the substance of proposed medical treatments and to develop opinions on their therapy.⁴⁹ First of all, it has to be remembered that dementia is a progressive disease, which in the initial phases leaves intact many cognitive abilities and has a different impact from case to case.⁵⁰ Therefore, generalisations equating dementia with incapacity to decide appear without rational and scientific grounding. In effect, empirical studies in which researchers directly assess the capacity to consent of people with mild to moderate dementia judge these individuals as able to understand treatment information and communicate their choice in more than half of cases, contradicting the data relating to doctors' perceptions on the matter.⁵¹ However, some scholars argue that even people with more advanced dementia often express articulate opinions on medical issues regarding them.⁵² Post and Whitehouse note how even at this stage the person shows moments of lucidity in which they can relatively easily make decisions on care.⁵³

⁴⁵ *Dorset County Council v EH*, (2009) EWHC 784 (Fam) par 101.

⁴⁶ *Dorset County Council v EH*, *above*, par 128.

⁴⁷ Harding, 'Legal Constructions', *above*, 437.

⁴⁸ De Boer, 'Advance Directives', *above*, 2-3; J Herring, 'Best Interests and Dementia' and WC Schmidt, 'Proxy Decision-making: a Legal Perspective' both in C Foster, J Herring and I Doron (eds), *The Law and Ethics of Dementia* (Hart 2014).

⁴⁹ L Barth, 'Chronologie eines rechts- und verfahrensförmigen Sterbeprozesses' (2008) *Zeitschrift zum Altenpflegerecht* 1; Gather and Vollmann, 'Physician-Assisted', *above*, 446; C Emmett et al, 'Homeward Bound or Bound for a Home? Assessing the Capacity of Dementia Patients to Make Decisions about Hospital Discharge: Comparing Practice with Legal Standards' (2013) 36 *International Journal of Law and Psychiatry* 73. See also SM Behuniak, 'Toward a Political model of Dementia: Power as Compassionate Care' (2010) 24 *Journal of Aging Studies* 231.

⁵⁰ On this point P Bielby, *Competence and Vulnerability in Biomedical Research* (Springer 2008), 158-159.

⁵¹ J Warner et al, 'Participation in Dementia Research: Rates and Correlates of Capacity to Give Informed Consent' (2008) 34 *Journal of Medical Ethics* 160; Mueller et al, *above*.

⁵² Barth, *above*, 1; Gather and Vollmann, 'Physician-Assisted', *above*, 446; Behuniak, *above*, 231.

⁵³ SG Post and PJ Whitehouse, 'Fairhill Guidelines on Ethics of the Care of People with Alzheimer's Disease: a Clinical Summary' (1995) 43 *Journal of the American Geriatric Society* 1423.

Therefore, in a statement reported by Livingston et al, the wife of a man living with dementia expressed relief that she had followed the actual indications of her husband with regard to a heart operation:

“We weren’t in agreement with each other...whether to have a heart operation...With hindsight...it was the right decision...he decided...it made his mental abilities much worse, but physically, he’s much better”⁵⁴

In a German legal case, a woman living with severe dementia, though not remembering the technicalities of the procedure, showed a firm will of refusing artificial nutrition as she was asked her opinion several times in five years and every time confirmed, referring to her inability to hear and to see “I want to die. This is not life anymore”.⁵⁵ Also, in an interview reported by Sabat a woman with moderate Alzheimer’s Disease showed a well argued opinion on how her care needed to be managed:

‘Interviewer: It didn’t give you the feeling that going back and doing some kind of speech therapy would be helpful to you?

Dr. M: No [...] It’s gotten, I know what my trouble is. And I think that what I would like it uh, only if there’s something that is, uh, a time, a uh, a time and with a person who there is a real (gestures back and forth with hands).

Interviewer: Back and forth – a relationship.

Dr. M: Um hum.

Interviewer: Let me back up for a second because I think I’m missing your point.

You don’t want your life to be . . .

Dr. M: Going always to see people to see what’s wrong with me.’⁵⁶

A number of nurses, doctors and relatives confessed how they would feel uncomfortable in disregarding such expressions of will of the person with dementia.⁵⁷

⁵⁴ G Livingston et al ‘Making Decisions for People with Dementia who lack Capacity: Qualitative Study of Family Carers in the UK’ (2010) 341 *British Medical Journal* 6.

⁵⁵ AG Siegen, 28.09.2007 reported in (2008) 7 *Gesundheitsrecht* 247.

⁵⁶ R Sabat, ‘Surviving Manifestations of Selfhood in Alzheimer’s Disease. A Case Study’ (2002) 1 *Dementia* 25, 30

⁵⁷ Derse, *above*.

Indeed, dismissing such statements as the utterances of an incapable individual, relying instead on previous declarations or the decisions of relative and guardians seems unjust and oppressive of the person's right to decide on medical treatment. Yet, this is what happens regularly in healthcare and legal practice, in which the opinions of the person living with dementia are set aside and decisions are made on the basis of their advance directives, best interests or presumed will. As However, the use of such tools in the case of individuals living with this condition results legally, ethically and practically problematic. In this regard, they have been at the centre of a vibrant debate in which scholars have pointed out the difficulty of justifying a system leading to disregard statements which, though formulated by a person living with dementia, seem relatively well articulated and representative of their will. In the next chapter I analyse more closely such a debate, showing how it makes further clear the necessity of changing the current approach based on a distorted vision of the person living with dementia.

3. Advance Directives and Surrogate Decision-Making

Advance directives are traditionally defined as legal declarations containing instructions about care and medical treatment (in terms of both consent and refusal) set up by a person when they have capacity to consent for the time in which they will be incapable.⁵⁸ These anticipated intentions can be conveyed through various means of advance care planning. They can be oral statements complying with specific requirements of legal validity, signed written documents with different levels of formality (*living wills*), or they may assume the form of conditions and attributions of powers and tasks within a lasting power of attorney (LPA) or directed at a proxy or judicially appointed guardian or deputy.⁵⁹ Depending on the jurisdiction, one or more of these advance care planning tools may be available to a person.⁶⁰ Because of the way in which they enter into force they are typically used for establishing the care wishes of a person in case they develop a degenerative condition like dementia.

⁵⁸ SP Shapiro, 'Do Advance Directives Direct?' (2015) 40 *Journal of Health Politics, Policy and Law* 487, 492; M Brazier and E Cave, *Medicine, Patients and the Law* (6th ed, Manchester University Press 2016), 176.

⁵⁹ H Nys, 'Anticipatory Decision Making and Incompetent Patients. Recent Developments in Europe' (1997) 16 *Medicine and Law* 1, 4-5; FG Pizzetti, *Alle Frontiere della Vita: il Testamento Biologico tra Valori Costituzionali e Promozione della Persona* (Giuffrè, 2008); M Winkler, *Vorsorgeverfügungen: Patientenverfügung, Vorsorgevollmacht, Betreuungs- und Organverfügung* (Beck 2016).

⁶⁰ Nys, *above*, 4-5; Pizzetti, *above*, 493-545.

However, the debate among legal scholars and philosophers originated in the 1990s, starting from a series of clinical cases, has posed doubts on their effectiveness in this context.

In 1991, Andrew Firlick, then a medical student, published a short one page piece in the *Journal of the American Medical Association (JAMA)*, reporting his experience with a patient whom he calls Margo. He writes:

‘I met Margo last summer during a gerontology elective after my first year in medical school. Margo has Alzheimer’s disease. Like her body, her mind is shrinking [...] Margo enjoys reading, especially mysteries, she says, though I’ve noticed that her place in the book jumps randomly from day to day [...]. Maybe she feels good just sitting and humming to herself, rocking back and forth slowly, nodding off liberally, occasionally turning to a fresh page [...]. Margo confused me [...]. Despite her illness, or maybe somehow because of it, Margo is undeniably one of the happiest people I have known. There is something graceful about the degeneration her mind is undergoing, leaving her carefree, always cheerful. [...] How does Margo maintain her sense of self?’⁶¹

This excerpt caught the attention of philosopher Ronald Dworkin, who in his book *Life’s Dominion*, poses the following question; let suppose that Margo, before developing dementia, had issued an advance directive asking to avoid curing her in case she gets this condition: what has to be done by doctors, relatives and carers?⁶² Do they have to follow the advance directive, risking to cause the death of someone who seems perfectly happy to continue to live? Or do they have to keep treating Margo, ignoring her advance directive? Does an individual’s right to autonomy include the power to dictate that a certain medical treatment be not performed on them even though once they have dementia they plead for it?⁶³

Such questions apply not only to the case in which the person has signed an advance directive, but also when there is no anticipated statement. They involve the wider problem of whether the opinions of people living with dementia have validity

⁶¹ A Firlick, ‘Margo’s Logo’ (1991) 265 *Journal of the American Medical Association* 201, 201.

⁶² R Dworkin, *Life’s Dominion. An Argument about Abortion and Euthanasia* (Harper Collins 1993), 218-241. Some of the themes at the centre of this chapter had already been discussed in R Dworkin, ‘Autonomy and the Demented Self’ (1986) 64 *The Milbank Quarterly* 4.

⁶³ Dworkin, *Life’s Dominion*, above, 221.

and must be followed or whether other means should be used to make the decision including not only advance directives, but also the transfer of decisional power to a surrogate who decides in the person's best interest.

The trenchant solution proposed by Dworkin starts from the liberal 'integrity view' and is in line with the traditional model of advance directives, underpinning many national legislations, as a declarations which substitute the person when they have been declared incapable to consent.⁶⁴ He affirms that recognising the autonomy of people with advance stage dementia does not make any sense, as they are not capable of appropriately deciding on their care.⁶⁵ Indeed, such a recognition would be justified only to the extent that it allows the individual to express an overall vision of their life. However, though they may have an opinion on single choices or on what gives to them immediate pleasure (*experiential interests*), people with dementia would lack the ability to cultivate the *critical interests* necessary to coherently plan their lives according to what they consider right and valuable.⁶⁶ Therefore, their current will has to be disregarded and instead the wishes should be enforced that they expressed before developing their condition.⁶⁷

Such a position has been widely criticised. Dresser notes how Dworkin fails to consider that even many individuals without a cognitive impairment live their life day by day, without following a coherent plan.⁶⁸ She asserts that a lot of people do not have a clear idea on how their care should be managed when they become ill and they change plans all the time.⁶⁹ Moreover, the subjective experience of dementia is often more positive than it may seem from the outside and the person's quality of life tends to depend more on the environment around them than on their cognitive impairment.⁷⁰

⁶⁴ *Ibid*, 224-225.

⁶⁵ *Ibid*, 225-226.

⁶⁶ *Ibid*, 229-231.

⁶⁷ *Ibid*, 231-232.

⁶⁸ R Dresser, 'Dworkin on Dementia: Elegant Theory, Questionable Policy' (1996) 25 *Hastings Center Report* 32, 35-36. This element of people's approach to decisions in general is also stressed by M Friedman, *Autonomy Gender Politics* (Oxford University Press, 2006), 39.

⁶⁹ Dresser, 'Dworkin', *above*, 34. Surveys carried on in the US show that a relatively small percentage of individuals issue advance directives and even in such a case a lot of people are in favour of giving their families or doctors a certain power to overrule their will. A Sehgal et al, 'How Strictly do Dialysis Patients want their Advance Directives Followed?' (1992) 267 *Journal of the American Medical Association* 59.

⁷⁰ Dresser, 'Dworkin', *above*, 34; H Series, 'The Happy Dementia Patient', in Foster, Herring and Doron (eds), *above*, 105-110.

Jaworska, starting from the concept of autonomy as ability to value, claims that people living with dementia often have the capacity to make choices on their care.⁷¹ Indeed, even though they may not be able to form an overall vision of their life, they still cultivate stable critical interests that go beyond the pursuit of their immediate pleasure.⁷² As shown by real life cases, they are able to feel concerned about being a burden to their relatives or about the existential experience of their condition, and some of them decide to volunteer as research participants because they want to contribute to improve others' lives: all behaviours showing a commitment to values such as love for the family or community wellbeing.⁷³ They can also have strong feelings about their right to live independently, though they may need others' assistance in order to understand how to concretely realise this.⁷⁴ The traditional approach to advance directives constitutes a barrier to the expression of such concerns and feelings as it demands to ignore them in order to follow what indicated in the anticipated declaration.

As noted by Donnelly, this approach is also flawed from a more technical point of view as it assumes that anticipated and contemporaneous decisions can be treated in the same way.⁷⁵ However, as argued by Buchanan, they are different in at least three important aspects. First, when expressing an anticipated will the person cannot be aware of future progresses in medicine or more effective treatments that may be available at the moment in which the decision will have to be enforced. Second, it is at least debatable that a healthy person, is really able to grasp how it would feel living with a chronic condition. Third, in making an advance decision the person may not have the possibility of consulting widely with others and seek advice.⁷⁶

For this reason, a number of commentators argue that while it is justifiable to promote the contemporaneous autonomy of a person, there is no real theoretical justification for giving precedence to the past wishes of a person living with dementia

⁷¹ A Jaworska, 'Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value' (1999) 28 *Philosophy and Public Affairs* 105.

⁷² *Ibid*, 113-131.

⁷³ *Ibid*, 113-115 and 117-119.

⁷⁴ *Ibid*, 126-128. Such arguments resound with what emerging from the experience of doctors, nurses and relatives seen in Section 1.

⁷⁵ M Donnelly, 'Developing a Legal Framework for Advance Healthcare Planning: Comparing England & Wales and Ireland' (2017) 24 *European Journal of Health Law* 67, 69.

⁷⁶ A Buchanan, 'Advance Directives and the Personal Identity Problem' (1988) 17 *Philosophy and Public Affairs* 277, 278-283.

over their present will.⁷⁷ Indeed, such individuals cannot be considered as the same person they used to be because many of the links between them and their past self have gone. However, even if claiming that the person living with dementia remains the same person in their embodied and social dimension, equally valued and worthy of respect by the people surrounding them throughout the course of their life, one has to admit that they have distinctive opinions and interests that need to be respected even though they appear different than those they used to have before.⁷⁸ Therefore, in light of the considerations reported above, the barriers which the traditional approach to advance directives poses to the person ability to express their wishes seem not justifiable and appear even more worthy of being removed.

This appears even truer in light of the significant practical limitations and challenges posed by advance directives and identified by researchers and practitioners within and outside the field of dementia care. Indeed, as noted by Fagerlin and Schneider, people normally release such declarations much before they even develop the condition mentioned in them, having just a superficial understanding of it, derived from impressions and non-verified assumptions.⁷⁹ At this stage it is also difficult to foresee which treatments and practices may be needed at the moment the person develops a certain condition.⁸⁰ Therefore, it may be very difficult to provide sufficiently adequate instructions on the treatments the individual wishes to refuse or accept, leaving often significant doubts to doctors, proxies or relatives on whether a specific directive is really applicable to the concrete case or whether the person would have asked for different things had they signed the declaration in a different moment.⁸¹ This dynamic is aggravated by the fact that such documents are written by the person

⁷⁷ See also JA Robertson, 'Second Thoughts on Living Wills' (1991) 21 *Hastings Center Report* 7; Dresser, 'Dworkin', *above*, 35; A Maclean, 'Advance Directives, Future Selves and Decision-Making' (2004) 14 *Medical Law Review* 291, 297-303; J Herring, 'Losing it? Losing What? The Law and Dementia' (2009) 21 *Child and Family Law Quarterly* 3, 18-20. Others like Buchanan, *above*, 285-286 use an extreme version of the theory to draw the morally debatable conclusion that people living with dementia have no personhood and thus no interests and rights to be respected.

⁷⁸ See the reconstruction proposed by JC Hughes, 'Views of the Person with Dementia' (2001) 27 *Journal of Medical Ethics* 86; Nuffield Council on Bioethics, *above*, xviii.

⁷⁹ A Fagerlin and CE Schneider, 'Enough. The Failure of the Living Will' (2004) 34 *Hastings Center Report*, 33-34.

⁸⁰ MJ Thiel, 'Personal Capacity to Anticipate Future Illness and Treatment Preferences' in P Lack, N Biller-Andorno and S Brauer (eds), *Advance Directives* (Springer 2014), 17-35.

⁸¹ S Bonner, M Tremlett and D Bell, 'Are advance Directives Legally Binding or Simply the Starting Point for Discussion on Patients' Best Interests?' (2009) 339 *British Medical Journal* 1230. See also J Gather and J Vollmann, 'How to Decide? Evaluating the Will of a Person with Dementia in the Light of Current Behavior, Advance Directive and Legal Representatives' Perspectives' (2015) 28 *Journal of Gerontopsychology and Geriatric Psychiatry* 17.

in isolation, which means not only that the individual often does not have the opportunity of adequately gather information, being challenged on their false convictions or discussing choices, but also that people around them are not fully aware of his or her opinions and views on care, being unable to interpret or reconstruct their will when the moment comes.⁸² Finally, with specific regard to dementia, it may be difficult to establish when the advance directive enters into force. Indeed, in the individual living with dementia, mental abilities do not disappear all of a sudden, but they rather fade away gradually, making difficult to establish at what point the person becomes incapable.⁸³ For all these reasons, advance directives, rather than promoting the will of the person, appear as a barrier to its correct interpretation. Indeed, they provide a legal mechanism that, because of the distance between anticipated declaration and moment of the choice, and because of the difficulties in recording a person's specific wishes, risks to create more doubts than it would solve.

Similar issues emerge when an advance directive is not available and the will of the person needs to be reconstructed by a surrogate. With regard to European legal systems two main paradigms of surrogate decision making exist: best interests and reconstruction of will and preferences or presumed will (also known as substituted judgement). The former is generally described as an 'objective' standard as it looks at what would be 'objectively better' for the person in light of supposedly factual considerations.⁸⁴ As noted by Miola, such considerations also keep an eye on subjective elements and possible desires of the person,⁸⁵ but such evaluations are analysed and may be set aside in light of what is thought to be the 'welfare' of the person. The presumed will mechanism requires the identification of how the person, if capable, would have made the decision, trying to infer their hypothetical wishes from elements such as previous statements of the person, their values, their personality,

⁸² Fagerlin and Schneider, *above*, 35-36; DI Shalowitz, E Garrett-Mayer and D Wendler, 'The Accuracy of Surrogate Decision Makers. A Systematic Review', (2006) 166 *Archives of Internal Medicine* 493, 493-497.

⁸³ Derse, *above*, 59-61; A Qureshi and A Jori, 'Issues Involving Informed Consent for Research Participants with Alzheimer's Disease' (2008) 6 *Journal of Academic Ethics* 197, 202. See also House of Lords, *Mental Capacity Act 2005: Post-Legislative Scrutiny* (The Stationery Office 2014), 32. For a broader discussion of this issue see also Section 5.

⁸⁴ On the definition of best interests see HJ Taylor, 'What are 'Best Interests'? A critical evaluation of 'Best Interests' Decision-Making in Clinical Practice' (2016) 24 *Medical Law Review* 176, 179-186.

⁸⁵ J Miola, 'Proxy Decision-Making' in Foster, Herring and Doron (eds), *above*, 150-152 and 154-157. See also J Herring, 'Best Interests and Dementia' in Foster, Herring and Doron (eds), *above*, 302-305.

habits or previous similar choices.⁸⁶ Depending on the jurisdiction one or the other paradigm may be adopted, or even there could be combined models which, for example, require the surrogate to decide in the person's best interest but 'taking into account' the person's previous wishes.⁸⁷ Anyway, all these models present significant challenges in relation to dementia and treatment decisions.

Indeed, in relation to best interests, especially in choices so intimate such as those on care it could be difficult to establish what is 'good for a person' in absolute terms.⁸⁸ In this regard contrasting views can be presented by doctors, relatives or other people around the individual.⁸⁹ Moreover, the concept of 'best interest' of the individual living with dementia seems to presuppose that someone knows better than the person what has to be done and can impose it on them from the outside. For this reason, the best interest model appears rather paternalistic and constitutes a strong barrier to the consideration of the genuine wishes of the person.⁹⁰ Indeed, it leaves much room for the person's desires to be disregarded in favour of other evaluations pertaining to the individual's 'objective wellbeing'. In this sense, substituted judgement seems more respectful of the person's autonomy as it relies on their statements and behaviours. However, reconstructing the will of the person might be far from easy, for example because of the cognitive fluctuations and changes of opinion, which may leave contradictory signs of what their real wishes are.⁹¹ Moreover, as noted by Fagerlin and Schneider relatives and friends of the person have often a very poor knowledge of their intimate care intentions: this can be a significant obstacle to a correct reconstruction of such intentions.⁹² Therefore, also in this field there is the need of a model which,

⁸⁶ A Buchanan and DW Brock, *Deciding for Others. The Ethics of Surrogate Decision-Making* (Cambridge University Press 1989), 112-116.

⁸⁷ For example, the English Mental Capacity Act adopts a best interests standard attenuated by subjective elements such as the consideration of the person's values and past wishes (see section 4 MCA), but at least for how it is applied it substantially remains an 'objective' paradigm. See Herring, 'Best Interests', *above*, 302-305. On the contrary legislation in Germany adheres more to a substituted judgement scheme, see R Coeppicus, *Das "Gesetz über Patientenverfügungen" und Sterbehilfe: Wann sind die Umsetzung von Patientenverfügungen und eine Sterbehilfe rechtmäßig?* (Ecomed 2010), 71-73.

⁸⁸ Taylor, 'What are', *above*, 183.

⁸⁹ See for example R McDougall, 'Best Interests, Dementia, and End of Life Decision-Making: the case of Mrs S' (2005) 24 *Monash Bioethical Review* 36. See also S Holm, 'Autonomy, Authenticity, or Best Interest: Everyday Decision-Making and Persons with Dementia' (2001) 4 *Medicine, Health Care and Philosophy* 153, 156.

⁹⁰ See among others GB Weiss, 'Paternalism Modernised' (1985) 11 *Journal of Medical Ethics* 184, 184; AG Tuckett, 'On Paternalism, Autonomy and Best Interests: telling the (competent) Aged-Care Resident what they Want to Know' (2006) 12 *International Journal of Nursing Practice* 166, 168-169.

⁹¹ Miola, *above*, 149-150.

⁹² Fagerlin and Schneider, *above*, 35-36.

giving primacy to the person wishes would make their interpretation and reconstruction easier. In chapter 4, I will show how such a model may be seen to emerge in Article 12 UN Convention on the Rights of Persons with Disabilities and in Chapter 7 I will look at promising practices which go towards the concrete realisation of such a more practical approach.

4. Challenges in communication and the decisional process

Previous sections have shown how the view of people living with dementia as inevitably incapable individuals who have to be substituted in treatment choices is in many cases not in line with reality and creates barriers hindering the person's right to decide. However, even if one accepts that these people are able to form an opinion on medical treatment, it is also evident how there are a number of practical obstacles impacting on their possibility of exercising their power to choose. Indeed, even convinced supporters of these individuals' right to decide on medical treatment admit that making sure they grasp the implications of their choices and that these are correctly understood can be often difficult.⁹³ Such difficulties are analysed in this section, which points out that, though the impairment of the person plays a role in creating them, what really produces such barriers is that professionals, carers and the current approach to healthcare choices are not adequately responsive to the needs of people living with dementia.

The first and most frequent barrier relates to the lack of tools to manage the individual's impairment of memory. Because of memory loss, the person living with dementia may not remember crucial elements relating to a proposed treatment.⁹⁴ These gaps may appear quite extensive already in individuals living with moderate dementia, so that they do not seem to recall, for example, what does a certain medication treat, what the collateral effects of a certain procedure are, or how it will be performed.⁹⁵

⁹³ P Higgins, 'Involving People with Dementia in Research' (2013) 109 *Nursing Times*, 20; R Pratt, 'Nobody's ever Asked me How I Felt' in H Wilkinson (ed), *The Perspectives of People with Dementia: Research Methods and Motivations* (Jessica Kingsley 2002); Derse, *above*, 59.

⁹⁴ S Kim et al, 'Assessing the Competence of Persons with Alzheimer's Disease in Providing Informed Consent for Participation in Research' (2001) 158 *American Journal of Psychiatry* 712, 715-716; M Gatz, 'Cognitive Capacities of Older Adults who Are asked to Consent to Medical Treatment or to Clinical Research' (2006) *Behavioral Sciences and the Law* 462, 466-468; LM Fields and JD Calvert, 'Informed Consent Procedures with Cognitively Impaired Patients: A review of ethics and best practices' (2015) 69 *Psychiatry and Clinical Neurosciences* 462, 466-468.

⁹⁵ See also Bielby, *above*, 158-160.

People living with this condition can also seem not up to date about the current state of medicine, which could make it difficult for them to understand even simple information on medications.

Equally, the person may not remember facts of general life which can play a role in medical decisions.⁹⁶ Therefore, for example, they may refuse relocation in a nursing home or accept an invasive treatment assuming that they will be assisted in the recovery by their partner, who in reality has passed away. A similar effect may have, in dementia with Lewy-bodies, hallucinations.⁹⁷ Indeed, such hallucinations are often well formed, featuring people, children or animals, and being accompanied by related phenomena like passage hallucinations or sense of presence depicting in the person's mind a parallel reality which conditions their choices.⁹⁸

At times, due to the gaps in short-term memory and executive functioning, people living with dementia may not realise that they need care or treatment.⁹⁹ Indeed, they can be unaware of their memory problems, impacting on their ability to make conscious decisions on medications such as cholinesterase inhibitors.¹⁰⁰ In other cases, involving individuals who had received an explicit dementia diagnosis, the consciousness of memory problems may have the effect of weakening the person's self-confidence, making them unsure on their opinions on treatment.¹⁰¹ Moreover, these individuals may have a scarce drive towards dealing with questions relating to their healthcare as they try to focus more on the present and on the positive aspects of

⁹⁶ S Holm, *above*, 155. The importance of being aware of the context in which medical decisions are made and their wider repercussions is pointed out by many experts such as J Drane, 'The Many Faces of Competency' (1985) 15 *Hastings Center Report* 17, 18-21; T Grisso and PA Appelbaum, *The Assessment of Decision-Making Capacity: A Guide for Physicians and Other Health Professionals* (Oxford University Press 1998), 42-54; LC Charland, 'Decision-Making Capacity' *Stanford Encyclopedia of Philosophy* (2011) < <https://plato.stanford.edu/entries/decision-capacity/#InfCon> > accessed 28 June 2018; Fields and Calvert, *above*, 466.

⁹⁷ See Chapter 1 section 2.

⁹⁸ IG McKeith et al, 'Diagnosis and Management of Dementia with Lewy Bodies. Fourth Consensus Report of the DLB Consortium' (2017) 89 *Neurology* 88, 89.

⁹⁹ Snyder, *above*, 10-11.

¹⁰⁰ S Cosentino, 'Memory Awareness Influences Everyday Decision Making Capacity about Medication Management in Alzheimer's Disease' (2011) *International Journal of Alzheimer's Disease* 1, 61-62.

¹⁰¹ C Goodman et al, 'Preferences and Priorities for Ongoing and End-of-Life Care: A Qualitative Study of Older People with Dementia resident in Care Homes' (2013) 50 *International Journal of Nursing Studies* 1639.

their lives.¹⁰² Indeed ignoring one's condition and a potentially difficult future is a widespread coping mechanism adopted by people living with dementia.¹⁰³

However, these appear as the sort of problems that could be avoided or greatly mitigated by reminding the person of things they may not recall or by explaining treatment information in simpler terms or by rectifying misunderstandings.¹⁰⁴ Unfortunately, according to empirical studies on capacity assessments in clinical settings, medical and legal professionals tend to assume that they have to limit to what they see at first sight, without asking themselves what would happen if the person were helped in understanding and reasoning on the implications of the proposed medication.¹⁰⁵ Therefore, also memory gaps or misunderstandings which could be accommodated with a little bit more of explanation become elements leading to the deprivation of the person's power to decide, and this just because care staff is not providing appropriate help, erecting a barrier to the full expression of the person's will.

In this regard, also the majority of national legislations on the matter do not require to actively help the person before declaring someone incapable.¹⁰⁶ Even those, like the English Mental Capacity Act 2005, who contain such norms (section 3) are often not faithfully applied.¹⁰⁷ In addition, in the last decades in many European countries legal capacity reforms have been enacted based on the principle that the person needs to be helped in making decisions rather than substituted.¹⁰⁸ However, many of them still allow the possibility that choices can be made for the person when support is not sufficient or when this is in line with their best interests. These approaches leave the door open to substitution even when the person would simply need support or an arrangement more in line with their needs.

¹⁰² K Bronner et al, 'Which Medical and Social Decision topics are important after Early Diagnosis of Alzheimer's Disease from the perspective of People with Alzheimer's Disease, Spouses and Professionals?' (2016) 9 *BMC Research Notes* 1.

¹⁰³ On this see M De Boer et al, 'Suffering from Dementia – the Patient's Perspective: a review of the literature' (2007) 19 *International Psychogeriatrics* 1021, 1030-1031.

¹⁰⁴ JE Soukup, *Alzheimer's Disease. A Guide to Diagnosis, Treatment, and Management* (Praeger 1996), 110-112 e 153-155; M. Giampieri, 'Communication and informed consent in elderly people' (2012) 78 *Minerva anesthesiologica* 236, 237-238.

¹⁰⁵ Marson, 'Consistency', *above*; Mueller et al, *above*.

¹⁰⁶ See for example Article 2 of the Italian Civil Code or the Spanish Ley 41/2002. For a summary of European legislations on legal capacity and capacity to consent to medical treatment see <<http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2016-Decision-making-and-legal-capacity-in-dementia>> accessed 24 April 2018.

¹⁰⁷ House of Lords, *above*, 32.

¹⁰⁸ For an overview of these legislations see <www.international-guardianship.com/guardianship.htm> accessed 26 July 2018.

Indeed, in reality, the effectiveness of the disclosure is often jeopardised by the fact that it happens in noisy environments as hospital wards often are, or while parallel conversations are taking place in the same room, a situation which makes it difficult for a person with dementia to take up information.¹⁰⁹ Moreover, Cowdell reports how care staff often tend to ‘bombard’ their patients with information without giving them the time to process it and using in some cases quite dismissive and even aggressive manners.¹¹⁰ In this regard, apart from difficulties relating to the management of memory gaps, another significant barrier to the right of people living with dementia to decide on medical treatment comes from the way in which doctors and carers communicate with them.

Issues in communication are identified as a problem in the vast majority of cases reported in empirical studies on decision-making in dementia care, independently from the geographical area or the care setting.¹¹¹ This problem is strongly felt by people living with dementia, as it is evident from the statement of a man with this condition, reported by Hulko:

‘Well, having um a difficulty coming out with the right words for example or phrases or um having difficulty with uh numbers and um dates, times, um having difficulty coming up with um, difficulty um, coming up with just a common expression uh, or um even words that are very frequently used by anyone without the disease and um having difficulty coming up with just ordinary expressions’.¹¹²

¹⁰⁹ M Truscott, ‘Life in the Slow Lane’ (2004) 4 *Alzheimer’s Care Quality* 11, 16; Cowdell, *above*, 7; E Bouchard Ryan, KA Bannister and AP Anas, ‘The Dementia Narrative: Writing to Reclaim Social Identity’ (2009) 23 *Journal of Aging Studies* 145, 149.

¹¹⁰ Cowdell, *above*, 8.

¹¹¹ See for example G Livingston et al, ‘Making Decisions for People with Dementia who Lack Capacity: qualitative study of family carers in UK’ (2010) 341 *British Medical Journal* 1; Smebye, Kirkevold and Engedal, *above*; R Daly, F Bunn and C Goodman, ‘Shared Decision-Making for People living with Dementia in Extended Care Settings: protocol for a systematic review’ (2016) 355 *British Medical Journal* 1; L Groen-van de Ven et al, ‘The challenges of shared decision making in dementia care networks’ (2016) 28 *International Psychogeriatrics* 1; E Mariani et al, ‘Shared Decision-Making in Dementia care planning: barriers and facilitators in two European countries’ (2017) 21 *Aging Mental Health* 31.

¹¹² Hulko, *above*, 136.

A woman with early stage Alzheimer's notes: 'I lose one word and then I can't come up with the rest of the sentence'.¹¹³ Another man says: 'for a while I search for a word and I can see it walking away from me. It gets littler and littler. It always comes back, but at the wrong time'.¹¹⁴ Because of such issues doctors, carers or relatives may have difficulties in understanding what the person wants in terms of medical treatment.¹¹⁵ Moreover, the conversation about a certain treatment choice may be made difficult by the person's deficit of attention, which leads them to lose the flow of the conversation even when minor distractions occur.¹¹⁶

Another element which may create issues in understanding the person's will is related to their tendency to change idea and apparently contradict themselves. Indeed, individuals living with dementia may often not be able to recall their previously expressed wishes or the reasoning and rationale beyond them.¹¹⁷ Holm notes how their desires can be quite instable, so if their attention is diverted even for a short period of time, they may forget needs that they once thought very important.¹¹⁸ Moreover, because of the fluctuations in their cognitive abilities they may appear completely unable to participate in the moment in which a consultation is planned, while being perfectly lucid the day after.¹¹⁹ These dynamics may create considerable uncertainties in the interpretation of the person's will, so that the people around them may misunderstand their wishes or may renounce to even start a conversation with the person, assuming that understanding their statements will be in any case too difficult. In addition, such dynamics may push medical professionals towards choices conditioned by the fear of being accused of performing treatments legitimised by unclear declarations, rather than on the willingness to enact the person's own choice.¹²⁰

¹¹³ M Trabert, 'The DRC Club' (1997) 2 *Perspectives – A Newsletter for Individuals with Alzheimer's Disease* 7, 7.

¹¹⁴ Reported by L Snyder et al, 'Supportive Seminar Groups: and Intervention for Early Stage Dementia Patients' (1995) 35 *The Gerontologist* 691, 694.

¹¹⁵ Livingston, *above*.

¹¹⁶ JE Soukup, *above*, 109-114; C Kennard, 'Talking to People with Dementia, <http://alzheimers.about.com/od/frustration/a/talking_dementi.htm> accessed 7 November 2014.

¹¹⁷ Holm, *above*, 155.

¹¹⁸ *Ibid*.

¹¹⁹ M Trachsel, H Hermann and N Biller-Andorno, 'Cognitive Fluctuations as a Challenge for the Assessment of Decision-Making Capacity in Patients with Dementia' (2015) 30 *American Journal of Alzheimer's Disease and Other Dementias* 360, 361.

¹²⁰ H Helmchen and H Lauter (ed), *Dürfen Ärzte mit Demenzkranken forschen?* (Thieme 1995) 41-42; P Gallagher and K Clark, 'The Ethics of Surgery in the Elderly Demented Patient with Bowel Obstruction' (2002) 28 *Journal of Medical Ethics* 105, 106. See also SM Benbow et al, 'Mentally Incapacitated Adults and Decision Making: implications of the Law Commission consultation paper for old age psychiatrists' (1992) 16 *Psychiatric Bulletin*, 740-742.

However, also in this case the problems reported above seem to arise or be substantially aggravated because of contextual factors such as excess of background noise or a communication pace which does not leave time to the person to process the information received.¹²¹ In this regard, the source of many misunderstandings and ignoring behaviour against people living with dementia seems to be poor training of carers and doctors. Harding reports a series of statements by informal carers showing how staff of care structures often lack an adequate knowledge of dementia or how they do not take into account the needs of the person.¹²² In her empirical study, an informal carer of a woman with dementia complains: ‘in her first admission nursing staff seemed not to understand anything at all about dementia’.¹²³ Another who was caring for a man with the same condition lamented ‘during his stay in hospital I visited my dad twice a day, this was because they did not understand his needs’.¹²⁴ In this regard, specific and robust training on social aspects of dementia and on communication with individuals living with cognitive impairments tends still to be generally absent or too limited throughout Europe.¹²⁵ Moreover, here too legal capacity legislations do not offer any help. Indeed, there is no specific norm imposing that conversations on treatment decisions are carried on by professionals specifically trained on how to interact with an individual living with a certain condition.

Poor interactions and poor communication with the person living with dementia may increase the frailty of the individual and the risk of them being exposed to harmful and abusive behaviours on behalf of people around them. Indeed, already because of their cognitive difficulties they can feel unsure of themselves and hence be more prone to go along with the opinions of others, even if they do not agree with them.¹²⁶ The fact that the person is ignored, or that their doctors, nurses or carers appear to not understand or to not be willing to understand the person can aggravate such dynamics. In addition, the absence of mechanisms and figures who can assist the person in appropriately clarifying their statements leaves the door open to the manipulation of their sometimes vague declarations. For these reasons undue influence is also a strong

¹²¹ Cowdell, *above*, 8.

¹²² R Harding, *Duties to Care. Dementia, Relationality and the Law* (Cambridge University Press 2018), 147-149.

¹²³ *Ibid* 148.

¹²⁴ *Ibid* 148.

¹²⁵ For an overview see M Tsolaki et al, ‘Consensus Statement on Dementia Education and Training in Europe’ (2010) 14 *Journal of Nutrition Health and Aging* 131.

¹²⁶ See for example LK Fellows, ‘Competency and Consent in Dementia’ (1998) 46 *Journal of the American Geriatric Society* 922, 923; Bronner et al, *above*, 154.

and significant barrier to the expression of the genuine will of the person living with dementia with regard to medical treatment. Such a dynamic is reported as recurring frequently in various areas of legal decision-making, including will making or management of the person's finance,¹²⁷ and episodes of attempts to put pressure on the person in relation to healthcare choices and to orient their choice process are also documented in empirical studies and reports from various European countries.¹²⁸ For this reason, individuals living with dementia are defined as particularly at risk of undue pressure and abuse.¹²⁹

To such forms of abuses legislations tend to respond by providing 'external' safeguards which consist in the annulment of declarations which are the product of external pressure, mechanisms for reporting suspicious behaviours and inhibiting the contact with the person¹³⁰ or criminal sanctions in serious cases.¹³¹ However, in order to be activated such safeguards require often articulate procedures and may be put in place after the undue influence has taken place and some unwanted treatments have already been administered. Moreover, decisions on medical treatment are often made behind closed doors, so that abusive behaviours may often go undetected and unreported. Indeed, often dynamics of undue influence unfold within the circle of family members or of the healthcare team of the person without the presence of an impartial figure which can monitor the movements around the individual living with dementia.¹³² In this regard, empirical studies in various sectors of decision-making

¹²⁷ See C Peisah et al, 'The Wills of Older People: risk factors for Undue Influence' (2009) 21 *International Psychogeriatrics* 7; M van Bavel et al 'Elder Abuse in Europe. Background and Position Paper' (EuROPEAN 2010) < <http://www.combatingelderabuse.eu/wp-content/themes/Visionpress/docs/ElderAbuseinEurope.pdf>> accessed 30 September 2018; S Davidson, P Rossall and S Hart, 'Financial Abuse. Evidence Review' (Age UK 2015), 5-7 < https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/money-matters/financial_abuse_evidence_review-nov_2015.pdf> accessed 30 September 2018.

¹²⁸ See Gallagher and Clark, *above*, 106-107; Help Age International, 'Briefing paper for the first working session of the Open Ended Working Group on Ageing' (2011), 7-9 < https://social.un.org/ageingworkinggroup/documents/HelpAge_briefing_%20paper_%20for%20the%201st%20session%20of%20the%20OEWG_%20April%202011.pdf> accessed 24 January 2018; Smebye, Kirkevold and Engedal, *above*, 250; SM Horning et al, 'A Case of Elder Abuse and Undue Influence: Assessment and Treatment from a Geriatric Interdisciplinary Team' (2013) 12 *Clinical Case Studies* 373; Mariani et al, *above*, 36.

¹²⁹ B Penhale, 'Abuse, Safeguarding and Dementia' in Foster, Herring and Doron (eds), *above*, 258-262; B Fang and E Yan, 'Abuse of Older Persons with Dementia: A Review of the Literature' (2018) 19 *Trauma, Violence and Abuse* 127, 135-136.

¹³⁰ SD Pattison, *Medical Law and Ethics* (3rd ed, Sweet and Maxwell 2009), 139-142.

¹³¹ See J Herring, *Vulnerable Adults and the Law* (Oxford University Press 2016), 183-223.

¹³² L Broström, 'Due and Undue Influence in Supported Decision Making: Mapping the moral landscape' (XXXV International Congress of Law and Psychiatry, Prague, July 2017).

show how formal and informal carers may not be willing to act as whistle blowers when they witness suspicious behaviour so that they may often go unreported.¹³³ Therefore, at the moment, the legal safeguard traditionally put in place in European legislations do not seem to be able to systematically prevent that the right to choose on medical treatment of the person living with dementia be curtailed by external pressures.

However, lack of appropriate legal provisions and lack of training and willingness of carers and professionals are not the only reasons why people living with dementia are confronted with the barriers described above. Many of the dynamics reported so far are actually due to resources and institutional constraints that carers and health professionals often face. Therefore, doctors, nurses and carers often may not have time to stop and talk with the person, or conversations may happen in inadequate settings because no better place is available.¹³⁴ Equally, abuses or lack of reporting of undue influence may be due to the overloading of carers and professionals, the lack of time and energy to put attention also to episodes of undue pressure or the fear of consequences with regard to the relations with their clients' families or with their employees.¹³⁵ Therefore, even legislative guidelines requiring to take into consideration the environment in which discussions happen or the way in which information on treatment is explained where everywhere in place it would be still difficult to put them in practice because of institutional and resource constraints.

5. Dementia and the legal approach to capacity: shortcomings

All the barriers and issues reported above seem to be at least co-caused or aggravated by the way in which the law deals with healthcare decision-making of individuals living with dementia. As noted by Donnelly, the current legal approach to dementia appears quite narrow as it tends to look at all the problems just from the point of view of mental capacity,¹³⁶ that is the possession of sufficient intellectual abilities

¹³³ Smebye, Kirkevold and Engedal, *above*, 246-247; Gallagher and Clark, *above*, 107; Fang and Yan, *above*, 135.

¹³⁴ On this point see O St-Amant et al, 'Making Care Decisions in Home-Based Dementia Care: Why Context Matters' (2012) 31 *Canadian Journal on Aging* 423, 428-29; Smebye, Kirkevold and Engedal, *above*.

¹³⁵ Gallagher and Clark, *above*, 106-107; Fang and Yan, *above*, 135; Penhale, *above*, 256-257.

¹³⁶ M Donnelly, 'A Legal Overview' in Foster, Herring and Doron (eds), *above*, 276-279.

for deciding ‘rationally’. This capacity centred approach does not allow to see how many of the obstacles faced by individuals living with cognitive impairments like dementia derive from external factors not directly relating to their brain. Therefore, by adopting this angle, the law may be seen as failing to provide solutions to the real problems in care choices by people with dementia.¹³⁷

In this regard, current capacity tests and consent regulations have been criticised for being ‘hypercognitivist’ and too rationalistic.¹³⁸ Indeed, their components focus exclusively on abilities related to the rational comprehension of the nature and consequences of a medical treatment and on the capacity to logically draw conclusions, evaluations and choices from such information.¹³⁹ In this regard, researchers have pointed out how these regulations ignore important dynamics such as feelings, identity, practical reasoning and narrative.¹⁴⁰ In this regard, in light of empirical evidence the current narrow approach to capacity to consent to treatment is scientifically untenable.¹⁴¹

Starting from studies in the field of cognitive theory of emotions, Charland affirms that the affective sphere has an important positive role in medical decisions.¹⁴² He claims that emotions are crucial when it comes to appreciate and evaluate the implications of a certain treatment on one’s life, to give personal meaning to situations.¹⁴³ Choosing a medical treatment is not just about comprehending its effects, but probably most importantly, it is about saying how one would feel about them. Also, White notes how emotion helps to recognise and elaborate contrasts between desires.¹⁴⁴ Indeed the trigger to acknowledge internal conflicts comes normally from the uncomfortable sensation of having wishes whose realisation is mutually exclusive.¹⁴⁵

¹³⁷ *Ibid.*

¹³⁸ R Berghmans, D Dickenson and RT Meulen, ‘Mental Capacity: in search for Alternative Perspectives’ (2004) 12 *Health Care Analysis* 251, 252; Herring, ‘Losing’, *above*, 26. For an overview of the debate on this question see M Donnelly, *Healthcare Decision-Making and the Law. Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press 2010), 96-100; Charland, ‘Decision-Making Capacity’, *above*.

¹³⁹ See LC Charland, ‘Appreciation and Emotion: Theoretical Reflections on the MacArthur Treatment Competence Study’ (1998) 4 *Kennedy Institute of Ethics Journal* 359, 360-364.

¹⁴⁰ Berghmans, Dickenson and Meulen, *above*, 252; E Howe, ‘Ethical Aspects of Evaluating a Patient’s Mental Capacity’ (2008) 6 *Psychiatry* 15, 16-17; H Hermann et al ‘Emotion and Value in the Evaluation of Medical Decision-Making Capacity: a Narrative Review of Arguments’ (2016) 7 *Frontiers of Psychology* 1.

¹⁴¹ TM Breden and J Vollman, ‘The Cognitive Based approach of Capacity Assessment in psychiatry: a philosophical critique of the MacCAT-T’ (2004) 12 *Health Care Analysis* 273, 276-282.

¹⁴² Charland, ‘Appreciation’, *above*, 364-372.

¹⁴³ *Ibid.*

¹⁴⁴ BC White, *Competence to Consent* (Georgetown University Press 1994), 136-37.

¹⁴⁵ *Ibid.*

As stated by Herman et al, feelings constitute a specific source of knowledge about the overall nature of a person's current situation revealing the 'meaning aspects of our world' and are thus 'essential in generating, defining, and keeping track of our goals and preferences'.¹⁴⁶

Another important aspect of decision-making which is unaccounted for by the traditional rationalistic approach is that of values.¹⁴⁷ Indeed, in order to understand the sense of a decision, it is important to look at why it has been made.¹⁴⁸ This does not necessarily require that a person shows a very stable set of values or that their statements need to be coherent with what they have said in the past, as some seem to argue,¹⁴⁹ but simply that one has to take into account the level of their beliefs and try to trace how they may have changed. Moreover, as affirmed by Benaroyo and Widdershoven, in this field it is also important to consider the interpretation of the world and the situation at the basis of the decision, in other words the narrative in against which the choice takes place.¹⁵⁰ They observe how capacity to consent and healthcare decision-making is not a theoretical matter, but a practical one, which primarily requires the ability to give meaning to a situation.¹⁵¹ This capacity may lack in the person because, for example, they are not comfortable in a certain circumstance feeling factually incompetent to make a choice, or indeed because of an impairment like dementia.¹⁵² In such cases the two authors suggest that their carers should help them to get a practical grip on their situation, not limiting to assessing their capacity, but contributing to develop in the person a sense of the dynamics they are living.¹⁵³

Acknowledging the importance of the 'non-cognitive' elements of treatment decision-making does not just mean that one also has to assess the person's ability to have emotions, to value or to build a narrative.¹⁵⁴ Rather it implies accepting that

¹⁴⁶ Hermann et al, *above*, 3.

¹⁴⁷ JOA Tan et al, 'Competence to Make Treatment Decisions in Anorexia Nervosa Thinking Processes and Values' (2006) 13 *Philosophy, Psychiatry and Psychology* 267, 277-279; Charland, 'Decision-Making Capacity', *above*.

¹⁴⁸ B Freedman, 'Competence, Marginal and Otherwise' (1981) 4 *International Journal of Law and Psychiatry* 53, 55; LC Charland, 'Mental Competence and Value: the Problem of Normativity in the Assessment of Decision-Making Capacity' (2001) 8 *Psychiatry, Psychology and Law* 135, 136-137.

¹⁴⁹ Buchanan and Brock, *above*, 25-32 and 84.

¹⁵⁰ L Benaroyo and G Widdershoven, 'Competence in Mental Health Care: a Hermeneutic Perspective' (2004) 12 *Health Care Analysis* 295, 305.

¹⁵¹ *Ibid*, 297-299

¹⁵² *Ibid*, 299-301

¹⁵³ *Ibid*.

¹⁵⁴ This is the position expressed, among others, by Charland, 'Appreciation', *above*, 371-372; Breden and Vollman, *above*, 281-282.

considerations pertaining to the latter domains may be more prominent than logical reasons, so that an individual may decide to give them precedence over rational arguments. After all do not we mainly make choices because of emotions, because we are afraid of pain, or because we are attached to certain ideas or ideologies?

This may be even truer in the case of people with dementia as, because of the deterioration of cognitive abilities, they tend to rely on other intellectual resources to make choices, being guided more by their emotional-irrational sphere.¹⁵⁵ In this sense, as noted by Berghmans et al, the current approach to decision-making puts them automatically in a position of disadvantage¹⁵⁶ resulting discriminatory. Indeed, capacity legislations and models of healthcare decision-making are based on the principle according to which an adult must be presumed to have capacity unless it is proven that they have a mental condition and that this impacts on their judgement.¹⁵⁷ This means that people with no signs of intellectual or cognitive or psychiatric impairment will not be subject to the hypercognitive capacity tests in use in modern legal systems, remaining free to make decisions on the basis of their emotions, fears, and embarrassing wishes. Only mentally disabled individuals like people living with dementia run the risk of being questioned in their decisional ability and have to demonstrate that they satisfy a rationalistic standard that very few of their fellow human beings would enforce in usual life situations.

Besides being not representative of the true reality of decision-making, the current legal approach to capacity to consent also results impractical and too rigid in relation to dementia. As noted by Herring, it appears based on a sharp binary distinction between capacity and incapacity.¹⁵⁸ Indeed, an incapacity assessment has the effect of drawing a straight bright-line between the moment in which the person is presumed completely capable of making a decision or a class of decisions, and one in which they are considered totally unable to do so.¹⁵⁹ However, if such an approach could make sense in cases in which cognitive abilities are lost all of a sudden such as coma, it appears much trickier to apply to progressive conditions like dementia.¹⁶⁰ Here, the memories and reasoning abilities of the person fade away gradually and with

¹⁵⁵ S Post, *The Moral Challenge of Alzheimer's Disease* (John Hopkins Press 1995).

¹⁵⁶ Berghmans et al, *above*, 258-259.

¹⁵⁷ Berghmans et al, *above*, 258-259. See as examples section 2 English MCA or Article 2 Italian Civil Code.

¹⁵⁸ Herring, 'Losing', *above*, 4-6.

¹⁵⁹ J Herring, *above*, 66. See also Donnelly, 'A Legal', *above*, 278.

¹⁶⁰ Donnelly, 'A Legal', *above*, 276-279.

significant fluctuations.¹⁶¹ Often the person may appear to be ‘somewhere in between’ capacity and incapacity or ‘fail’ only some elements of the assessment. In this regard, the current binary approach to capacity, for example, may assume absolutely able to make decisions alone a person who is ‘just about capable to consent’, who, though able to grasp the general implications of their choice, would probably still need some help with regard to specific elements, an help hat legal capacity legislation would not provide, as the person is formally considered ‘autonomous’. On the other hand, an individual whom has ‘just about’ failed the mental capacity test risks that from that moment their opinions start being disregarded by default, even though they might still be able to articulate wishes and feelings.¹⁶²

As noted by Miola, because of the difficulty in ‘fitting’ such a binary category in the case of dementia, even experienced assessors or surrogates may have doubts with regard to the capacity or incapacity of the person.¹⁶³ Indeed, empirical studies involving doctors confirm how they are frequently in disagreement with each other especially with regard to the capacity of individuals in the initial and mid stages of dementia.¹⁶⁴ Marson et al performed an investigation on capacity judgements regarding people with mild Alzheimer Disease by geriatricians and neurologists from five medical centres, showing how their assessments diverge in almost half of cases.¹⁶⁵ Moreover, Qureshi and Johri observe how there is a lack of guidance to medical professionals on how to manage consent issues in cases in which the person’s capacity is intermittent.¹⁶⁶ Finally, Pickering Francis maintains that the currently used concept of capacity as a thresholds leads practitioners to consider an ongoing, fixed status rather than more correctly as a spectrum and something that continuously changes over time.¹⁶⁷ For all these reasons, a series of scholars are advocating for more flexible solutions with regard to legal capacity and capacity to consent in borderline cases.¹⁶⁸

¹⁶¹ See above Chapter 1

¹⁶² Herring, *Vulnerability*, above,

¹⁶³ Miola, above, 149-150. See also S O’ Keeffe, ‘A Clinician’s Perspective: Issues of Capacity in Care’ 14 *Medico-Legal Journal of Ireland* 41, 44.

¹⁶⁴ DC Marson et al, ‘Determining the Competency of Alzheimer Patients to Consent to Treatment and Research’ (1994) 8 *Alzheimer Disease and Associated Disorders* 5, 11-12.

¹⁶⁵ DC Marson et al, ‘Consistency’, above.

¹⁶⁶ Qureshi and Johri, above, 202.

¹⁶⁷ Pickering Francis, above, 542-543

¹⁶⁸ See for example GT Laurie, ‘A commentary on Re DL’ in PR Ferguson and GT Laurie, *Inspiring and Medico-legal Revolution: Essays in Honour of Sheila AM McLean* (Routledge 2015).

6. Conclusion

People living with dementia face a number of barriers to the exercise of their right to make healthcare choices. These barriers mostly derive from prejudice, inadequate human, physical and time resources to provide individuals living with dementia with the help they need in making decisions, and the lack of a framework which guides professionals, institutions and carers in addressing the issues emerging in relation to healthcare choices of people living with dementia.

The first barrier, relating to prejudice, manifests itself in medical and legal professionals and carers automatically considering individuals living with dementia as incapable of reasoning and deciding on medical treatment. This is seen as inevitably due to the person's impairment. On the contrary, in many cases the deterioration of mental abilities is not as serious as to render the person unable to express any opinion on their care. Such an absolute loss of capacity to decide occurs only in the final stages of the condition.

Before that phase the person's power to decide is generally hindered by contextual barriers originating from the way in which conversations on treatment choices are carried out. Among these barriers there are lack of support with regard to memory gaps, care staff inexperience with people living with dementia, time constraints and the scarce attention towards creating a favourable environment for conversations.

In such a situation, regulations on legal capacity and capacity to consent to treatment do not appear to lend a great deal of help. At times they may be even seen to fuel or aggravate the negative dynamics described above. Indeed, they still subordinate the power to make decisions on medical treatment to the presence in the person of a set level of mental capacity. Therefore, they indicate conditions like dementia as a legally justifiable ground for stripping individuals of their legal capacity, increasing the risk that people living with this condition are deprived of their power to choose. Moreover, tests for legal capacity tend to set the bar even higher than the standard we all adopt in judging the capacity to decide of people. In addition they presuppose a sharp binary distinction between mental capacity and incapacity, which is difficult to apply in the case of dementia. Finally, the emphasis on mental capacity leads to see all decision-making problems as caused by the person's brain, providing no basis for addressing the needs of support and adjustments or to avoid the risk of

undue influence. In this regard, capacity legislations are still informed by a ‘passive’ approach, in which people are only assessed but not helped to make decisions.

Current legal approaches do not even provide effective solutions with regard to the last phase of dementia, in which the person appears unable of nearly any interaction with the world outside. Indeed tools like advanced directives, surrogate decision-making, substituted and best interests judgement appear often paternalistic, morally controversial and difficult to apply in practice.

Therefore, if we want to truly empower people living with dementia to make decisions on medical treatment and stop to deprive them of what is a fundamental right, we need to embrace a new approach to healthcare decision-making; an approach which does not fuel prejudice against people living with conditions like dementia, which actively helps such individuals in making decisions and that ideally avoids uncertainties in the evaluation and reconstruction of the person’s will.

Chapter 4 will explore how such a model can emerge from Article 12 CRPD. Then Chapters 5 and 6 will analyse how the two main European transnational organisations (CoE and EU) can contribute to the spreading of this model and to promote a new vision of healthcare decision-making and dementia also tackling prejudice. Chapter 7 will then study some initiatives developed at a national level which show how it could be concretely possible to remove barriers such as negative attitudes against people living with dementia, problems of communication and lack of support and adequate safeguards, and lack of training of medical professionals and carers.

However, the systemic change needed to tackle these obstacles requires a more inclusive view of the person living with dementia and the reality of decision-making than the one which has given origin to the current system. The next chapter aims to define such an alternative view.

CHAPTER 3

Towards a more inclusive vision of People Living with Dementia

1. Introduction

Chapter 2 has documented how people living with dementia face a number of barriers in exercising their right to decide on medical treatment and how, in order to overcome them, a new approach to capacity to consent is needed, based on a less medicalised and stigmatising view of the person living with this condition. This chapter aims to set out such a view, drawing from two existing theoretical accounts: the social model of disability¹ and Fineman's vulnerability theory.² In this way, it delineates the theoretical framework of this dissertation, clarifying the standpoint from which its research problem is addressed and identifying the values that need to inform rules, policies and practices governing its field of study, explored in subsequent chapters.

The claim underpinning this part is that the social model and vulnerability theory can be the basis for an approach to healthcare decision-making of individuals living with dementia which focuses on creating the conditions for the exercise of the person's right to choose, rather than on capacity assessments and surrogate decision-making. Indeed, both accounts emphasise the importance of relational and social dynamics in shaping the condition of individuals such as people living with dementia, and advocate for an active engagement of social institutions in accommodating disadvantage in all aspects of life, including healthcare choices. In order to explore such a claim I look at the main seminal texts relating to the analysed theories, extracting the main ideas and putting them in relation with the case of people living with dementia.

¹ UPIAS, 'Fundamental Principles of Disability' (1976), 3 < <http://disability.studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf>> accessed 25th March 2015; M Oliver, *The Politics of Disablement* (Macmillan 1990), 46-49; M Priestley, 'Constructions and Creations: Idealism, Materialism and Disability Theory' (1998) 13 *Disability & Society* 75.

² M Fineman, 'The Vulnerable Subject: anchoring Equality in the Human Condition' (2008) 20 *Yale Journal of Law and Feminism* 1, 8-12; M Fineman, 'The Vulnerable Subject and the Responsive State' (2010) 60 *Emory Law Journal* 251, 266-267; M Fineman, "'Elderly as Vulnerable: rethinking the Nature of Individual and Societal Responsibility' (2012) 20 *The Elder Law Journal* 71.

The Chapter is structured as follows. Section 2 analyses the main ideas of the social model of disability, studying how they lead to a radical change of perspective compared to the traditional medicalised vision still dominant in the field of dementia care. Section 3 focuses on how the social model can be applied in relation to dementia, and outlines its implications with regard to decisions on medical treatment of individuals living with this condition. Section 4 turns to Fineman's vulnerability theory, explaining the main ideas and analysing how it further extends and supports the claims of the social model of disability. In particular, the Section shows how vulnerability theory provides a more precise account with regard to legal personality and decision-making which, also in relation to consent to treatment of people living with dementia, leads to overcome the rigidities characterising current legislation on the matter and in particular to reject the binary category capacity/incapacity, which often constitutes a strong barrier to the full expression of the person's will. Section 5 explores how adopting such a new vision of legal personality leads to a legal and policy approach based on the responsive state, which presupposes that social institutions actively engage in helping and accommodating the needs of people in positions of disadvantage. In relation to treatment decisions of individuals living with dementia, this leads to require that the state, the law and all other social institutions take responsibility for creating the right conditions for the person to express their will and provide to them the necessary support to make healthcare choices. Finally, the Conclusion points out how, by looking at treatment decisions of people living with dementia through the lenses of the social model and of Fineman's vulnerability theory, it is possible to lay down the basis for a regulatory model which, being based on a more inclusive view of the individual, removes many of the barriers faced by people living with this condition.

2. The social model of disability

The general approach to conditions like dementia is still characterised by a rather narrow perspective which focuses predominantly on the impairment of the person, failing to consider the significant role played by the way in which people react to such an impairment or how care services are organised around it.³ This is a dynamic which

³ C Baldwin, 'Technology, Dementia and Ethics: Rethinking the Issue', (2005) 25 *Disability Studies Quarterly* 1, but see also Chapter 1 and then further Section 3 of this Chapter.

is by no means confined to the area of healthcare decision-making or to the case of people living with dementia, still informing the general attitude towards many chronic conditions and impairments.⁴

This approach is designated as the individual or medical model of disability.⁵ The term was coined in 1983 by Michael Oliver which by it refers to an approach which looks at disabled people solely in relation to their impairment.⁶ Here, disability is seen as a personal tragedy, something that concerns just the disabled individual and makes them something less compared to supposedly ‘normal’ people.⁷ As observed by Brisenden, all difficulties are seen solely from the perspective of proposed treatment, with the person being subject to hours of rehabilitation, without considering how this fits into their life.⁸ So, disabled individuals are treated like objects of care, rather than full members of society.⁹ Moreover, when total rehabilitation is not possible, they are marginalised, excluded or hidden. An example of this could be seen in the practice, widespread in Europe until the 1980s, of segregating disabled people in asylums.¹⁰ It has also been seen how the view of (cognitive) conditions as an inescapable deficit of the mind, leads to exclude people living with dementia from decisions on their care, as doctors and caregivers often assume they are incapable of reasoning.¹¹

Instead, Oliver proposes an alternative view, the ‘social model’, which sees disability as a social creation, as the product of external dynamics, rather than

⁴ See for example CH Sin, ‘Medicalising Disability? Regulation and Practice around Fitness Assessment of Disabled Students and Professionals in Nursing, Social Work and Teaching Professions in Great Britain’ (2009) 31 *Disability and Rehabilitation* 1520; A Ndi, ‘Setting the Stage of ‘Ab/normality’ in Rehabilitative Narratives: Rethinking Medicalization of the Disabled African Body’ (2012) 32 *Disability Studies Quarterly* <<http://dsq-sds.org/article/view/3195/3066>> accessed 3 October 2018.

⁵ M Oliver, ‘The Individual and Social Models of Disability’ (Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians, 1990) 2-5 in <<http://disability-studies.leeds.ac.uk/files/library/Oliver-in-soc-dis.pdf>> accessed 25 March 2015. See also Oliver, *The Politics, above*, 46-59; K Selman, ‘Trends in Rehabilitation and Disability: Transition from a Medical Model to an Integrative Model’ [2004] *Disability World* 8 in <http://disabilityworld.org/01-03_04/access/rehabtrends.shtml> accessed 27 January 2015.

⁶ See M Oliver, *Social Work with Disabled People* (Macmillan 1983), who uses mainly the term ‘individual model’, though the expression ‘medical model’ tends to be used more by other scholars. See also S Brisenden, ‘Independent Living and the Medical Model of Disability’ (1986) 1 *Disability, Handicap and Society* 173.

⁷ Oliver, *The Politics, above*, 46-48; Brisenden, *above*, 173-176; R Traustadottir, ‘Disability Studies, the Social Model and Legal Developments’ in OM Arnardóttir and G Quinn (eds), *The Un Convention on the Rights of Persons with Disabilities. European and Scandinavian Perspectives* (Nijhoff 2009), 1.

⁸ Brisenden, *above*, 176. See also Oliver, *The Politics, above*, 54-59; R Traustadottir, ‘Disability Studies, the Social Model and Legal Developments’ in Arnardóttir and Quinn (eds), *above*, 1.

⁹ Brisenden, *above*, 177-178.

¹⁰ Oliver, *The Politics, above*, 32-36. For the foreign literature, with a specific focus on mental disability, see the book by F Basaglia (ed), *L’Istituzione Negata* (Baldini Castoldi Dalai 1968).

¹¹ See above Chapter 2.

inevitable natural causes.¹² This theoretical account is described in the book *The Politics of Disablement*,¹³ and builds mainly on the elaborations of the UK's disabled people's movement, which saw its decisive affirmation in the 1960s-70s in Great Britain, though similar ideas have been developed in other countries of the world.¹⁴ In this sense it builds on the work of the British Union of Physically Impaired Against Segregation (UPIAS).¹⁵

UPIAS based its main message on the distinction between 'impairment' and 'disability', arguing that the latter is 'imposed on top of our impairments' and that it is society which 'disables' people living with impairments.¹⁶ Drawing from this, Oliver further explains that, as confirmed by anthropological studies, certain impairments are perceived as troublesome in certain societies but not in others.¹⁷ Therefore, disability appears 'culturally produced and socially structured'.¹⁸ In this regard, the point is not curing the impairment or 'normalising' the person, but removing the societal barriers which disabled people face in their everyday life.¹⁹ Indeed, the community can be a powerful means to support disabled individuals and provide services, helping them to flourish and realise their human potential, beyond their impairment.²⁰ This of course does not necessarily mean that impairments do not play a role in the life of disabled individuals or that treatment and rehabilitation is not important for them, but that one cannot limit to such aspects.

Such ideas have formed the basis for disability activists to demand the removal of disabling barriers through specific legislation.²¹ In this context, the action of disability

¹² For a general review of the central ideas of the social model and their developments see Priestley, *above*.

¹³ Oliver, *The Politics, above*.

¹⁴ On the origins of the disabled people's movement see C Barnes, *above*, 2-4.

¹⁵ Oliver, *The Politics, above*, 2.

¹⁶ UPIAS, *above*, 3. On this distinction see also C Thomas, 'Disability and Impairment' in J Swain et al (eds), *Disabling Barriers – Enabling Environments* (Sage 2004).

¹⁷ Oliver, *The Politics, above*, 14-17.

¹⁸ *Ibid*, 22. See also J Ryan and F Thomas, *The Politics of Mental Handicap* (Penguin 1980), 101.

¹⁹ See C Barnes and G Mercer (eds), *Implementing the Social Model of Disability: Theory and Research* (The Disability Press 2004); T Shakespeare, 'The Social Model of Disability' in LJ Davis (ed), *The Disability Studies Reader* (4th ed, Routledge 2013).

²⁰ D Nahak, 'Role of Civil Society in the Empowerment of the Disabled' (2008) 46 *Mainstream Weekly* available at <www.mainstreamweekly.net/article595.html> accessed 14 June 2018; Keyes, SH Webber and K Beveridge, 'Empowerment through Care: using Dialogue between the Social Model of Disability and an Ethic of Care to Redraw Boundaries of Independence and Partnership between Disabled People and Services' (2015) 9 *ALTER* 236.

²¹ For the English context see, for example, C Barnes, *Disabled People in Britain and Discrimination: a case for Anti-discrimination Legislation* (Hurst & Co, 1991); J Campbell and M Oliver, *Disability Politics: Understanding our Past, Changing our Future* (Routledge, 1996). For the American context,

movements has led to the approval in many countries of revolutionary regulations such as the Americans with Disabilities Act (1990) or the norms on disability based discrimination in the British Equality Act 2010. This trend has developed in the last years at a global level, spreading not only throughout Europe, but also in non-western countries and being one of the triggers for international human rights legislation such as the UN Convention on the Rights of Persons with Disabilities.²² The use of the social model in this context has more clearly brought up aspects of it which relate to changing the life condition of disabled people, putting more emphasis on the active vindication of rights and the practical and political challenges in empowering and including disabled individuals. In this regard, in line with the social model emphasis on barriers removal, scholars and activists advocate for a policy and legal approach based not just on respect and non-discrimination, but also focusing on realising substantive equality.²³ This means that the social model presupposes not only and not so much that disabled people are treated according to the same standards of others and are not subject to unfair treatment, but most importantly that the state or other institutions through policies, laws and the investment of resources really provide them with the tools, mechanisms and accommodations they need to be included in society and fully enjoy their life on an equal footing with others.²⁴

As shown by Berensford, the social model is of great importance in the context of mental disability.²⁵ Here the focus is on removing attitudinal barriers such as prejudice, stereotype, stigma, blame or labelling.²⁶ In this regard, especially movements of mentally disabled people reclaim the entitlement to be respected as individuals with a different but legitimate way of seeing the world.²⁷ Therefore, they vindicate the right

see F Bowe, *Handicapping America*, (Harper and Row, 1978); H Hahn, 'Academic Debates and Political Advocacy: the US Disability Movement' in C Barnes, M Oliver and L Barton (ed), *Disability Studies Today* (Polity 2001) 162.

²² See Chapter 4.

²³ S Fredman, 'Disability Equality: A Challenge to the Existing Anti-Discrimination Paradigm?' in EF Emens and MA Stein (eds), *Disability and Equality Law* (Routledge 2005); OM Arnardóttir, 'A Future of Multidimensional Disadvantage Equality?' in Arnardóttir and Quinn (eds), *above*, 54-64;

²⁴ A Lawson, *Disability and Equality Law in Britain: The Role of Reasonable Adjustment* (Hart 2008), 1-59; T Minkowitz, 'CRPD and Transformative Equality' (2017) 13 *International Journal of Law in Context* 77.

²⁵ P Berensford, 'Social Work and a Social Model of Madness and Distress: developing a Viable Role for the Future' (2005) 12 *Social Work and Social Sciences Review* 59, 64-71.

²⁶ Berensford, *above*, 66-69; Joseph Rowntree Foundation, 'Towards a Social Model of Madness and Distress? Exploring what Service Users say' (JRF 2010) 19-28. <www.jrf.org.uk/sites/default/files/jrf/migrated/files/mental-health-service-models-full.pdf> accessed 14 June 2018. See also M Price, 'Defining Mental Disability' in Davis (ed), *The Disability Studies Reader*, *above*.

²⁷ R Ciofi, 'La Malattia Mentale, come Vissuto della Persona, nell'ottica Fenomenologica e Sociologica' (2002) 37 *Rivista di Psichiatria* 138; JC Jaramillo Estrada and DA Restrepo Ochoa,

to decide for themselves, to be empowered and helped to shape their lives, rather than being dismissed as ‘mad’.²⁸ Moreover, they challenge psychiatric and medical authority, demanding that service users are at the centre of therapy rather than the will of their physicians.²⁹ In this context, the social model shares ideas and pathways with movements for the liberation of people living with mental conditions such as Antipsychiatry, Mad Pride and the various European anti-institutional movements.³⁰ Also in this area the ideas of the social model have served to movements of users of psychiatry and people living with mental conditions to fight for the respect of fundamental rights such as that to decide on their care. For this reason, the social model provides a strong ground also to address the obstacles faced by people living with dementia in deciding on medical treatment such as being ignored because of prejudice and not being properly assisted. Indeed, looking at capacity to consent through the lenses of the social model permits to claim even more strongly how it is legal capacity legislation and practice that needs to change, banning behaviours or rules depriving the person of decisional power and providing assistance in overcoming the barriers to their right to decide.³¹

However, foundational claims of the social model are still at the centre of debate, having been subject to criticism by what could be defined as a ‘second generation’ of disability scholars. Some of the points at the centre of criticism are particularly relevant to the case of people living with dementia. A first point of discussion is that according to which impairment would tend to be overlooked in social model analysis.³² Morris,

‘Normality and Mental Health: analysis of a Multivalent Relationship’ (2015) 8 *Journal of Psychology CES* 37.

²⁸ B Lewis, ‘A Mad Fight: Psychiatry and Disability Activism’ in Davis (ed), *The Disability Studies Reader, above*, 115-117. See also EJ Maccallum, ‘Othering and Psychiatric Nursing’ (2002) 9 *Journal of Psychiatric and Mental Health Nursing* 87; L Pritchard-Jones, ‘“This Man with Dementia” ‘Othering’ the Person with Dementia in the Court of Protection’ (2017) 24 *Medical Law Review* 518, 521-525.

²⁹ Lewis, ‘A Mad Fight’, *above*, 115-117.

³⁰ See for example T Szasz, ‘The Myth of Mental Illness’ (1960) 15 *American Psychologist* 113; Basaglia (ed), *above*; G Antonucci, *I pregiudizi e la Conoscenza. Critica alla Psichiatria* (Apache 1986); T Szasz, *The Manufacture of Madness: A Comparative Study of the Inquisition and the Mental Health Movement* (Syracuse University Press 1997). For an analysis of these links see Lewis, ‘A Mad Fight’, *above*, 118-128.

³¹ For the moment see I Hoffman and G Könczei, ‘Legal Regulations relating to the Passive and Active Legal Capacity of Persons with Intellectual and Psychosocial Disabilities in light of the Convention on the Rights of Persons with Disabilities and the Impending Reform of the Hungarian Civil Code’ (2010) 33 *Loyola of Los Angeles International and Comparative Law Review* 143, 144-146; P Bartlett, ‘The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law’ (2012) 75 *The Modern Law Review* 754, 758-768.

³² B Hughes and K Paterson, ‘The Social Model of Disability and the Disappearing Body: towards a Sociology of Impairment’ (1997) 12 *Disability and Society* 325.

starting from her own experience as a disabled person, affirms that ‘while environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is is to deny the personal experience of physical or intellectual restrictions’.³³ Shakespeare and Watson even accuse the social model of having turned impairment into a sort of taboo.³⁴ Therefore, according to them, this approach seems sometimes more an ideology assuming that it is sufficient to change the society to make the problem of disability disappear. In an article of 2013, Michael Oliver has dismissed such criticism, affirming how his account does not imply the denial of the impairment level, but rather advocates for inserting it in a wider perspective.³⁵ Nonetheless, sometimes the impression does arise that the way in which the social model has been applied, especially by activists, tends to ignore the objective practical problems directly caused by impairments.

In order to address such issues, Williams proposes to think at disability in terms of interaction between societal dynamics and impairment.³⁶ Starting from the perspective of critical realism,³⁷ he advocates ‘bringing back’ impairment in the debate on disability as even the physical and psychological characteristics of every person influence the impact on them of social dynamics.³⁸ So, disability is ‘an emergent property, located, temporally speaking, in terms of interplay between the biological reality of physiological impairment, structural conditioning (i.e. enablements/constraints) and socio-cultural interaction/elaboration’.³⁹ In terms of impairment/society interactions Garland-Thomson refers to the concept of *misfitting*.⁴⁰ She identifies disability as a situation in which an individual does not fit into the social structure surrounding them and ‘the shape and function of their bodies comes in

³³ J Morris, *Pride against Prejudice* (The Women’s Press 1991), 10. See also L Crow, ‘Including all our Lives’ in J Morris (ed), *Encounters with Strangers: Feminism and Disability* (The Women’s Press 1996).

³⁴ T Shakespeare and N Watson, ‘The social model of disability: an outdated ideology?’ (2002) 2 *Research in Social Science and Disability* 9.

³⁵ M Oliver, ‘The Social Model of Disability: thirty years on’ (2013) 28 *Disability and Society* 1024.

³⁶ SJ Williams, ‘Is Anybody there? Critical Realism, Chronic Illness and the Disability Debate’, (1999) 21 *Sociology of Health and Illness* 797.

³⁷ Critical realism developed from the works by Roy Bhaskar which, in opposition to post-structuralism and social constructionism at the basis of accounts like the social model, concentrates on the factual reasons beyond societal mechanisms, rather than on their interpretation as social constructions. R Bhaskar, *Reclaiming Reality* (Verso 1989); R Bhaskar, *A Realist Theory of Science* (Verso 1997).

³⁸ Williams, *above*, 810-811. See also M Archer, *Realist Social Theory: the Morphogenetic Approach* (Cambridge University Press 1995), 288.

³⁹ Williams, *above*, 810.

⁴⁰ R Garland-Thomson, ‘Misfits: A Feminist Materialist Disability Concept’ (2011) 26 *Hypatia* 591.

conflict with the shape and stuff of the built world'.⁴¹ Indeed, she notes, disabled people are one of those categories like children, older individuals, women or migrants, whom often find themselves in a marginalised position because the architecture of society does not take them into account.⁴² These visions of disability have the advantage of describing it as socially produced, but acknowledging in the meantime the role of the body and the specificities of the experience of every disabled person. Therefore, they permit to explain those situations arising especially in the advanced stages of dementia, in which it does not seem possible to fully accommodate the person's impairment, though still putting attention on the role of societal barriers.

Another issue, related to the question of the dialectic impairment/disability is that, according to some scholars, the social model runs the risk of overlooking differences between disabled people.⁴³ Indeed, coherently with the focus on the social level the traditional version of the social model conceptualises disability as a unitary form of oppression talking about 'disability'.⁴⁴ However, the experience of disability can be very different from person to person.⁴⁵ First, such differences are due to the particular nature of each impairment, so that, for example, a person in a wheelchair and an individual living with a mental health condition, though facing some similar dynamics for example in terms of prejudice, have a fundamentally different life experience.⁴⁶ In addition, the condition of disabled person is also influenced by the interaction between the disability level and a range of other factors such as class, gender, race age or culture, so that the reality faced, for example, by a middle-class white disabled man is not comparable with that of a black disabled woman of more disadvantage social background.⁴⁷ Therefore, insisting on perceiving disability as a homogeneous dynamic may pose the risk that policies, laws and interventions in this area do not match with

⁴¹ Garland-Thomson, *above*, 594.

⁴² *Ibid*, 597.

⁴³ M Corker, 'Differences, Conflations and Foundations: the Limits to Accurate Theoretical Representation of Disabled Peoples Experience?' (1999) 14 *Disability and Society* 627; Shakespeare and Watson, *above*, 18-28; L Terzi, 'The Social Model of Disability: a Philosophical Critique' (2004) 21 *Journal of Applied Philosophy* 141, 153-155.

⁴⁴ On the use of the term 'disabilities' and 'disability' see R Kayess and P French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 *Human Rights Law Review* 1, 23.

⁴⁵ Terzi, *above*, 153-154.

⁴⁶ Corker, *above*; Shakespeare and Watson, *above*, 18-28; Williams, *above*, 803-807.

⁴⁷ W Hulko, 'From "Not a Big Deal" to "Hellish": Experiences of Older People with Dementia' (2009) 23 *Journal of Aging Studies* 132; DF Warner and TH Brown, 'Understanding how Race/Ethnicity and Gender define Age-Trajectories of Disability: An Intersectionality Approach' (2011) 72 *Social Science and Medicine* 1236; J Moodley and L Graham, 'The Importance of Intersectionality in Disability and Gender Studies' (2015) 29 *Disability and Gender* 24.

the needs of a number of individuals. For this reason especially ‘second generation’ scholars and activists refer to ‘disabilities’ rather than disability.⁴⁸ In this regard, also the conceptualisation proposed by authors such as Williams or Garland-Thomson have indeed aim for a better consideration of the specificities of each disabled individuals by recalling attention on the differences between impairments and the particular way social structures react to them.⁴⁹

In the next chapters I will explain how in relation to the case of people living with dementia it is particularly important to bear in mind these aspects. In addition, I will explore how Fineman’s vulnerability theory may contribute to avoid overlooking the level of impairment and put adequate attention on diversity in disability discourse.

3. The social model and dementia

The social model has started only quite recently to be applied in the context of dementia.⁵⁰ Indeed, as already noted, the approach to this condition still tends to concentrate predominantly on the deficits of the person and on the impact and management of the symptoms typical of this condition. This narrow focus dates back to the very beginnings of dementia as a diagnostic category, that is to when, in 1906, Alzheimer and Perusini analysed the first known clinical case of dementia,⁵¹ and Kraepelin classified the disease as a specific medical condition in his handbook *Psychiatrie* (1910).⁵² Indeed, the main point of the works of the three researchers, consisted in conceptualising dementia simply as a neuropathology caused by organic alterations of the brain and rejecting of the vision, dominant at that time, according to which dementia was an inevitable and natural consequence of aging.⁵³ Such a vision became more and more dominant in the scientific community, which in the meantime discovered a number of different subtypes of this condition, so that in 1980 the American Psychiatric Association included ‘primary degenerative dementia’ in the

⁴⁸ Corker, *above*; Shakespeare and Watson, *above*, 18-28; Terzi, *above*, 153-154; Williams, *above*, 803-807.

⁴⁹ Garland-Thomson, *above*, 592-596; Williams, *above*, 807-812.

⁵⁰ See in this sense Mental Health Foundation, ‘Dementia, Rights, and the Social Model of Disability. A new direction for Policy and Practice?’ (MHF 2015), 1-2 and 6-8 <www.mentalhealth.org.uk/publications/dementia-rights-and-social-model-disability> accessed 16 June 2018.

⁵¹ KA Lyman, ‘Bringing the Social Back: A Critique of the Biomedicalization of Dementia’ (1989) 29 *The Gerontologist* 597, 598.

⁵² See E Kraepelin, *Psychiatrie. Ein Lehrbuch für Studierende und Ärzte* (8th ed, V 2, 1910), Chapter 7.

⁵³ *Ibid.*

third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III), officially identifying it as a specific pathology of the brain and establishing criteria for its diagnosis.⁵⁴

This process of ‘medicalisation’ of dementia, on the one hand, has allowed to achieve a better understanding of this condition and its causes, distinguishing it from normal aging and supporting the development of medical research on the disease. However, on the other hand, it has produced the prejudice and narrow approach⁵⁵ whose consequences have been seen in Chapter 1, and that sees dementia as a personal and familiar tragedy, as a ‘death of the mind’ or an ‘unbecoming of the self’ which makes the life of the person dreadful and meaningless.⁵⁶ Looking at dementia from this perspective leads to interpret all the person’s behaviours as a product of the disease, to consider the person automatically incapable on the basis of their condition and to justify forms of medical control in which independence is generally discouraged.⁵⁷

In the last four decades such an approach has been contested by scholars, care professionals, activists and people living with dementia. Among the first to criticise the traditional model of dementia there have been the members of the Bradford Dementia Group, reuniting scholars from various disciplines with the aim of studying the social and relational aspects of this phenomenon, and in particular by Tom Kitwood, the founder of the Group and the main proponent of the person-centred dementia care approach. This view was developed in the early 1990s and it is summed up in Kitwood’s book *Dementia Reconsidered*.⁵⁸ It evolved following autonomous, though parallel, routes than the social model of disability by which it is in part influenced.⁵⁹ Indeed, similarly to the social model, it claims that the numerous problems faced by people living with dementia often come from their social environment and the attitudes of others.⁶⁰ Therefore it advocates for defining this condition in terms of interplay between cognitive impairment and social environment,

⁵⁴ American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed, APA 1980), 107-112.

⁵⁵ Lyman, *above*, 602-604.

⁵⁶ Such rhetoric is described in many studies analysed in Chapter 2 Section 2.

⁵⁷ Lyman, *above*, 602-604. See also BF Hofland, ‘Autonomy in Long Term Care: Background Issues and a Programmatic Response’ (1988) 28 *The Gerontologist* 3.

⁵⁸ T Kitwood, *Dementia Reconsidered. The Person comes First* (Open University Press 1997).

⁵⁹ Such influences are confirmed by Brooker, *above*, 14-15; Baldwin, ‘Narrative’ *above*, 223-224 both members of the Bradford Dementia Group.

⁶⁰ Kitwood, *Dementia Reconsidered, above*, 46-53.

focusing not just on the pathologies of the brain, but on the wider question of living with dementia.⁶¹

Kitwood maintains that the narrow, medicalised ‘standard paradigm’ of dementia is not able to give a full and faithful explanation of this phenomenon.⁶² Indeed, some biomedical studies pose substantial doubts that neuropathology is alone determinant of the condition,⁶³ and clinical experience shows how traits of dementia like change of personality or the impression of the ‘vanishing of the person’s self’ are much less reported by people who are constantly supported and well cared for.⁶⁴ Indeed, observes Kitwood, individuals living with dementia are often victims not of their condition, but of a ‘malignant social psychology’⁶⁵ informing the behaviour of relatives and carers, and resulting in treachery, disempowerment, infantilisation, intimidation, labelling, stigmatisation, outpacing, invalidation, banishment, objectification, ignoring behaviour, imposition, withholding, accusation, disruption, mockery or disparagement against the person.⁶⁶

The traditional medical model does not account for these dynamics and indeed, by looking at the individual living with dementia only from the perspective of disease, it feeds into the negative and deterministic view that, as seen in Chapter 2, creates many problems also in relation to the right to decide on healthcare matters.⁶⁷ Therefore, Kitwood advocates for a new paradigm which puts at the centre the person rather than the disease⁶⁸ and looks at dementia also in its biographical, relational and social dimension.⁶⁹ In this regard, he argues that the care of the person has to involve a ‘positive work’ which is based on recognition and respect.⁷⁰ By looking at them from this perspective, individuals with dementia do not appear anymore as ‘sick people’, but rather as ordinary individuals that may simply have a different but still legitimate way of living and thinking.⁷¹ In this way, also in relation to healthcare choices, this

⁶¹ See also T Kitwood, ‘The Dialectics of Dementia: with Particular Reference to Alzheimer’s Disease’ (1990) 10 *Ageing & Society* 177, 186-193; Kitwood, *Dementia Reconsidered*, above, 34-36 and 50.

⁶² T Kitwood, ‘Brain, Mind and Dementia: with particular reference to Alzheimer’s Disease’ (1989) 9 *Ageing and Society* 1.

⁶³ See also Kitwood, *Dementia Reconsidered*, above, 25.

⁶⁴ *Ibid*, 34.

⁶⁵ See also Kitwood, ‘The Dialectics’, above, 181-186

⁶⁶ Kitwood, *Dementia Reconsidered*, above, 46-47.

⁶⁷ *Ibid*, 37. See also Chapter 2.

⁶⁸ Kitwood, *Dementia Reconsidered*, above, 7-8 and 69-73.

⁶⁹ Kitwood, ‘The Dialectics’, above, 186-193.

⁷⁰ T Kitwood, ‘Towards a Theory of Dementia Care: Ethics and Interaction’ (1998) 9 *Journal of Clinical Ethics* 23, 27-29.

⁷¹ Kitwood, *Dementia Reconsidered*, above, 9-10

perspective leads to claim that also individuals living with dementia must be recognised the possibility to decide for themselves and that legal mechanisms should be eliminated which impose of them hypercognitive and rationalistic standards which are not respectful of their particular way to see life.

The ideas of the person-centred care approach to dementia echo in many ways those of the social model of disability. Indeed, as noted by Baldwin, by conceptualising dementia in terms of interplay between brain conditions and social environment, the person-centred approach implicitly adopts the distinction, central in the social model, between disability and impairment.⁷² Moreover, by affirming that loss of agency and personality often come from social dynamics and others' 'malignant social psychology', Kitwood and his followers seem to embrace the idea that in the field of disability the focus should be on the social barriers oppressing the person.⁷³ However, having been constructed mostly in relation to older individuals near the end of their lives and in an optic of care, the person-centred approach to dementia focuses more on care and promoting an attitude of respect and kindness rather than empowering people living with dementia. Therefore, it lacks the social model's drive towards fostering change at a systemic level and vindicating rights, which is crucial in the area of legal capacity and healthcare decisions. Indeed, as seen in Chapter 2, here there is the need to challenge deeply rooted legal and mind structures.

For this reason, in recent decades, activists and scholars in the field of dementia are increasingly turning to the social model as a tool for promoting change, inclusion and empowerment of individuals living with this condition.⁷⁴ Organisations such as Mental Health Foundation or Dementia Alliance International (DAI) argue that embracing the social model would make sure that people living with dementia are centre stage in policy discourse, that they are part of a broader social movement for change and that the barriers oppressing them are tackled.⁷⁵ In this regard, Marshall affirms that looking at dementia as to a disability would permit to focus more decisively on the personal experience and on enabling the person to manage their life,

⁷² Baldwin, 'Narrative' *above*, 223.

⁷³ C Baldwin, 'Technology', *above*.

⁷⁴ For a general idea see P Dorenlot, 'Applying the Social Model of Disability to Dementia: Present-Day Challenges' (2005) 4 *Dementia* 459; C Baldwin, 'Narrative(,) Citizenship and Dementia: the Personal and the Political' (2008) 22 *Journal of Aging Studies* 222, 223-224

⁷⁵ Mental Health Foundation, *above*, 20-29. See also Dementia Action Alliance, 'The Human Rights of People Living with Dementia: from Rhetoric to Reality' (DAI 2016), 3-7 <www.dementiaallianceinternational.org/wp-content/uploads/2016/10/The-Human-Rights-of-People-Living-with-Dementia-from-Rhetoric-to-Reality_2nd-Edition_July-2016_English.pdf> accessed 16 June 2018.

emphasising remaining abilities of the person rather than deficits.⁷⁶ Moreover, it would allow to understand how people living with dementia are marginalised and discriminated in our society.⁷⁷

As noted by Gilliard et al, this is the starting point of a new holistic approach to dementia, which does not deny the medical implications of the condition, but advocates for a broader vision of the social dynamics involved, leading to an active engagement with such factors.⁷⁸ In relation to legal capacity and healthcare decisions of people living with dementia, adopting the perspective of the social model permits to advocate more strongly for the necessity to remove the barriers preventing the person to exercise their decisional power with regard to care matters and to change regulations in this field. Therefore, it can form a basis for developing practices and even reforms which really focus on creating the conditions for the exercise of their decisional power by the person, rather than using the person's impairment to deprive them of their right to decide. Indeed, applying to this case the distinction between impairment and disability, and classifying dementia as one of those forms of disability that are mainly the product of barriers originating from society (and that society can also remove), leads to consider also the issues emerging in the area of treatment decisions of individuals living with this condition not as an inevitable consequence of their cognitive impairment, but rather as the result of prejudice, lack of arrangements which fit the needs of the person, or the inadequacy of legislations based on over rationalistic standards of choice making. In this regard, the social model seems to offer a paradigm which takes more seriously the concerns expressed by people living with dementia, carers, professionals and scholars with regard to the traditional approach to healthcare decision-making. For this reason, it appears to offer a paradigm on which to build a new system which really addresses the issues and barriers analysed in Chapter 2.

However, applying the ideas of the social model in this specific area requires more attention to some specific dynamics characterising the field of treatment decisions of individuals living with dementia, adapting and refining the model in relation to them. The first factor is that in this condition the impact of impairment can be so significant

⁷⁶ M Marshall, 'Emerging trends in Dementia Care: Some Thoughts on the next Ten Years' (Alzheimer's Disease International Conference, Edinburgh, September 1994).

⁷⁷ *Ibid.*

⁷⁸ J Gilliard et al, 'Dementia care in England and the Social Model of Disability. Lessons and Issues' (2005) 4 *Dementia* 571, 574-576.

that even if all external barriers have been removed and the right services and means of support are in place, the person does not manage to express a clear, articulate and comprehensible decision on their care. In this regard, here, in the dialectic impairment/disabling barrier, the former may have a more prominent role than it does in other cases such as that of wheelchair users, or that of other intellectual disability or mental health conditions. For this reason, it can be that, at times, more attention needs to be paid, in this specific case, to overcoming the effects of the impairment, though of course a careful look needs always to be kept on external barriers. So, following the work done especially by ‘second generation’ disability theorists,⁷⁹ it is particularly important to keep the emphasis on the definition of disability as interaction between impairment and societal barriers.

In addition, in relation to dementia, it is particularly important to bear in mind the significant differences of experiences among people living with this condition. Indeed, because of the variability of subtypes, symptoms and external factors impacting on the person’s lifestyle the issues and situations faced by individuals with dementia change significantly from case to case.⁸⁰ Therefore, this is one of the paradigmatic cases in which disability, though presenting some generally characteristics experienced by everyone, cannot be considered as a completely homogeneous dynamic.

Another element that needs to be considered is that, once moving to analyse the issues faced by people living with dementia in the specific area of capacity to consent and healthcare decision-making, it is necessary to define how the claims of the social model translate in relation to capacity and legal personality. Indeed, the aim of the social model is mainly to provide a general vision of disability, inspiring wide ideas which can be relevant for a number of different situations. Therefore, while it offers a powerful framework to reconceptualise disability and advocate for the removal of socially created disabling barriers, it does not provide a specific theory of how such barriers arise in a certain situation, or on what specific part of society is responsible for a certain barrier, or through which specific process to tackle a certain set of barriers. Indeed, as noted by Owens more than a full developed theory it is a macro-scheme whose message can be ‘filled’ and brought forward through the combination with other

⁷⁹ See section 2.

⁸⁰ See Chapter 1 Section 2 and Chapter 2 Section 4.

accounts.⁸¹ This is not to say that the social model has not provided a basis for quite specific analyses of the reality of disabled people, and that even with regard to legal capacity and legal personality has not led especially in the context of the movement for the liberation of mentally disabled individuals, to powerful claims in terms of fuller recognition of legal personality and respect of the autonomy and decisions of the individual.⁸² Only, in order to fully unveil the implications of its message in an area such as that of treatment decisions of people living with dementia, it is necessary to look at theoretical accounts that support and extend its claims in this context. In order to do so I will refer, in the next sections, to the construction of vulnerability developed by the American legal scholar Martha Fineman.

4. Vulnerability Theory and a new vision of Legal Personality

Fineman's Vulnerability theory is an approach developed in the context of feminist socio-legal theory, which has been increasingly gaining ground as an account of legal personality and a tool to better reflect on the role of social institutions like the law and the state in shaping the life condition of individuals.⁸³ It focuses on reconceptualising the too narrow and individualistic idea of human being still dominant in today's western legal and political culture, with particular regard to dynamics of disadvantage. In this regard, it has a number of points in common with the social model of disability and can further extend and support its claims in relation to healthcare choices of individuals living with dementia.

Fineman's analysis is linked to the critique brought forward within feminist thought to the liberal view of the individual as a completely rational, autonomous and independent being, who needs to be left free to shape their life without external interference.⁸⁴ Under this traditional view, still at the basis of the current approach to

⁸¹ J Owens, 'Exploring the Critiques of the Social Model of Disability: the Transformative Possibility of Arendt's notion of Power' (2015) 3 *Sociology of Health and Illness* 385, 388.

⁸² See above Section 2.

⁸³ For a discussion on the evolution of this approach see N Selberg and L Wegerstad, 'Interview with Professor Martha Albertson Fineman' (2011) 34 *Retfaerd* 4; M Fineman, 'Vulnerability and Inevitable Inequality' (2017) 4 *Oslo Law Review* 133. On the potential of Fineman's vulnerability theory in political and legal discourse see NA Kohn, 'Vulnerability Theory and the Role of Government' (2014) 26 *Yale Journal of Law and Feminism* 1, 2-10.

⁸⁴ For an overview of such a critique see N Stoljar, 'Feminist Perspectives on Autonomy' *Stanford Encyclopedia of Philosophy* (2013) <<https://plato.stanford.edu/entries/feminism-autonomy/>> accessed 14 October 2018. See also K Abrams, 'From Autonomy to Agency: Feminist Perspectives on Self-Direction' (1999) 40 *William and Mary Law Review* 805.

treatment decisions and capacity to consent,⁸⁵ vulnerability, frailty and incompetence are considered as deviations from the rule represented by ‘autonomous’ people, and legitimise paternalistic practices (e.g. incapacitation and deprivation of the power to decide) which ‘protect’ the individual from their alleged weakness.⁸⁶ Instead, the American scholar advocates for the rejection of such an independence focused vision considering it as fundamentally utopian.⁸⁷ Indeed, she notes how modern societies are so focused on the ideology of autonomy and individualism that they tend to forget how everyone is inevitably dependent and influenced by others.⁸⁸ Moreover, she points out how liberal theory seems to forget that all people are potentially exposed to harm, frailty, illness or financial difficulties.⁸⁹ For this reason, she suggests to substitute, at the centre of social, political and legal discourse, the idea of the autonomous individual with that of the vulnerable subject.⁹⁰ This would lead to recognise that every person is at a certain extent vulnerable.

Indeed, according to Fineman, vulnerability is intrinsic to the human condition.⁹¹ For this reason it cannot be considered as an exception, a deviation from the rule, but needs to be primarily recognised as a universal characteristic shared by all people.⁹² Universal vulnerability derives from the fact that every individual is both ‘embodied’ and ‘embedded’ in society.⁹³ The first dimension relates to the materiality of human bodies (including the brain), which change overtime, break, fall ill and become old, exposing each person to the ever-present possibility of injury, misfortune and

⁸⁵ See above Chapter 1 Section 3.

⁸⁶ M Fineman, ‘Elderly’, *above*, 84-88; J Herring, *Vulnerable Adults and the Law* (Oxford University Press 2016), 18-20.

⁸⁷ M Fineman, *The Autonomy Myth* (The New Press 2005).

⁸⁸ Similar claims are also present in works such as M Sandel, *Liberalism and the Limits of Justice* (1st ed, Cambridge University Press 1982); M Sandel, ‘Morality and the Liberal Ideal’, (1984) 190 *New Republic* 15. The emphasis on (inter)dependence from others and social relationships is also a central tenet in a series of works focusing on the reconceptualisation of the individual and autonomy. See for example J Nedelsky, ‘Reconceiving Autonomy: Sources, Thoughts and Possibilities’ (1989) 1 *Yale Journal of Law and Feminism* 7, 7-15; C MacKenzie and N Stoljar, ‘Introduction: Autonomy Refigured’; L Barclay, ‘Autonomy and the Social Self’; N Stoljar, ‘Autonomy and the Feminist Intuition’; C MacKenzie, ‘Imagining Oneself Otherwise’, all in C MacKenzie and N Stoljar (eds), *Relational Autonomy. Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford University Press 2000).

⁸⁹ Fineman, ‘Elderly’, *above*, 86-88. See also Herring, *above*, 6-17.

⁹⁰ Fineman, ‘The Vulnerable Subject: anchoring Equality’, *above*, 8-12.

⁹¹ *Ibid.*

⁹² M Fineman, ‘The Vulnerable Subject and the Responsive State’, *above*, 266-267.

⁹³ See also A Grear, ‘Vulnerability, Advanced Global Capitalism and Co-symptomatic Injustice’ in M Fineman and A Grear (eds), *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Routledge 2013), 49-50; Fineman, ‘Vulnerability’, *above*, 143.

dependency.⁹⁴ For this reason, besides being universal, vulnerability is also constant, as, because of the inevitable frailty of the human body, one can mitigate possible manifestations of vulnerability but can never eliminate the possibility of harm.⁹⁵ The level of ‘embeddedness’ refers to the fact that we all live with others in society, so we are also exposed to the possibility of harmful actions by fellow members of the human community.⁹⁶ In this regard, vulnerability may derive from the interactions between embodied differences and societal structure, and in particular from the reaction of society to our bodily vulnerability and the social and economic consequences of illness or injury.⁹⁷ Moreover, it may be due to choices made at a collective level, which shape the way in which society is organised and can contribute to enhance or attenuate one’s vulnerability.⁹⁸ Therefore, while vulnerability as a state of being is universal, it is experienced in a particular way by every person, depending on their social positioning.⁹⁹ Therefore, in Fineman’s account, vulnerability is a complex reality that takes often place at the intersection between body/individual dimension and society.

This vision echoes the claims of the social model of disability.¹⁰⁰ Indeed, the idea of vulnerability as deriving from both embodiment and embeddedness in society resembles quite closely the definition of disability in terms of interaction between impairment and societal barriers.¹⁰¹ However, Fineman’s theory gives to such elaborations a broader meaning. Indeed, while the social model focuses mainly on the case of disabled people, vulnerability theory refers to human condition in general, allowing for a reflection which regards not only a category of people but all members of society. As noted by Clough, it provides an important unifying aspect to the social model, emphasising the feature of impairment as a various but fundamentally universal dimension of human condition.¹⁰² In this regard, it brings forward more powerfully the claim, already present in the social model, that phenomena like disability are not pathological, but need to be accepted as part of human complexity. In this regard, it

⁹⁴ Fineman, ‘The Vulnerable Subject: Anchoring Equality’, *above*, 9-10; Herring, *above*, 11-12; Fineman, ‘Vulnerability’, *above*, 144-145.

⁹⁵ Fineman, ‘The Vulnerable Subject and the Responsive State’, *above*, 267.

⁹⁶ *Ibid*, 268; Fineman, ‘Vulnerability’, *above*, 145.

⁹⁷ Fineman ‘The Vulnerable Subject: Anchoring Equality’, *above*, 10.

⁹⁸ *Ibid*, 9-10.

⁹⁹ Fineman, ‘The Vulnerable Subject and the Responsive State’, *above*, 268-269.

¹⁰⁰ The similarity is especially clear if we consider the works of ‘second wave’ disability theorists like Morris or Williams.

¹⁰¹ See above Section 2.

¹⁰² B Clough, ‘Disability and Vulnerability: challenging the Capacity/Incapacity Binary’ (2017) 16 *Social Policy and Society* 469, 479.

makes clear how also in the area of treatment decisions of individuals living with dementia, the person should not be treated as if they have something less than others, but needs to be simply recognised as someone who experiences their vulnerability in a different way than others because of their brain but also and most importantly because of their social positioning. In this way, it further challenges those behaviours, analysed in Chapter 2, guided by prejudice and stigmatising attitudes which often hinder the persons' ability to express their will on medical treatment. Indeed, it leads to see how individuals living with dementia should not be patronised for their inevitable vulnerability, but rather be helped in facing the societal factors co-causing it in a way that takes into account and respects the particular way in which they experience it.

By referring to the particularity of each person's experience of vulnerability, Fineman's account also draws more attention to the specificities and nuances of the different situations in which different individuals living with dementia may find themselves in, echoing the ideas of 'second generation' disability theorists who advocate for a better consideration of the differences characterising the various personal experiences of single disabled people. Indeed, as already seen, in its traditional Oliverian theorisation, the social model tends to refer to disability as to a unitary dynamic and form of oppression.¹⁰³ Vulnerability theory contributes to counterbalance this aspect, clarifying how also with regard to long term impairments and disability the particular level is as important as the universal one, allowing a more faithful representation of the variability of symptoms and experiences typical of this condition.

Therefore, the social model of disability and Fineman's vulnerability theory show significant elements of continuity, as they both conceptualise disability and disadvantage in terms of interaction between the personal and embodied dimension and social structures-barriers, arguing for a change society so that it can better respond to the needs of disabled people and individuals exposed to social jeopardies. However, there are also tensions between the two theoretical accounts so that they may lead to (partially) divergent directions in terms of policy and legal approach.

In this regard, the social model of disability, which originated within the context of the disability movement as an ideological tool to demand the removal of societal

¹⁰³ See Section 2.

barriers oppressing disabled people, keeps a strong emphasis on the individual and the goal of enabling the person to be in control of their life and personal choices. On the other hand, Fineman's vulnerability theory tends to concentrate predominantly on the social level and on urging the state to take action through service provision and resilience building initiatives. Because of this, the social model provides a more natural basis for a political discourse centred on the human rights of disabled people and the goal of empowering these individuals to make decisions for themselves, while vulnerability theory rather tends to move on the level of wider welfare policies of which the individual (not only disabled) is the recipient.¹⁰⁴ As noted by Satz, by adopting such a wider perspective and by concentrating on state intervention Fineman's theory avoids the problem still characterising many disability policies inspired by the social model, which are overly focused on antidiscrimination and fail to promote a more general reorganisation of society which takes into account from the start the needs of disabled individuals.¹⁰⁵ However, on the other hand, while the social model appears generally aware of the risks of state's interventionism and of the need to protect the individual from the risk of oppressive interventions, vulnerability theory does not seem to have thoroughly elaborated on this potential 'dark side' of social engineering.

In this regard, some scholars express concern at the use of the term vulnerability in relation to disabled people.¹⁰⁶ Indeed, this concept has normally been instrumental to supporting paternalistic initiatives¹⁰⁷ being a means of stigmatisation¹⁰⁸ and social control on people living with impairments.¹⁰⁹ In this context, disability scholars

¹⁰⁴ In this regard, Fineman, 'The Vulnerable Subject and the Responsive State', *above*, 251 notes that the 'development of the concept of vulnerability and the idea of a vulnerable subject began as a stealthily disguised human rights discourse, fashioned for an American audience. The concept has evolved from those early articulations, and I now think it has some significant differences as an approach, particularly in that a focus on vulnerability is decidedly focused on exploring the nature of the human part, rather than the rights part, of the human rights trope'.

¹⁰⁵ AB Satz, 'Disability, Vulnerability, and the Limits of Antidiscrimination' (2008) 83 *Washington Law Review* 513.

¹⁰⁶ For a summary of these critiques see Herring, *above*, 22-23; R Harding, *Duties to Care. Dementia, Relationality and Law* (Cambridge University Press 2017), 20-21; Clough, *above*, 474-475.

¹⁰⁷ G Wishart, 'The Sexual Abuse of People with Learning Difficulties: Do we Need a Social Model Approach to Vulnerability?' (2003) 5 *Journal of Adult Protection* 14, 20-26.

¹⁰⁸ See M Harrison and T Sanders, 'Vulnerable People and the Development of "Regulatory Therapy"' in A Darling, T Newburn and P Somerville (eds), *Supporting Safer Communities: Housing, Crime and Neighborhoods* (Chartered Institute of Housing 2006), 155; G Moon, 'Risk and Protection: the Discourse of Confinement in Contemporary Mental Health Policy', (2000) 6 *Health and Place* 239, 241; J Warner, 'Community Care, Risk and the Shifting Locus of Danger and Vulnerability in Mental Health' in A Peterson and I Wilkinson (eds), *Health Risk and Vulnerability* (Routledge 2008), 30.

¹⁰⁹ B Fawcett, 'Vulnerability: Questioning the Certainties in Social Work and Health' (2009) 52 *International Journal of Social Work* 473; B Daniel, 'Concepts of Adversity, Risk, Vulnerability and

maintain that employing the term vulnerability brings the focus on impairments, inabilities and shortcomings of people in disadvantaged positions, rather than on societal barriers.¹¹⁰ Therefore, Dunn, Clare and Holland note how vulnerability may increase the risk that the person is deprived of their decisional power under the motivation that they need protection.¹¹¹ With specific regard to people living with dementia, Harding argues that, while the vulnerability approach has potential as a way of shifting legal and political attention from the autonomous individual subject to universal dependence, because of the specificity of the experience of living with dementia ‘it does not take us far enough’.¹¹² Indeed, because of the prominence in dementia care of a rhetoric putting emphasis on social death, dissolution of the self, inevitability of decline, the negative connotation of vulnerability may be particularly emphasised in this context, leading to reinforce practices aiming at containing/controlling the person, instead of an appreciation of their potential and strengths.¹¹³ In this regard, she expresses the concern that, by adopting universal vulnerability as a starting point, one runs the risk of overlooking the specific interpersonal relationships of dependence and interdependence.¹¹⁴

However, Fineman notes that the negative meaning associated with the concept of vulnerability derives from the misrepresented vision proposed by liberal theory.¹¹⁵ Indeed, with its ideology of autonomy and non-interference it has provoked the stigmatization of vulnerability and dependency, which has been seen as a pathology.¹¹⁶ In effect, the power of Fineman’s approach lies in the fact that it takes an under-theorised concept, characterised by a negative connotation, and gives to it a new meaning, emphasising the importance of a radical change of perspective.¹¹⁷ Therefore,

Resilience: a Discussion in the Context of the “Child Protection System” (2010) 9 *Social Policy and Society* 231.

¹¹⁰ Wishart, *above*, 20-26; A Hollomotz, ‘Beyond “Vulnerability”’: an Ecological Model Approach to Conceptualizing Risk of Sexual Violence against People with Learning Difficulties’ (2009) 39 *British Journal of Social Work* 99.

¹¹¹ M Dunn, I Clare and A Holland, ‘To Empower or Protect? Constructing the “Vulnerable Adult” in English Law and Public Policy’ (2008) 28 *Legal Studies* 234, 241-251.

¹¹² Harding, *above*, 19.

¹¹³ *Ibid*, 19-20.

¹¹⁴ *Ibid*.

¹¹⁵ Fineman, ‘Elderly’, *above*, 96-100. This vision is also shared by A Campbell, ‘Dependency Revisited: The Limits of Autonomy in Medical Ethics’ in M Brazier and M Lobjoit (eds), *Protecting the Vulnerable: Autonomy and Consent in Healthcare* (Routledge 1991), 101; J Anderson and A Honneth, ‘Autonomy, Vulnerability, Recognition, and Justice’ in J Christman and A Anderson, *Autonomy and the Challenges to Liberalism* (Cambridge University Press 2009), 127.

¹¹⁶ Fineman, ‘Elderly’, *above*, 87.

¹¹⁷ Fineman, ‘The Vulnerable Subject: Anchoring Equality’, *above*, 9.

through this idea, she emphasises how vulnerability is a normal and even positive dimension of humanity, declaring in an explicit way how a radical change of perspective is needed.¹¹⁸ Moreover, despite the emphasis on the universal nature of vulnerability, the works of the American scholar are also disseminated with references to the necessity of looking at the particular condition and specific relationships shaping every person's life.¹¹⁹ In this regard, the recalling of the role played by social embeddedness in determining the vulnerability faced by a person, is only another way of expressing how we should put attention to the influence of the relationships surrounding each individual. So, also with regard to decision-making, Fineman's account advocates for the recognition of the fact that real autonomy and the power to shape one's life cannot be attained without substantial assistance from social institutions and relational networks surrounding a person.¹²⁰

In this regard, vulnerability theory also leads to a different approach in the field of legal capacity and choice making on medical treatment. Indeed, by insisting on the universality of vulnerability, and by indicating it as a concept which needs to inform the vision of the individual at the centre of legal discourse, it advocates for an approach to legal personality that really accepts vulnerability and dependency as a physiological characteristic of human nature. In this regard, Herring notes how, while the current legal conception of the self emphasises autonomy and liberty as key rights whose interference requires strong justification, if 'we start from the norm of vulnerable, interdependent, caring people then the nature of legal intervention becomes different', putting at the centre relationships and care.¹²¹ As affirmed by Clough the richer understanding of vulnerability proposed by Fineman questions the traditional binary division between legal capacity and incapacity, between those with cognitive impairments and those without.¹²² Instead, it considers everyone as vulnerable to relationships of domination which unequally distribute the resources necessary to enable meaningful choices, and to social, political and legal norms which disavow and devalue.¹²³ Therefore also in this context vulnerability plays on the same side of the

¹¹⁸ Indeed, Fineman notes how, by recognising that everyone is vulnerable we see how our vulnerability may have positive effects and may be generative as it makes us reach out to others, form relationships and use our creativity to overcome obstacles. Fineman, 'Elderly', *above*, 96.

¹¹⁹ See for example M Fineman, 'Equality and Difference – The Restrained State' (2015) 66 *Alabama Law Review* 609, 612-616.

¹²⁰ Fineman, 'The Vulnerable Subject and the Responsive State', *above*, 260.

¹²¹ Herring, *above*, 18.

¹²² Clough, *above*, 476.

¹²³ *Ibid.*

social model and further brings forward its programme of challenging barriers oppressing disabled people like individuals living with dementia, such as the othering, stigmatising approach to decision-making which deprives them of the possibility to choose for themselves. Therefore, Fineman's vulnerability theory offers a basis, anchored to a broad view of the individual, for reforms and regulations which really empower individuals living with this condition.

5. Vulnerability, Dementia and the Responsive State

Advocating for the centrality of the vulnerable individual in legal and political discourse implies that the state, the law and all other social institutions need to put at the centre of their concerns the vulnerabilities of their citizens and take responsibility for accommodating them. In this regard, Fineman's account also challenges the liberal ideology of non-interference and non-intervention of the state.¹²⁴ Indeed, by recognising that everyone is at some extent vulnerable and dependent it leads to see that it is not enough to just 'leave people free' to plan their life without interference as argued by liberal theorists. Instead, society needs to take action in helping its members to face their dependence and frailties.¹²⁵

In effect, the particular life condition of each individual ultimately depends on whether they benefit from services and adjustments which accommodate their needs. We often look at disabled people, at individuals living with dementia, or at other categories such as children, older people or citizens living in poverty, and see them as weak and in need of protection, patronising them for this. However, as pointed out by Lindeman, able-bodied working adults tend to forget how their lives are made possible by a number of accommodations and social arrangements without which they will also be in a position of disadvantage.¹²⁶ Indeed, people tend to highlight the adjustments put in place to deal with the vulnerabilities of others but overlook the fact that they also are dependent from fellow individuals who provide them with the equipment and assistance needed for exercising their skills, who give them access to products such as electricity or food, who offer them emotional support. They forget that they benefit

¹²⁴ Fineman, 'The Vulnerable Subject: Anchoring Equality', *above*, 5-8; Fineman, 'The Vulnerable Subject and the Responsive State', *above*, 251-255.

¹²⁵ Fineman, 'The Vulnerable Subject: Anchoring Equality', *above*, 13; Fineman, 'The Vulnerable and the Responsive State', *above*, 269.

¹²⁶ K Lindeman, 'The Ethics of Receiving' (2003) 24 *Theoretical Medicine and Bioethics* 501, 502.

from shops' extended hours, ATMs or elevators, all services without which their life would be extremely more difficult to manage.¹²⁷ All these and other adjustments are the way in which society builds the resilience of its members.

In Fineman's words 'resilience is the critical, yet incomplete, solution to our vulnerability'.¹²⁸ Indeed, it is impossible to completely eliminate vulnerability, as it is intrinsic to human condition, but every individual needs to be equipped to resist and recover from harm and adversities. In this sense, the American scholar identifies at least five different types of resources which social institutions can provide to build resilience: physical, human, social, ecological and environmental.¹²⁹ Physical resources are the material means essential for the wellbeing of everyone such as housing, food or money for appropriate care and services. Human resources are the 'human capital' which is normally provided through education, training, knowledge and experience which provides to individuals the necessary insight to navigate the different situations of life. Social resources are provided through the network of relationships one forms with surrounding individuals and social institutions. They give each person a sense of community and belonging and offer them the emotional and practical support needed to express their personality and make choices. Ecological resources relate to the environment and context in which one is positioned and which, depending on how it is structured, can enhance or hinder one's possibilities to fully enjoy life. Finally, existential resources refer to the value system of an individual and the possibility to cultivate such an ideal background and live according to it.

In Chapter 2 it has been shown how the lack of such resources has a strong impact on the right of people living with dementia to decide on medical treatment. Indeed, the scarcity of physical and ecological resources creates a situation in which medical professionals, carers and care structures do not have the capacity to provide to the person the environment and support they need to express their will.¹³⁰ To this situation also contributes the lack of adequate human resources, that is of professionals and carers who are properly trained to communicate with the person and are able to understand their declarations.¹³¹ For this reason and because of dynamics of stigma and prejudice, the social resources, represented by the people around the individual

¹²⁷ See also Herring, *above*, 10-11.

¹²⁸ Fineman, 'Vulnerability', *above*, 146

¹²⁹ *Ibid.*

¹³⁰ See Chapter 2 Section 4.

¹³¹ *Ibid.*

living with dementia, often do not contribute to promote the person's right to decide, but rather oppress them and deny them the possibility to decide for themselves.¹³² Finally, it has also been seen how people living with dementia are often not given the opportunity of cultivating and making use of their spiritual resources, as they tend to not be recognised in their ability to value, sense of self and full personality.¹³³

To the provision of these resources can surely contribute the family and the network of personal relationships in which the person is embedded. However, many of them can only be brought into existence through wider and more articulate structures governed by the state.¹³⁴ Indeed, in relation to treatment decisions of individuals living with dementia it has been seen how the inability of medical professionals and carers to assist the person in making choices is often due to the insufficient level of resources invested by the state in care services.¹³⁵ Also barriers like prejudice, negative attitudes against people living with dementia and inadequate legal capacity legislation require wide ranging actions and deep systemic changes which are very difficult to obtain without the contribution of public institutions.

In this regard, Fineman advocates for adopting a legal and political model based on the responsive state.¹³⁶ She notes how, until now, public institutions have tent to withdraw progressively from their role of regulatory force of society, under the ideology of the minimal state.¹³⁷ However, state institutions 'form systems that play an important role in lessening, ameliorating, and compensating for vulnerability'¹³⁸ as they 'provide us with resources in the form of advantages or coping mechanisms that cushion us when we are facing misfortune disaster and violence'.¹³⁹ Therefore, the state has an obligation to ensure the presence of social institutions which can build access to social goods and opportunities on an equal basis for all members of society.¹⁴⁰ In this regard, it must recognise positions of inequality, universal vulnerability and dependency acting as an instrument to build resilience and promote social justice in both its law making and enforcement functions.¹⁴¹ Therefore, also in

¹³² Chapter 2 Sections 2 and 4.

¹³³ See the position by A Jaworska, 'Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value' (1999) 28 *Philosophy and Public Affairs* 105, analysed in Chapter 2 Section 3.

¹³⁴ Fineman, 'Vulnerability', *above*, 146.

¹³⁵ See Chapter 1 section 4.

¹³⁶ Fineman, 'Vulnerability', *above*, 148-149.

¹³⁷ Fineman, 'The Vulnerable Subject: Anchoring Equality', *above*, 5-6.

¹³⁸ *Ibid*, 13.

¹³⁹ Fineman, 'The Vulnerable Subject and the Responsive State', *above*, 270.

¹⁴⁰ *Ibid*, 256.

¹⁴¹ Fineman, 'Vulnerability', *above*, 149.

relation to treatment decisions of people living with dementia, an approach focusing on the responsive state shifts the attention on how, citing Clough, '[legal and policy] responses can best be framed to facilitate autonomy in a thicker and more meaningful sense, which may involve access to particular resources, or supports in making decisions'.¹⁴²

Coherently with these premises also vulnerability theory, like the social model, puts emphasis on substantive rather than just formal equality and advocates for a policy and legal approach which focuses on creating the conditions for people to shape their life, rather than just clinging on the dogma of the individual as a solitary artificer of their destiny.¹⁴³ This approach has often led to see state intervention as a possible danger to personal freedom and self-determination eroding the possibilities for a robust action of social institutions towards the promotion of possibility of choice and the provision of the necessary accommodations and support to obviate to people's intrinsic vulnerability.¹⁴⁴ Instead, Fineman, building on a long tradition of feminist thought,¹⁴⁵ emphasises that true autonomy and freedom to decide for oneself cannot be attained without an 'underlying provision of substantial assistance, subsidy and support from society and its institutions, which give individuals the resources they need to create options and make choices'.¹⁴⁶ Indeed, autonomy is not an innate characteristic but 'must be cultivated by a society that pays attention to the needs of its members'.¹⁴⁷

Such claims echo the views of disability theorists who advocate for the necessity to actively support people living with impairments and remove the societal barriers oppressing them.¹⁴⁸ In this regard, vulnerability theory further specifies the implications of such stances for decision-making and offers a more articulate reflection on how they lead to a change in expectations towards the state and social institutions. Applying its ideas in the field of treatment decisions of individuals living with dementia leads to advocate even more strongly for an active engagement of public authorities and social institutions in creating the conditions for the person to express their will on healthcare matters. Indeed, by combining the perspective of Fineman's

¹⁴² Clough, *above*, 478. See also C Mackenzie, 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability' in C Mackenzie, C Rogers and S Dodds (eds), *Vulnerability. New Essays in Ethics and Feminist Philosophy* (Oxford University Press 2014), 55.

¹⁴³ Fineman, 'The Vulnerable Subject and the Responsive State', *above*, 256-262.

¹⁴⁴ *Ibid*, 258-259.

¹⁴⁵ See for example SAM McLean, *Autonomy Consent and the Law* (Routledge 2009), 19-20.

¹⁴⁶ Fineman, 'The Vulnerable Subject and the Responsive State', *above*, 260.

¹⁴⁷ *Ibid*, 260.

¹⁴⁸ See *above* Section 2.

vulnerability theory and the social model, it becomes clear that also in this situation the first question to be considered is whether state/institutional, not individual functioning is adequate.¹⁴⁹ This analysis angle is also adopted in this thesis and explored in the next chapters which indeed aim to study how state(s) and public institutions can contribute to create the necessary conditions for people living with dementia to decide on medical treatment.

However, in today's world, state/social institutions are not a monolith, they do not act on a single level or only according to a unitary, centralised mechanism. Indeed a now extensive body of literature in legal and political theory shows how because of the rise of international cooperation, the prominence of transnational governance systems, globalisation trends and the increased interconnectedness created by new technologies state power is increasingly distributed between traditional national bodies, supranational organisations and private actors.¹⁵⁰ So, Ost and van de Kerchove note how the model according to which they are organised resembles more the shape of a complex net than that of a pyramid.¹⁵¹ Others refer to the concept of multilevel governance to designate a system in which power, political and regulatory functions are organised in different layers.¹⁵² This is particularly evident if one looks at Europe. Here, the political and legal landscape appears clearly shaped by the stratified action of different institutions and normative sources which include international principles, policies and norms promoted by regional organisations such as the Council of Europe or the European Union, and the initiatives developed at a national level both by governments or national/local institutions. In addition, modern society and politics is characterised by an increasing public relevance of private bodies such as companies, charities and NGOs, which are taken up functions traditionally pertaining to the state,

¹⁴⁹ Fineman, 'Vulnerability, above, 147.

¹⁵⁰ See for example D Held and A McGrew, 'The End of the Old Order?' (1998) *Review of International Studies* 219, 219-243; M Shaw, *Theory of the Global State: Globality as an Unfinished Revolution* (Cambridge University Press 2000), 116; D Treisman, *The Architecture of Government: rethinking Political Decentralization* (Cambridge University Press 2007); NK Göksel, *Globalisation and the State* (2004) 15 *SAM Papers* 1, 6; N Spina, 'Explaining Political Decentralization in Parliamentary Democracies' (2013) 1 *Comparative European Politics* 428.

¹⁵¹ F Ost and M van de Kerchove, *De la Pyramide au Réseau ? Pour une théorie dialectique du droit* (Facultés Universitaires Saint-Louis 2002).

¹⁵² I Pernice, 'Multilevel Constitutionalism and the Treaty of Amsterdam: European Constitution-Making Revisited?' (1999) 36 *Common Market Law Review* 703, 708-725; L Hooghe and G Marks, *Multi-level Governance and European Integration* (Rowman and Littlefield 2001).

complementing and influence the action of governments and law making bodies.¹⁵³ This emerges not only from the (controversial) trends that in many countries have seen the privatisation of public services also in the field of healthcare, or the increasing demands placed on families and younger generations to step in to obviate the state inability to fund extensive care for a rapidly aging population.¹⁵⁴ It also finds expression in a greater engagement and influence of non-state interest groups, professionals, academics and lay citizens in policy processes. This is evident also in the area of disability and healthcare, in which activists and disability rights associations are now often involved in the development of new regulations or actions, and often are the real initiators of processes of change.¹⁵⁵ In addition, especially in matters of high technical and organisational complexity national, European and International bodies regularly decide to take advantage of the advice of academics or individuals with specific professional experience in a certain sector.¹⁵⁶

Therefore, if a century ago ‘the state’ could have been comfortably identified with national centralised institutions, today it appears as a much more complex and articulate entity which includes on the one hand supranational institutions such as the UN, the CoE or the EU and on the other hand is influenced by peripheral entities such as local authorities and non-governmental or private societal structures. These different articulations of the state and society interact, control and influence each other. Depending on how these interactions work the various institutions can be more or less responsive to the needs of a given category of people in a certain situation. The rationale beyond the existence of these different layers and mechanisms is that, as noted by Fineman, also state and social institutions are vulnerable to a variety of internal and external corruptions and disruptions, so that they also need to be supported

¹⁵³ In addition to already cited literature see also JM McCormick, *Weber, Habermas and Transformations of the European State* (Cambridge University Press 2007), 243-245; M Barberis, *Europa del Diritto* (Il Mulino 2008), 249-265.

¹⁵⁴ See H Maarse, *Privatisation in European Health Care: a Comparative Analysis in Eight Countries* (Elsevier 2004); MI Broese van Groenou and A De Boer, ‘Providing Informal Care in a Changing Society’ (2016) 13 *European Journal of Ageing* 271.

¹⁵⁵ One of the clearest examples is the UN Convention on the Rights of Persons with Disabilities in which disabled people’s of organisations were involved from the beginning in the negotiations. On this point see P Harpur, ‘Nothing About Us Without Us: The UN Convention on The Rights of Persons with Disabilities’ in *Oxford Research Encyclopedia of Politics* (2017). It will be seen in Chapter 5 how many institutions of the Council of Europe regularly commission research, involving academics and professionals as consultants in the policy process.

¹⁵⁶ It will be seen in Chapter 5 how many institutions of the Council of Europe regularly commission research, involving academics and professionals as consultants in the policy process.

and monitored in their activities.¹⁵⁷ Therefore, distributing the resilience building function of the state across different levels and autonomous bodies, allows the various institutions to control and help each other in putting in place all necessary provisions to make sure that individuals are equipped to face their inevitable vulnerabilities.

In line with the ideas explained so far, in the next chapters I will look at the relevant actions which have been or can be undertaken in order to advance the right to decide on medical treatment of people living with dementia at various level of state and society. I will first focus on the International UN level. In this context, States have shown quite a clear will to be more responsive to the needs of individuals living with cognitive impairments by ratifying a Convention such as the CRPD which is in line with many of the values analysed in this chapter and in Article 12 explicitly advocates for State Parties to engage in creating the conditions for the person to exercise their legal capacity.¹⁵⁸ Subsequently, I will explore how regional organisations such as the CoE and the EU can assist their Member States in realising their objective of being more responsive also in the field of treatment decisions of individuals living with dementia, by promoting the values and principles of the Convention, monitoring the measures put in place by governments in this area, providing channels for the exchange of ideas and good practices, reminding States their obligations to offer adequate services to people living with this condition and, especially in the case of the EU, providing funding to helping institutions in fulfilling such an obligation.¹⁵⁹ Finally, I will study what concrete initiatives may emerge from single European countries which can contribute to create the conditions for people living with dementia to express their will on treatment and to support the person in making decisions.¹⁶⁰

6. Conclusion

Through the analysis conducted in this chapter it emerges how adopting the perspective of the social model of disability and Fineman's vulnerability theory leads to a vision of the person living with dementia which is more inclusive and adherent to lived reality. Therefore, these accounts put in a different light the issues analysed in

¹⁵⁷ Fineman, 'The Vulnerable Subject and the Responsive State', *above*, 256.

¹⁵⁸ See Chapter 4.

¹⁵⁹ See Chapters 5 and 6.

¹⁶⁰ See Chapter 7.

Chapter 2 and provide a conceptual basis for a model of healthcare decisions which avoids the issues and barriers emerging in everyday care and legal practice.

In particular, the theoretical perspective adopted in this work permits to understand more clearly that the difficulties faced by people living with dementia are often not inevitable and pathological consequences of their brain's deterioration but rather are due to the way in which society responds or fails to respond to such an impairment. Therefore, also in relation to legal personality and capacity to consent, it is necessary to abandon the traditional approach based on a sharp binary distinction between capable and incapable people or vulnerable and non-vulnerable individuals. Instead, research, policies and legal provisions need to concentrate on removing the barriers faced by the person in deciding on medical treatment and creating the conditions for them to fully express their will.

This places also a precise responsibility on the different layers of the state, international/regional/local governance, and social institutions to actively engage in providing services and support to people living with dementia in making treatment decisions. Therefore, adopting the views of the social model and Fineman's vulnerability theory poses the basis for a model of legal capacity legislation, which does not focus so much on assessing the cognitive abilities of the person, but rather intervenes in empowering everyone to make choices for themselves, despite the state of their brain.

In the next chapter I will explore how such a model is embodied by the CRPD and in particular by its Article 12, which appears in line with many of the values analysed here, translating them into legal principles.

CHAPTER 4

Legal Capacity, Capacity to Consent and the UN Convention on the Rights of Persons with Disabilities

1. Introduction

The UN Convention on the Rights of Persons with Disabilities (CRPD), was adopted by the UN General Assembly on the 13th December 2006 and entered into force on the 3rd May 2008.¹ It is the first binding treaty reaffirming the rights of individuals living with ‘long-term physical, mental, intellectual or sensory impairments’.² The Convention pays particular attention to legal capacity as, due to its nature of ‘gatekeeper’ of legal personality,³ it is a fundamental prerequisite for the full enjoyment and exercise of any right.⁴ In this regard, Article 12 CRPD creates a new human rights and support oriented model⁵ which appears to embrace the values analysed in the previous chapter, being in line with many of the core tenets of the social model and Fineman’s vulnerability theory.

¹ UN Convention on the Rights of Persons with Disabilities (adopted 13 December 2006 UN General Assembly Res 61/106 (2006) UN Doc A/RES/61/106, opened for signatures 30 March 2007, entered into force 3 May 2008) 2515 UNTS 3 (CRPD). The text was prepared by the Working Group established by the Ad Hoc Committee in its 2nd session. See Ad Hoc Committee, ‘Report of the Second session’ (2003) UN Doc A/58/118 & Corr.1. So far the Convention has been signed by 160 State Parties and Regional Organisations and ratified/acceded by 174. For the list of signatories and ratifications and for the negotiations archives see <www.un.org/development/desa/disabilities/convention-on-the-rights-of-personswithdisabilities.html> accessed 1 August 2017.

² Article 1(2) CRPD. F Mégret, ‘The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?’ (2008) 30 *Human Rights Quarterly* 496, 503-514; P Bartlett, ‘The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law (2012) 75 *The Modern Law Review* 754, 755-757.

³ See Chapter 1 Section 3.

⁴ T Degener and A Begg, ‘From Invisible Citizens to Agents of Change: A Short History of the Struggle for the Recognition of the Rights of Persons with Disabilities at the United Nations’ in V Della Fina, R Cera and G Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities. A Commentary* (Springer 2017), 23. On the importance of legal capacity for the real enjoyment of human rights see A Dhanda, ‘Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?’ (2007) 34 *Syracuse Journal of International Law and Commerce* 429, 456-460. This aspect was also pointed out by disabled people’s organisations in the negotiations of the Convention, as it emerges from Ad Hoc Committee, ‘Daily summary of Discussions related to Article 9 Equal Recognition as Persons before the Law’ Volume 4#3, 26 May 2004, intervention by People with Disabilities Australia, National Association of Community Legal Centres and Australian Federation of Disability Organizations <<http://www.un.org/esa/socdev/enable/rights/ahc3sum9.htm>> accessed 20 November 2017.

⁵ J Craigie, ‘A Fine Balance: Reconsidering Patient Autonomy in light of the UN Convention on the Rights of Persons with Disabilities’ (2015) 29 *Bioethics* 398; T Degener and A Begg, *above*, 23-24.

This chapter provides an overview of Article 12 provisions, clarifying their meaning and implications for healthcare decision-making of people living with dementia. In this regard, it explores how they could provide normative tools capable of promoting the right to decide of such individuals through supported decision-making. In this way it further advances answering the main research question of the thesis by detailing the normative framework through which it is possible to create better conditions for people living with dementia to exercise their right to choose on medical treatment.

The analysis adopts a doctrinal perspective, interpreting CRPD principles in light of their literal content, the normative context in which they are inserted and the *travaux préparatoires*. In order to get insights on the various interpretive issues, it refers to relevant scholarly works, reports and jurisprudence of international bodies. In this regard, it relies especially on the documents released by the UN Committee on the Rights of Persons with Disabilities, the body entrusted by the Convention with the task of advising State Parties on the correct interpretation of its provisions,⁶ and in particular to General Comment No 1, focusing on Article 12 CRPD.⁷

Therefore, Section 2 gives a brief summary of the general principles underpinning the Convention and contained in its first part, studying how they tie in with many of the values analysed in Chapter 2 and express the innovative vision characterising the CRPD. Section 3, then focuses on Article 12(1) and (2) CRPD, investigating how it proposes a human rights approach to legal capacity, which leads to the rejection of the traditional model based on the discriminatory distinction capacity/incapacity and on the deprivation of decisional power in case of mental disability. Section 4 concentrates on the idea of supported decision-making (Article 12(3) CRPD), the legal tool proposed by the Convention to promote the wishes of a disabled person in case they face difficulties in expressing their will. In addition, Section 5 deals with Article 12 provisions concerning legal capacity safeguards and with the problem of avoiding of possible self-harm and undue influence. Finally, section six looks at statements of principle deriving from CRPD provisions such as Articles 25 (health), or 17 (integrity), and by UN bodies on the basis of Article 12, remarking the implications of the new

⁶ Information on the Committee can be found in <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>> accessed 17 January 2018.

⁷ Committee on the Rights of Persons with Disabilities (11th session), ‘General Comment No. 1 Article 12: Equal recognition before the law’ (2014) UN Doc CRPD/C/GC/1, 6.

approach to legal capacity described in this chapter in the field of treatment choices. The conclusion, summarises the main elements forming the approach to legal capacity and treatment decisions emerging from the CRPD and emphasise how they can contribute to solve the issues emerging in the field of healthcare decision-making of people living with dementia.

2. The CRPD: general principles and normative underpinnings

The CRPD and the Paradigm Shift in the vision of disability

During negotiations for the CRPD State-Parties and disabled people's organisations (DPOs) agreed that the text 'has to reflect the social model'⁸ and to 'avoid the construction of disability as solely medical'.⁹ The influence of such an approach emerges from Convention provisions such as paragraph e) of the Preamble, which affirms that 'disability results from the interaction between persons with impairments and attitudinal and environmental barriers', and Article 9, referring to the 'identification and elimination of obstacles and barriers' impacting disabled individuals.¹⁰ By adopting this framework, the Convention promotes a paradigm shift in the law's approach to disability.¹¹ Indeed, as affirmed by the UN High Commissioner on Human Rights, it sees disabled people not anymore as 'objects of charity' but as 'subjects of rights' and 'active members of society'.¹² Therefore,

⁸ Statement of the European Disability Forum, Ad Hoc Committee 'Compilation of Comments on Articles of the Draft Text of the Working Group' (2004). Similar statements were made by Australia, Guatemala, Cuba, Venezuela and Thailand, Ad Hoc Committee, 'Daily Summary of Discussions' Volume 5 #1, 23 August 2004. The negotiations archives are available at <<http://www.un.org/esa/socdev/enable/rights/adhoccom.htm>> accessed 9 October 2017.

⁹ Ad Hoc Committee, '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' (2003) UN Doc A/AC.265/2003/4+ Corr.1.

¹⁰ On the influence of the social model on the CRPD see also R Kayess and P French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 *Human Rights Law Review* 1, 7.

¹¹ Ad Hoc Committee, 'Press Conference by Chairman of Ad Hoc Committee on Convention on Disabled Persons' Rights' (2006) <http://www.un.org/press/en/2006/060815_Disabilities.doc.htm> accessed 9 October 2017.

¹² Ad Hoc Committee, 'Statement by Louise Arbour, UN High Commissioner for Human Rights to the Resumed 8th Session of the Ad Hoc Committee on the Convention on the Rights of Persons with Disabilities' (2006) <<http://www.un.org/esa/socdev/enable/rights/ahc8hrmsg.htm>> accessed 10 October 2017. See also T Mladenov, 'The UN Convention on the Rights of Persons with Disabilities and its Interpretation' (2013) *ALTER* 69, 72-73. Coherently with this spirit DPOs united in the International Disability Caucus (IDC) were granted the right to participate in the negotiations and gave a crucial contribution to the drafting of the text. Ad Hoc Committee, Report (2002) UN Doc A/57/357, 4-6. On the participation of DPOs see also AS Kanter, 'The Promise and Challenge of the United

already from the outset it emerges how the CRPD embraces some of the key ideas explained in Chapter 2, so that also in relation to treatment decisions of people living with dementia, it provides a solid foundation to claim that these individuals need to be recognised as persons with full rights and that the barriers need to be removed that prevent them from exercising such rights.

However, it is not clear which version of the social model underpins the Convention. Kayess and French maintain that the CRPD is based on a radical understanding of the model.¹³ Indeed, its provisions would seem to look predominantly at social barriers, paying less attention to the role played by impairments. However, Harpur notes how the definition of disability in terms of ‘interaction’ between impairment and societal barriers (Preamble paragraph e) and Article 1(2) CRPD show a certain receptiveness to the ideas of ‘second generation’ disability scholars.¹⁴ In reality, the Convention combines elements from both versions of the model.¹⁵ This permits to the CRPD, throughout its articles, to put adequate emphasis on the social dynamics shaping the life condition of disabled individuals, but still paying attention to the impact of impairment on disabled people’s lives and recognising diversity within the category of disability.¹⁶

In this regard, the Convention appears to be in line also with Fineman’s vulnerability theory. There is no evidence that this account had a direct influence on the development of the Convention.¹⁷ However, many principles of the CRPD appear to echo the claims brought forward by the American scholar. Indeed, the definition of disability as the interaction between impairment and societal barriers resembles

Nations Convention on the rights of Persons with Disabilities’ (2007) 34 *Syracuse Journal of International Law and Commerce* 287, 297-306.

¹³ Kayess and French, *above*, 7. On the various versions of the social model see Chapter 3 Section 2.

¹⁴ P Harpur, ‘Embracing the New Disability Rights Paradigm: the Importance of the Convention on the Rights of Persons with Disabilities’ (2012) 27 *Disability & Society* 1, 3. As admitted by Kayess and French, *above*, 21, the language of the CRPD is not rigorously adherent to the social model using, for example, the expression ‘persons with disabilities’, which may suggest that disability comes from the person, rather than society.

¹⁵ Kanter, *above*, 291. MA Stein, ‘Disability Human Rights’ (2007) 95 *California Law Review* 75 notes how the CRPD is also influenced by other ideas such as that of ‘right to development’, which identifies development and social justice as a basis for fundamental rights, and Nussbaum’s relational vision of dignity.

¹⁶ T Degener, ‘A New Human Rights Model of Disability’ in Della Fina, Cera and Palmisano (eds), *above*, 47-54.

¹⁷ Indeed, Fineman’s account on vulnerability started being developed in the first half of the years 2000s and the first important works detailing its fundamental claims were published in between 2008 and 2012, when the CRPD had already been adopted by the UN General Assembly. Therefore, though similar ideas were probably circulating among scholars and activists already during the time in which the Convention was being drafted, it cannot be claimed that Fineman’s vulnerability theory had a direct influence on its text.

closely the idea of vulnerability as caused by the interaction between embodied and embedded differences.¹⁸ In addition, as it will be seen in relation to Article 12, the CRPD seems quite close to the approach to legal personality advocated by Fineman.¹⁹ Finally, the entire Convention is a means to claim the obligation of the state(s) to be responsive to the needs of disabled people and actively engage in creating the conditions for them to fully enjoy their rights.

Autonomy

An expression of the paradigm shift underpinning the Convention is contained in Article 3(a) CRPD, which affirms, as a general principle, that of respect for the ‘individual autonomy’ of disabled individuals. As noted by Mladenov, this is the attribute according to which people can be seen as active *subjects* shaping their lives, rather than *objects* who passively bear others’ choices.²⁰ The link between recognition as a full human being and autonomy is particularly evident in relation to mentally disabled people whose autonomy has often been restricted by segregating practices and laws denying them the freedom to choose.²¹ It has also been seen how the autonomy and ability to decide for themselves of people living with dementia is still questioned inside and outside the field of treatment decisions.²²

The CRPD affirms, in Preamble (n), ‘the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices’. This formulation seems to be rather adherent to a liberal conception of the individual as totally independent and detached from others. However, the Convention goes beyond the classical focus on self-determination and making decisions for one’s self.²³ Indeed, O’Cinneide notes how the entire CRPD is centred on the importance of relationality for real autonomy, recognising that disabled people depend on social support for the enjoyment of their rights, and requiring State Parties

¹⁸ See Chapter 3 Section 4.

¹⁹ See further Section 3.

²⁰ Mladenov, *above*, 73.

²¹ See for example F Basaglia (ed), *L’Istituzione Negata* (Dalai 1961).

²² See Chapter 2. See also Nuffield Council on Bioethics, *Dementia: ethical issues* (Nuffield 2009), 79-80 <<http://nuffieldbioethics.org/wp-content/uploads/2014/07/Dementia-report-Oct-09.pdf>> accessed 13 January 2018; European Union Agency for Fundamental Rights, ‘Involuntary placement and involuntary treatment of persons with mental health problems’ (2012); European Union Agency for Fundamental Rights, ‘Legal Capacity of Persons with Intellectual Disabilities and Persons with Mental Health Problems’, (2013) both in <<http://fra.europa.eu/en/publications-and-resources/publications>> accessed 5 November 2017.

²³ Mladenov, *above*, 73.

to actively promote their empowerment and independence.²⁴ In this regard, it is in line with Fineman's claim that autonomy presupposes an active engagement of social institutions and of the people around the individual in order to create the opportunities for them to exercise their power of choice. The adherence to such an approach emerges, for example, in Article 19 CRPD, on independent living, which affirms that every disabled individual shall have access to the support services necessary to promote 'living and inclusion in the community'.²⁵ Moreover, Article 12 CRPD advocates for disabled people to be actively 'supported' in making decisions for themselves.²⁶ Therefore, the CRPD contains a general principle requiring the state and the society around disabled individuals like people living with dementia to engage in removing barriers and creating the conditions for the exercise of their autonomy.

Equality and non-discrimination

The theme of barriers removal is further developed by the principle of equality and non-discrimination.²⁷ Indeed, as noted by Arnardóttir, the Convention is characterised by a strong focus on substantive equality, which does not only require that all people are treated in the same way, but that socio-economic barriers affecting individuals in situations of disadvantage are removed.²⁸ In this regard, it again shows the adherence of the Convention to a vision such as that advocated by the social model and Fineman's focused on barriers removal and the duty of society to accommodate disadvantage.

Therefore, on the one hand, Article 5(2) affirms that State Parties shall 'guarantee to persons with disabilities equal and effective legal protection against discrimination', intended as 'distinction, exclusion or restriction' on the basis of their impairment.²⁹ On the other hand, the Convention also advocates for equality of opportunity,³⁰

²⁴ C O'Conneide, 'Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and New Possibilities' in OM Arnardóttir and G Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian perspectives* (Martinus Nijhoff 2009), 3. See also L Series, 'Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms' (2015) 40 *International Journal of Law and Psychiatry* 80, 85; Della Fina, 'Article 3 [General Principles]' in Della Fina, Cera and Palmisano, *above*, 124.

²⁵ The link between this provision and the right of autonomy is also stressed in Committee on the Rights of Persons with Disabilities (18th session), 'General Comment No. 5 on Living Independently and being Included in the Community' (2017) UN Doc CRPD/C/GC/5, 1-4.

²⁶ See further Section 4.

²⁷ Article 3 (b), (e) and (g) and Article 5 CRPD.

²⁸ OM Arnardóttir, 'A Future of Multidimensional Disadvantage Equality?' in Arnardóttir and Quinn (eds), *above*, 46.

²⁹ On non-discrimination in the CRPD see also R Cera, 'Article 5 [Equality and Non-Discrimination]' in Della Fina, Cera and Palmisano (eds), *above*, 161-167.

³⁰ Article 3(e) CRPD.

implying that action is taken to provide to disabled individuals with the resources necessary to have the same possibilities of choice of all other individuals. Through such principles the Convention offers a first important foundation to ground the idea of a state obligation to actively contribute to build, in Fineman's words, the physical, human, social, ecological and environmental resources necessary for a person to overcome their vulnerability also in relation to treatment decisions.³¹

Indeed, Article 5(3) CRPD obliges State Parties to take 'all appropriate steps to ensure that reasonable accommodation is provided'. As noted by Kayess and French, this principle is probably the main expression of the substantive approach to equality at the centre of the CRPD as it requires the adoption of 'necessary and appropriate modification and adjustments'³² to guarantee to disabled people the enjoyment and exercise of their human rights on an equal basis with others.³³ Such protection and accommodation is not only directed against barriers directly related to disability, but also to other dynamics which can negatively impact on the condition of disabled individuals.³⁴ Indeed, paragraph (p) of the Preamble urges to address also '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.'³⁵

With regard to treatment choices of individuals living with dementia, the aforementioned principles imply not only that these people cannot be discriminatorily deprived of the possibility to decide, but that the many contextual barriers to their power to choose need to be removed. In this regard, the principle of reasonable accommodation provides a normative basis to claim that in the field of medical decision-making State(s) are truly responsive, investing resources in the promotion of the person's capacity to decide.

³¹ See Chapter 3 Section 5.

³² Article 2(4) CRPD.

³³ Kayess and French, *above*, 9.

³⁴ T Degener, 'Intersections between Disability, Race and Gender in Discrimination Law' in D Schieck and A Lawson (eds), *European Union Non-Discrimination Law and Intersectionality. Investigating the Triangle of Racial, Gender and Disability Discrimination* (Routledge 2011), 33-38; G de Beco, 'Protecting the Invisible: An Intersectional Approach to International Human Rights Law' (2017) 17 *Human Rights Law Review* 633, 645-656; W Ringel, 'Non-discrimination, Accommodation, and Intersectionality under the CRPD: New Trends and Challenges for the UN Human Rights System' (2017) 20 *Max Planck Yearbook of United Nations Law Online* 98.

³⁵ With particular regard to gender also Article 3(g) CRPD inserts among the Convention General principles, that of equality between men and women.

Inclusion

In Chapter 2 it has been shown how one of the first barriers to the decisional power of people living with dementia is that they are kept out of choices on their care because of prejudice.³⁶ This is one of the ways in which they, as many individuals experiencing mental health and neurological conditions, are excluded from ordinary social interactions. Such dynamics are often triggered by stigma³⁷ deriving from unjustified fear of diversity, labelling or other forms of socio-economic oppression,³⁸ and leading to rejection or marginalisation by the community.³⁹ Of course, they do not necessarily derive just from disability, being often the result of the interplay between health, age, gender, race or class factors.⁴⁰

A statement against these attitudes is provided by the principle of social inclusion.⁴¹ The UN Department of Economic and Social Affairs refers to it as ‘the process of improving the terms of participation in society for people who are disadvantaged [...] through enhanced opportunities, access to resources, voice and respect for rights’⁴² Similarly the World Bank identifies it as the process of enhancing the opportunities of individuals disadvantaged on the basis of their identity to be part of society.⁴³ Therefore, by referring to this right in relation to all disabled people, the CRPD clarifies that even individuals living with a severe cognitive impairment should not be excluded and stigmatised. Therefore, also in relation to treatment decisions of people living with dementia behaviours according to which the person’s opinion is disregarded, assuming them incapable to reason, need to be abandoned.

³⁶ Chapter 2 Section 2.

³⁷ N Rüscha et al ‘Mental Illness Stigma: Concepts, Consequences, and Initiatives to reduce Stigma’ (2005) 20 *European Psychiatry* 529.

³⁸ N Kabeer, ‘Social exclusion and the MDGs: the challenge of ‘durable inequalities’ in the Asian context’ (Asia Conference: Promoting Growth, Ending Poverty, London, March 2015) <www.eldis.org/vfile/upload/1/document/0708/DOC21178.pdf> accessed 13 January 2018.

³⁹ I take this definition of stigma from E Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Prentice Hall 1963), 2-3; R Kurzban and M Leary, ‘Evolutionary Origins of Stigma: the Functions of Social Exclusion’ (2001) 127 *Psychological Bulletin* 187, 187. In this sense see also L Sayce, *From Psychiatric Patient to Citizen: Overcoming Discrimination and Social Exclusion* (Macmillan 2000); SP Hinshaw, *The mark of Shame: Stigma of Mental Illness and an Agenda for Change* (Oxford University Press 2007).

⁴⁰ Y Berman and D Phillips, ‘Indicators of Social quality and Social Exclusion at National and Community level’ (2000) 50 *Social Indicators Research* 329; World Bank, ‘Inclusion Matters: The Foundation for Shared Prosperity’ (2013) in <<https://openknowledge.worldbank.org/handle/10986/16195> License: CC BY 3.0 IGO> accessed 9 March 2009; UN, ‘Leaving No One Behind: the imperative of Inclusive Development. Report on the World Social Situation’ (2016) UN Doc ST/ESA/362, 20.

⁴¹ Article 3(c) CRPD.

⁴² UN, *above*, 20.

⁴³ World Bank, *above*.

Accessibility

A normative basis to tackle more ‘practical’ barriers in the field of decision-making can be found in the right to accessibility.⁴⁴ Indeed, this principle refers not only to the removal of barriers impeding the access to physical environments, but also to issues of communication, readability or availability of services which prevent disabled people to live their life to the full and enjoying their rights.⁴⁵ In relation to healthcare the Committee on Economic, Social and Cultural Rights (CESCR) identifies, in its General Comment No. 14, four components of accessibility: non-discrimination (universal access to health facilities), physical accessibility (being able to physically reach hospitals and ambulatories) economic accessibility (affordability) and information accessibility (being put in condition to understand information on medical treatment).⁴⁶ The last component is of special importance for people living with dementia, as it has been seen that a lot of problems with regard to healthcare decisions arise from the fact that information on medical treatment is not explained to them in a way that matches with their needs.⁴⁷

In this regard, Article 9(1) CRPD provides a clear statement for the overcoming of such obstacles requiring State Parties to promote the elimination of barriers in ‘information, communication and other services’. In order to achieve this goal Article 9(2) prescribes that training is provided to staff of public and private organisations, so they are able to properly provide accessible information. Moreover, Articles 2 and 4(f) urge State Parties to assure that services are possibly designed from the beginning to be usable by all people without the need for adaptation. In relation to treatment decisions, this implies that public and private actors need to make sure that explanations, guidelines or protocols are written taking into account the possible

⁴⁴ Articles 3(f) and 9 CRPD. The Committee on the Rights of persons with disabilities emphasises how such a principle is linked to that of reasonable accommodation and how it is also a prerequisite for independence and inclusion of disabled individuals. See Committee on the Rights of Persons with Disabilities (11th Session), ‘General comment No. 2. Article 9: Accessibility’ (2014) UN Doc CRPD/C/GC/2, 1 and 10. See also F Seatzu, ‘Article 9 [Accessibility]’ in Della Fina, Cera and Pamisano (eds), *above*, 228-233.

⁴⁵ See A Palacios and F Bariffi, *La discapacidad como una cuestión de derechos humanos. Una aproximación a la Convención Internacional sobre los Derechos de las Personas con Discapacidad* (Cinca 2007), 105-104; L Waddington, ‘A Disabled Market: Free Movement of Goods and Services in the EU and Disability Accessibility’ (2009) 15 *European Law Journal* 575, 576-578.

⁴⁶ Committee on Economic, Social and Cultural Rights (22nd session), ‘General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)’ (2000) UN Doc E/C.12/2000/4, 3-4.

⁴⁷ See Chapter 2 Section 4.

difficulties of comprehension of disabled people such as individuals living with dementia.

3. Article 12 CRPD and the right to legal capacity

Personhood, autonomy and legal capacity

The values informing the CRPD emerge also in Article 12, which specifies them in relation to legal capacity. Article 12(1) CRPD affirms that all disabled people have ‘the right to recognition everywhere as persons before the law’. As noted by Quinn, this norm is a direct expression of the Convention paradigm shift towards the recognition of disabled people as fully fledged members of society.⁴⁸ Indeed, legal personality is the juridical tool through which an individual or a group is recognised as a bearer of rights and duties.⁴⁹

Article 12(2) further develops the statement of principle contained in Article 12(1), affirming that ‘States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’. As confirmed by the Committee on the Rights of Persons with Disabilities, in the CRPD the term legal capacity refers both to the entitlement to hold rights (legal standing) and to exercise them (legal agency).⁵⁰ Therefore, Article 12(2) promotes a true conceptual revolution as it classifies the power to make legal choices as a fundamental right, something no one can be deprived of, at least on the basis of disability.⁵¹ This means that under the Convention legal capacity cannot be dependent anymore on the mental capacity of the

⁴⁸ G Quinn, ‘Personhood and Legal Capacity. Perspectives on the Paradigm Shift of Article 12 CRPD’ (HPOD Conference, Cambridge Mass, 2010) <www.nuigalway.ie/%2Fcdlp/%2Fdocuments/%2Fpublications/%2FHarvard%2520Legal%2520Capacity%2520ggq%2520draft%25202.doc&ei=kqVXVIPPGZeLaP3SguAP&usg=AFQjCNFaq5CVo50nWjY0vnAMvdKsRo3mGA&sig=yPXGGjEC-KgpQH2EP2dc7Q&bvm=bv.78677474,d.d2s> accessed 1 August 2017. See also J Stavert, ‘The Exercise of Legal Capacity, Supported Decision-Making and Scotland’s Mental Health and Incapacity Legislation: Working with CRPD Challenges’ (2015) 4 *Laws* 296, 299.

⁴⁹ B Smith, ‘Legal Personality’ (1928) 37 *Yale Law Journal* 283.

⁵⁰ Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 3-4. On this point see also M Bach, ‘What does Article 12 of the CRPD require? Theoretical starting points and questions/implications for Law and Policy’ (2009) <<http://www.inclusionireland.ie/content/page/capacity>> accessed 29 January 2015.

⁵¹ See Hoffman and Könzei, *above*, 145-146; O Lewis, ‘Advancing Legal Capacity Jurisprudence’ (2011) 6 *European Human Rights Law Review* 700, 700; E Flynn and A Arstein-Kerslake, ‘The Support Model of Legal Capacity: fact, fiction or fantasy?’ (2014) 32 *Berkeley Journal of International Law* 124, 127-130.

individual.⁵² In this sense the Committee notes that ‘under Article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as a justification for denying legal capacity’.⁵³ In this way the CRPD adopts a universal model in which legal capacity is considered a fundamental attribute of each individual independently of the impairment they may or may not have. Under this approach even people living with severe dementia should be recognised, in principle, as having the same level of legal capacity of everyone else.

This vision shows a significant discontinuity with the traditional approach to legal personality which, in line with the liberal concept of autonomy, subordinates the recognition of legal capacity to the presence in the person of mental capacity.⁵⁴ Under this classical approach, the two concepts are so conflated to be considered the same entity.⁵⁵ As noted by Dhanda, following this approach, a mentally disabled person can see all or part of their decisional power transferred to a guardian or deputy risking a sort of *civil death*.⁵⁶ Instead, the CRPD relies on a conception of the individual putting more at the centre their relationality. In this regard, it appears in line with feminist scholars like Fineman, who claim that there is no real autonomy and freedom to choose unless society and the people around the decision-maker actively work for making sure that the person benefits from an adequate spectrum of alternatives and receives all the support they require to make a certain decision.⁵⁷ As explained by Quinn, the Convention recognises that ‘most of us, most of the time, both think and act irrationally’.⁵⁸ While traditional liberal theory tends to perceive the individual as an atom, ‘shorn of all cultural and social bonds’, there is, behind Article 12, the awareness that our ability to decide is really determined by the environment in which we act.⁵⁹

⁵² Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 3-4. On the distinction between legal and mental capacity see N Devi, J Bickenbach and G Stucki, ‘Moving towards Substituted or Supported Decision-Making? Article 12 of the Convention on the Rights of Persons with Disabilities’ (2011) 5 *ALTER* 249, 252; A Arstein-Kerslake and E Flynn, ‘The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: a roadmap for equality before the law’ (2015) 20 *The International Journal of Human Rights* 471, 474-475.

⁵³ Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 3.

⁵⁴ Quinn, ‘Personhood and Legal Capacity’, *above*, 6-9.

⁵⁵ P Bielby, ‘The Conflation of Competence and Capacity in English Medical Law: A Philosophical Critique’ (2005) 8 *Medicine, Health Care and Philosophy* 357. See also Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 4.

⁵⁶ Dhanda, *above*, 438-456. On the functioning of this *civil death* around the world see ML Perlin, ‘“Striking for the Guardians and Protectors of the Mind”: The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law’ (2013) 117 *Penn State Law Review* 1159, 1160-1173.

⁵⁷ See Chapter 3 Section 5.

⁵⁸ Quinn, ‘Personhood and Legal Capacity’, *above*, 6-9.

⁵⁹ *Ibid*, 8.

Moreover, it acknowledges that the concept of ‘mental capacity is not [...] an objective, scientific and naturally occurring phenomenon’ but is ‘contingent on social and political contexts’.⁶⁰ Indeed, it has also been seen how this concept is based on a narrow and distorted perception of what making decisions is in reality.⁶¹ Therefore, it cannot be assumed as an impartial criteria for regulating legal personhood.

Through this principle the CRPD challenges the rationalistic legal approach and the negative attitudes of legal and medical professionals, which de facto strip people living with dementia of their power to decide for themselves. Indeed, it clarifies how even in this case all situations in which the person is assumed ‘incompetent’ or ‘demented’ and thus disregarded in their opinions are not acceptable.

The rejection of the capacity/incapacity distinction

As noted by Richardson, Article 12(1) and (2) implies, with regard to disabled adults, the abandonment of the traditional binary divide between legal capacity and incapacity.⁶² Indeed, according to the CRPD, there is no point at which the person’s disability makes them lose their power to decide. As affirmed by Clough, in this way Article 12 challenges the hyper cognitivist, artificial, othering, stigmatising incompetence model traditionally characterising western legal capacity legislations,⁶³ which, it has been seen, creates a series of issues in the field of treatment decisions of people living with dementia. In this regard, it appears to adopt a view of legal personality very close to that proposed by Fineman, who claims that in legal and political discourse we should stop dividing people into capable and incapable, vulnerable and invulnerable, as liberal theorists seem to suggest. Instead we need to recognise that we are all at a certain extent vulnerable.⁶⁴

The consequence of adopting this perspective is the rejection of tests of legal capacity/incapacity stating the cognitive prerequisites for the validity of legal decisions.⁶⁵ Under the classical distinction reported by Wong et al, there are three

⁶⁰ *Ibid*, 4.

⁶¹ See Chapter 2 Section 5.

⁶² G Richardson, ‘Mental Disabilities and the Law: from Substitute to Supported Decision-Making?’ (2012) 65 *Current Legal Problems* 333, 343.

⁶³ B Clough, ‘Disability and Vulnerability: Challenging the Capacity/Incapacity Binary’ (2017) 16 *Social Policy and Society* 469, 479.

⁶⁴ On this point see Chapter 3 Section 4.

⁶⁵ See Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 4. On capacity tests with a focus on Anglo-American tradition see A Buchanan, ‘Mental Capacity, Legal Competence and Consent to Treatment’ (2004) 97 *Journal of the Royal Society of Medicine* 415; M Donnelly,

types of legal capacity tests.⁶⁶ The first, the *status approach*, presumes that a person with a diagnosis of mental impairment is for this sole reason incapable of making legal decisions.⁶⁷ This test is to be refused as it assumes that all mentally disabled people are incapable to make decisions, without verifying at what extent this is factually true in the specific case.⁶⁸ According to the second type, the *outcome approach*, the attribution of legal incapacity is made according to the decision content, so that the person is judged incapable if their choices seem irrational. Also this model appears discriminatory, as it leads to disregard choices just because they are socially unacceptable.⁶⁹ Under the third test, the *functional approach*, the capacity of the person is assessed on the basis of their actual ability to understand the substance and consequences of a single decision.⁷⁰ Here the assessment is not abstract, but case specific.⁷¹ An example of this kind of tests are the MacAT-T and section three English Mental Capacity Act 2005.⁷²

This last approach, used to receive higher approval among experts, as it takes into account the nuances of the specific case and validates even decisions that others may consider irrational.⁷³ Also for these reasons, scholars such as Keys or Szmukler, Daw and Callard have maintained that the CRPD was imposing a ‘functionalist approach’ on legal capacity.⁷⁴ However, in General Comment No 1, the Committee clarifies that

Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism (Cambridge University Press 2010), 131-147.

⁶⁶ JG Wong et al, ‘Capacity to make Healthcare Decisions: its importance in clinical practice’ (1999) 29 *Psychological Medicine* 437, 438-441. See also BC White, *Competence to Consent* (Georgetown University Press) 44.

⁶⁷ See White, *above*, 41; E Salvaterra, ‘*Capacità e Competence*’, in L Lenti, E Palermo and P Zatti (eds), *I diritti in medicina*, in S Rodotà and P Zatti (eds), *Trattato di biodiritto*, (Giuffrè 2010) . See also EE Etchells et al, ‘Assessment of Patient Capacity to Consent to Treatment’ (1999) 14 *Journal of General Internal Medicine* 27.

⁶⁸ White, *above*, 41; E Salvaterra, *above*. A number of studies show how many people living with cognitive or mental health conditions are in reality able to make decisions on their care See for example Etchells et al, *above*. For empirical studies on the impact of mental impairments on decision-making see LJ Fitten et al., ‘Assessing Treatment Decision-Making Capacity in Elderly Nursing Home Residents’ (1990) 38 *Journal of the American Geriatrics Society* 1097; O Okonkwo et al, ‘Medical Decision-Making Capacity in Patients with Mild Cognitive Impairment’ (2007) 69 *Neurology* 1528.

⁶⁹ Dhanda, *above*, 432-433.

⁷⁰ *Ibid*, 431-433.

⁷¹ White, *above*, 354.

⁷² See Chapter 1 Section 3.

⁷³ See JF Drane, ‘The many faces of competency’ (1985) 15 *The Hastings Centre Report* 17; M Donnelly, ‘Capacity Assessment under the Mental Capacity Act 2005: delivering on the Functional Approach?’ (2009) 29 *Legal Studies* 464, 464-466.

⁷⁴ M Keys, ‘Legal Capacity Law Reform in Europe: an Urgent Challenge’ (2009) 1 *European Yearbook of Disability Law* 61, 72; G Szmukler, R Daw and F Callard, ‘Mental Health Law and the UN Convention on the Rights of Persons with Disabilities’ (2014) 37 *International Journal of Law and Psychiatry* 245, 248-249.

also the functional approach needs to be rejected as ‘it is discriminatorily applied to people with disabilities’ and ‘presumes to be able to accurately assess the inner-workings of the human mind’.⁷⁵ In this regard, it remarks how in all the three approaches cited above, ‘a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity’ and ‘Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires the provision of support in the exercise of legal capacity’.⁷⁶ It has been seen with regard to treatment decisions of people living with dementia how such norms subordinate the person’s decisional power to the reaching of a rationalistic standard not imposed on others.⁷⁷

Therefore, by refusing the binary distinction capacity/incapacity, Article 12(2) contributes to promote the right to decide on care of these individuals. It also avoids the problem, typical of the classical approach, of assessing at what point of their gradual cognitive deterioration the person has to be regarded as mentally incapable.⁷⁸ Finally, it removes the dilemma of whether the previous ‘non-demented’ declarations instead of the actual will of the individual should be respected: indeed, even in case of severe dementia all the statements of the individual are in principle valid.

The rejection of substituted decision-making

The direct practical consequence of this human rights approach to legal capacity is that transferring the individual’s decisional power to a third person who decides for them is not an acceptable response to their possible difficulties in decision-making. General Comment No 1 expressly emphasises that ‘States parties must review the laws allowing for guardianship and trusteeship’ and ‘replace regimes of substitute decision-making’.⁷⁹ Here the Committee refers to the classical oppressive notion of guardianship which, as reported by Glen, is generally defined as the legal process by which the state deprives a person of the power to make decisions, and grants that power to another individual or entity.⁸⁰ However, as a consequence of reforms put in place in many European and Extra-European countries, today the word guardianship is often used to designate both substituted decision-making measures and arrangements more

⁷⁵ Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 4.

⁷⁶ *Ibid.*

⁷⁷ See above Chapter 2 Section 5.

⁷⁸ Wong et al, *above*, 439 identify this as a general shortcoming of the functional approach.

⁷⁹ Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 6.

⁸⁰ K Glen, ‘Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond’ (2012) 44 *Columbia Human Rights Law Review* 93, 93.

respectful of the person's autonomy.⁸¹ Therefore, in order to understand what provisions are in line with the CRPD, it is necessary to look at the single norms and nuances of national legislations.

In this regard, the Committee affirms that have to be considered forms of substituted decision-making, illegitimate under Article 12, all those measures in which:

- a) legal capacity is removed from a person, even for a single decision;
- b) a substitute decision-maker can be appointed against the will of the person;
- c) the substitute decision-maker decides according to 'what is believed to be in the objective "best interests" of the person concerned' instead of choosing on basis of the person's will and preferences'.⁸²

In relation to treatment decisions of people living with dementia, this principle derived from the CRPD, seems to address the problem that decisions are made for the person even when they have opinions on their own. In this regard, it proposes a radical solution, denying the very same possibility that someone can be substituted in making choices.

4. Supported Decision-Making

The Supported decision-making approach to legal capacity

Article 12(3) CRPD states that, instead of depriving the person of their decisional power, 'States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity'. Therefore, consistently with its universal legal capacity approach, the Convention states that also in the case of individuals living with severe cognitive impairments the law cannot take away their capacity to make decisions, but rather it has to put in place the means to remove the societal barriers that the person faces in exercising their legal capacity and that, in the logic of the CRPD, are seen as the real hurdles which prevent them from being recognised as fully fledged individuals. This statement shows a decisive option for an 'active' approach to legal capacity, in which the person is not

⁸¹ For an overview of such reforms see T Carney 'Searching for workable Alternatives to Guardianship for Vulnerable Populations?' (2015) 1 *Ethics, Medicine and Public Health* 113, 113-116.

⁸² See Committee on the Rights of Persons with Disabilities, 'General Comment', *above*, 6.

just ‘assessed’ but is ‘helped’ in developing and voicing their decision through supported decision-making, and is respected in their decisions which are still recognised legal effect. Indeed, here support by others, rather than mental capacity, is indicated as the key prerequisite of choice making.

Through this norm, the CRPD applies also to the field of legal capacity the ideas of the social model of disability, affirming how rather than focusing on impairment it is necessary to look at the social dynamics impacting the life of disabled people and to use the social and relational network, also with regard to choice making.⁸³ Moreover, by requiring that State Parties provide access to measures of support, Article 12(3) CRPD provides a strong normative basis for claiming, in line with Fineman’s vulnerability theory, that state and society should be responsive and invest resources in creating the conditions for disabled individuals like people living with dementia to make decisions.

General Comment No. 1 clarifies the key elements that need to characterise supported decision-making.⁸⁴ In summary it demands that:

- a) the rights and preferences of the person are always respected;
- b) support measures are proportional to the person’s needs;⁸⁵
- c) support should be available to everyone and costs, difficulties of communication and severity of impairment, should not be an obstacle to it;
- d) legal capacity support ‘should not hinge on mental capacity assessments’;
- e) the person can refuse the support and there are safeguards to prevent abuses.

However, neither the Convention nor the General Comment provide a specific definition of this concept. Therefore, a series of questions remain open.

The first concerns who has to materially assist the person in making choices. The Committee states that support ‘encompasses both informal and formal support arrangements’.⁸⁶ In relation to both cases, commentators emphasise the necessity that

⁸³ See Chapter 3 Section 2.

⁸⁴ Committee on the Rights of Persons with Disabilities, *above*, 7.

⁸⁵ This aspect is pointed out also by G Quinn, ‘A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities’ (2009) 1 *European Yearbook of Disability* 89, 105-106; ALAMO, ‘Comment on the Draft General Comment No. 1’ (2014) < <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>> accessed 1 February 2015.

⁸⁶ Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 4. On the various kinds of formal and informal arrangements see also A Douglas, ‘Mental Capacity Updating New Zealand’s Law and Practice’ (2016) 51-52 < http://www.aspenltd.co.nz/mc/assets/Full_Report.pdf> accessed 18 January 2018.

the support person is a trusted individual who has an ongoing relationship with the beneficiary and a good knowledge of their personality and desires.⁸⁷ Informal arrangements, in which family members or friends voluntarily help the person, emphasise this dimension of proximity, besides being less costly.⁸⁸ Support may even be provided by more than one individuals with differentiated roles forming a ‘circle of support’ or ‘support network’.⁸⁹ Formal support arrangements would entail the appointment through a formal act (e.g. lasting power of attorney or authority decision) of a caretaker helping the individual in a series of choices.⁹⁰ As stressed by Glen, such kind of mechanisms can be useful especially when the person lives alone and has no family, as it happens nowadays with many older people.⁹¹ Moreover, being formally appointed, the support person is usually subject to regular scrutiny by a designated body. Also in this case the role may be shared by a series of individuals. An important contribution may be also given by independent advocates, who have the advantage of being external to the family, so impartial and less inclined to exert pressure on the person.⁹² As stated by Mirfin-Veicht, support can also take the form of peer advocacy/peer support or self-advocacy in which an individual which lives the same disability of the beneficiary helps them in making decisions.⁹³

Another open question concerns the possible means of support that need to be put in place according to the CRPD. As all measures need to be ‘tailored to the person’s

⁸⁷ J Tracy, ‘Supporting Nick to Make Decisions: An Exploration of Ways to Promote Choice and Control’ (2015) 2 *Research and Practice in Intellectual and Developmental Disabilities* 29; L Knox, JM. Douglas and C Bigby, ‘Becoming a Decision-Making Supporter for Someone with Acquired Cognitive Disability following Traumatic Brain Injury’ (2016) 3 *Research and Practice in Intellectual and Developmental Disabilities* 12, 15-18.

⁸⁸ T Carney and F Beaupert, ‘Public and Private Bricolage : challenges balancing Law, Services and Civil Society in advancing CRPD Supported Decision-Making’ (2013) 36 *UNSW Law Journal* 175, 180-181; P Gooding, ‘Navigating the “Flashing Amber Lights” of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns’ (2015) 15 *Human Rights Law Review* 45, 64; C Bigby, ‘Delivering Decision Making Support to People with Cognitive Disability. What has been learned from Pilot Programs in Australia from 2010 to 2015’ (2017) 52 *Australian Journal of Social Issues* 222.

⁸⁹ M Bach and L Kerzner, ‘A New Paradigm for Protecting Autonomy and the Right to Legal Capacity’ (2010) < www.lco-cdo.org/disabilities/bach-kerzner.pdf> accessed 31 January 2015; N Devi, ‘Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities’ (2013) 41 *The Journal of Law Medicine and Ethics* 792, 795.

⁹⁰ Carney and Beaupert, *above*, 183-185; Devi, Bickenbach and Stucki, *above*, 255-256; A Douglas, *above*, 51-52.

⁹¹ K Glenn, ‘The Challenge: the CRPD and the Right to Legal Capacity’ (2013) 42 *International Law News* 12, 14.

⁹² Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 4.

⁹³ B Mirfin-Veicht, *Exploring Article 12 of the United Nations Convention on the Rights of Persons with Disabilities: An Integrative Literature Review* (Donald Beasley Institute 2016). Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 4.

circumstances'⁹⁴ it is difficult to identify them on an a priori basis. However, the Committee gives some examples. The first kind of support means it identifies consist in providing accessible information, reminding or explaining a certain point in simple terms.⁹⁵ Another way of supporting the person may be through 'the development and recognition of diverse, non-conventional methods of communication' in case of individuals with difficulties in expressing themselves like many people living with advanced dementia.⁹⁶ Also it may consist in creating a favourable or quieter environment. Trying to further qualify what supported decision-making entails, the CRPD Handbook for Parliamentarians states that the support person(s) is or are someone who 'explain(s) the issues when necessary, and interpret(s) the signs and preferences of the individual' and can, for example, 'communicate the individual's intentions to others or help him/her understand the choices at hand' or 'help others to realise that a person with significant disabilities is also a person with a history, interests and aims'.⁹⁷ Therefore, it highlights three components of support: explanation, interpretation and management of the relationship with others.

As affirmed by the Committee, supported-decision making should cover all the possible situations regarding decision-making of disabled people.⁹⁸ In this regard, Bach and Kerzner, describe support as a *continuum*, a dynamic process that follows the person in the evolution of the disability, articulated in three levels: 'legally independent decision-making', in which the disabled person is substantially able to make decisions on their own, 'supported decision-making', in which the person is assisted by someone that tries to help them in expressing their wishes and 'facilitated decision-making', when, in case of significant disability, every attempt of communicating with the person is useless, so it is necessary to reconstruct their will from previous declarations.⁹⁹

⁹⁴ Article 12(4) CRPD.

⁹⁵ Committee on the Rights of Persons with Disabilities, 'General Comment', *above*, 4. See also S McDaid and S Delaney, 'A Social Approach to Decision-Making Capacity: exploratory research with People with Experience of Mental Health Treatment' (2011) 26 *Disability and Society* 729, 739; Devi, *above*, 795-796.

⁹⁶ Committee on the Rights of Persons with Disabilities, 'General Comment', *above*, 4. On this point see also Tracy, *above*, 30-32

⁹⁷ Office of the High Commissioner for Human Rights, *From Exclusion to Equality. Realizing the Rights of Persons with Disabilities. Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol* (UN 2007), 89-90.

⁹⁸ Committee on the Rights of Persons with Disabilities, 'General Comment', *above*, 6.

⁹⁹ Bach and Kerzner, *above*, 89-93.

Supported decision-making and severe impairments

The universal support model proposed by the CRPD has been criticised for being utopian in relation to serious impairments like very severe dementia or coma.¹⁰⁰ Already in the responses to the Draft General Comment, scholars and DPOs have stated how, in such extreme cases, it may seem impossible to avoid forms of substituted decision-making, because not only the person is unable to speak, but also their basic brain functions seem almost totally compromised.¹⁰¹ Dawson advocates a more ‘realistic’ interpretation of the CRPD, which allows for a limited application of substituted decision-making.¹⁰² In this regard, State Parties like The Netherlands, Norway and Poland made reservations to the Convention, specifying that they interpret Article 12 as permitting substituted decision-making in extreme circumstances.¹⁰³ In this regard, positions in the debate seem split between those who maintain that the CRPD allows for a limited role of substituted decision-making¹⁰⁴ and those who argue that this mechanism is in any case impermissible.¹⁰⁵

¹⁰⁰ For a summary of such critiques see Gooding, *above*, 53-55.

¹⁰¹ See among others Canadian Association for Community Living, ‘Response to Draft General Comment No. 1 on Article 12. UN Committee on the Rights of Persons with Disabilities’ (2014) 4-5 <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>>; Centre pour l'égalité des chances et la lutte contre le racisme-CECLR, ‘Observation générale sur l'article 12 de la Convention, relatif à la reconnaissance de la personnalité juridique dans des conditions d'égalité’ (2014) 4-5 <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>>; Essex Autonomy Project, ‘Comment on Draft General Comment No 1’ (2014) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>>; J Stavert, ‘Submission to Committee on the Rights of Persons with Disabilities on the Draft General Comment on Article 12’ (2014), 2 <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>>. All accessed 1 February 2015.

¹⁰² J Dawson, ‘A Realistic Approach to Assessing Mental Health Laws’ Compliance with the UNCRPD’ (2015) 40 *International Journal of Law and Psychiatry* 70, 74. See also W Martin et al, ‘Achieving CRPD Compliance. Is the Mental Capacity Act of England and Wales compatible with the UN Convention on the Rights of Persons with Disabilities? If not, what next?’ (Essex Autonomy Project 2014) 13 and 29 <<https://autonomy.essex.ac.uk/wp-content/uploads/2017/01/EAP-Position-Paper-FINAL.pdf>> accessed 5 December 2017.

¹⁰³ For a list of reservations to the CRPD see <https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&clang=_en> accessed 1st December 2017.

¹⁰⁴ See also Stavert, ‘The Exercise’, *above*, 300-301; S Callaghan and CJ Ryan, ‘An Evolving Revolution: Evaluating Australia’s Compliance with the Convention on the Rights of Persons with Disabilities in Mental Health law’ (2016) *UNSW Law Journal* 596, 605-610; Douglas, ‘Mental Capacity’, *above*, 44-48.

¹⁰⁵ T Minkowitz, ‘Abolishing Mental Health Laws to Comply with the Convention on the Rights of Persons with Disabilities’ in B McSherry and P Weller (eds), *Rethinking Right-Based Mental Health Laws* (Hart, 2010) 156; Flynn and Arstein-Kerslake, ‘The Support Model’, *above*, 129-130. Dhanda, *above*, 460-462 advocates for an interpretation excluding substituted decision-making, but admits the text ambiguity on this point.

In reality, as noted by Series, even the Committee includes, under the category ‘supported decision-making’ practices which are traditionally considered substituted decision-making.¹⁰⁶ Indeed, in paragraph 21 of General Comment No 1, it suggests that where, after significant attempts have been made, it is not possible to determine the opinion of the person, the decision should be made on the basis of ‘the best interpretation of will and preferences’ that is, by reconstructing their desires.¹⁰⁷ This is clearly a situation in which the person is substituted as the decision is materially expressed by a third person, and the Committee seems to endorse it. Also, Arstein-Kerslake and Flynn argue that Article 12 ban on substituted decision-making does not require states to eliminate all schemes in which a person has to make decisions for another.¹⁰⁸ For example, powers of attorney or situations in which a representative is appointed to make decisions on the basis of the person’s wishes would be still acceptable.¹⁰⁹

In this regard, even a convinced supporter of Article 12 like Quinn admits that the Committee’s position according to which pure support is always the only possible and sufficient remedy, may be considered more as a fiction.¹¹⁰ Though, he maintains, it is a necessary fiction as it permits to make a strong political statement in favour of support and avoids that especially judges could attempt to widen the range of exceptions to this paradigm.¹¹¹ However, Callaghan and Ryan, note how the terminological confusion produced by such a fiction is hindering the reform process as, in the eyes of a series of practitioners and States, it undermines the seriousness and practical applicability of Article 12 model, as what is proposed by this norm appears to most professionals as simply impossible to achieve.¹¹²

The case of people living with dementia shows how, from the strictly technical-legal point of view, the uncompromising model of universal legal capacity proposed by the CRPD and its Committee is at least partially untenable. Indeed, it does not seem to take into due account what happens in the very last phases of the condition in which

¹⁰⁶ Series, ‘Comments’, *above*, 6. For an overview on the traditional legal regulation on decisions of incapable people in healthcare and substituted judgement in common law systems see L Harmon, ‘Falling off the Vine: Legal Fictions and the Doctrine of Substituted Judgment’ (1990) 100 *Yale Law Journal* 1, 16-55; Donnelly, *Healthcare Decision-Making*, *above*, 176-192.

¹⁰⁷ Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 5.

¹⁰⁸ Arstein-Kerslake and Flynn, ‘The General Comment’, *above*, 477-478.

¹⁰⁹ *Ibid.*

¹¹⁰ Quinn, ‘Personhood and Legal Capacity’, *above*, 16-17.

¹¹¹ *Ibid.*, 17.

¹¹² Callaghan and Ryan, *above*, 607.

the person is generally unable to speak or even to move, and their capacity to interact with the people and the environment around them is so compromised that it is inevitable to substitute them in the decision.¹¹³ So, the approach emerging from the Convention appears not completely evidence based.

However, though with the caveat that there are (few) cases in which this support focused model of universal legal capacity is not valid, the approach emerging from Article 12 CRPD would still be a significant improvement compared to the traditional model of capacity to consent and treatment decisions of people living with dementia. Indeed, the latter, being centred on the myth of rationality and the gatekeeping function of cognitive capacity, appears much less evidence based than the one proposed by Article 12 CRPD. As already seen in Chapter 2, also for people living without a specific impairment making decisions is not so much a matter of cognition and often the most important choices in an individual's life are determined by irrational factors rather than rational considerations.¹¹⁴ Therefore, by rejecting such a 'hypercognitivist' model of decision-making and mental capacity, the CRPD moves away from a system that discriminatorily applies to people living with impairments like dementia a rationalistic standard of capacity not imposed on others.¹¹⁵ In addition, by qualifying legal capacity as a fundamental right of every individual and identifying supported decision-making as the mechanism that needs to be put in place in case a disabled individual experiences any difficulty in making choices, it significantly attenuates the risk, often present in the case of individuals living with dementia, that the person is stripped of the possibility of making decisions too soon and that choices are made for them by others, despite the fact that they may still have articulate opinions and the ability to voice them.

¹¹³ Also the studies which classify a high percentage of their participants living with dementia as capable to consent still report that a percentage of these individuals are absolutely unable to form or communicate an even simple opinion on treatment as emerging from T Mueller et al, 'Comparison of Three Different Assessments of Capacity to Consent in Dementia Patients' (2015) 28 *GeroPsych* 21; T Mueller et al, 'Assessing Capacity to Consent to Treatment with Cholinesterase Inhibitors in Dementia using a Specific and Standardized version of the MacArthur Competence Assessment Tool (MacCAT-T)' (2017) 29 *International Psychogeriatrics* 333.

¹¹⁴ See in particular above Chapter 2 Section 5. With regard to healthcare decision-making this aspect is pointed out also by AS Pomerantz and A de Nesnera, 'Informed Consent, Competency, and the Illusion of Rationality' (1991) 13 *General Hospital Psychiatry* 138; BA Noah, 'The (Ir)rationality of (Un)informed Consent' (2016) 34 *Quinnipiac Law Review* 691, 701-703.

¹¹⁵ On this shortcoming of the traditional approach to legal capacity and treatment decisions of people living with dementia see above Chapter 2 Section 5.

Therefore, notwithstanding the concerns of some scholars and practitioners, Article 12 CRPD appears to propose an approach to legal capacity which, though not completely unproblematic, improves on the current system and is worth promoting and implementing. In this regard, in relation to the debate regarding this provision of the Convention, Callaghan and Ryan suggest to avoid focusing too much on the problem of the appropriateness of the Committee's idea of universal legal capacity, as this may divert the attention from what are the really important and positive messages of Article 12 CRPD, such as the condemnation of all legal capacity regimes discriminating on the basis of disability and the fact that in any decisional process, and also in case of serious impairments, the will of the person needs to be centre stage.¹¹⁶ Indeed, what really seems to be the message emerging from the CRPD and General Comment No 1 in relation to pervasive impairments, is that when it is inevitable to substitute the person one has to prefer a 'subjective' paradigm, rather than one based on the notion of 'best interests'. This is very important especially in the field of decisions on medical treatment. Indeed, as already seen, though all surrogate methods have disadvantages, the 'best interests' paradigm is particularly problematic as it does not permit to take into account the nuances of such highly subjective decisions, such as those regarding medical care, and results paternalistic.¹¹⁷

Advance directives

In this regard, the Committee appears to endorse also advance directives as a means of support which allows the person to clarify 'will and preferences which should be followed at a time when they may not be in a position to communicate'.¹¹⁸ Indeed, it states how 'all persons with disabilities have the right to engage in advance planning' of which advance directives are one of the main examples.¹¹⁹ However, it has been seen how this instrument poses moral, legal and practical concerns particularly in relation to people living with dementia.¹²⁰ Moreover, because of its essence of declaration of a legally capable person for the time they are incapable¹²¹ it seems to presuppose the sharp divide capacity/incapacity, an idea overcome by the

¹¹⁶ Callaghan and Ryan, *above*, 609.

¹¹⁷ On this point see Chapter 2 Section 3.

¹¹⁸ Committee on the Rights of Persons with Disabilities, 'General Comment', *above*, 5.

¹¹⁹ *Ibid.*

¹²⁰ See Chapter 2 Section 3.

¹²¹ M Brazier and E Cave, *Medicine, Patients and the Law* (6th ed Manchester University Press 2016), 176.

CRPD. In this sense, Scholten and Gather observe that under Article 12 advance directives could virtually never become effective or operate only in rare cases.¹²²

For these reasons it may appear strange that this legal tool is still mentioned and even endorsed in General Comment No. 1. In reality, in the Article 12 model of decision-making, it is still important, only it has a different role than in the past. Indeed, the Committee refers to this mechanism as one (among many) ‘form of support’ which combined together can contribute to reconstruct the will of the person.¹²³ Therefore, it does not act anymore as a substitute of the person’s actual statements, which enters into force at a given moment and dictates their will for them. Instead, it is an instrument more directed at integrating and double-checking the person’s actual declarations in the context of wider support relationships. Morrissey notes how, as the person can set out the circumstances in which the advance directive is activated or deactivated, it can enter into force gradually and even for a limited period of time, serving as a communication tool which ensures that the person’s will is respected in moments of crisis, but without impacting on legal capacity.¹²⁴ Therefore, people living with dementia can decide to write, with the help of a supporter, an advance directive for particularly ‘bad days’ or for the time in which, in the last stage of their illness, they will not be able to express detailed opinions. When the time will occur, their support person, doctors or carers will refer to that document but, if in one moment of lucidity different opinions will emerge from the person’s statements or behaviours, they will have to take them into account as well. Moreover, the Committee also stresses how the support that the person should receive, includes also the drafting of advance care plans.¹²⁵ Therefore such a declaration will be constructed through the ongoing interaction with the supporter, relatives, specialised organisations, and become a document that the person writes and periodically updates in order to leave a trace of their wishes.

This approach avoids the dilemmas emerging in the field of care decisions of individuals with dementia when the anticipated will contrasts with current utterances

¹²² M Scholten and J Gather, ‘Adverse Consequences of Article 12 of the UN Convention on the Rights of Persons with Disabilities for Persons with Mental Disabilities and an Alternative Way Forward’ (2017) *Journal of Medical Ethics* 1, 5.

¹²³ Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 5.

¹²⁴ F Morrissey, ‘The Introduction of a Legal Framework for Advance Directives in the UN CRPD era: the views of Irish service users and consultant psychiatrists’ (2015) 1 *Ethics, Medicine and Public Health* 325, 330.

¹²⁵ Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 5.

of the person or there are doubts that what it is written in the advance directive really reflects the actual wishes of its author.¹²⁶ Indeed, here there is no divide between a time in which the person has the power to decide and one in which only the advance directive needs to be followed. Rather, the whole situation is seen as a process of change which is followed by the supporter and accounted for in the advance directive.

5. Protection and Safeguards

The problem of self-harmful decisions

Another point on which the critics of the Convention have focused, is that Article 12 would not seem to offer indications on what to do in case of self-harming decisions of the person¹²⁷ or when the individual seems unable to grasp the substance of a certain choice.¹²⁸ Indeed, there are cases in which the law may arrive after a document has been signed or a decision made, too late for giving support. In addition, despite all efforts, supported decision-making practices are not always successful.¹²⁹ The remedy to all such situations was traditionally the binary concept of incapacity, which used to act as a ground for invalidating harmful decisions. But in the CRPD system, in which this category is not admissible anymore, there is the need to find alternative mechanisms which take on this function. In this regard, Donnelly expresses concern as General Comment No 1 does not provide a solution for such issues, risking that its focus on promoting the autonomy and equality of disabled people could result in endangering their dignity, their right to live a safe and well lived life.¹³⁰

However, as remarked by Arstein-Kerslake, on the one hand, the CRPD does not exclude the possibility to use the legal remedies, present in all private law legislation, that permit to invalidate declarations which are the result of misrepresentation.¹³¹ Moreover, the function of clarifying the will of the person and setting aside statements product of incorrect understanding, may be included among the supporter's role of

¹²⁶ For an analysis of this problem see Chapter 2 Section 3.

¹²⁷ Richardson, *above*, 349; Gooding, *above*, 61-62; Dawson, *above*, 73.

¹²⁸ S Werner, 'Individuals with Intellectual Disabilities: a Review of the Literature on Decision-Making since the Convention on the Rights of People with Disabilities (CRPD)' (2012) 34 *Public Health Reviews* 1, 17-18

¹²⁹ See A Ward, 'Abolition of Guardianship? "Best Interests" versus "Best Interpretation"' (2015) 32 *Scots Law Times* 150.

¹³⁰ M Donnelly, 'Best Interests in the Mental Capacity Act: time to say goodbye?' (2016) 24 *Medical Law Review* 318, 323-326.

¹³¹ Arstein-Kerslake and Flynn, 'The Right to Legal Agency', *above*, 26.

interpreting and reconstructing the person's wishes seen above. As noted by Cendon, in this context the support person may enter in a dialectic dynamic with the disabled individual, inviting them to better reflect on decisions which appear vitiated by a distorted perception of reality.¹³² In a recent study, Zinkler and I have analysed a case of supported decision-making of a man with Schizophrenia and a life-threatening pneumonia, who refused both antipsychotics and antibiotics. The carers and guardian, after having tried to persuade the person and in consideration of the fact that he expressed the will of remaining alive, interpreted his will in the sense of respecting the person's refusal of antipsychotics and administering the minimum necessary of antibiotics in order to eliminate the risk of death of pneumonia.¹³³ This sort of mechanisms are all based on negotiation and a central role of the person's will, therefore appear less oppressive of the traditional remedies based on incapacitation.

In this scenario there would probably still be some scope for mechanisms of assessment of the person's capacity to make decisions. Only, they would not have the aim of evaluating whether they reach a certain cognitive threshold for the validity of their legal acts, but rather it would serve to establish the weight of various declarations and the kind of support they would need, looking also at other external factors than their intellectual abilities. Indeed, as suggested by the Council of Europe Commissioner on Human Rights, functional tests can help in determining the kind of support that should be made available to the individual or in distinguishing the moments in which he or she may be in the best conditions to reason.¹³⁴

Safeguards

All the support practices mentioned above presuppose a strong interaction between the disabled individual and the network of people around them. This interaction gives the possibility to empower the person through support, but it can also allow forms of undue influence. Ward maintains that Article 12 text is confusing and can leave the

¹³² P Cendon, 'L' Amministrazione di Sostegno non va abrogata, va applicata!' (2016) <<https://www.personaedanno.it/articolo/lamministrazione-di-sostegno-non-va-abrogata-va-applicata-paolo-cendon>> accessed 20 January 2018.

¹³³ M Zinkler and K De Sabbata, 'Unterstützte Entscheidungsfindung und Zwangsbehandlung bei schweren psychischen Störungen – ein Fallbeispiel' (2017) 35 *Recht und Psychiatrie* 207. See also de Bhailis and Flynn, *above*, 16.

¹³⁴ CoE Commissioner on Human Rights, 'Who gets to Decide? Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities' (2012) CommDH/IssuePaper 2, 9.

door open to possible pressures by supporters.¹³⁵ In this regard, it may be easy for support persons or family members to misuse the ‘interpretation’ of the person’s will to manipulate the statements of the beneficiary.

This problem emerges also in systems based on substituted decision-making, as here legal representatives and carers are somehow even authorized by the law to disregard the person’s will in favour of considerations of their ‘objective’ best interests.¹³⁶ Moreover, Gooding points out how everyone is subject to external influences so we should not set a different standard for disabled people, requiring that they make decisions in complete isolation.¹³⁷ Nonetheless, the same Committee for the Rights of Persons with Disabilities recognises that individuals benefitting from supported decision-making may be particularly exposed to undue influence.¹³⁸

For this reason Article 12(4) CRPD specifies that ‘States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse’ and to guarantee that ‘measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence’. According to the second part of Article 12(4) CRPD, the first of such safeguards should consist in the cited legal capacity measures being ‘proportional and tailored to the person’s circumstances’ and to ‘apply for the shortest time possible’. In this sense, the affirmation made by the Committee that the person may refuse support at any time is also a valuable presidium against abuse.¹³⁹ In order to make sure such rules are observed and the dynamics characterising the specific support relationship are properly monitored Article 12(4) provides that all measures ‘are subject to regular review by a competent, independent and impartial

¹³⁵ A Ward, ‘Adults with Incapacity: Freedom and Liberty, Rights and Status: Part 1’ (2011) *Scots Law Times* 21.

¹³⁶ For literature see EJ Emanuel and LL Emanuel, ‘Proxy Decision Making for Incompetent Patients. An Ethical and Empirical Analysis’ (1992) 15 *Journal of the American Medical Association* 2067, 2068-2069 and for national reports see Law Commission of Ontario, ‘Legal Capacity, Decision-Making and Guardianship’ (2014), 197-228 <<https://www.lco-cdo.org/wp-content/uploads/2014/06/capacity-guardianship-discussion-paper.pdf>> accessed 24 January 2018; House of Lords Select Committee, ‘Mental Capacity Act 2005: post-legislative scrutiny’ (2014), 38-39.

¹³⁷ Gooding, *above*, 56. See also RM Gordon, ‘The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making’ (2000) 23 *International Journal of Law and Psychiatry* 61, 62; Series, ‘Relationships’, *above*, 82-84.

¹³⁸ Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 5. Such risk is even higher when the person is of advanced age as stressed by Help Age International, ‘Briefing paper for the first working session of the Open Ended Working Group on Ageing’ (2011) <https://social.un.org/ageing-working-group/documents/HelpAge_briefing%20paper%20for%20the%201st%20session%20of%20the%20OEWG_%20April%202011.pdf> accessed 24 January 2018.

¹³⁹ Arstein-Kerslake and Flynn, ‘The General Comment’, *above*, 479.

authority or judicial body'. The Committee also advocates for mechanisms allowing third parties 'to challenge the action of a support person if they believe that the support person is not acting in accordance with the will and preferences of the person'.¹⁴⁰ General Comment No 1 notes how such protective safeguards represent a substantial improvement compared to the ones usually characterising traditional capacity legislations. In fact, while the latter avoid undue influence by transferring the power to choose to a legal representative who is supposed to be less vulnerable to pressures, the former maintains at the centre the will and preferences of the person.¹⁴¹

Of course, also in this case, the CRPD and the Committee only set general principles which will then have to be specified by national legislations, taking into account the nuances of specific contexts and circumstances. In this regard, it would have to be established, for example, if the review of legal capacity measures should be performed by an administrative or judicial authority, how frequent reviews should be, how they have to be conducted (e.g. through home inspections, oral questioning etc.) or how third parties may materially challenge the behaviour of the support person (e.g. judicially, through an ombudsman or through an accredited NGO).

In this regard, a number of scholars have noted how it could be difficult to detect undue influence and to distinguish it from 'healthy' support relationships. Indeed, using the definition of the Committee itself, undue influence occurs when 'the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation'.¹⁴² Such dynamics often develop beyond closed door and are difficult to detect even by the person themselves.¹⁴³ Broström points out how often undue pressure is involuntary and exercised by absolutely well intentioned people.¹⁴⁴ Moreover, Kohn, Blumenthal and Campbell, show that especially in the case of older people also a sense of deference or lack of trust in themselves may have distortive effects on the person's will.¹⁴⁵ In order to avoid such inconveniences, it may be useful to associate to the 'external' safeguards proposed by the Convention, based on the control of authorities or third parties, more

¹⁴⁰ Committee on the Rights of Persons with Disabilities, 'General Comment', *above*, 7.

¹⁴¹ *Ibid.*, 5.

¹⁴² Committee on the Rights of Persons with Disabilities, 'General Comment', *above*, 5.

¹⁴³ See Chapter 2 Section 4.

¹⁴⁴ L Broström, 'Due and Undue Influence in Supported Decision Making: Mapping the moral landscape' (XXXV International Congress of Law and Psychiatry, Prague, July 2017).

¹⁴⁵ NA Kohn, JA Blumenthal and AT Campbell, 'Supported Decision-Making: A Viable Alternative to Guardianship?' (2013) 117 *Penn State Law Review* 111, 1123.

‘internal’ ones. For example, the action of the various members of a person’s network of support (doctors, formal carers, relatives, independent advocate) which have different interests, may be used so that each member checks the behaviour of others, making sure that abusive practices are stopped already at their beginning. In Chapter 7 I will look at some example of such practices to prevent undue influence.

6. The CRPD, health and medical treatment

Right to Health and capacity to decide on medical treatment

The messages contained in Article 12 CRPD and in General Comment No 1 are also echoed in other norms of the Convention and in statements by other UN bodies, specifically referring to the area of health and medical treatment. In this regard, such provisions and statements further clarify the implications of the CRPD approach to choice making in relation to medical treatment.

In this regard, Article 25(1) CRPD requires the enjoyment by disabled individuals of ‘the highest attainable standard of health without discrimination on the basis of disability’. Article 25(1) paragraph (d) specifies that, in order to realise this goal, State Parties have to guarantee that care is administered to disabled people ‘on the basis of free and informed consent’, putting at the centre the rights, dignity, autonomy and needs of the person. This formulation partly echoes that of Article 12 ICESCR and the relevant jurisprudence of the Committee on Economic, Social and Cultural Rights (CESCR), in charge of monitoring the implementation of the Covenant.¹⁴⁶ The CESCR, in its General Comment No. 14, identifies four determinants of the right to health: *availability* of adequate care services, *accessibility* of services and information, *acceptability* and *quality*.¹⁴⁷ The third determinant (acceptability) refers to the necessity that all health services comply with principles of medical ethics and respect individuals, minorities, gender and life cycle requirements.¹⁴⁸ Paragraph 18 of the Comment clarifies that this right and its determinants should be realised without any discrimination also on the basis of disability.¹⁴⁹

¹⁴⁶ For general information on the CESCR see <<http://www.ohchr.org/EN/HRBodies/CESCR/Pages/CESCRIndex.aspx>> accessed 15 December 2017.

¹⁴⁷ Committee on Economic, Social and Cultural Rights (22nd session), ‘General Comment No. 14’, *above*, 3-4.

¹⁴⁸ *Ibid.*

¹⁴⁹ *Ibid* 7. On the conception of the right to health characterizing the ICESCR and the CRPD see also IR Pavone, ‘Article 25 [Health]’ in Della Fina, Cera and Palmisano, *above*, 474-480.

Article 25 CRPD specifies with particular regard to medical treatment, the principle of universal recognition of legal capacity. Indeed, in General Comment No 1 the Committee on the Rights of Persons with Disabilities emphasises how such provisions are linked to Article 12 CRPD, as the concept of ‘high standard healthcare’ presupposes the recognition of the person’s capacity to decide on the modalities of their care.¹⁵⁰ Therefore, the Committee confirms that Articles 12 and 25 CRPD, read in conjunction, oblige States Parties to avoid that substitute decision-makers ‘provide consent on behalf of persons with disabilities’.¹⁵¹ This requires medical staff to ensure ‘appropriate consultation that directly engages the person with disabilities’ and that ‘assistants or support persons do not substitute or have undue influence’ on the person’s decision.¹⁵² Moreover, it also demands that all the information on medical treatments is presented to the person in an accessible way, which permits them to be fully involved in the decisional process regarding their care.¹⁵³

Therefore, this provision further confirms that, with regard to treatment choices, also mentally disabled individuals like people living with dementia have always the right to decide, that there should be no binary distinction between capacity and incapacity to consent on the basis of disability, that all the person’s statements are legally valid in principle, and that if, because of their impairment, the person faces challenges in expressing a choice they need to be supported through a more inclusive style in medical consultations. By designating adequate informed consent procedures as an element of the standard of health services that State Parties need to guarantee, Article 25 CRPD makes further clear how, as claimed by the social model and Fineman’s vulnerability theory, the state(s) has an obligation to be responsive to the needs of individuals such as people living with dementia and to create the conditions for them to exercise their right to decide on medical treatment. In this regard, the reference to ‘adequate consultation’ sessions, and the ability of staff to assist the person in consenting to treatment confirms the duty of the state(s) to provide the necessary ‘ecological’ and ‘human’ resources for deciding on healthcare, through training for medical and care staff and by making available adequate spaces for the conversation between the person and the professionals responsible for their care. In the following

¹⁵⁰ Committee on the Rights of Persons with Disabilities, ‘General Comment’, *above*, 10.

¹⁵¹ *Ibid.*

¹⁵² *Ibid.*

¹⁵³ See also Quinn, ‘A Short Guide’, *above*, 111; Pavone, *above*, 478.

Chapters it will be studied how such a goal can be realised by governments and professionals can be given opportunities to train in communication and the management of consent procedure involving individuals living with dementia through local and European level initiatives.¹⁵⁴

As stated by Weller, also in the CRPD the right to health is situated at the intersection of ‘the three planes of individual autonomy, health and public health governance, and the expertise of health professionals’ which all need to be taken into account.¹⁵⁵ This means that empowering the person to shape their care plan according to their needs is an essential requirement for them to be truly healthy. Therefore, the assessment of what is medically best for the individual will have to put at the centre the subjective determination of what the person prefers, rather than objectively determined standards.¹⁵⁶

However, inserting autonomy in the wider context of the right to health also implies that the recognition of the power to decide on medical treatment even to individuals experiencing mental impairments like dementia cannot result in leaving the person alone to make self-harmful and ill informed choices. Rather, it leads to use supported decision-making and the interpretation of will and preferences to solve misunderstandings, overcome moments of confusion or delirium, fill cognitive gaps and clarify obscure or contradicting statements in order to truly promote the wellbeing of the person. Indeed, the message of conceptions such as that of the social model or vulnerability theory, echoed by the CRPD, is that it is not sufficient to leave people alone in deciding but it is necessary to engage with them in order to promote true self-determination. In this regard, as noted by Hendriks, because of the long history of marginalization and abuse characterizing our society’s approach to disability, the CRPD understandably puts emphasis on the refusal of paternalistic practices.¹⁵⁷ However, Frederiks notes how providing treatment and medical aids to minimise the impact of illnesses and impairments as far as reasonable and possible is equally important for promoting the independence of disabled individuals.¹⁵⁸ This aspect

¹⁵⁴ See Chapter 5 Section 3; Chapter 6 Section 3; Chapter 7 Section 4.

¹⁵⁵ P Weller, ‘The Right to Health: The Convention on the Rights of Persons with Disabilities’ (2010) 35 *Alternative Law Journal* 66, 67.

¹⁵⁶ *Ibid*, 69.

¹⁵⁷ A Hendriks, ‘UN Convention on the Right of Persons with Disabilities’ (2007) 14 *European Journal of Health Law* 273, 278-279.

¹⁵⁸ BJM Frederiks, ‘The Rights of People with an Intellectual Disability in the Netherlands: From Restriction to Development’ 14 *European Journal of Health Law* 149.

emerges also if one reads the provisions under discussion in connection with Article 10 CRPD, affirming the right to life of disabled people, and with Article 17 of the Convention according to which ‘every person with disabilities has a right to respect for his or her physical and mental integrity’. Such provisions impose to find a synthesis between the promotion of the person’s freedom of choice and therapeutic considerations.

Involuntary treatment

From the just explained formulation of the right to health derives that any form of forced or involuntary treatment is unacceptable under the CRPD. Minkowitz argues that the Convention, through various articles, prohibits ‘Mental Health Act provisions enforcing medical interventions without free and informed consent’, any exception to free and informed consent for disabled people and any norm authorizing compulsory treatment of any kind.¹⁵⁹ Arstein-Kerslake and Flynn include forced treatment among the discriminatory measures prohibited by Article 12.¹⁶⁰ They also claim the inappropriateness under the CRPD of milder limitations to the person’s agency such as imposing them to wash at certain times or regimenting their care and life according to a priori schedules.¹⁶¹ Also Callaghan and Ryan agree that Article 12 bans ‘substituted decision-making, including via involuntary treatment orders’.¹⁶² Indeed, The Committee on the Rights of Persons with Disabilities specifies, in General Comment No 1, that ‘forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (art. 17), freedom from torture (art. 15), and freedom from violence, exploitation and abuse (art. 16)’.¹⁶³

However, the Officer of the UN High Commissioner for Human Rights (OHCHR) maintains, commenting on Article 14 on deprivation of liberty, that the CRPD does not exclude that the freedom of (mentally) disabled people cannot be even preventively compressed for reasons of care or treatment but that the legal grounds upon which such

¹⁵⁹ T Minkowitz, ‘Prohibition of Compulsory Mental Health Treatment and Detention under the CRPD’ (2011) 8-9 available at <<https://ssrn.com/abstract=1876132>> accessed 17 December 2017.

¹⁶⁰ A Arstein-Kerslake and E Flynn, ‘The Right to Legal Agency: Domination, Disability and the Protections of Article 12 of the Convention on the Rights of Persons with Disabilities’ (2017) 13 *International Journal of Law in Context* 22, 22-23

¹⁶¹ *Ibid*, 28-30.

¹⁶² Callaghan and Ryan, *above*, 596.

¹⁶³ Committee for the Rights of Persons with Disabilities, ‘General Comment’, *above*, 11.

restriction of liberty is determined ‘must be de-linked from the disability and neutrally defined so as to apply to all persons on an equal basis’.¹⁶⁴ Upon ratification of the Convention, States Parties such as Australia, Norway and The Netherlands have inserted interpretive declarations specifying that according to them the CRPD still permits compulsory care or treatment in extreme circumstances and subject to sufficient legal safeguards.¹⁶⁵

As noted by Kayess and French, paradoxically the current text of the CRPD contains no explicit provision on involuntary treatment.¹⁶⁶ The insertion of specific norms on the matter was debated during the Convention negotiations in relation to Article 17.¹⁶⁷ The draft text of this norm affirmed, in paragraph 2, that States Parties ‘shall protect persons with disabilities from forced intervention aiming at correcting, improving or alleviating any actual or perceived impairment’ and, in paragraph 4, it affirms the necessity that involuntary treatment is minimised and administered only in exceptional circumstances and undertaken in the least restrictive setting possible. However, this formulation was opposed by DPO’s because it seemed to approve compulsion for disabled individuals though limiting its scope.¹⁶⁸ For this reason the final text of Article 17 only consists in the twenty three words long recognition of the rights to mental and physical integrity of disabled individuals with no further specification.

As noted by Bartlett, such a text and its convoluted drafting history do not offer decisive elements either in favour or against the total abolition of involuntary treatment.¹⁶⁹ Therefore, we need to reconstruct the position of the Convention on such a topic starting from its general principles and other relevant norms. In this regard,

¹⁶⁴ OHCHR, ‘Annual report of the High Commissioner for Human Rights to the General Assembly’ (2009) UN Doc A/HRC/10/49. See also OHCHR, ‘Persons with Disabilities’ Dignity and Justice for Detainees’ (2008) Week Information Note No. 4, 2, available at <http://www.ohchr.org/EN/UDHR/Documents/60UDHR/detention_infonote_4.pdf> accessed 26 July 09. In relation to this interpretation P Bartlett and R Sandland, *Mental Health Law* (Oxford University Press 2013), 276 note how, for it to make sense, it should be intended as requiring not only that the ‘language of disability’ is avoided in relevant legislations but also that apparently neutral criteria are not disproportionately applied to disabled people; otherwise the problem would just have been moved from the realm of direct to that of indirect discrimination. Here the two authors also criticise this interpretation because it seems to lead to the problematic consequence of expanding the possibilities for preventive limitations of liberty for all citizens.

¹⁶⁵ The texts of such declarations is available at <https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtsg_no=IV-15&chapter=4&lang=_en&clang=_en> accessed 17 December 2017.

¹⁶⁶ Kayess and French, *above*, 30.

¹⁶⁷ For a synthesis of the debate on this issue see Bartlett, *above*, 769-771.

¹⁶⁸ *Ibid.*

¹⁶⁹ *Ibid.*

already from Article 3 CRPD it can be derived that any practice that diminishes the dignity and autonomy of disabled people is not justifiable under the Convention. As stated by the UN Special Rapporteur on Torture, involuntary treatment surely can be included in such practices, as the sole imposition of a treatment is humiliating and distressing, thus not even justifiable under therapeutic reasons.¹⁷⁰ Moreover, Article 25 CRPD, as we have seen, affirms that medical treatment is permissible only if the disabled person has personally accepted it. Also, Article 14(1) CRPD prohibits any deprivation of liberty on the basis of disability, providing a further indication against forced treatment, as normally such a practice presupposes the confinement or even physical restraint of the person.¹⁷¹ Therefore, in light of the cited principles is it possible to affirm that involuntary treatment is generally in contrast with the CRPD.

However, Szmukler, Daw and Callard argue that excluding involuntary treatment altogether would be seriously problematic in relation to circumstances (including, for example, severe dementia or coma) in which treatment should be provided to a person who cannot materially make treatment decisions for themselves.¹⁷² Hendriks also notes how in exceptional and carefully examined circumstances it can paradoxically play a role in promoting the independence and dignity of the disabled person.¹⁷³ Indeed, in the already cited case study of the man with schizophrenia and pneumonia, the administration of medications despite the refusal of the person had indeed the aim of promoting his autonomous wish to continue to live.¹⁷⁴ In reality, in all the cited situations the treatment, though it is not covered by a specific act of consent delivered in the precise moment, it is performed in application of a plan or a reconstructed wish, which appears to have been approved by the person. The scheme here is that of ‘Ulysses pacts’ by which a person in moments of lucidity agrees on practices that need to be put in place in order to manage moments of crisis, despite the fact that they reject them in the specific moment.¹⁷⁵ As affirmed by Mirfin-Veicht, such mechanisms can be deemed in line with the CRPD.¹⁷⁶

¹⁷⁰ Special Rapporteur on Torture, ‘Report of the Special Rapporteur on Torture and other Inhuman or Degrading Treatment or Punishment’ (2013) UN Doc A/HRC/22/53.

¹⁷¹ F Seatzu, ‘Article 14 [Liberty and Security of Person]’ in Della Fina, Cera and Palmisano, *above*.

¹⁷² Szmukler, Daw and Callard, *above*, 248.

¹⁷³ Hendriks, *above*, 279.

¹⁷⁴ Zinkler and De Sabbata, *above*.

¹⁷⁵ Mirfin-Veicht, *above*.

¹⁷⁶ *Ibid*.

7. Conclusion

In conclusion, the UN Convention on the Rights of Persons with Disabilities proposes a new rights and support based approach to legal capacity. Such an approach appears to embody the values analysed in Chapter 3. Therefore, it provides a model of legal capacity and healthcare decision-making which can empower people living with dementia in choosing their care and permits to better address the legal moral and practical issues emerging in this area. This model is characterised by the following elements.

First, it qualifies legal capacity as an inalienable human right, recognising the power to make decisions to all individuals included those with severe cognitive impairments. Coherently, it rejects the binary distinction capacity/incapacity and refuses mental capacity tests when they lead to a deprivation of decisional power on the basis of (mental) disability. Therefore, with regard to treatment decisions of people living with dementia, it provides a powerful statement against behaviours in which the opinion of the person is disregarded because of prejudice or labelling. It also avoids the problem of defining when the individual becomes capable and proposes a more viable approach to advance directives.

Adopting this perspective leads to maintain that if a disabled individual like a person living with dementia struggles to make decisions on their care the remedy should be helping them through supported decision-making. This mechanism consists in a relationship which accompanies the person throughout the progression of their condition till the very final stages. It can result in a number of different practices but it always needs to put at the centre the will of the person and not amount to forms of undue influence. In this regard, the person can be helped remembering things they do not remember and to communicate, or, in case of very extensive impairment, they may be empowered to express their desires through best interpretation of their will and preferences.

However, the implementation of the CRPD model poses a series of challenges. First, it certainly presupposes that the principles explained above are really abound to in national legislations and practices. This demands to persuade and put pressure on national governments, parliaments and judges so that they really take action to promote the CRPD. It also requires them to establish how the principles of the Convention

translate in terms of detailed rules and concrete behaviours. In this regard, it is also necessary to identify which specific means of support are needed in the case of people living with dementia. In addition, it is crucial to create the conditions for these means of support to be effectively applied in practice. This includes providing adequate training to professionals and informal carers and making sure they have adequate resources in terms of money, time and facilities. Also it requires the establishment of mechanisms directed to avoid or minimise the risk that support degenerates into undue influence. Finally, in order to guarantee that such practices and resources are always put to the advantage of the person's power to decide on treatment, it is necessary to raise awareness among professionals and lay persons, making sure they truly embrace a less stigmatising and medicalised view of dementia and that they really believe that capacity to consent is a fundamental right of every individual, including people living with dementia.

In the next chapters I will explore how such issues could be addressed through the actions of the two main European regional organisations (the Council of Europe and the European Union) and through initiatives by public bodies, care structures, NGOs, research institutions or single individuals in single countries of the continent.

CHAPTER 5

The Council of Europe: Powers and Potential

1. Introduction

The CoE is an intergovernmental organisation grouping 47 European Member States, with the aim of promoting democracy, human rights, and the rule of law.¹ It is the leading organisation for the promotion of human rights on the continent.² In this regard, it has a series of powers allowing it to promote coordinated policies on a European scale and is equipped with particularly authoritative monitoring bodies and a human rights court (the European Court of Human Rights) to which every citizen can apply and whose decisions are binding for Member States and private parties.³ Indeed, the CoE has acquired significant authority among national governments and public opinion, and has often proven quite effective at impelling Member States to comply with its human rights standard.⁴

This chapter investigates how such powers and mechanisms can be used to promote a model of legal capacity and treatment decisions for people living with dementia congruent with the CRPD. In particular, it focuses on the possible role of CoE bodies in specifying the normative content of the Convention, prompting Member States to implement its principles, and guaranteeing that the necessary conditions are in place so that the right to choose of individuals living with this condition is respected. There are already signs of such bodies' potential in this area, emerging from documents such as the CoE Disability Action Plan 2006-2015 and Disability Strategy 2017-2023, reports by monitoring bodies, and case law of the European Court of

¹ For an overview on the CoE see F Benoît-Rohmer and H Klebes, *Council of Europe law. Towards a pan-European Legal Area* (CoE 2005); TEJ Kleinsorge (ed), *Council of Europe* (Wolters Kluwer 2010); A Royer, *The Council of Europe* (CoE 2010); JW Hart, 'The European Human Rights System' (2010) 102 *Law Library Journal* 534, 534-537; J Rehman, *International Human Rights Law* (2nd ed Longman 2010), 183-243; DL Shelton and PG Carozza, *Regional Protection of Human Rights* (2nd ed Oxford University Press 2013), 13-53; K Sithole, 'The Council of Europe, Rights and Political Authority' (2013) 21(1) *European Review*, 118. See also <<http://www.coe.int/en/web/portal/home>> accessed 30 November 2015.

² On the relevance of the CoE in the field of human rights promotion within the European context see the presentation page of the organisation in < <http://www.coe.int/it/web/moscow/the-coe/about-coe>> accessed 16 December 2015.

³ See further Section 2.

⁴ Hart, *above*, 534-537; Sithole, *above*, 118-125.

Human Rights. My analysis starts from these and other CoE materials released in the area of mental disability, aging, and health, studying first what has already been achieved and then trying to understand what more can be done for the future. Because the majority of these sources are normative documents, my research mainly relies on doctrinal analysis, though it still uses content analysis in the (limited) cases in which a certain source (e.g. a page on the CoE website) describes only a certain initiative (e.g. an awareness raising campaign), rather than dictates rules or guidelines.

The chapter is organised as follows. Section two provides a brief overview of the structure of the CoE and its main bodies. In this regard it mainly focuses on the Committee of Ministers, the Parliamentary Assembly, the European Court of Human Rights (ECtHR), and monitoring bodies: the European Committee of Social Rights (ECSR), the Commissioner for Human Rights, and the European Committee for the Prevention of Torture (CPT). Section three concentrates on relevant recommendations and resolutions of the Committee of Ministers and the Parliamentary Assembly, studying how they can urge Member States to implement the principles of the CRPD through organic policy plans, awareness raising, training incentives, and dissemination of promising practices. It first provides a brief explanation of the nature of recommendations and resolutions as normative documents, then goes into the analysis of single measures. Section four then turns to the ECtHR and, starting from relevant judgments in the field of legal capacity of disabled individuals, it investigates the potential of the Court case law for promoting the CRPD approach in the area of treatment decisions of people living with dementia. Section five deals with the work done in the fields of disability, health, and aging by a series of CoE monitoring bodies, exploring how they can contribute to creation of conditions for the promotion of the right of individuals living with this condition to express their opinion on medical treatment. Section six focuses specifically on the debate concerning involuntary treatment, best interests, and advance directives carried on within the CoE, especially with regard to the Oviedo Convention on Human Rights and Biomedicine and with special attention to the recent Draft Additional Protocol on Involuntary Placement and Involuntary Treatment of People with Mental Disorders. The conclusion summarises the strengths, weaknesses, and potential of CoE action in relation to treatment decisions of people living with dementia.

2. CoE General Structure

Committee of Ministers

CoE bodies are regulated by the Treaty of London (CoE statute), by which the organisation was created in 1949⁵ and are structured so as to cover the executive, rule-making and judiciary functions necessary for the attainment of its goals. The Committee of Ministers (Articles 13-21 CoE Statute) is the executive organ of the CoE and is responsible for its political initiative (Article 15 CoE Statute).⁶ It is made up of the Ministers of Foreign Affairs of CoE Member States (Article 14 CoE Statute). Its work results in policies mainly contained in Recommendations and drafts of Conventions such as the European Convention on Human Rights (ECHR), the European Social Charter, or the Convention on Human Rights and Biomedicine.⁷ In this regard, the Committee plays an important role in promoting cooperation and political dialogue between national governments and in monitoring their action (see Committee of Ministers Resolution (84)21 and Secretariat memorandum Monitor/Inf(2004)3).⁸

The Committee of Ministers is supported by its deputies' session and rapporteur groups⁹ such as those on Human Rights (GR-H) and Social and Health Questions (GR-SOC).¹⁰ In addition, as noted by Palmer, the Committee may appoint bodies of experts with advisory tasks.¹¹ Examples in this sense are the Committee of Experts on the Rights of People with Disabilities (DECS-RPD), the Committee of Bioethics (DH-

⁵ Statute of the Council of Europe, May 5th, 1949, 87 UNTS 1030.

⁶ On the Committee of Ministers see, in general, G De Vel, *The Committee of Ministers of the Council of Europe* (CoE Press 1995); Benoît-Rohmer and Klebes, *above*, 48-55; Royer, *above*, 10-11; S Palmer, 'The Committee of Ministers' in Kleinsorge (ed), *above*, 93-101. See also <http://www.coe.int/t/cm/home_en.asp> accessed 26 February 2016.

⁷ See Section 3 and 4.

⁸ De Vel, *above*, 26-29. In this regard, the Committee can be asked by the Parliamentary Assembly, the Secretary General, or Member States to look at the situation of human rights in a specific country and can ask the Secretary General to gather information in this respect Benoît-Rohmer and Klebes, *above*, 121-124.

⁹ These bodies are made up of permanent representatives of each government. De Vel, *above*, 32-36. See also CoE, Committee of Ministers. Procedures and working methods (2016) in <https://wcd.coe.int/ViewDoc.jsp?id=1950611&Site=COE&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383#P831_63713> accessed 3 March 2016.

¹⁰ See <http://www.coe.int/t/cm/subsidiaryGroups_en.asp> accessed 3 March 2016.

¹¹ Palmer, *above*, 96-98. See also <http://www.coe.int/t/democracy/committees_en.asp#> accessed 4 March 2016.

BIO), and the Drafting Group on Aging (CDDH-AGE). The work of the Committee of Ministers is coordinated by the Secretary General and the Deputy Secretary General.¹²

Parliamentary Assembly

The Parliamentary Assembly (Articles 22-35 CoE Statute) is made up of 318 MPs designated by Member States' parliaments.¹³ As reported by Benoît-Rohmer and Klebes, its main role is as an independent forum for discussion and for soliciting the Committee of Ministers through recommendations and resolutions to take action on crucial issues for the promotion of human rights in Europe (Article 23 CoE Statute).¹⁴

According to Article 24 CoE Statute, the Assembly may form Committees of members focusing on specific areas, such as the Committee on Legal Affairs and Human Rights, the Committee on Equality and Non-discrimination, which has a specialised Sub-committee on Disability, and the Monitoring Committee.¹⁵ This last committee has the duty to issue reports focusing on the human rights situation of single countries.¹⁶ The Assembly may issue recommendations to governments on the basis of such reports and may also punish persistently non-compliant states by annulling their parliamentary delegation credentials.¹⁷

The interaction between Parliamentary Assembly and Committee of Ministers is favoured by mechanisms such as the duty of the Committee to take action when a recommendation by the Assembly is received (Article 15 CoE).¹⁸ In addition, members of the Assembly may put written and oral questions to the Committee of Ministers.

¹² See Benoît-Rohmer and Klebes, *above*, 71-74.

¹³ On the Parliamentary Assembly in general see Benoît-Rohmer and Klebes, *above*, 48-55; Royer, *above*, 10-11; TEJ Kleinsorge, 'The Parliamentary Assembly: Europe's Motor and Conscience', in Kleinsorge (ed), *above*, 74-89. See also, <<http://www.assembly.coe.int/nw/Home-EN.asp>> accessed 27 February 2016.

¹⁴ Benoît-Rohmer and Klebes, *above*, 65-66.

¹⁵ See Royer, *above*, 13. See also <http://website-pace.net/en_GB/web/apce/committees> accessed 26 February 2016.

¹⁶ Resolution 1115(1997) adopted 29 January 1997.

¹⁷ The monitoring activity of the Parliamentary Assembly started around the second half of the 1970s and developed thanks to Order No. 488, also known as Halonen Order (1993), and Resolution 1031(1994). On this point see Kleinsorge, 'The Parliamentary Assembly', *above*, 85-88. On the actual system of monitoring by the Assembly see Benoît-Rohmer and Klebes, *above*, 118-122.

¹⁸ *Ibid* 70-71.

European Court of Human Rights

The European Court of Human Rights (ECtHR) is regulated by Articles 19-51 European Convention on Human Rights (ECHR). It is made up of a number of full-time judges equal to that of State Parties of the ECHR (Article 20 ECHR), elected by the Parliamentary assembly (Article 22 ECHR).¹⁹ It is an autonomous jurisdictional body whose decisions are guided only by the principles of Human Rights Law.²⁰ It is in charge of judging violations of the European Convention and of clarifying its right interpretation.²¹ The ECHR is regarded as one of the most important human rights conventions on a European level.²² Signed in Rome on the 4th November 1950, it focuses on civil rights²³, has binding force,²⁴ and has been ratified by all the Member States of the Council of Europe.²⁵

Cases may be brought in front of the Court by state parties of the ECHR (Article 33 ECHR) and by ‘any person, nongovernmental organisation or group of individuals claiming to be the victim of a violation by one of the High Contracting Parties’ (Article 34 ECHR), once all internal remedies have been exhausted (Article 35 ECHR).²⁶ After the recourse has been presented and provided it is admissible, the Court considers it in a public procedure, normally in front of a panel of seven judges (Article 38

¹⁹ On this point see Mowbray, *above*, 26-27.

²⁰ *Ibid.*

²¹ The Court may also issue advisory opinions to the Committee itself (Article 47 ECHR). For a general overview on the ECtHR see S Greer, *The European Convention on Human Rights. Achievements, Problems and Prospects* (Cambridge University Press 2006), 136-192; P van Dijk et al (eds), *Theory and Practice of the European Convention on Human Rights* (4th ed Intersentia 2006), 35-44; MW Janis, RS Kay and AW Bradley, *European Human Rights Law. Text and Materials* (3rd ed Oxford University Press 2008), 67-116; A Mowbray, *above*, 10-63. See also < <http://www.echr.coe.int/Pages/home.aspx?p=home>> accessed 26 February 2016.

²² MW Janis, RS Kay and AW Bradley, *European Human Rights Law. Text and Materials* (3rd ed Oxford University Press 2008), 3, refer to the ECHR as establishing ‘not only the most successful system of international law for the protection of human rights, but one of the most advanced form of any kind of international legal process’. Sithole, *above*, 118 defines the Convention as ‘the bedrock of the most advanced system of international human rights protection’. On the relevance and importance of the ECHR see also S Greer, *The European Convention on Human Rights. Achievements, Problems and Prospects* (Cambridge University Press, 2006); DJ Harris et al, *Law of the European Convention on Human Rights* (2nd ed, Oxford University Press 2009), 30-36.

²³ AWB Simpson, *Human Rights and the End of the Empire* (Oxford University Press 2001), 601-602.

²⁴ On the normative force of treaties in International and human rights law see Rehman, *above*, 19-22; MN Shaw, *International Law* (7th ed Cambridge University Press 2014), 66-69.

²⁵ On the Convention see in general Greer, *above*; P van Dijk et al (eds), *Theory and Practice of the European Convention on Human Rights* (4th ed Intersentia 2006); Janis, Kay and Bradley, *above*; K Reid, *A Practitioner’s Guide to the European Convention on Human Rights* (4th edition Sweet and Maxwell 2011); Mowbray, *above*; E Wicks and C Ovey (eds), *Jacobs, White and Ovey: The European Convention on Human Rights* (6th ed Oxford University Press 2014); WA Schabas, *The European Convention on Human Rights. A Commentary* (Oxford University Press 2015).

²⁶ On the exhaustion of domestic remedies see Janis, Kay and Bradley, *above*, 36-38.

ECHR).²⁷ Judgments of the Court can be appealed in front of the *Grand Chambre*, which operates a panel of seventeen judges (Articles 43, 44 and 46 ECHR).²⁸

European Committee of Social Rights

The European Committee of Social Rights (ECSR) is the body in charge of monitoring the compliance of State Parties legislation with the ERC and the RevERC and is made up of 15 experts of social rights elected by the Committee of Ministers (Article 25(1) ESC).²⁹ It adopts conclusions on state reports presented on a yearly basis issuing interpretative declarations.³⁰ In addition, the Committee of Social Rights adopts statements of interpretation, clarifying its position on specific questions.³¹ Moreover, since 1998, the ECSR also receives collective complaints issued by organisations included in a special list, which have the right to appeal to the Committee.³² Once a complaint has been received, the ECSR examines it and asks for observations from the member-state concerned. At the end of the procedure, the Committee issues a decision clarifying whether there has been a human rights violation and what measures must be undertaken in order to remove the violation.³³ The jurisprudence of the European Committee is summarised in the Digest of the Case Law of the ESCR.³⁴

Other monitoring bodies

²⁷ For further explanation on the procedure in front of the Court see Mowbray, *above*, 27-58.

²⁸ On the judgements of the ECtHR see section 3.3.

²⁹ The functioning of the Committee is regulated by Articles 21-29 European Social Charter (ESC), part IV of the Revised Social Charter (RevESC) and its Additional Protocol on a System of Collective Complaints (1995). On the European Committee of Social Rights see, in general, N Valticos, 'La Charte sociale européenne: sa structure, son contenu, le contrôle de son application' (1963) 26 *Droit Sociale* 466; R Brillat, 'The Supervisory Machinery of the European Social Charter' in G De Burca and B De Witte (eds), *Social Rights in Europe* (Oxford University Press 2005); O De Schutter and M Sant'Ana, 'The European Committee of Social Rights' in G De Beco (ed), *Human Rights Monitoring Mechanisms of the Council of Europe* (Routledge 2012), 72.

³⁰ See De Schutter and Sant'Ana, *above*, 78-80.

³¹ See De Schutter and Sant'Ana, *above*, 83-84.

³² See Brillat, *above*, 32-34.

³³ On the system of collective complaints see M Jaeger, 'The Additional Protocol to the European Social Charter Providing for a System of Collective Complaints' (1997) 10 *Leiden Journal of International Law* 69; RR Churchill and U Khaliq, 'The Collective Complaints System of the European Social Charter: An Effective Mechanism for Ensuring Compliance with Economic and Social Rights' (2004) *European Journal of International Law* 417.

³⁴ See ECSR, *Digest of the Case Law of the European Committee of Social Rights* (CoE 2008), 108.

Duties of general human rights monitoring and awareness raising are assigned to the Commissioner for Human Rights.³⁵ In this regard, as noted by Benoît-Rohmer and Klebes, the role of this office is mainly preventive.³⁶

According to Articles 8 and 3(f) Resolution (99)50, the Commissioner may issue recommendations, opinions, and reports and bring them to the attention of the Parliamentary Assembly and the Committee of Ministers, to which he or she has to present an annual report (Article 3(h) Resolution (99)50). The main activity of the Commissioner consists of visiting member-states to assess their human rights situation.³⁷ These visits permit the Commissioner to meet representatives of the government, parliament, the judiciary, and human rights associations or NGOs and discuss the main human rights issues regarding the interested country.³⁸ This also allows the Commissioner to start a fruitful process of dialogue through which he can suggest solutions, tailored to the local context, in order to increase the level of human rights protection.³⁹ Assessment visits result in country reports, which contain detailed recommendations to the member-states.⁴⁰ Also, information collected during the Commissioner's visit provides material for thematic reports which this office releases periodically. In this context, the Commissioner can also consult external experts and commission research on a certain topic.⁴¹

The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) has similar powers regarding the respect of the European Convention for the Prevention of Torture and Inhuman or Degrading

³⁵ The powers of the Commissioner are regulated by Committee of Ministers Resolution (99)50. He or she is elected by the Parliamentary Assembly under recommendation of the Committee of Ministers (Articles 9, 10 and 12 Resolution (99)50). On the Commissioner in general see Benoît-Rohmer and Klebes, *above*, 76; T Hammarberg, 'The Council of Europe Commissioner for Human Rights' in G Alfredsson (ed), *International Human Rights Monitoring Mechanisms: essays in honour of Jakob Th Möller* (Nijhoff 2009), 515; L Sivonen, 'The Commissioner for Human Rights' in De Beco (ed), *above*, 17; M Bond, *The Council of Europe and Human Rights* (CoE, 2013), 70-71; A Weber, 'Commissioner for Human Rights' in E Abdelgawad and H Michel (eds), *Dictionary of European Actors* (Larcier 2015). See also <<http://www.coe.int/en/web/commissioner>> accessed 26 February 2016.

³⁶ Benoît-Rohmer and Klebes, *above*, 76.

³⁷ Weber, *above*.

³⁸ *Ibid.*

³⁹ Sivonen, *above*, 23-24.

⁴⁰ *Ibid.*

⁴¹ See Sivonen, *above*, 28-30. See also Hammarberg, *above*.

Treatment or Punishment. This Convention entered into force on the 1st of February 1989⁴² and was ratified by all Member States of the Council of Europe.⁴³

The CPT includes a member for every Member State of the CoE, who serves in their personal capacity (Article 4 Convention on Torture) and is elected by the Committee of Ministers (Article 5 Convention on Torture). Like the Commissioner, this Committee's core activity is conducting visits to Member States. As summarised by Kicker, the CPT has the power to enter any place of deprivation of liberty at any time (Article 9 Convention on Torture).⁴⁴ At the end of each visit, the Committee issues a confidential report (Article 11 Convention on Torture). It may also issue immediate observations, requiring prompt action in order to solve particularly serious problems (Article 8(5) Convention on Torture), or public statements, stigmatising the behaviour of states which refuse to cooperate (Article 10(2) Convention on Torture). The recommendations issued in the various state-reports are reported, adopting a systematic style, in annual General Reports.

⁴² On the Convention and the Committee on the Prevention of Torture see in general K Ginther, 'The European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment' (1990) 2 *European Journal of International Law*, 123; A Cassese, 'The European Committee for the Prevention of Torture and Inhuman or Degrading Punishment comes of Age' in N Blokker and S Muller (eds), *Towards More Effective Supervision by International Organs. Essays in honour of Henry G. Schermers* (Nijhoff 1994), 115; MD Malcom, *Preventing Torture: the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment* (Clarendon, 1998); R Morgan, 'The CPT Model: an examination' in L Sicilianos (ed), *The Prevention of Human Rights Violations. Contribution on the Occasion of the Twentieth Anniversary of the Marangopoulos Foundation for Human Rights* (Nijhoff 2001); R Morgan and M Evans, *Combating Torture in Europe: the Work and Standards of the European Committee for the Prevention of Torture* (CoE, 2001); R Kicker, 'The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (the CPT)' in De Beco (ed), *above*, 43. See also < <http://www.cpt.coe.int/en/default.htm>> accessed 3 March 2016.

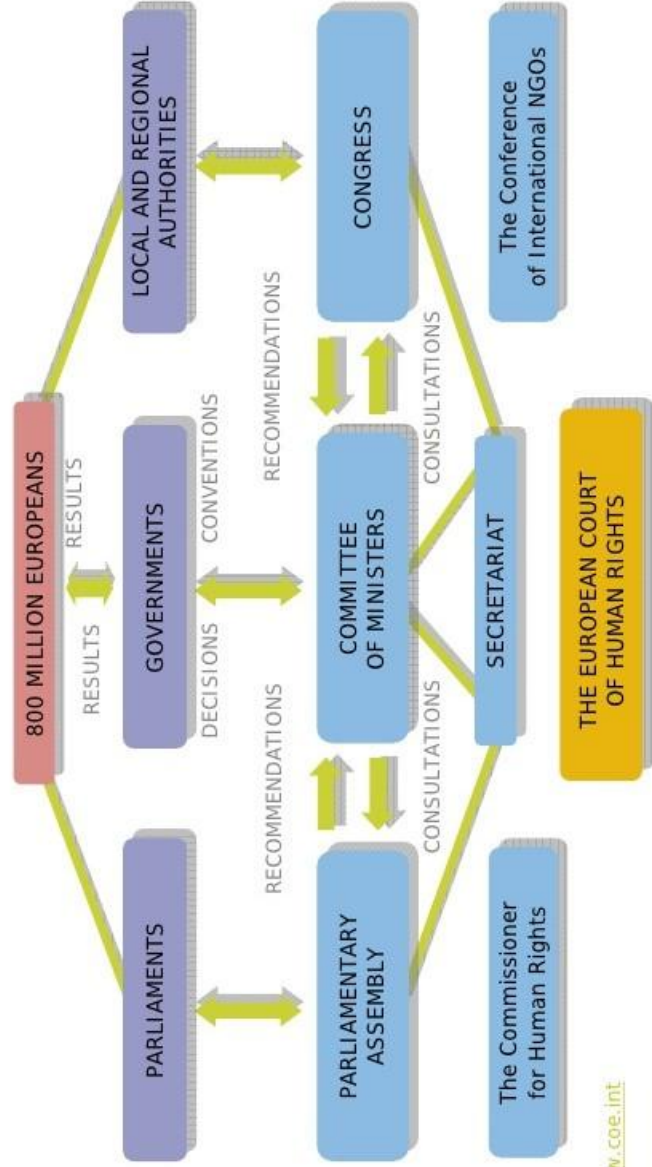
⁴³ See < <http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/126>> accessed 3 March 2016.

⁴⁴ Kicker, *above* 49-59. Ginther, *above*, 128-129.

How it works?



- Dialogue between the Council of Europe's main bodies
- The Secretariat is divided into directorates covering main activities
- Results take various forms: conventions, recommendations, conferences and reports



3. Policies to promote the CRPD: Recommendations and Resolutions

Recommendations, Resolutions and care decisions of people living with dementia

The first ways in which CoE institutional structures can contribute to the implementation of Article 12 and CRPD principles is by promoting them among Member States and their citizens and by persuading governments to take action in order to translate them into reforms, national policies and practices. In this regard, the Committee of Ministers and Parliamentary Assembly in particular can develop policy plans reaffirming the values of CRPD and suggest specific rules and initiatives in this field. Moreover, they can solicit actions to concretely advance a supported decision-making culture, such as awareness raising initiatives, training programmes on human rights and disability, or channels for the dissemination of promising practices. The instrument through which this can be done is called a Recommendation.⁴⁵

Parliamentary Assembly Recommendations (Rule 25.1.a Parliamentary Assembly Rules of Procedure)⁴⁶ are addressed to the Committee of Ministers with the aim of urging it to take action on a certain issue.⁴⁷ Recommendations of the Committee of Ministers are addressed to Member States and detail the CoE policies in a specific area.⁴⁸ They enter into force without ratification.⁴⁹ Moreover, as observed by De Beco, they can be proactive, setting a wider strategy for preventing future violations.⁵⁰

Recommendations do not have binding force.⁵¹ However, because of the authority of their issuing bodies, they can exert a good level of political influence.⁵² In this

⁴⁵ The Commissioner on Human Rights and the CTP also issue recommendations, but they are essentially the last part of their reports, so I will look at them later on when analysing the monitoring bodies reports.

⁴⁶ Resolution 1202 (1999) adopted on 4 November 1999 and subsequent modifications.

⁴⁷ As the Assembly is independent from national governments and expresses the voice of Europe's people

⁴⁸ De Vel, *above*, 37; Benoît-Rohmer and Klebes, *above*, 56. On the role and functioning of the Committee of Ministers see *above* section 2.1.

⁴⁹ G De Vel and T Markert, 'Importance and Weakness of the Council of Europe Conventions and of the Recommendations addressed by the Committee of Ministers to Member States', in B Haller, HC Kruger and H Pretzold, *Law in Greater Europe: Towards a Common Legal Area. Studies in Honour of Heinrich Klebes* (Kluwer Law, 2000), 345.

⁵⁰ G De Beco, 'Introduction: the role of European Human Rights Monitoring Mechanisms', in De Beco (ed), *above*, 3.

⁵¹ De Vel and Markert, *above*, *passim*.

⁵² Indeed, Assembly Recommendations served to this independent body representing the people of Europe can put political pressure on the Committee of Minister. In turn, Committee of Ministers Recommendations can kick-start change processes at a continental level. Indeed, their proposals often

regard, they may be an instrument of pressure in the hands of NGOs. Moreover, they may be used by the ECtHR and national courts as interpretive documents.⁵³ Finally, in some cases, provisions included in Recommendations have become part of binding EU legal documents.⁵⁴

Parliamentary Assembly Resolutions can also be helpful in affirming statements of principle promoting the application of the CRPD.⁵⁵ These documents contain a decision by the Assembly ‘on a question of substance which it is empowered to put into effect, or an expression of view for which it alone is responsible’ (Rule 25.1.b Parliamentary Assembly Rules of Procedure). They are not binding and do not require an explicit response from the Committee of Ministers.⁵⁶ However, they can be used to bring attention to one or more problems.

Currently, the CoE has not issued specific recommendations or resolutions on healthcare decisions of people living with dementia. However, it has released important recommendations in the field of legal capacity of mentally disabled people and of aging. The most important, in relation to the CRPD, are Committee of Ministers Recommendations Rec (2006)5 on the ‘Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society’ 2006-2015⁵⁷ and the Council of Europe Disability Strategy 2017-2023 ‘Human Rights: a reality for all’,⁵⁸ which continues the work done by the Plan. The Committee of Ministers Recommendation R(99)4 on the ‘Legal Protection of Incapable Adults’ is also relevant to this topic, although somewhat outdated. In the field of older people’s rights, the Committee of Ministers’ recommendations Rec(2014)2 on ‘The Promotion of Human

stem from the mutual agreement of a vast majority of European governments and are the expression of a widespread and recognised need for change. Benoît-Rohmer and Klebes, *above*, 107-109.

⁵³ G Puppinc, ‘Status of the recommendations of the Committee of Ministers in the legal field of the Council of Europe – Synthesis’ (2012) in <<http://ecj.org/PDF/status-of-the-recommendations-of-the-committee-of-ministers-in-the-legal-field-of-the-council-of-europe%E2%80%93synthesisenglish.pdf>> accessed 1st of December 2015. See, as an example, *Prisma Presse v. France*, (2003) 15(3-6) *Revue Universelle des Droits de l’Homme*, 211; Romanian Constitutional Court, decision of 20 July 1999. In general see Benoît-Rohmer and Klebes, *above*, 108-109; Puppinc, *above*.

⁵⁴ See for example the resolution of the European Parliament of 28 September 2011 on human rights, sexual orientation and gender identity at the United Nations, which refers explicitly to Recommendation CM/Rec(2010)5 on discriminations founded on sexual orientation or gender identity. On this point see Benoît-Rohmer and Klebes, *above*, 109; Puppinc, *above*. I will also show that the CoE and EU policies on disability seem influenced by one another.

⁵⁵ The Committee of Ministers can also emanate Resolutions, but they concern the specification of constitutional or procedural issues. See Benoît-Rohmer and Klebes, *above*, 29-30.

⁵⁶ *Ibid* 66.

⁵⁷ See <[www.coe.int/t/e/.../Rec\(2006\)5%20Disability%20Action%20Plan.doc](http://www.coe.int/t/e/.../Rec(2006)5%20Disability%20Action%20Plan.doc)> accessed 2 December 2015.

⁵⁸ Available at <<https://rm.coe.int/16806fe7d4>> accessed 5 August 2018.

Rights of Older Persons’ and Rec(2009)6 on ‘Ageing and Disability in the 21st century’ are noteworthy. With regard to Parliamentary Assembly resolutions, valuable statements have been issued in Resolution 1642 (2009) entitled ‘Access to Rights for People with Disabilities’⁵⁹ and Resolution 2039 (2015) on ‘Equality and Inclusion for People with Disabilities’.

Promoting the values of the CRPD

As noted by Flynn, the Disability Action Plan 2006-2015 was published a few months prior to the adoption of the CRPD and follows its approach, echoing many of the Convention provisions.⁶⁰ Therefore, it is a first step in the incorporation of these principles in a system, such as that of the CoE, which provides particularly effective enforcement mechanisms.⁶¹ The Plan also provides for the creation of the European Coordination Forum for the Disability Action Plan (CAHPAH), now Committee of Experts on the Rights of Persons with Disabilities (DECS-RPD),⁶² made up of representatives of governments, CoE institutions and NGOs, with the role of advising national governments on the implementation of this document.⁶³ The CoE Disability Action Plan embraces the social model of disability and the human rights approach to legal capacity. Indeed, Section 2.2 of the Introduction acknowledges that disabled people should be seen as persons rather than just patients.⁶⁴ Also, Action Line No. 12, affirming the right to legal personhood of disabled people, challenges the binary concept of incapacity and the link between rationality and decisional power at a European level.

Similar messages are repeated in the CoE Disability Strategy 2017-2023, but with a clearer endorsement of the CRPD and Article 12 which are now explicitly referred to throughout the document. For example, paragraph 11 of the Strategy recalls the paradigm shift from a medicalised to a human rights-based approach promoted both by the UNCRPD and the Disability Action Plan 2006-2015. In this regard, it affirms

⁵⁹ See <<http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=17697&lang=en>> accessed 4th December 2015.

⁶⁰ E Flynn, *above*, 58-59.

⁶¹ See section 2.

⁶² European Committee for Social Cohesion, Human Dignity and Equality, ‘Protection of the rights of persons with disabilities. Council of Europe action and challenges’ < <https://rm.coe.int/16802edb67>> accessed 8 August 2018.

⁶³ E Flynn, *From Rhetoric to Action. Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press 2011), 59-61.

⁶⁴ Disability Action Plan 3.9.1 also stresses that health care professionals need to acknowledge the social model of disability.

that the interpretation and implementation of principles or actions undertaken under the Strategy itself need to be guided by the provisions of the Convention (paragraph 23), which is thus formally indicated as the evaluative framework in this area. Regarding legal capacity, paragraphs 61-63 explicitly cite Article 12 and emphasise how the power to make all necessary decisions for one's life is a fundamental requirement for full enjoyment of human rights. These paragraphs note how many European legislations still allow forms of substituted decision-making in which disabled people are stripped of the possibility to exercise their rights and they urge governments to reform these systems.

Therefore, in relation to treatment decisions of people with dementia, CoE disability policies confirm that the person needs to be recognised as an individual with full rights, including that of making their own decision, and that the state and society need to create the conditions for the exercise of such rights. Similar ideas are also affirmed in relation to older people by Parliamentary Assembly Recommendation 1796 (2007). This document, advocates for old age - which plays a crucial role in determining the condition of the majority of people living with dementia - ⁶⁵to be regarded as a complex process dependent on social structures and urges policies that accommodate the needs of older individuals. With more specific regard to the right to make choices, recommendation Rec(2014)2 II.12, echoes the CRPD and affirms that all older people (including older people living with dementia) 'enjoy legal capacity on an equal basis with others'. Such a reaffirmation is surely important because, as noted by Van Bueren, both older people with or without dementia may suffer *de facto* limitations of their decisional power deriving from prejudice and overly invasive use of the power given to guardians with the scope of assistance.⁶⁶

Specifying the principles of the CRPD

Paragraph 3.12.2.VI of the Disability Action Plan indicates how such values and principles translate in terms of specific legal rules. It requires the provision by Member States of 'appropriate assistance to those people who experience difficulty in exercising their legal capacity' and in paragraph 3.12.3 urges them to set up 'specific

⁶⁵ See *above* Chapter 1.

⁶⁶ G Van Beuren, 'Background briefing paper', for the International Symposium on the Rights of Older People, January 2009, in <<http://www.globalaging.org/elderrights/world/2009/humanrightseurope.pdf>> accessed on 25 April 2016.

legislative measures, bodies, reporting procedures and redress mechanisms’ in order to guarantee that disabled people are not discriminated and unjustly deprived of the power to make decisions. Disability Action Plan 3.9.1 clarifies the implications of such statements in relation to treatment decisions, stating that disabled people ‘should be consulted and fully involved’ in the decision-making process regarding their care and should be ‘consulted to the maximum possible extent’ (Disability Action Plan 3.9.3.II). Moreover, line 3.9.3 VI of the Action Plan indicates specific means of support in order to assist the person in healthcare decision-making. It urges Member States ‘to ensure that reasonable steps are taken to provide all relevant information [...] in a format understandable to the disabled person’ (Disability Action Plan,).

However, such declarations do not define the ‘maximum possible extent’ or ‘reasonable effort’, remaining vague on what the extent of the duties of doctors or carers. Moreover, as noted by the Fundamental Rights Agency, the Action Plan does not provide a complete set of guidelines regulating support in the full spectrum of situations in which disabled people may find themselves and does not clearly establish what kind of measures are acceptable, referring for that to Recommendation R(99)4.⁶⁷

This document, issued by the Committee of Ministers in 1999, contains some provisions which align with Article 12 CRPD. Indeed, Principle 3 R(99)4, entitled ‘maximum preservation of capacity’, affirms that ‘a measure of protection should not automatically result in a complete removal of legal capacity’ (Principle 3(1)). Also, it states that measures with a lower impact on the decisional capacity of the person are preferred (Principle 5) and that they should be tailored to the circumstances of the specific case. Moreover, Principle 4(2) R(99)4 specifies an important distinctive characteristic of supported decision-making a kind of test of whether a certain measure is really a measure of support by requiring that the support person ‘acts jointly with the adult concerned’.

However, as it was written much earlier than the Convention, the R(99)4 contains elements that do not align with it.⁶⁸ For example, Principle 3(1) still allows restrictions

⁶⁷ FRA, *Legal Capacity of Persons with Intellectual Disabilities and Persons with Mental Health Problems* (FRA 2013), 18.

⁶⁸ Recommendation R(99) 4 was issued during a vibrant debate on legal capacity legislation. Between the 1990s and the 2000s this debate brought, o reforms of legal capacity regulation to various countries such as France, Germany, Austria, England and Italy. E Carbone, ‘Liberta’ e protezione nella riforma dell’Incapacità d’agire’ in < <http://www.altalex.com/documents/news/2004/12/10/liberta-e-protezione-nella-riforma-dell-incapacita-di-agire#sdfootnote18sym>> accessed 1st December 2015. At that time, the

of legal capacity where this appears necessary for the protection of the person, leaving the door open to paternalistic practices. In effect, it authorizes incapacitation for reasons of ‘protection’ of the person, exposing them to the risk that doctors or carers, simply overrule decisions they do not agree with with the pretext of ‘saving the person from harmful choices’. Moreover, the norm does not limit the use of substituted decision-making to extreme circumstances, suggesting that people could be deprived of their decisional power even when they have expressed an articulate opinion. In this regard, the fact that the Action Plan refers to the R(99)4 as a whole, without distinguishing the various provisions, may cause confusion and could allow someone to claim that deprivation of legal capacity is not necessarily in contrast with current European human rights standards, even after the CRPD.

This confusion seems to be partially rectified by paragraph 63 of the Disability Strategy 2017-2023, which reads:

‘States are required under the UNCRPD, as far as possible to replace substituted decision-making with systems of supported decision-making. Possible limitations on decision-making should be considered on an individual basis, be proportional and be restricted to the extent to which it is absolutely necessary.’

This line apparently adopts a formulation which is less radical than that of the CRPD and especially of the Committee. As we have seen, the latter states that substituted decision-making is never admissible. The CoE Disability Strategy instead seems to allow this possibility, though in very limited cases. However, in substance, the two approaches appear similar. As we have seen, the UN Committee includes some forms of substitution in its definition of supported decision-making, although it does not admit this explicitly. In this regard, the Coe Disability strategy states in reality the same idea, but expressed in more exact terms. On one hand, it admits that sometimes substitution is inevitable, reassuring professionals, carers, and activists working with people living with serious conditions such as late stage dementia. On the other hand, it clarifies how substituted decision-making should be used only when ‘absolutely necessary’. Indeed, it seems to go as far as to maintain that exceptions can be made not even for categories of people but just for single cases, suggesting a particularly

Recommendation used to be considered quite advanced, however it does not reflect many of the ideas that have emerged in recent years. M Keys, ‘Legal Capacity Law Reform in Europe: An Urgent Challenge’, (2009) 1 *European Yearbook of Disability Law* 68.

small proportion of situations in which it is acceptable to deviate from the principle of supported decision-making.

Recommendation Rec(2014)2 on the rights of older people also contributes towards spreading an approach to legal capacity based on supported decision-making. Rec(2014)2 II.13 states that older people have the right to receive appropriate support in exercising their legal capacity and that an eventually appointed representative 'should support the older person on his or her request and in conformity with his or her will and preferences'. Rec(2014)2 goes on to give useful indications with regard to specific provisions which should concretely characterise a system based on support by referring to specific national examples. For example, it praises the Czech reform of legal capacity legislation, which has abolished full incapacitation and has introduced a series of trusteeship measures that accompany the person in the decision rather than substituting them. The recommendation also endorses the Dementia Strategy adopted by Denmark in 2010 which issues specific recommendations to strengthen support services for people living with this condition.

In summary, Committee of Ministers and Parliamentary Assembly recommendations provide some useful indications on how a human rights and support-based model such as that proposed by the CRPD may translate in terms of specific rules. It also details valuable provisions related to treatment decisions of people living with dementia by reaffirming legal capacity as a fundamental right, emphasising that the person needs to be constantly involved in the decisional process of their care, and clarifying that a capacity regulation truly based on support must abolish full incapacitation, guarantee that the person is assisted in the way they desire, ensure that capacity measures apply for the shortest time possible, and establish that inspection mechanisms. However, the fact that outdated sources such as recommendation R(99)4 have not yet been declared abrogated can still create confusion about the exact CoE position in this area. Moreover, the documents cited above fail to clarify a series of elements such as what specific safeguards and monitoring mechanisms should be preferred to monitor the quality of support. They also do not provide a complete repertoire of support means that State parties would have to provide. This is certainly due to the fact that CoE policies need to be general enough to be applicable in the different situations of the various Member States. However, another explanation can

be found in the fact that, as noted by Mirfin-Veicht,⁶⁹ practice has not yet produced a vast set of examples of supported decision-making tools, so it is still early to draw general indications in this regard.

Promotion initiatives

Paragraph 64 of the European Disability Strategy affirms that, in order to promote the principles affirmed in its policy plans, the CoE undertakes actions aiming at urging and supporting Member States to improve their legislation, policies and practices on legal capacity, organise training events and awareness raising initiatives, and disseminate promising practices. These types of actions have always characterized CoE policy activities in this area, even before the Disability Strategy.

With regard to the first aspect, Parliamentary Assembly resolutions in particular show the commitment of the CoE towards maintaining the attention of its Member States on such themes. Indeed, Resolutions 1642 (2009) and 2039 (2015) urge Member States to ratify and implement the CRPD and invite them to include disability issues in their political agenda.⁷⁰ In relation to training and awareness raising, the CoE regularly organises and funds events throughout Europe open to policy-makers, professionals and lay people. Examples include the training courses for carers and social workers organised in the Vologda Region, Russian Federation, the International Symposium on “Human Rights and Disability” organised in Vienna in 2014,⁷¹ or the International seminar on prejudice against disabled people, organised in Copenhagen in 2017.⁷² Such events are valuable occasions to disseminate the messages contained in the various CoE documents on disability, to discuss related issues, and to exchange thoughts and experiences of good practices established in various countries of Europe. This last function is also covered by the research activity of the Committee of Experts on the Rights of People with Disabilities, which regularly publishes reports on specific topics. In 2017 it published a study conducted in cooperation with the National

⁶⁹ B Mirfin-Veicht, *Exploring Article 12 of the United Nations Convention on the Rights of Persons with Disabilities: An Integrative Literature Review* (Donald Beasley Institute 2016), VIII.

⁷⁰ See Section 3.

⁷¹ On these initiatives see European Committee for Social Cohesion, Human Dignity and Equality, *above*.

⁷² For information on this event see <<https://www.coe.int/en/web/chairmanship/-/international-seminar-in-copenhagen-denmark-on-changing-attitudes-and-prejudice-about-persons-with-disabilities>> accessed 8 August 2018.

University of Ireland (Galway) specifically focusing on legal capacity.⁷³ This document contains a review of the most innovative reforms and practices in this area, constituting an important instrument of information for governments, care structures, charities, and individuals.

Thanks to these initiatives, the CoE has managed to produce some tangible change in practices and legislations on legal capacity in Europe. This was publicized in the evaluation report of the Disability Action Plan 2006-2015, released by the DECS-RPD⁷⁴ and seeing the collaboration of various NGOs which presented their evaluation papers, such as the European Disability Forum (EDF)⁷⁵ and the European Association of Service Providers for Persons with Disabilities (EASPD).⁷⁶ The Evaluation Report emphasises how, after the release of the Disability Action Plan, many CoE Member States have started processes of reform concerning their legal capacity and antidiscrimination legislations, removing the legal barriers existing in this area. Such reforms have taken place in Iceland, Norway and Ireland.⁷⁷ Moreover, as also noted by the EASPD, the Action Plan promoted principles affirmed in the International context to a growing number of political actors, officers, professionals, and common people.⁷⁸ In this context, some countries such as Austria have started programmes to train various members of the justice profession on the ways to address cases involving disabled people.⁷⁹ Related to medical treatment, the Evaluation Report emphasises how the principles of person-centred care are now central in the organisation of health services even in the case of disabled people in the majority of Member States.⁸⁰

Despite these significant results, there are still numerous challenges. Indeed, there are still national regulations which appear to discriminate against mentally disabled

⁷³ Council of Europe, *A study on the Equal Recognition before the law. Contribution towards the Council of Europe Strategy on the Rights of Persons with Disabilities* (2017).

⁷⁴ CoE, *Abridged Evaluation Report. Implementation of the Council of Europe to promote the rights and full participation of people with disabilities in society: including the quality of life of people with disabilities in Europe 2006-2015* (CoE, 2015), 73-75 in <http://www.coe.int/t/dg3/Disability/Source/2015_Disability_conference/Abridged_Evaluation_Report_en.pdf> accessed 1st March 2016.

⁷⁵ EDF, *Report on the Implementation of the Disability Action Plan 2006-2015* (CoE, 2015), in <<https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016802ff569>>, accessed 20 April 2016; EDF, *Analysis Paper Developing a Disability Action Plan 2016-2020* (CoE, 2015) in <https://www.google.it/?gws_rd=ssl#q=EDF+report+disability+action+plan> accessed 20th April 2016.

⁷⁶ EASPD, *Enjoyment of Rights: towards the new CoE Disability Action Plan* (CoE, 2015) in <http://www.easpd.eu/sites/default/files/sites/default/files/Publications/easpd_report_on_coe_dap_docx.pdf> accessed 1 March 2016.

⁷⁷ CoE, *Abridged Report*, above, 54-55.

⁷⁸ EASPD, above, 4-5.

⁷⁹ CoE, *Abridged Report*, above, 54.

⁸⁰ *Ibid*, 43.

individuals.⁸¹ Moreover, as noted by Ferrante, a lot of work is still needed in order to ensure that professionals and carers really adopt an approach based on supported decision-making.⁸² In this regard, the potential of the Committee of Ministers and of the Parliamentary Assembly to exert political pressure on Member States is still partially unexploited, as there are currently no initiatives of naming and shaming against governments which have not engaged in reform processes with regard to legal capacity policies. Also, although the CoE organises many awareness raising and training events, it seems utopian to expect that it would have the necessary resources to carry on such initiatives for every *equipe*, hospital, or local community existing in Europe. On a similar note, CoE institutions have the capacity only to ‘make known’ promising practices, but not to actively invest money in their realisation, leaving unaddressed one of the most influential factors in stopping processes of change in the reality of politics and care services: lack of funding. Finally, as we have seen before, recommendations and resolution are not well equipped to specify the exact content of the CRPD model of legal capacity and to impose their respect in single concrete cases as they are non-binding documents that must be applicable to all Member States.

4. Applying the CRPD through the ECtHR

ECtHR judgments: general characteristics

A more effective contribution in this sense may be given by the ECtHR through its case law. As we have seen, it has the power to issue binding judicial decisions concerning human rights complaints brought forward by individuals, groups of individuals, or NGOs against a member-state. Therefore, its judgments have an immediate impact on the situation of people and, because they are issued in relation to concrete cases, provide a specific indication of what human rights principles mean in practice. In addition, ECtHR judgments can influence the way in which national judges interpret human rights by suggesting new ways to look at a certain legal issue through

⁸¹ *Ibid*, 56.

⁸² A Ferrante, ‘The Council of Europe Disability Action Plan: results, lessons learnt and challenges ahead’ presentation at the Conference ‘Promoting Human Rights of Persons with Disabilities: Ambitions, Impact and Challenges Ahead’, Dublin 5-6 November 2015, transcript in CoE, *Council of Europe Conference in cooperation with the Department of Justice and Equality Ireland. 5 November 2015* (CoE, 2015), 17-18 in <http://www.coe.int/t/dg3/Disability/Source/2015_Disability_conference/presentations/Transcript_Day_1_DublinConference_5-11-2015.pdf> accessed 21st April 2016. See also CoE, *Abridged Report, above*, 56. See also EDF, *Analysis Paper, above*, 37. See also CoE, *Abridged Report, above*, 45.

the so-called ‘dialogue between Courts’.⁸³ As shown by Janis, Kay and Bradley, the Court has a high level of legitimacy and prestige, so the vast majority of its judgments are enforced and respected.⁸⁴

The Court has the power to order States to remove the regulations which, in a specific situation, do not align with the European human rights standard, and it may require the government to pay damages to the victim of the violation.⁸⁵ As affirmed by Harris et al, the Court judges with respect to three categories of obligations.⁸⁶ The first category is that of negative obligations, which require Member States to abstain from human rights violations. The second is that of positive obligations, which require Member States to take action in passing reforms or creating the legal, political, or social conditions for the exercise of a certain right. The third category of obligations pertains to ‘horizontal effect’ (also called *Drittwirkung*) and holds states responsible for not preventing or reacting to violations by private individuals.⁸⁷ This concept may be of great importance in relation to dementia. Indeed, in this case violations often arise because citizens misuse the spaces left open by the law.

Therefore, the ECtHR offers protection on a large spectrum of violations, also when not directly caused by governments, as it can respond to harmful behaviours in the field of treatment decisions such as the violation of a person’s autonomy through the neglect of his or her will, discriminatory legislation or inadequate policies of hospitals and care structures.⁸⁸ Moreover, ECHR principles, which form the legal basis of ECtHR decisions, are formulated in quite broad terms. Therefore, as noted by Schabas, it is possible to read them in a way that accounts for the evolution of society.⁸⁹ For this reason the Court can interpret them in light of new sources such as the CRPD,

⁸³ See VVAA, *Implementation of the judgments of the European Court of Human Rights: a shared judicial responsibility?* (CoE, 2014). See also A Drzemczewski, *The European Human Rights Convention in Domestic Law* (Clarendon Press 1983); M Hunt, *Using Human Rights Law in English Courts* (Hart 1997).

⁸⁴ Janis, Kay and Bradley, *above*, 107-109.

⁸⁵ On the nature of the resolutions contained in ECtHR judgement and their efficacy see H Waldock, ‘The Effectiveness of the System Set up by the European Convention on Human Rights’ (1980) 1 *Human Rights Journal*, 1; Greer, *above*, 155-165; Janis, Kay and Bradley, *above*, 103-116; D Anagnostou and A Mungiu-Pippidi, ‘Domestic Implementation of Human Rights Judgments in Europe: Legal Infrastructure and Government Effectiveness matter’, (2014) 25 *The European Journal of International Law*, 205.

⁸⁶ Harris et al (eds), *above*, 18-21.

⁸⁷ On the concept of *Drittwirkung* see K Lewan, ‘The Significance of Constitutional Rights in Private Law: Theory and Practice in West Germany’ (1968) 17 *International and Comparative Law Quarterly*, 571. For an overview on the *Drittwirkung* in European human rights law see van Dijk et al (eds), *above*, 28-32.

⁸⁸ See Section 3.

⁸⁹ Schabas, *above*, 47-49.

making them a gateway through which the Convention enters the CoE Human Rights enforcement system.⁹⁰

ECtHR judgements and legal capacity

Relevant judgements for the field of treatment decisions of people living with dementia have been issued by the Court in relation to Articles 3 ECHR (prohibition of torture), 5 (right to liberty and security), 6 (right to a fair trial), 8 (right to respect for private and family life), 14 (prohibition of discrimination), and 18 (limitation on use of restrictions on rights). Such cases do not necessarily involve people living with dementia or focus on healthcare decisions, but they affirm principles and rules relating to the right to legal capacity and the rejection of incapacitation, the provision of support in decision-making, and safeguards which can be applied in this area.

On the first aspect, the case law of the ECtHR may offer some guidance on the concrete provisions and legal capacity measures in contrast to the CoE human rights standard by indicating which specific oppressive national rules should be repealed. However, until now even the Court has appeared to follow the partially outdated model indicated in recommendation R99(4). Indeed, its decisions tend to focus on limiting the duration and scope of incapacitating measures rather than clearly advocating for their rejection. Nonetheless, they still provide some valuable statements on norms and practices that can be acceptable or unacceptable also in relation to the case of treatment decisions of people living with dementia.

As noted by the European Commissioner on Human Rights, the ECtHR has established the principle that even the existence of a serious impairment is not in itself a valid reason to deprive a person of his or her legal capacity.⁹¹ In the case *Shtukaturov v Russia*, a Russian citizen had been incapacitated following his mother's request without being previously consulted by the judge. Therefore, the applicant alleged a violation of Article 8 ECtHR, maintaining, among other allegations, that his incapacitation was unjustified.⁹² In response to this claim, the Court first affirmed that the existence of a mental disability, even a serious one, does not justify a deprivation

⁹⁰ See also L Clements and J Read, *Disabled people and European human rights: A review of the implications of the 1998 Human Rights Act for disabled children and adults in the UK* (Policy Press 2003), 17.

⁹¹ Commissioner for Human Rights, *Who Gets to Decide? The Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities* (CoE 2013), 15-16.

⁹² ECtHR, *Shtukaturov v Russia*, No. 44009/05, 27 March 2008, para. 73.

of legal capacity. Secondly, it stated that legal capacity measures should be tailored to the conditions of the individual. In this regard, the ECtHR, assessing the Russian legal capacity regulation, noted that a system based on the binary distinction between full capacity and total incapacity is not compliant with the principle of proportionality.⁹³

Another principle affirmed by the ECtHR is that an individual may be incapacitated only if there is clear evidence that such a measure is needed.⁹⁴ In this context, the ECtHR, in the case *X and Y v Croatia*, affirmed that the judgment concerning the need of incapacitating the person has to be done on the basis of the assessment made by a medical expert.⁹⁵ In the already cited case *Shtukaturv v Russia*, the Court affirmed that a declaration of legal incapacity issued solely on the basis of documental evidence was in breach of Article 6(1) on the right to a fair trial.⁹⁶ Nonetheless, the judgment is not an act of the medical expert but is the responsibility of the judge, who has to confirm that the assessment of the medical expert is not arbitrary.⁹⁷

The case law of the European Court of Human Rights also establishes principles in terms of legal capacity safeguards. In the case *JT v UK*, the Court affirmed that, under Article 8 ECHR, a mentally disabled person has the right to choose their guardian or trustee. The situation at the basis of the decision was that of an individual who wanted to exclude her mother from her legal representation.⁹⁸ The Court has also emphasised in the already analysed *X and Y v. Croatia* that the person – such as an individual with dementia - even when placed under guardianship, must be fully informed on the judicial actions and affairs carried out in their name.⁹⁹ Finally, in the case *Stanev v Bulgaria*, the ECtHR affirmed the right of the person to directly access the Court in order to obtain the restoration of legal capacity.¹⁰⁰ The case *DD v Lithuania* focused, among other issues, on the change of guardian required by the fact that the person and the legal representative had shown huge disagreements and had a

⁹³ *Ibid.*

⁹⁴ ECtHR, *HF v Slovakia*, No. 54797/00, 8 November 2005.

⁹⁵ ECtHR, *X and Y v. Croatia*, No. 5193/09, 3 November 2011, para. 87.

⁹⁶ ECtHR, *Shtukaturv v Russia*, *above*. See also ECtHR, *Salontaji-Drobnjak v. Serbia*, No. 36500/05, 13 October 2009, para. 127.

⁹⁷ *Ibid.*

⁹⁸ ECtHR, *JT v UK*, No. 26494/95 30 March 2000 para 133.

⁹⁹ See ECtHR, *X and Y v. Croatia*, *above*.

¹⁰⁰ ECtHR, *Stanev v. Bulgaria*, No. 36760/06, 17 January 2012, para. 244. See also, ECtHR, *Matter v. Slovakia*, No. 31534/96, 5 July 1999, para. 68; ECtHR *Salontaji-Drobnjak v. Serbia*, *above*; ECtHR, *Kędzior v Poland*, No. 45026/07, 16 October 2012, para. 89.

conflictual relationship.¹⁰¹ In this situation, the Court affirmed that ‘the fact that an individual has to be placed under guardianship [...] does not mean that he is incapable of expressing a view on his situation’, which needs to be respected.¹⁰²

Such judicial statements are certainly important also in the field of treatment decisions of people living with dementia. Indeed, for the first time at a European level, they challenge the binary ‘all or nothing’ approach to legal capacity, which we have seen appears practically and legally problematic in the case of people living with this condition. Moreover, they provide clear statements affirming the illegality of those prejudices still frequent in medical and legal professionals, which lead them to automatically assume that the person living with dementia is incapable. However, they still leave open the possibility of a person being deprived of their legal capacity on the basis of a functional assessment, and are therefore not completely in line with Article 12 CRPD. Full alignment would require a much stronger statement in favour of the right to legal capacity of every person and on supported decision-making as the only remedy, except for very extreme circumstances, in case of difficulties in making decisions.

Despite this, some judgments of the ECtHR are doing a good job in promoting a more support-based approach to legal capacity. Already in the case *DD v Lithuania*, the Court seemed to promote a regulatory model based on the reconstruction and implementation of the person’s will. In addition, it refers to the concept of support in other two cases, the case *Kruskovic v Croatia* and the case *Vaudelle v France*. In the first case, a man who was divested from his legal capacity had a daughter, went to the Birth Register Office, and registered himself as the father of the baby.¹⁰³ However, the County Office of State Administration ordered the annulment of the declaration two years later, saying that it had to be deemed invalid as the applicant was legally incapable. The ECtHR qualified this as a violation of Article 8 ECHR.¹⁰⁴ The Court blamed the behaviour of the Birth Register Office and the County Office of State Administration, as they annul the person’s declaration and failed to support the individual, for example by suggesting he call his already-appointed guardian.¹⁰⁵ In the case *Vaudelle v France*, an incapacitated person was criminally convicted and tried in

¹⁰¹ ECtHR, *DD v Lithuania*, No. 13469/06, 14 February 2012, para. 84.

¹⁰² *Ibid.*

¹⁰³ ECtHR, *Kruskovic v Croatia*, No. 46185/08, 21 June 2011, para. 42.

¹⁰⁴ *Ibid.*

¹⁰⁵ *Ibid.*

absentia, without him being notified and adequately informed of the procedure.¹⁰⁶ Indeed, the criminal court considered his participation in the trial to be useless, as he would not been able to follow the proceedings.¹⁰⁷ The ECtHR dismissed this argument, maintaining that if adequately supported and assisted by a psychiatrist or by his lawyer, the applicant could have attended the hearings.¹⁰⁸

In light of such judgments, Bartlett, Lewis and Thorold note that Article 8 ECHR, as interpreted by the ECtHR, could now be regarded as establishing a positive obligation on Member States, a duty to actively engage in promoting the conditions for the exercise of legal capacity and the presence of mechanisms of support in order to assist the person to in overcome the difficulties he or she may experience when choosing for themselves.¹⁰⁹ As admitted by the three authors, to date there is no specific judgment of the ECtHR specifically affirming this position, which seems to run sub-trace to some judgments. However, developing this interpretative line can be a possible way to promote a model based on supported decision-making at the CoE level.¹¹⁰

In general, the cases considered thus far by the ECtHR show how the Court can be a good channel to promote the concrete realisation of the principles of the support and human rights approach to legal capacity proposed by the CRPD. Indeed, its case law shows that when disabled people challenge national legal capacity legislations and practices in front of its judges, they often succeed in their claims. Unfortunately, because of the costs and logistic complexities characterising such a procedure, the number of claims in relation to the right to make decisions of disabled individuals are still limited, so the Court has not had the opportunity to express itself on a range of important issues in this area. Moreover, many decisions of the Court are still partly trapped in a vision of legal capacity which pre-dates the CRPD and therefore now appears outdated. This is also due to the fact that a lot of claims so far have asked the ECtHR just to limit the scope of substitute decision-making practices rather than pose the problem of the rejection of the very same idea of incapacity and substituted decision-making. Therefore, also in relation to capacity to consent to treatment of individuals living with dementia, it could be a good strategy for the future for

¹⁰⁶ ECtHR, *Vaudelle v France*, No 35683/97, 30 January 2001.

¹⁰⁷ *Ibid.*

¹⁰⁸ *Ibid.*

¹⁰⁹ Bartlett, Lewis and Thorold, *above*, 153

¹¹⁰ *Ibid.*

individuals or NGOs to incentivise European litigation in this area and push the ECtHR to consider a more radical interpretive position and embrace more decisively the principles of Article 12 CRPD by giving to it the opportunity to issue more extensive guidelines on the rules and support for various situations in which people living with this condition find themselves.

Through this channel it would be possible to achieve substantial progress with regard to the extensiveness and efficacy of the ECtHR action in promoting the right to legal capacity of individuals like people living with dementia. However, this positive evolution in the Court's approach may be impeded by the fact that general norms of International law and International human rights law do not formally establish a hierarchical superiority of the principles established at the International level, such as those of the CRPD, over norms developed at a regional level such as those of the ECHR.¹¹¹ As emerging from Article 32 ECHR, the European Convention on Human Rights is the only binding authority on the Court.¹¹² Therefore, there is no formalised legal metatheory which permits to ground the claim that the ECtHR is obliged to step out of the traditional pathway it has followed so far in deciding cases in matters of disability, to take a fuller account of the CRPD. In this regard, one could even object that it is the CRPD which needs to be interpreted in light of the ECHR, rather than the norms of the latter that have to be applied in a way that is compatible with the UN Convention.

However, a possible counter argument to this objection is that the European Court of Human Rights has recognised in its case law that 'the [European] Convention should so far as possible be interpreted in harmony with other rules of international law of which it forms part' and that it needs to be interpreted in light of the rules of the

¹¹¹ As noted by J Vidmar, 'Norm Conflict and Hierarchy in International Law: towards a Vertical International Legal System' in E De Wet and J Vidmar (eds), *Hierarchy in Interantional Law: The Place of Human Rights* (Oxford University Press 2012), International law has mainly developed as a system of horizontal rules in which it is questionable whether it is possible to establish an hierarchy of sources at a not purely theoretical level. M Koskenniemi, 'Fragmentation of International Law: Difficulties arising from the Diversification and Expansion of International Law'(A/CN.4/L.682 13 April 2006), 10-15 <http://legal.un.org/ilc/documentation/english/a_cn4_l682.pdf> accessed 7 June 2019, refers to the concept of fragmentation of International law to indicate a system, characterising especially International legal order of the last decades, in which international treaties are developing in historically, geographically or functionally limited systems which are separate and autonomous from each other and which have their own principles and ethos. This fragmentation creates the risk of conflicting and incompatible rule-systems and institutional practices.

¹¹² On the sources used by the ECtHR for the solution of cases brought in front of them see K Dzehtsiarou, 'What is Law for the European Court of Human Rights' (2018) 49 *Georgetown Journal of International Law* 89.

Vienna Convention on the Law of the Treaties which obliges the Court to take into account in the hermeneutic process of any treaty provision the other International rules relevant for the parties.¹¹³ This could be assumed as a legal-interpretive basis to ground a duty of the ECtHR to interpret the ECHR in light of the CRPD in relation to cases regarding citizens of the European continent, as all countries of Europe have now ratified the UN Convention. In this regard, as noted by Ulfstein, the ECtHR has already referred to International principles as tools for the so called ‘evolutive’ interpretation of ECHR provisions,¹¹⁴ through which the European Convention is interpreted in light of the evolution of society, the European common legal sensibility and the wider legal context.¹¹⁵ In this sense, it has been shown in Section 3 of this Chapter that the Member States of the CoE have approved, through the CoE Committee of Ministers, recommendations (e.g. the Disability Action Plan 2006-2015 or the CoE Disability Strategy 2017-2023) which are recognised value of interpretive documents in front of the ECtHR.¹¹⁶ These documents can be used to claim that the common European legal tradition and sensibility in the context of human rights of disabled people has shifted in the direction of the CRPD and that the ECtHR has to take this into account when interpreting the norms of the European Convention.

Of course, even if such arguments would be accepted by the Court, embracing more fully the vision proposed by the CRPD would still require a significant change in the approach and sensibility which has so far characterised the action of the ECtHR.¹¹⁷ In this regard, there might be many cases in which the Court, also in light of previous case law, would find insurmountable tensions between the principles of

¹¹³ ECtHR, *Al-Asdani v United Kingdom*, No 35763/97, 21 Nov 2001, para. 55. On this point see also L Wildhaber, ‘The European Convention on Human Rights and International Law’ (2007) *The International and Comparative Law Quarterly* 217, 219-221.

¹¹⁴ G Ulfstein, ‘Interpretation of the ECHR in the Light of other International Instruments’ (Pluri Courts Research Paper No. 15-05 2015). Relevant cases in this field are ECtHR, *Demir and Baykara v Turkey*, No. 34503/97, 12 Nov 2008, para. 67; ECtHR, *Hassan v the United Kingdom*, No 29750/09, 16 Sept 2014.

¹¹⁵ On the notion of evolutive interpretation see J Gerards, ‘The European Court of Human Rights and the National Courts: giving shape to the notion of ‘Shared Responsibility’ in J Gerards and J Fleuren (eds), *Implementation of the European Convention on Human Rights and of the Judgements of the ECtHR in national Case Law. A comparative analysis* (Intersentia 2014), 36.

¹¹⁶ On the interpretive value of recommendations see above Section 3.

¹¹⁷ In this regard it has to be remembered that the idea of human rights underpinning the ECHR is mainly that of principles that limit the action of States and protect citizens from abuses by political power (on this point see E Bates, *The Evolution of the European Convention on Human Rights: from its Inception to the Creation of a European Court of Human Rights* (Oxford University Press 2010), 33-389). On the other hand, the CRPD, though it also aims to protect the civil rights of disabled people, concentrates mostly on providing a basis for a more active involvement of governments in providing services to disabled individuals and promote their social rights.

the CRPD and the ECHR, considering ‘not possible’ to interpret the latter in light of the former. For this reason it would probably take a long time for the European Court of Human Rights to enact a visible change of approach in the direction of the UN Convention, and also in this case such a shift will probably never lead to a complete resonance of ECtHR case law with the vision of the CRPD. However, any step towards a better promotion of principles such as those affirmed in Article 12 CRPD will still represent an improvement compared to the current situation.

5. Monitoring and creating the conditions for the right to decide

The ESC and RevESC system

Besides promoting CRPD principles among Member States and work for their enforcement in specific cases, CoE institutions have also the potential of contributing to create the conditions for a support based approach to treatment decisions. In this regard a particularly important role can be played by the system of the European Social Charter and Revised European Social Charter, and by the Committee for Social Rights.¹¹⁸ Indeed, such a complex of norms and monitoring tools, focuses on issues and principles relating to the basic social and economic need of people, including the right to adequate healthcare services.

The European Social Charter (ESC) was adopted on the 18th October 1961 and entered into force on the 26th February 1965. It was created in order to integrate the protection of human rights provided by the ECHR with further provisions focusing on social rights.¹¹⁹ As reported by Harris, in the 1990s the CoE developed an amended version of the European Social Charter (RevESC),¹²⁰ opened to signatures on the 3rd of May 1996 and entered into force on the 1st of July 1999.¹²¹ However there are still

¹¹⁸ For a brief explanation on the powers of the Committee see above Section 2.

¹¹⁹ On the Charter in general see AH Robertson and JG Merrills, *Human Rights in Europe. A study of the European Convention on Human Rights* (3rd ed Manchester University Press 1993), 349-352; C Benelhocine, *The European Social Charter* (CoE 2012). See also D Harris, *The European Social Charter* (University Press of Virginia, 1984); D Harris and J Darcy, *The European Social Charter* (2nd ed, Transnational Publishers, 2001); G De Burca and B De Witte (eds), *above*.

¹²⁰ D Harris, ‘A fresh Impetus for the European Social Charter’ (1992) 41 *International and Comparative Law Quarterly* 659.

¹²¹ See < <http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/163>> accessed 3 March 2016.

member-states that have not ratified it.¹²² Therefore, the first version of the Charter applies to them.

The two versions of the ESC contain a series of principles imposing that medical services are organised in a way that respects the autonomy and rights of all their users. In this regard, they echo both the spirit of the CRPD and of those theories such as the social model of disability, which advocate for a less medicalised approach to chronic conditions. Such provisions can be cited in judgements by national courts and also by the ECtHR as an interpretive parameter of ECHR norms, serving at the basis for claiming the entitlement to a more respectful care also in the case of people living with dementia. On their basis the Committee for Social Rights can also undertake monitoring actions through non-binding reports on collective complaints, state reports or interpretive declarations.¹²³

With regard to the first kind of documents the Committee, in the context of disability, has issued, for the moment, only few decisions in relation to cases regarding the right to education of mentally disabled children, so the potential of such tools in the field of legal capacity and healthcare is still unexploited.¹²⁴ However, important principles regarding medical treatment of mentally disabled people and older individuals are contained in some state reports and interpretive declarations.¹²⁵ In relation to them, De Schutter and Sant'Ana note how, though not binding, they can be very promising tools in order to promote the dialogue between CoE and national governments, in search of solutions which permit to enhance the level of protection of social rights.¹²⁶ Indeed, such documents are the product of an intense activity characterised by the exchange of information and opinions between ECSR and single member-states. Therefore, also in the field of treatment decisions of individuals living with dementia they may be precious in creating a shared European repertoire of good practices and in helping to develop holistic solutions that fit into the context of a specific Member State.¹²⁷

¹²² < <http://www.coe.int/en/web/turin-european-social-charter/signatures-ratifications> > accessed 29 January 2016.

¹²³ On the functioning of the Committee see *above* Section 2.

¹²⁴ ECSR, *Mental Disability Advocacy Center (MDAC) v. Bulgaria*, complaint No. 41/2007; ECSR, *European Action of the Disabled (AEH) v. France*, Complaint No. 81/2012. For the text of complaints, declarations and report of the ECSR see <<http://www.coe.int/en/web/turin-european-social-charter/case-law>> accessed 4 March 2016.

¹²⁵ See section 3.4.2.

¹²⁶ De Schutter and Sant'Ana, *above*, 87-88.

¹²⁷ *Ibid.*

Healthcare services and healthcare decisions

Relevant provisions to the right to make treatment decisions of people living with dementia are contained in Article 11 ESC and RevESC (the right to protection of health), Article 13 ESC and RevESC (the right to social and medical assistance), Article 14 ESC and RevESC (the right to benefit from social welfare services) and Article 23 RevESC (the right of elderly persons to social protection). Here, the Charter focus on social rights leads to put attention on the services and contextual conditions which are essential in order to truly guarantee the right to autonomy and freedom of choice of individuals. In this regard, the ECSR gives indications on the kind of social support needed in order to permit an adequate exercise of autonomy and advocates for a broader approach to healthcare, which takes into account not only the aim of curing the disease, but also the general wellbeing of the person.

Article 11 in both versions of the ESC, binds Member States to take measures not only to cure illnesses, but also to put in place structures which are responsible for providing advice on healthcare issues. In this regard, Article 13, which also has the same formulation in the older and the revised version of the Charter, focuses on the conditions necessary for such a holistic approach to be realised. In this context, it obliges Member States to guarantee to everyone a good standard of care (Article 13(1)) and to assure that they receive advice and support necessary in order to prevent, remove or alleviate personal and family want. This kind of provisions, that put emphasis on the necessity of support in case of illness, have a strong relevance to the area of treatment decision-making of people living with dementia. Indeed, as we have seen, the reason why carers and medical professionals fail to listen to the person and to support them in deciding on their care is often due to the fact they are overburdened, or they do not have enough time, or they lack adequate facilities and tools.¹²⁸

In addition, Article 13(2) ESC and RevESC states that people receiving social and medical assistance ‘shall not, for that reason, suffer from a diminution of their political or social rights’. In relation to this provision, the Committee of Social Rights has noted how it implies that discriminations against individuals receiving assistance must be eradicated and that existing provisions on equality and non-discrimination should be interpreted so to avoid that material living conditions, social status or any other

¹²⁸ See Chapter 2.

circumstances may become a reason for restriction with regard to human rights.¹²⁹ Unfortunately, despite this statement, the Committee has judged as compliant with Article 13(2) ESC and RevESC a number of Member States which retain quite old-fashioned legislations on legal capacity and that result in limiting the right to autonomy of people typically interested by healthcare procedures such as older people and individuals living with cognitive impairments.¹³⁰ However, the formulation of the Article seems to leave room for an interpretive stream which derives from such a provision the implicit obligation of not depriving even a person with a serious mental impairment of their capacity to express their wishes on care. In effect, Article 13(2) ESC and RevESC, could be used by associations, through the system of collective complaints, in order to push the Committee to establish the principle according to which the necessity of a certain medical treatment is not a sufficient reason to impose it, even to a mentally disabled person such as an individual living with dementia.

In this regard are also relevant the provisions contained in Article 14, remained unchanged in the revised version of the ESC, which recognise the right of every person to benefit from social welfare services. The right to welfare services is crucial when dealing with rights of people such as those living with dementia even in relation to questions strictly regarding medical treatment. Indeed, in this area health and social care are so intertwined to be often very difficult to be distinguished.¹³¹ Moreover, in relation to this Article, the European Committee of Social Rights has affirmed that effective and equal access to social and welfare services implies that ‘any decision should be made in consultation with and not against the will of the client’, ‘remedies shall be available in terms of complaints’ and ‘a right to appeal to an independent body in urgent cases of discrimination and violation against human dignity’ must be granted.¹³² Therefore, even under the ERC, the will of the person is regarded as central and should be respected as much as possible.

Starting from Article 23 RevESC, the Committee has developed useful principles in relation to legal capacity of older people, which apply also to the many older individuals living with dementia. Indeed, Article 23(1) obliges State Parties to adopt

¹²⁹ See, for example, ECSR, *Conclusions I*, Statement of Interpretation on Article 13§2; ECSR, *Conclusions XIII-4*, Statement of Interpretation on Article 13§2; ECSR, *Conclusions XVIII-1*, Malta, Article 13-2; Conclusions 2013, Portugal, Article 13-2.

¹³⁰ See, as examples, ECSR, *Conclusions 2013, Austria*, Article 13-2; ECSR, *Conclusions 2013, Hungary*, Article 13-2; ECSR, *Conclusions 2013, Italy*, Article 13-2.

¹³¹ See chapter 1.

¹³² ECSR, *Digest, above*, 108.

appropriate measures to enable older people to remain full members of society. Starting from this provision the Committee clarifies that it implies that such individuals shall suffer no ostracism or deprivation of their legal capacity on the basis of their age.¹³³ In Conclusions 2003 on France, the ECSR admits that older people may have problems in exercising their legal capacity. These difficulties, however, should be overcome, according to the Committee, by providing ‘procedures for assisted decision-making’.¹³⁴ The ECSR Digest also clarifies that such provisions should be read in connection with those contained in Articles 11, 12 and 13 ESC and RevESC, issuing, in this way, one of the clearest declarations in favour of a model of legal capacity based on supported decision-making contained in a CoE document.¹³⁵

In this context, the Committee, in Conclusions 2013 on The Netherlands, reports an example of good practice in the field of healthcare in relation to the case of people living with dementia.¹³⁶ Indeed, it commends a series of projects, carried on by the Dutch government, such as the National Programme on care for the elderly, the Dementia Delta Plan, the Ambient Assisted Living Joint Programme, and the ‘Visible link’ programme.¹³⁷ In this context the Committee notes that, also thanks to such projects, care services in Holland appear to be ‘integrated into mainstream care wherever possible’.¹³⁸ Moreover, it stresses that, from the report presented by the national government, emerges that ‘a programme aimed at providing integrated multi-agency, demand-driven care for dementia patients began in March 2008’.¹³⁹

To sum up, the principles affirmed in Articles 11, 13, 14 and 23 RevESC, have a notable potential in creating the conditions for a model of legal capacity and treatment decisions based on supported decision-making also in the field of healthcare. However, the reports and declarations of the Committee of Social Rights on this matter are still rather limited in number. As already said, this body has not yet had the opportunity to deal with collective complaints in the area of treatment choices of people living with dementia. Moreover, apart from some exceptions, in many state reports and interpretive declarations the Committee fails to take a specific position with regard to how healthcare services should be organised in order to really allow also people living

¹³³ ECSR, *Digest, above*, 147.

¹³⁴ ECSR, *Conclusions 2003, France*, 186.

¹³⁵ ECSR, *Digest, above*, 147.

¹³⁶ ECSR, *Conclusions 2013, The Netherlands*, Article 23.

¹³⁷ *Ibid.*

¹³⁸ *Ibid.*

¹³⁹ *Ibid.*

with cognitive impairments to express their will on care. Nonetheless, the way in which relevant ESC and RevESC are formulated and the powers of the Committee leave definitely open the possibility for such kinds of statements to be issued in the future.

Human Rights Commissioner and CPT reports

A contribution towards creating the conditions for a full exercise of the right to decide in the case of treatment decisions of disabled people like individuals living with dementia can come from the reports of the European Commissioner of Human Rights and the Committee for the Prevention of Torture (CPT) issued on the basis of their country visits.¹⁴⁰ Such documents have generally the function of providing a systematic analysis of the most crucial human rights issues, in relation to a specific country or a specific topic, and to provide an organic set of indications on how to improve the level of protection of human rights in a certain area.¹⁴¹ In general, as already seen, the reports of both the Commissioner and the CPT play an important role in the development of dialogue with Member States on human rights issues.¹⁴² Also, because they originate from first hand inspections, they can be quite effective in shading light on what is exactly problematic in the policies, legislations and practices of a country also with regard to legal capacity.

In his report entitled ‘Who gets to Decide’ the European Commissioner for Human Rights offers a systematic analysis of the situation of European national legislations and transnational regulations with regard to the right to legal capacity of people with psychosocial disabilities.¹⁴³ The report, prepared with the help of experts in the field, affirms how too many national legislations still admit forms of substituted decision-making or plenary guardianship, provoking the automatic loss of rights by the person (sections 2.1 and 2.2). In addition, it stigmatises the frequent lack of support based alternatives to traditional guardianship (section 2.3). Therefore, in the part dedicated to recommendations to Member States the Committee openly advocates for abandoning the traditional liberal concept of personhood in favour of a more relational vision. Moreover, it requires the implementation of new regulations based on

¹⁴⁰ On the powers and functioning of these two bodies see above Section 2.

¹⁴¹ In relation to the Commissioner see Sivonen, *above*, 19-28. See also Weber, *above*. In relation to the CPT see Kicker, *above*, 48-63.

¹⁴² See sections 2.5 and 2.6.

¹⁴³ CoE Commissioner for Human Rights, *Who Gets to Decide*, *above*.

supported decision making (section 5.1). In this context, the Commissioner recognises the difficulty of putting in place legal measures truly based on support, avoiding hidden forms of old-style guardianship. In order to facilitate the identification of the appropriate forms of support he indicates two examples of good practices. The first is that of the personal ombudsmen, taken from Swedish law. The Ombudsmen is a body dedicated to the protection of the rights of vulnerable individuals, which intervenes without need of formalities, at the simple request of the person. The second example is that of networks of support, taken from Canadian law, which permits to a person to nominate in advance a group of people with the duty to assist them in case they develop a physical or mental impairment. Such principles are reaffirmed by the Commissioner on Human Rights also in the state report on Norway.¹⁴⁴ Here, the Commissioner, while commending the government for having ratified the CRPD, stigmatises the fact that the national legal capacity regulation is still too much based on substituted decision-making.

An important principle, with regard to legal capacity and medical treatment has been affirmed also in the Annual report 2010 of the European Committee for the Prevention of Torture.¹⁴⁵ In this context the Committee states that

‘Patients should, as a matter of principle, be placed in a position to give their free and informed consent to treatment. The admission of a person to a psychiatric establishment on an involuntary basis should not be construed as authorising treatment without his consent’.¹⁴⁶

Therefore if the person has not been put in the position of giving his or her free and informed consent and is not adequately assisted in the decision-making process, the treatment has to be considered as torture.

¹⁴⁴ CoE Commissioner for Human Rights, *Commissioner's report following his visit to Norway*, , published on 23 January 2014, 13, in < <https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2751937&SecMode=1&DocId=2272542&Usage=2>> accessed 3 March 2016.

¹⁴⁵ CTP, Annual Report 2010, in < <http://www.cpt.coe.int/en/annual/rep-21.pdf>> accessed 3 March 2016.

¹⁴⁶ *Ibid*, paragraph 41.

6. The Oviedo Convention and the Draft Protocol on Involuntary Treatment

The Oviedo Convention

The European Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, also known as the Oviedo Convention, is the first international binding instrument specifically dealing with issues of bioethics and bio-law.¹⁴⁷ It is the result of the drafting work carried on by the Steering Committee on Bioethics (CAHBI), now Committee of Bioethics (DH-BIO), established in 1992 by the Committee of Ministers.¹⁴⁸ The text of the Convention was finally adopted by the Committee of Ministers on the 19th November 1996 and opened for signatures in Oviedo, Spain, on the 4th April 1997. So far it has been signed by 35 states and ratified by 29.¹⁴⁹ As noted by Adorno the Convention is a binding instrument aiming at establishing general principles which have to be specified by additional protocols.¹⁵⁰

The implementation of the Oviedo Convention is essentially left to States Parties. Indeed, this treaty does not establish a proper monitoring body.¹⁵¹ Moreover, Article

¹⁴⁷ On the Convention see, in general, MAM de Wachter, 'The European Convention on Bioethics' (1997) 27 *Hastings Center Report* 13; HR Abbing, 'The Convention on Human Rights and Biomedicine. An Appraisal of the Council of Europe Convention' (1998) 5 *European Journal of Health Law*, 377; BR Kern, 'Die Bioethik-Konvention des Europarates: Bioethik versus Arztrecht?' (1998) 11 *Medizinrecht* 485; HL Schreiber, 'The European Bioethics Convention : Legal Aspects' in A. Schauer, H.-L. Schreiber, Z. Ryn, J Andres (ed), *Ethics in Medicine*, (Vandenhoeck and Ruprecht 2001), 242; R Adorno, 'The Oviedo Convention: A European Legal Framework at the intersection of Human Rights and Health Law' (2005) *Journal of International Biotechnology Law* 133; E Doppelfeld, 'Council of Europe in the field of Bioethics: the Convention on Human Rights and Biomedicine and other legal instruments' (2008) 34 *Intensive Care Medicine* 939.

¹⁴⁸ The process started with the Resolution No. 3, addressed to the Committee of Ministers by the 17th Conference of European Ministers of Justice, which took place in Istanbul, on the 5th-7th June 1990. The invitation contained in the Resolution was adopted by the Parliamentary Assembly with the Recommendation 1160(1991) and finally put in practice with the creation of the Steering Committee by the Committee of Ministers in 1992. On this aspect see Council of Europe, 'Explanatory Report to the Convention on Human Rights and Biomedicine' in <<https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016800ccde5>> accessed 23 February 2016.

¹⁴⁹ For information on signatures and ratifications see <http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164/signatures?p_auth=ioBwhIyI> accessed 23 February 2016.

¹⁵⁰ Adorno, *above*, 134-135. V Bellver Capella, 'Pasos hacia una bioética universal: el Convenio Europeo sobre Derechos Humanos y Biomedicina' in CM Romeo Casabona (ed), *El Convenio de Derechos Humanos y Biomedicina. Su entrada en vigor en el ordenamiento jurídico español* (Comares, 2002) 55 notes that the Convention tries to establish the level of protection that European governments agree to be essential, but that each state party has the right to approve stricter regulations.

¹⁵¹ As emerging from DH-BIO, *above*, 3-8, the DH-BIO cannot assess the compliance of member-states and cannot receive complaints by governments or individuals.

29 Oviedo Convention, only permits to Member States and the DH-BIO to request advisory opinions to the ECHR.¹⁵² However, infringements of the Oviedo Convention may be brought in front of the European Court of Human Rights if they imply also a violation of the ECHR.¹⁵³ This situation may occur quite frequently, as already from the Preamble it emerges how the Oviedo Convention is essentially seen as specifying the rights affirmed in the European Convention of Human Rights. In addition, Article 23 Oviedo Convention affirms the duty of State Parties to provide adequate judicial protection in relation to the provisions of the Convention.¹⁵⁴ Therefore, national judges are called to base their judgements on the Convention norms, interpreting existing national regulations in the light of such principles. Indeed, as affirmed by Adorno, some provisions such as those concerning the right to information on medical treatment may be considered enough detailed to be self-executing and to be the basis for claims in terms of civil or administrative liability, without requiring further actions by the government or parliament.¹⁵⁵

The Oviedo Convention and Consent to Treatment

As affirmed by de Wachter, the provisions on consent to treatment are considered one of the major achievements of the Oviedo Convention.¹⁵⁶ Such regulation includes important principles on treatment decisions of mentally disabled people, which still are at the centre of a wide debate and may be relevant also in the case of people with dementia.¹⁵⁷

Article 5(1) Oviedo Convention states that ‘an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it’ while Article 5(2) clarifies that the person themselves ‘shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks’. In addition, Article 5(3) affirms that ‘the person concerned may freely withdraw consent at any time’.

Article 6 Oviedo Convention, entitled ‘protection of persons not able to consent’ deals specifically with the problem of treatment decisions of mentally disabled people

¹⁵² Council of Europe, ‘Explanatory Report’, *above*, paragraph 165.

¹⁵³ See Adorno, *above*, 136.

¹⁵⁴ See Adorno, *above*, 136.

¹⁵⁵ Adorno, *above*, 135-136. See also C de Sola, ‘El Convenio de Bioética entra en vigor en España’ *Diario Médico*, 3 October 2000.

¹⁵⁶ De Wachter, *above*, 13.

¹⁵⁷ See onwards.

in general. In this context, Article 6(1) states that ‘an intervention may only be carried out on a person who does not have the capacity to consent, for his or her direct benefit’. Article 6(3) affirms that ‘where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorisation of their representative or an authority or a person or body provided for by law’ and that in such circumstances ‘the individual concerned shall as far as possible take part in the authorisation procedure’. Article 7 specifies that a mentally disabled person may be administered an intervention aimed at curing their mental impairment without consent provided safeguards are in place such as supervisory, control and appeal procedures, and without such treatment, serious harm is likely to result to the person.

In general, the regulation of the Oviedo Convention, on the one hand, may appear problematic as it admits that a representative may decide for the person and that, in some circumstances, an intervention may be carried on without the explicit consent of the individual interested. However, on the other hand, it affirms that even a person unable to consent has to be involved as much as possible in the decision concerning his or her medical treatment. Therefore, as also noted by Paskalev and Vidalis, the formulation in broad terms of the norms of the Oviedo Convention leaves room for interpretations which can be in line with the more recent principles of the CRPD.¹⁵⁸ It is all down to how State Parties and CoE institutions will intend to specify such principles in additional protocols.

The Draft Additional Protocol

Unfortunately, the most recent initiatives in this area seem not to go in the right direction, as shown by the draft of additional protocol entitled ‘Working document concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment’ (Draft Additional Protocol) recently released by the Committee on Bioethics.¹⁵⁹ Such working document has been at the centre of a wide debate especially among activists.

¹⁵⁸ A Paskalev and T Vidalis, ‘Vague Oviedo: Autonomy, Culture and the case of previously Competent Patients’ (2001) 24 *Bioethics* 145.

¹⁵⁹ The document is available at <[http://www.coe.int/t/dg3/healthbioethic/Activities/08_Psychiatry_and_human_rights_en/INF\(2015\)7%20Protocole%20psy%20E.pdf](http://www.coe.int/t/dg3/healthbioethic/Activities/08_Psychiatry_and_human_rights_en/INF(2015)7%20Protocole%20psy%20E.pdf)> accessed 23 February 2016.

The Draft Additional Protocol is made up of twenty articles, divided in six chapters. The first chapter clarifies the object and scope of the document and Chapter II, entitled ‘general provisions’ reaffirms the principle of legality of the measures related to involuntary treatment and involuntary placement (Article 3), the principles of necessity and proportionality (Article 4), the rights of the individual to choose a person of trust and to be assisted by a lawyer (Articles 6 and 7), and the right to receive adequate care and being treated in an appropriate environment (Articles 8 and 9).

Chapter III deals specifically with the ‘criteria for involuntary placement and involuntary treatment’. In this regard, Article 11 states that involuntary treatment may be used only if the person’s mental condition represents ‘a significant risk of serious harm to his or her health and his or her ability to decide on treatment is severely impaired’. The measure must be avoided if other alternatives and less intrusive options are available (Article 11(1)-ii). The procedure for involuntary treatment is regulated in Chapter IV. This Chapter affirms that the necessity of involuntary treatment and involuntary placement shall be justified in the light of a medical report (Article 12(1)) and shall be established through a judicial decision based on medical evidence and taking into account the opinion of the person concerned (Article 12(2)). The decision should state the maximum period beyond which the measure shall be reviewed. Article 15 establishes that such measures should be terminated when, according to the doctor in charge of the person care, the criteria set in Article 11 are no longer met. Article 16 provides that people subject to involuntary placement and/or treatment may request a review of their measures by applying to a court (Article 16(1)).

Finally, Chapter V, affirms the right of the person under involuntary treatment to be informed about their rights and to communicate with their lawyer, representative and person of trust (Articles 17 and 18). Chapter VI obliges State Parties to keep records for all people under involuntary placement or involuntary treatment (Article 19), and to ensure that compliance with the provisions of the Additional Protocol are subject to independent monitoring (Article 20).

In the end of 2015, the DH-BIO launched a public consultation on the Draft Additional Protocol inviting comments from individuals, NGOs and institutions from all the fields concerned, which closed on the 15th of November of the same year.¹⁶⁰ In

¹⁶⁰ See < http://www.coe.int/en/web/bioethics/-/public-consultation-on-a-working-document?redirect=http://www.coe.int/en/web/bioethics/psychiatry?p_p_id=101_INSTANCE_mUC

occasion of the public consultation and also after it closed activists, but also CoE bodies expressed concerns on the document. In this regard the CoE Commissioner for Human Rights affirms in his report that ‘he cannot subscribe too many of the basic assumptions underpinning the draft Additional Protocol and has serious misgivings about the compatibility of the draft’s approach with the UN Convention on the Rights of Persons with Disabilities’.¹⁶¹ The first point of concern, is already that the draft seems to consider human rights violations in the context of involuntary placement and involuntary treatment as mainly due to gaps in national legislations and provisions regarding safeguards.¹⁶² However, the Commissioner, in light of the experience acquired during his visits to many Member States, notes how even when such safeguards exist they often prove ineffective in practice.¹⁶³ Indeed, in many contexts the rights of the person are ‘routinely violated while respecting the letter of existing legal safeguards, including some that are very similar to those proposed in the draft Additional Protocol’.¹⁶⁴

In addition, both the Commissioner and the NGOs which sent observations on the Working Document point out that it appears strongly influenced by a medicalised vision of disability which makes it in contrast with the CRPD. In this regard, the entry by the European Network of National Human Rights Institutions (ENNHRI) notes how the Draft Additional Protocol ‘only addresses how a person’s “mental disorder” affects their abilities and does not recognise the importance of attitudes and culture relating to the use of forced treatments’.¹⁶⁵ Instead, as noted by Mental Health Europe (MHE), adopting the model proposed by the CRPD would lead to question the same legitimacy of such measures.¹⁶⁶ On the contrary, the Draft Additional Protocol seems to admit that, in case of mental impairment, involuntary treatment is justifiable.

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¹⁶¹ CoE Commissioner for Human Rights, ‘Comments of the Council of Europe Commissioner for Human Rights on the “Working document concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment’, 1, in <<https://wcd.coe.int/ViewDoc.jsp?id=2394367&Site=CM>> 29th of January 2016.

¹⁶² *Ibid*, 1-2.

¹⁶³ *Ibid*, 2.

¹⁶⁴ *Ibid*, 2.

¹⁶⁵ ENNHRI, ‘Comments of the CRPD Working Group of the European Network of NHRIs (ENNHRI) on the Draft Additional Protocol to the Oviedo Convention’, 1, in <http://menneskeret.dk/files/media/dokumenter/handicapkonventionen/comments_on_draft_additional_protocol_to_the_oviedo_convention_final_20_06_14_logo.pdf> accessed 28 February 2016.

¹⁶⁶ MHE, ‘Position paper: Mental Health Europe response to the public consultation on the working document of the draft Additional Protocol to the Oviedo Convention’, 3-4, in <http://www.mhe-sme.org/fileadmin/Position_papers/MHE_response_to_the_public_consultation_on_the_working_do

With regard to more specific norms, MHE, observes, in relation to Article 12(1) Draft Additional Protocol, that by requiring that the assessment of the person is made only by one doctor, this Article does not guarantee that the involuntary treatment is managed in an impartial way by the people around the interested individual.¹⁶⁷ Moreover, the Commissioner for Human Rights affirms, with regard to Article 12(2) Draft Additional Protocol, that it does not guarantee an adequate involvement of the person in the treatment decision.¹⁶⁸ In fact this Article provides that the opinions of the person shall only be ‘taken into account’. This provision seems to allow the representative of the person to make independent decisions and leaves the door open to forms of substituted decision-making. Moreover, the Commissioner notes how the procedure for reviewing a measure of involuntary treatment, regulated in Article 16, requiring the intervention of a judge, seems too complex and may result in an obstacle for the exercise the right of appeal by a mentally disabled person.¹⁶⁹ Finally, the report by EU PERSON project notes how the Draft Additional Protocol puts insufficient attention on alternatives to involuntary treatment based on supported decision-making. Indeed, it observes, Article 5 Working Document refers to alternatives only in abstract terms. On the contrary it should clarify what forms of support may be used in this context, insisting on the necessity of employing existing networks of support and providing some examples of good practices.¹⁷⁰

7. Conclusion

In conclusion, CoE institutions have at their disposal a series of powers and mechanisms which can allow them to play an important role in the promotion of CRPD principles and of an approach to legal capacity based on supported decision-making also in relation to treatment decisions of people living with dementia. In particular, they can contribute to promote the principles of the Convention among Member States, professionals and common citizens through recommendations, awareness raising and dissemination of good practices, they can clarify and enforce such provisions through

cument_of_the_draft_Additional_Protocol_to_the_Oviedo_Convention.pdf> accessed 28 February 2016.

¹⁶⁷ *Ibid.*, 6.

¹⁶⁸ CoE Commissioner for Human Rights, ‘Comments’, *above*, 5.

¹⁶⁹ *Ibid.*

¹⁷⁰ EU Person Project, *above*, 10-11.

ECtHR case law and they can work in partnership with national governments to put in place the conditions for such principles to be really respected and extensively applied in practice.

However, the potential of such mechanism is still quite unexploited. Indeed, they are still rarely used to advance new rules or practices with specific regard to healthcare choices of people with dementia. For this reason, it is necessary that activists and scholars put pressure on CoE bodies to really take action in this field and that they continue to highlight how CoE powers can be important factors in promoting change. In addition, some documents emanated by the Council of Europe, such as the Draft Additional Protocol on involuntary placement and treatment and certain decisions of the ECtHR, still refer to quite an old fashioned approach to legal capacity, sending a confusing message as to what the real position of the CoE on such matter is. Therefore, there is also the need of a more serious internal debate, which really clarifies the policy aspects which the organisation as a whole should push forward and that guarantees that it comes across with a more consistent message.

CHAPTER 6

The EU and Treatment Decisions of People living with Dementia

1. Introduction

The European Union (EU) is an economic and political organisation established in 1957 and grouping 28 European countries.¹ Its main goal consists in promoting peace, prosperity, pluralism, equality and justice through the cooperation and integration of its Member States and citizens.² In this regard, EU institutions are also recognised relevant competencies in the fields of health, disability and equal opportunities, in relation to which they have quite significant legislative and monitoring powers.³ Moreover, having at its disposal a budget of about 145 billion euros per year,⁴ the EU has the capacity to financially support policies and processes of change, through a variety of funding schemes.⁵ For these reasons, it can play a valuable role also in the area of treatment decisions of people living with dementia, contributing to improve the current system and to promote the principles of the CRPD.

This chapter studies how EU powers and policy initiatives can be used to promote the legal capacity and the right to choose of people living with dementia in relation to healthcare decision-making. In this way, it contributes to answer the thesis research

¹ I take this definition from the presentation page on the EU's official website EU, 'The EU in brief' <https://europa.eu/european-union/about-eu/eu-in-brief_en> accessed 9 March 2017. Precisely, EU Member States are Austria, Belgium, Bulgaria, Croatia, Republic of Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, The Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden and the UK (see <https://europa.eu/european-union/about-eu/countries/member-countries_en> accessed 9 March 2017). Following the results of the referendum which took place on 23 June 2016 the UK is starting the process for leaving the Union (see <www.gov.uk/government/topical-events/eu-referendum/about> accessed 9 March 2017).

² Articles 2 and 3 Treaty on the European Union. For general information on the origins, evolution, scope, structure and field of action of the EU see the organisation website <https://europa.eu/european-union/index_en> accessed 9 March 2017.

³ For an overview on the powers of European Institutions see D Edward and R Lane, *Edward and Lane on European Union Law* (Edward Elgar 2013), 105-111, 128-135 and 177-278. On the role of EU institutions in monitoring the implementation of the UN Convention on the Rights of Persons with Disabilities and in promoting the right to decide of people living with dementia see further Sections 2 and 3.

⁴ For general information on the EU budget and how it is used see <https://europa.eu/european-union/topics/budget_en> accessed 9 March 2017.

⁵ For a general overview of EU funding schemes and projects see <https://europa.eu/european-union/about-eu/funding-grants_en> accessed 9 March 2017.

question by looking at how also the Union can play a meaningful role in clarifying the Convention principles, promote their application among governments and European citizens and favour the development and circulation of promising practices in the field of supported decision-making, complementing in this way the action of the Council of Europe. Indeed, in recent years, the EU has shown a significant commitment in this sense, being the first regional organisation to ratify the Convention.⁶ Moreover, it has emanated important policy documents such as the European Disability Strategy 2010-2020⁷ and the ‘European Initiative on Alzheimer’s Disease and other Dementias’.⁸ Also in this case, the analysis starts from these and other existing EU materials and initiatives developed in the area of mental disability, dementia policy, aging and health, to then try to understand what more can be done for the future. Similarly to Chapter 5 my research mainly relies on doctrinal analysis, employing the canonical rules of legal interpretation to shed light on the normative content and implications of the various legal and policy documents. Content analysis is used in the cases in which a source limits to describe a certain initiative, rather than dictate rules or guidelines, so that the document acts as a ‘testimony’ of what happens in practice.

The Chapter is structured as follows. Section 2 provides a brief overview of relevant EU competences and powers in the area of disability and dementia rights, aging and health. In this context, emphasis is put on the limitations and potential of each institution action for producing concrete change. Section 3 analyses the relevant general policies for the promotion of autonomy of people living with dementia developed at an EU level. In this regard, it concentrates on situating the issues at the centre of this work in the complex fabrics of EU strategies regarding disability, aging and health. Section 4 focuses on how the EU is acting to further implement the principles of the CRPD and on how it is engaging with the Committee on the Rights of Persons with Disabilities. In this context, it analyses in particular what mechanisms are or can be put in place to guarantee a constant dialogue between EU institutions and

⁶ Council Decision 2010/48/EC of 26 November 2009, concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities [2010] OJ L 23/35.

⁷ Commission, ‘European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe’ (COM(2010) 636 final 15 November 2010) <<http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52010DC0636&from=en>> accessed 1 April 2017.

⁸ Commission, ‘European Initiative on Alzheimer’s Disease and other Dementias’ (COM (2009) 380 final, 22 July 2009) <<http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52009DC0380&from=EN>> accessed 1 April 2017. For a complete overview of the initiatives undertaken by the EU in the field of dementia see further Section 3.

Member States and the Committee. It also studies what actions the Union has or should undertake in order to comply with the requests of the Committee itself. Section five, concentrates on the role played by the EU in promoting the development and dissemination of promising practices in the field of supported decision-making, with a particular focus on the healthcare sector. In this regard, it puts particular emphasis on how innovation programmes funded by the Union can contribute to the development of quality dementia training for professionals and more effective support techniques for the person living with this condition. The Conclusion emphasises how the action of EU institutions has significant potential to produce change in the field of treatment decisions of people living with dementia, though such potential is still vastly unexploited.

2. The EU: Powers and Potential

EU competences, legal capacity and treatment decisions

The functioning and institutional architecture of the EU is regulated by the Treaty on European Union (TEU)⁹ and the Treaty on the Functioning of the European Union (TFEU).¹⁰ Article 5(2) TEU affirms that ‘the Union shall act only within the limits of the competences conferred upon it by the Member States in the Treaties to attain the objectives set out therein’ (principle of conferral). Competences not conferred to the Union remain with the Member States. In relation to the CRPD this means that the EU can promote the implementation of the Convention only in the areas in which it has the competence to do so and within the powers given to it by its fundamental treaties. Such a limitation is recognised by Article 44 CRPD, which obliges regional organisations parties of the Convention declare in their instruments of formal confirmation or accession the extent of their competences in this regard. In compliance with such a provision, the EU Council has emanated the Decision 2010/48/EC of 26 November 2009 authorising the formal confirmation (equivalent to ratification) of the CRPD, deposited on 23 December 2010, and containing, in Annex II, the Declaration of Competence.¹¹ The declaration restates what already affirmed in Articles 3 (exclusive competences of the Union) and 4 TFEU (shared competences), as well as

⁹ Consolidated version of the Treaty on European Union [2012] OJ C 326/13.

¹⁰ Consolidated versions of the Treaty on the Functioning of the European Union [2012] OJ C 326/47.

¹¹ Council Decision 2010/48/EC, *above*, Annex II.

in other Articles of the Treaties such as Article 19 TFEU, regulating the EU action in the area of anti-discrimination. Therefore, paragraph 1 of the Declaration clarifies that the EU has exclusive competence in the regulation and management of its own administration, and in the areas of state aids, commercial policy, competition within the internal market and the customs union.¹²

Paragraph 2 of the Declaration of Competence states that the Union shares competence with Member States in relation to combating discrimination on the ground of disability (but also age, gender, sexual orientation, race, origin and religion), free movement of goods, persons, services and capitals, agriculture, transports, internal market, equal pay for men and women, trans-European network policy and statistics. In areas of shared competence both the EU and Member States may adopt legally binding acts.¹³ Article 2(2) TFEU states that, in this context States can exercise their normative power ‘to the extent the Union has not exercised its competence’. So national governments should act only after EU institutions have failed to do so. In reality, as pointed out by Schütze, praxis shows that the latter have often legislated at the same time of communitarian bodies.¹⁴

As noted by Craig, in order to understand the real scope of EU action in matters of shared competence we have to look at the rules regulating each specific area.¹⁵ For example, in the context of anti-discrimination, Article 19 TFEU seems to confer to the Union the power to combat all the main factors at the basis of inequality in a potentially indefinite range of situations. However, the procedure prescribed in order to adopt legislative measures in this context, giving prominence to the role of national representatives, has proven to be a significant limitation to the EU potential in promoting equality.¹⁶ Moreover, the EU Court of Justice case law has clarified that the provisions of Article 19 provide a legal basis only for anti-discrimination actions, not extending to initiatives promoting equality of opportunities.¹⁷ With regard to the EU

¹² The areas of exclusive competence of the Union include the monetary policy of countries of the ‘Euro zone’ and the conservation of marine biological resources and fisheries, that however are not relevant to the questions interested by the CRPD.

¹³ P Craig, ‘EU Competences’ in D Patterson and A Södersten (eds), *A Companion to European Union Law and International Law* (Wiley 2016), 84.

¹⁴ R Schütze, *European Union Law* (Cambridge University Press 2015), 239.

¹⁵ Craig, *above*, 85.

¹⁶ On this topic see further in this Section.

¹⁷ E Ellis and P Watson, *EU Anti-Discrimination Law* (2nd ed Oxford University Press 2012), 16. Such an interpretation has been affirmed by the EU Court of Justice, among others, in the cases C-13/05 *Chacón Navas v Eurest Colectividades SA* [2006] ECR I-6467; C-411/05 *Palacios de la Villa v Cortefiel Servicios SA* [2007] ECR I-8531.

competence in social policy, referred to in Article 4(2) letter b, Title X TFEU confines the action of Union Institutions to the field of employment and workers' rights, giving them in most cases just the power to complement the measures undertaken by national governments, rather than passing legislative acts.¹⁸ With specific regard to the CRPD, the EU Competence Declaration also specifies that the Union has competence in the implementation of the Convention principles when they affect previous European rules.¹⁹

In addition to such provisions, Articles 5 and 6 TFEU confer to the EU the competence of carrying out supporting, coordinating or supplementary actions in a range of other areas. As noted by Schütze, the precise content of such competences is difficult to identify.²⁰ However, a point on which scholars agree, is that in this context measures cannot be put in place with the specific scope of directly modifying and harmonising Member States legislations.²¹ As explained by Craig, in this context the EU is called to put forward various actions in order to support the realisation of the objectives set by the Treaties in relation to each substantive area. For example, initiatives may take the form of funding of best practices, periodic monitoring or evaluation.²²

Also in this case, in order to understand the role played by EU Institutions in practice, it is necessary to look at provisions and praxes in single competence areas. The use of measures encouraging the exchange of information, the dissemination of best practices and the setting of minimum standards and technical rules is advocated by Article 153(2) TFEU for the field of social policy, referred to by Article 5(3) as an area of coordinating competence. In this regard, the Union promotes advancements in social protection and inclusion through the Open Method of Coordination (OMC), a soft law mechanism put in place at the Lisbon EU Summit in 2000 and subsequently developed throughout the various phases of European political evolution.²³ Such a

¹⁸ Anyway, this does not prevent especially the EU Commission from playing a potentially significant role in the field of social policy through policy documents and soft law, or the allocation of strategic funds.

¹⁹ Council Decision 2010/48/EC, *above*.

²⁰ Schütze, *above*, 242-243.

²¹ *Ibid*, 243.

²² Craig, *above*, 86.

²³ For an overview on the Open Method of Coordination see European Parliament, 'The Open Method of Coordination' (European Parliament Research Service 2014) <<http://www.europarl.europa.eu/EPRS/EPRS-AaG-542142-Open-Method-of-Coordination-FINAL.pdf>> accessed 26 March 2017. See also E Szyszczak, 'Experimental Governance: The Open Method of Coordination' (2006) 12(4) *European Law Journal* 487; M Daly, 'EU Social Policy after

mechanism is applied in different ways depending on the policy area, but it is always characterised by the fact that, as the use of legally binding instruments and sanctions is excluded, it is based essentially on voluntary collaboration and political pressure. In this context, the Council sets out policy goals, which have to be pursued by Member States and whose realisation is evaluated against agreed indicators and benchmarks. The results emerging from various States are then compared and assessed against each other through reports, normally issued by the Commission, encouraging all Member States to apply the best practices.²⁴ Through this mechanism the EU has put in place initiatives to improve European benefit systems and to promote extensive access to quality personal care.²⁵

The OMC is employed also in the context of human health, indicated as an area of supporting, coordinating and supplementary competence by Article 6, letter b) TFEU. In this sector it has led to the development of a range of initiatives in the field of aging and dementia such as the already mentioned Joint Action for Mental Health in Europe²⁶ or the European Initiative on Alzheimer's Disease and other Dementias.²⁷ However, in this area, following a number of cases of the EU Court of Justice affirming the necessity of uniform standards and rights for European citizens moving abroad for medical treatment, the Union passed a legislative act entailing harmonisation of national laws such as Directive 2011/24/EU on the application of patients' rights in cross-border healthcare.²⁸ This act, though emanated primarily under Article 114 TFEU regarding the single market, which gives the legal basis legitimising it,²⁹ constitutes an important precedent of EU action based on binding instruments in the sector of healthcare.

Lisbon' (2006) 44 *Journal of Common Market Studies* 461; M Buchs, *New governance in European Social Policy: the open method of coordination* (Palgrave Macmillan 2007).

²⁴ Szyszczak, *above*, 486-488. European Parliament, 'The Open Method', *above*, 2.

²⁵ See for example Commission, 'Joint Report on Social Protection and Social Inclusion' (COM(2005)14 final 27 January 2015) < <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52005DC0014&from=EN>> accessed 26 March 2017. For a constantly updated list of EU initiatives in the sector of social policy see < http://eur-lex.europa.eu/summary/chapter/employment_and_social_policy/1709.html?root=1709> accessed 26 March 2017.

²⁶ <www.mentalhealthandwellbeing.eu/the-joint-action> accessed 9 March 2017.

²⁷ European Commission, 'European Initiative on Alzheimer's', *above*.

²⁸ European Parliament and Council Directive 2011/24/EU of 9 March 2011

on the application of patients' rights in cross-border healthcare [2011] OJ L 88/45. For an analysis on the EU competence in the sector of health see W Sauter, 'Harmonisation in Healthcare: The EU Patients' Rights Directive' [2011] *TILEC Discussion Paper* No. 2011-030 1, 2-11 < https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1859251> accessed 28 March 2017.

²⁹ Anyway, the Preamble of the Directive refers also to Article 168 TFEU, concerning the EU competence in the field of health.

Anyway, policy areas such as health also overlap with other fields, covered by shared competences such as that of anti-discrimination. Therefore, legally binding provisions concerning the quality of health and social care or the centrality of the person wishes with regard to treatment decisions of individuals such as people living with dementia, in this context may well be put in place through legislative measures under Article 19 TFEU.³⁰ However, even when the EU action remains on the level of policy and soft law it can contribute to the promotion of rights and principles such as that of the CRPD. In this regard, though scholars have emphasised the limitations deriving from the non-bindingness of actions ex Articles 5 and 6 TFEU, the level of strategic policy is the one through which organisations like the EU put in place organic and comprehensive long term programmes without which single legislative acts, normally much more limited in scope, would not come into being. The potential role of cooperation and EU policy-making in promoting the principles of the CRPD is stressed also by paragraph 3 of the EU Declaration of competence.³¹ However, the declaration limits to cite the Union's action in the field of employment, education, economy and social cohesion, failing to mention the work done in the field of health.

The list of competences reported above does not include legal capacity. Therefore, as stated by the initial report of the EU to the Committee on the Rights of Persons with Disabilities, the Union has no specific powers in this area.³² However, this does not mean that its institutions cannot play a role in the promotion of the legal capacity and the right to decide on medical treatment of individuals living with dementia.

The European Disability Forum, in its alternative report to the Committee on the rights of persons with Disabilities, argues that competences such as that in the areas of equality or health may justify actions of EU Institutions with regard to legal capacity and consent to treatment.³³ In relation to equality, the Mental Disability Advocacy

³⁰ An example of this is the Draft Antidiscrimination Directive Commission, 'Draft Antidiscrimination Directive' (COM(2008) 426 final 2 July 2008) <<https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52008PC0426:EN:HTML>> accessed 30 March 2017 which constitutes an attempt to issue binding antidiscrimination provisions in a variety of areas, which include also health and disability. However, the pathway towards the approval of the directives is at the moment at a stand-still point.

³¹ Council Decision 2010/48/EC, *above*, paragraph 3.

³² EU, 'Initial Report under Article 35 UNCRPD' (UN 2014), 40 <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/232/64/PDF/G1423264.pdf?OpenElement>> accessed 30 March 2017.

³³ European Disability Forum, 'Alternative Report to the UN Committee on the Rights of Persons with Disabilities' (EDF 2014), 27 <<https://www.dropbox.com/s/881g96uknfy8ps/2015%2003%2004%20EDF%20Alternative%20report%20final%20ACCESSIBLE.pdf?dl=0>> accessed 30th March 2017.

Centre (MDAC) notes that the EU Disability strategy affirms the commitment of the Union to combat discrimination based on disability.³⁴ In this context, the power of combating discrimination conferred to the Union by Article 19 TFEU can be seen as including the necessity to act in order to promote changes in current national legal capacity legislations which, in light of the CRPD, appear discriminatory against disabled individuals. In the field of health, the EU, has emphasised, in its initial report to the UN Committee on the Rights of Persons with Disabilities, that it has the competence to ‘carry out actions to support, coordinate and/or supplement the actions of Member States’.³⁵ In this regard, the MDAC notes how people with mental disabilities, being deprived of their legal capacity are deprived of the right, guaranteed to everyone else, to have access to healthcare tailored to their needs.³⁶ Therefore, in their work towards promoting the right to health the Union should consider issues of consent, including the right of disabled individuals such as people living with dementia to choose or reject medical interventions. In light of these considerations, the EU appears to have quite a wide array of powers to make an impact in promoting the right to decide on medical treatment of individuals living with dementia, though such powers are not yet used to the full because of restrictive interpretations with regard to the rules regulating the Union competences and because of the lack of a proactive political initiative of its Member States and Institutions with regard to disability rights and legal capacity.

3. EU Policies on Disability, Dementia, Health and Aging

Communications, Resolutions, Conclusions and healthcare choices of people living with dementia

Also due to the competences limitations seen above, the most used channel by the EU to promote principles such as those proposed by the CRPD and to concretely engage with the Convention and its Committee is that of strategic policy plans. Like the Council of Europe, also the European Union can contribute on the one hand to the promotion of the values and principles of the Convention among citizens and Member

³⁴ MDAC, ‘Legal Capacity in Europe. A Call to Action to Governments and to the EU’ (MDAC 2013), 36 <http://mdac.info/sites/mdac.info/files/legal_capacity_in_europe.pdf> accessed 30 March 2017.

³⁵ EU, ‘Initial Report’, *above*.

³⁶ MDAC, *above*, 38.

States, by reaffirming them in official policy documents and advising governments on how such provisions can be translated into specific rules and practices. In this regard, it can also put in place awareness raising actions, favour the creation of training programmes and contribute to the circulation of promising practices. The specific instruments employed in this case are mainly Commission Communications, European Parliament and Council Resolutions and Conclusions of the Council.

Communications are documents issued by the Commission and directed to the European Parliament and the Council.³⁷ They summarise the position of the Union's executive body on a certain issue and the actions it intends to undertake in that area.³⁸ In this regard they can contain both indications concerning actions that the Commission will undertake autonomously and proposals regarding measures to be adopted by the Council or the Parliament. These documents do not necessarily reflect the position of the plurality of Member States, as they are issued by a body which is not direct expression of national governments. However, they have a considerable authority and prestige as they come from the Institution which represents the will of the European Union in itself.³⁹

European Parliament and Council Resolutions summarise the position of each of the two bodies with regard to a certain issue, containing also proposals to other institutions.⁴⁰ Same nature have the Council conclusions, which formalise the agreement of the members of the Institution on a certain topic at the end of a session.⁴¹ Also these documents have a substantial authority as they report the position respectively of the organ expressing the voice of European citizens and of the one reuniting the representatives of all the Union's Member States.⁴²

³⁷ See < <https://ec.europa.eu/transparency/regdoc/?fuseaction=helpcote> > accessed 9 September 2018.

³⁸ *Ibid.*

³⁹ Council, 'Code of Conduct between the Council, the Member States and the Commission setting out internal arrangements for the implementation by and representation of the European Union relating to the United Nations Convention on the Rights of Persons with Disabilities', 2010/C 340/08, paragraph 6, confirms that the Commission is the organ that expresses the position of the Union also in matters concerning disability.

⁴⁰ N Moussis, *Access to European Union. Law, Economics, Policies* (22nd ed Intersentia 2016), 45; Council, 'Council Conclusions and Resolutions' < <https://www.consilium.europa.eu/en/council-eu/conclusions-resolutions/> > accessed 9 September 2018.

⁴¹ Moussis, *above*, 45; Council, 'Council Conclusions', *above*.

⁴² Indeed, the European Parliament is made up of members directly elected by European citizens, while the Council is composed by representative of each of the EU Member States. On the composition of these two institutions see Schütze, *above*, 151-184.

As it was happening with CoE Recommendations and Resolutions, also these policy documents have no binding force.⁴³ However, because of the authority of their issuing bodies, they can still exert a strong political influence on other institutions of the Union. In this regard, Communications, Resolutions and Conclusions are often at the start of policy processes that lead to concrete policy actions and may result even in new legislation. Moreover, they can also be used as interpretative documents in national and European litigation,⁴⁴ or be an instrument of political pressure towards Member States in the hands of NGOs but also and most importantly by European Institutions themselves. In this regard, a specific characteristic of these documents is that the provisions contained in them can be promoted through the Open Method of Coordination, which, as already seen, permits to set precise benchmarks against which the efforts of states may be measured, and implies regular and frequent monitoring, permitting to keep constantly high the attention on a certain issue. In addition, compared for example, to the CoE, the European Union has a comparatively greater availability of funds that can be used to sustain the proposed policy actions even with concrete financial investment in order to promote good practices and actively incentivise behaviours.⁴⁵

The EU has released a series of policy documents relevant to the area of consent to treatment of individuals living with dementia. Specifically focusing on disability and the promotion of the principles of the CRPD is the Commission Communication on the European Disability Strategy 2010-2020.⁴⁶ In addition, important documents have been released with regard to aging and even specifically in relation to dementia. They are the Communication (2009)⁴⁷ and the Resolution (2011)⁴⁸ on a European initiative on Alzheimer's disease and other dementias, and the Conclusions containing the Guiding Principles on Active Aging.⁴⁹

⁴³ Moussis, *above*, 45; Council, 'Council Conclusions', *above*.

⁴⁴ Moussis, *above*, 45-47.

⁴⁵ On this point see further Section 5.

⁴⁶ Commission, 'European Disability Strategy', *above*.

⁴⁷ Commission, 'European initiative on Alzheimer's Disease', *above*.

⁴⁸ European Parliament, 'European Parliament resolution of 19 January 2011 on a European initiative on Alzheimer's Disease and Other Dementias' (2010/2084(INI)) <<http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//NONSGML+TA+P7-TA-2011-0016+0+DOC+PDF+V0//EN>> accessed 1 April 2017.

⁴⁹ Council, 'Council Declaration on the European Year for Active Ageing and Solidarity between Generations (2012): The Way Forward' (16592/12 SOC 948 SAN 289, 7 December 2012). <<http://register.consilium.europa.eu/doc/srv?l=EN&f=ST%2017468%202012%20INIT>> accessed 1 April 2017.

Promoting the principles of the CRPD

The promotion of inclusion, autonomy and rights of individuals such as people living with dementia appears in many respects a central goal in the strategic policies brought forward by the European Commission. This emerges already in the context of Europe 2020, the overall European strategy for the decade in course focusing on fostering development and prosperity throughout the Continent.⁵⁰ It focuses on creating the conditions for a smart, sustainable and inclusive growth.⁵¹ In Communication COM(2010) 2020, which launched the strategy, this essentially translates into measures for sustainable economic growth and development.⁵² However, other initiatives have shown the Commission's willingness to interpret this general policy commitment in a wider way, which includes the promotion of disability and old age rights.

In this regard, the European Disability Strategy outlines a series of actions with the aim to 'empower people with disabilities so that they can enjoy their full rights, and benefit fully from participating in society'⁵³ and specifies that 'full economic and social participation of people with disabilities is essential if the EU's Europe 2020 strategy is to succeed in creating smart, sustainable and inclusive growth'.⁵⁴ In this context, the Disability Strategy contains at least one important statement relating to the right to legal capacity. Indeed, in section 3 (Equality), it states that the EU will promote through supporting and supplementing actions, 'the conformity of Member States legislation on legal capacity with the UN Convention'.⁵⁵ This line of the Strategy appears significant for a number of reasons. First of all, it makes clear that the policies of the Union and Member States on equality and legal capacity must comply with CRPD provisions such as Article 12. In this regard, it establishes another link directly connecting EU and CRPD level, incorporating the principles of the Convention and the interpretive statements released by its Committee as an evaluative

⁵⁰ For an overview on Europe 2020 see <http://ec.europa.eu/europe2020/europe-2020-in-a-nutshell/index_en.htm> accessed 1 April 2017.

⁵¹ Commission, 'Europe 2020. A European Strategy for Smart, Sustainable and Inclusive Growth' (COM(2010) 2020), 3
<<http://ec.europa.eu/eu2020/pdf/COMPLET%20EN%20BARROSO%20%20%200007%20-%20Europe%202020%20-%20EN%20version.pdf>> accessed 12 April 2014.

⁵² *Ibid.*

⁵³ Commission, 'European Disability Strategy', *above*, section 2.

⁵⁴ *Ibid.*, section 1.

⁵⁵ Commission, 'European Disability Strategy', *above*, 7.

framework of EU policies in this area. Moreover, it recognises that promoting legal capacity of disabled people is an essential step towards the wider goal of assuring equality for all European citizens, a task which, as already seen, is explicitly attributed to it by its Fundamental Treaties. In this sense, this statement may be used as a basis to advance the interpretive vision according to which the EU competence in the area of anti-discrimination could legitimise even some (limited) legislative and harmonising action directed towards reforming national legal capacity legislations facially discriminatory against disabled people. This position seems to be advocated also in the EDF shadow report which affirms that ‘equal recognition before the law falls directly within this competence as persons with disabilities are often denied or restricted their legal capacity on the basis of disability based discrimination’.⁵⁶ Therefore, such a provision opens up the possibility for a quite effective action of the Union also with regard to the promotion of the right to decide on medical treatment of people living with dementia.

However, at the moment, this aspect does not seem to have yet being given thorough attention by commentators and EU Institutions. In this respect, though valuable, the EU Disability Strategy fails to provide clear details on the implications of adopting a CRPD oriented approach to equality and legal capacity and on what national legislations must specifically provide for in order to comply with Article 12 CRPD. In effect, as of now the Union has not emanated any specific act, recommendation, communication or report urging Member States to align their legislations to Article 12 and indicating the concrete ways in which they should do this. In addition, also section 7, on health, rather focuses on access to healthcare and rehabilitation, not providing indications with regards to the rights of the person and consent to treatment.

Clearer indications on the rights to make decisions, even dictated with specific regard to the case of people living with dementia, come from documents in the area of policies on aging. These provisions are relevant to people living with this condition as dementia is a dynamic which stands at the intersection between disability and age. Here, already the EU Guiding Principles on Active Aging advocate for the necessity of keeping ‘older women and men involved in decision making, particularly in the areas that directly affect them’.⁵⁷ More specific affirmations on individuals living with

⁵⁶ EDF, *above*, 27.

⁵⁷ Council of the European Union, ‘Declaration Active Ageing’, *above*, 10.

cognitive impairments are contained in section 2.3 of the European Initiative on Alzheimer's Disease and Other Dementias (2009).⁵⁸ The Initiative recognises that 'the image of Alzheimer's disease and other dementias in European society is a negative one, often associated with fear and helplessness' and urges the creation of 'a European Network for rights and dignity of people with dementia, which should formulate recommendations on dignity, autonomy and social inclusion'.⁵⁹ The European Parliament Resolution of 2011 on Alzheimer's and other dementias emphasises how 'there is a stigma attached to Alzheimer's and the general attitude and approach to dementia is 'still the wrong one' as it is still characterised by a negative attitude towards people living with this condition. For this reason the Resolution 'emphasises that the dignity of people with Alzheimer's needs to be preserved and the stigma and discrimination against them needs to be eliminated'. Therefore, these two documents contain powerful statements against one of the dynamics which, as seen in Chapter 1, are among the greatest obstacles to the right to choose on medical treatment of people living with dementia: the stigma and prejudice which sees them as incapable individuals devoid of their self, instead of people with rights.

With specific regard to legal capacity, the Communication on the EU dementia initiative notes how at a certain stage of their condition, people living with dementia, because of their impairment, may be no longer able to manage completely alone and need help in deciding on matters such as medical treatment. In this regard, it emphasises that 'assistance could be provided by a guardian/lawful representative' but it is 'imperative' that the person is allowed 'to articulate his or her preferences'.⁶⁰ This statement is important in the context of treatment decisions of people living with dementia because it indicates support and 'assistance' as the way to overcome possible issues relating to their cognitive impairment. It still refers to guardianship as a possible means of support, but emphasises that the guardian's action must put at the centre the will of the person. In this regard, following a line adopted also in the context of the Council of Europe, though using a potentially controversial term, the EU Dementia Initiative indicates to national governments how they can use normative mechanisms already present in their legislation to implement supported decision-making.

⁵⁸ Commission, 'European Initiative on Alzheimer's Disease', *above*, 8-9.

⁵⁹ *Ibid.*

⁶⁰ *Ibid.*

The reported affirmations issued by the Commission and the European Parliament surely play a significant role in keeping up the attention of governments and citizens on the problems regarding decision-making of people living with dementia, advocating for an approach to legal capacity which is rights and support oriented. However, also in comparison with CoE strategic policies, the EU has not really embraced the task of clarifying how principles such as those affirmed by Article 12 CRPD may translate into specific rules. In this regard, it would be highly desirable if the Union would play in the future a more active role in this area. Indeed, because of the possibilities for continuing monitoring and benchmark setting offered by policy mechanisms such as the Open Method of Coordination, it might be particularly effective in pushing for specific changes in national legislation on legal capacity and decisions on medical treatment.

Awareness raising, research and training

An area in which the EU appears to be taking more decisive action is that regarding the promotion of awareness and knowledge on the CRPD and the issues relating to decision-making of individuals living with cognitive impairments, especially through research and training for professionals. The positive aspect of such initiatives is that many of them are conceived in relation to people living with dementia, providing tools precisely focusing on the problems emerging in this case. In this way, they contribute to remove the prejudice against individuals living with dementia which characterises the approach of many professionals and common members of society towards these people and that, as seen in Chapter 2, is one of the first barriers to their right to decide on medical treatment.

The European Parliament Resolution on Alzheimer's and other dementias encourages Member States to develop campaigns for the general public on the various aspects of living with this condition and to improve professionals' awareness, especially on three different components such as diagnosis, treatment and appropriate support.⁶¹ However, until now the Union, through the Commission, has mainly focused on professionals rather than the general public. Examples in this sense are a series of events organised with the support, also in terms of financial contribution, of the EU, such as the thematic conference 'Mental Health and Well-being in Older

⁶¹ European Parliament, 'Resolution of 19 January 2011', *above*.

People – Making it Happen’ (Madrid 28-29 June 2010), which contained some sessions and presentations on stigma and building resilience through services provided by society.⁶²

Promising initiatives have also been promoted by the EU through the involvement of NGOs in the field of dementia policy, and through the creation of networks of professionals in the field.⁶³ In this regard, the NGO Alzheimer Europe established the European Dementia Ethics Networks, funded through a grant of the German Ministry of Health and by the EU-Health Programme.⁶⁴ Such a Network is now an irreplaceable means for promoting the right to decide and supported decision-making in treatment decisions of people with dementia among European national governments and public opinion. Indeed, the association coordinating it groups together the largest national charities in the field of dementia care and policy, which are putting in place often quite extensive initiatives in order to fight stigma and spread a culture of respect and empowerment towards people living with dementia. Moreover, especially in recent years, Alzheimer Europe has embraced a serious commitment towards putting at the centre of its action people living with dementia and their opinions.⁶⁵ This is evident also from the conference of the association, held in Copenhagen between the 30 October and the 2 November 2016, whose programme was hosting many presentations delivered by people living with dementia and the first plenary session entitled ‘A Rights-based approach to Dementia’ was opened by the president Tina Leonard with a presentation entitled ‘Putting People with Dementia First’.⁶⁶ In recent years, the Ethics Network has issued a number of reports, shedding light on the reality faced by individuals living with dementia and their carers and pushing for the implementation of the principles affirmed in the EU Dementia Initiative also in relation to care decisions.⁶⁷ The materials issued in this context include the 2009 report on advance

⁶² For a summary and programme of the event see EU, ‘Mental Health and Well-Being in Older People – Making it Happen’ (2010) <https://ec.europa.eu/health/sites/health/files/mental_health/docs/ev_20100628_report_en.pdf> accessed 1 April 2017

⁶³ Commission, ‘Implementation report on the Commission Communication on a European initiative on Alzheimer’s disease and other dementias’ (SWD(2014) 321 final 16 October 2014), 13-15 <http://ec.europa.eu/health/sites/health/files/major_chronic_diseases/docs/2014_implreport_alzheimer_dementias_en.pdf> 1 April 2017.

⁶⁴ <<http://www.alzheimer-europe.org/Ethics>> accessed 14 April 2017.

⁶⁵ <<http://www.alzheimer-europe.org/>> accessed 14 April 2017.

⁶⁶ For information on the programme and papers delivered at the conference see <<http://www.alzheimer-europe.org/Conferences/Previous-conferences/2016-Copenhagen>> accessed 14 April 2017.

⁶⁷ See <<http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice>> accessed 14 April 2017.

directives and personhood in dementia⁶⁸ or the 2014 report on ethical dilemmas faced by carers and people living with dementia.⁶⁹

The EU initiative on Alzheimer's Disease and other Dementias has also resulted in the ALzheimer COoperative Valuation in Europe (ALCOVE) Joint Action, a programme funded through the EU Health Programme 2008-2013 in the context of the Union's supporting and coordinating competence in the field of health, to which nineteen Member States and some NGOs voluntarily took part with the aim of elaborating common principles and exchanging promising practices.⁷⁰ One of the seven 'Working Packages' (streams) of the programme focuses on 'Rights, Autonomy & Dignity of People living with Dementia' (WP7).⁷¹ In this context, at the conclusion of the programme, in 2013, a report has been released containing a number of principles and recommendations on autonomous decision making in dementia with a particular focus on care decisions.⁷² The praiseworthy aspect of this report is that it adopts as a starting point a rights approach to autonomy and legal capacity clarifying that 'the respect given to a person's right, choices and preferences is crucial'.⁷³ Moreover, it points out some of the main dynamics which provoke the exclusion of people with dementia from the choices regarding themselves. In this regards it emphasises that people living with dementia are often confronted with a presumption of incompetence as 'before the person has even spoken, his or her words are marked by a systematic devaluation', while 'the opposite approach should be promoted' and individuals with dementia should always be presumed capable and incapacity should not be automatically deduced from a dementia diagnosis.⁷⁴ The report also notes how the 'precautionary principle' and an attitude exceedingly focused on avoiding risks is

⁶⁸ <<http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2009-Advance-directives-and-personhood>> accessed 14 April 2017.

⁶⁹ <<http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2014-Ethical-dilemmas-faced-by-carers-and-people-with-dementia>> accessed 14 April 2017.

⁷⁰ Commission, 'Implementation Dementia Initiative', *above*, 13. The Member States participating in the action are Belgium, Cyprus, Czech Republic, Finland, France, Greece, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, The Netherlands, Norway, Portugal, Slovakia, Spain, Sweden, United Kingdom. For an overview of the ALCOVE initiative see <<http://www.alcove-project.eu/>> accessed 13 April 2017. For a synthesis on how EU Joint Actions in the field of health are structured see <https://ec.europa.eu/health/programme/policy_en> accessed 13 April 2017.

⁷¹ <http://www.alcove-project.eu/index.php?option=com_content&view=article&id=13&Itemid=122> accessed 13 April 2017.

⁷² ALCOVE, 'Rights, Autonomy & Dignity of People living with Dementia' (ALCOVE 2013) <http://www.alcove-project.eu/images/synthesis-report/ALCOVE_SYNTHESIS_REPORT_WP7.pdf> accessed 13 April 2017.

⁷³ *Ibid* 75.

⁷⁴ *Ibid* 76.

too often adopted, threatening the person's ability of being in control of his or her life.⁷⁵ In this regard, the report issues a very clear statement against one of the behaviours of healthcare professionals and carers which, as seen in Chapter 2, create more problems in relation to treatment decisions of individuals living with dementia. In this regard, also thanks to its nature of public document adopted by the EU, the report has a significant potential to directly influence the approach of people working in this area, improving substantially the situation of individuals living with dementia with regard to the right to make healthcare choices.

However, if we consider the specific recommendations expressed in the document, it appears still trapped in an old fashioned approach to legal capacity based on substituted decision-making. Indeed, it mainly focuses on mental capacity assessment and on how it needs to be carried out, accepting that in many situations the person can be deprived of his or her legal capacity. In fact, it simply affirms that 'when the person living with dementia is not able to decide alone, the selected healthcare proxy should be involved'.⁷⁶ It is true that, in this context, it is stressed that the proxy has to reconstruct the will of the person, rather than decide on the basis of the person's best interests.⁷⁷ However, the report seems to disregard the fact that, before reaching that stage, there are many less invasive support techniques that can be put in place in order to involve the individual in the decision.⁷⁸ In this regard, the European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP) notes how the entire approach of the EU to legal capacity appears too compromised with the old model based on substituted decision-making and compulsory treatment, and that even with regard to many significant affirmations contained in policy documents there is a doubt of how much real change they produce in reality.⁷⁹

⁷⁵ *Ibid* 76.

⁷⁶ *Ibid* 77.

⁷⁷ *Ibid*.

⁷⁸ On such support techniques see further Chapter 7.

⁷⁹ ENUSP, 'Proposals for the List of issues on the European Union' (2015) <https://www.google.it/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKewjH8NfKtd7TAhXBKFAKHc1DAycQFggjMAA&url=http%3A%2F%2Fdisabilitycouncilinternational.org%2Fdocuments%2FINT_CRPD_ICO_EUR_19778_E.doc&usg=AFQjCNFRT05GqJxmfxvfWfQVhZpSTcp8w&sig2=uWaii4M6jTN7uAHo7bjsqg> accessed 30 April 2017.

4. The EU engagement with the Committee on the Rights of Persons with Disabilities

The study of EU strategic policies on disability, aging and dementia shows also how, in order to comprehend the potential of the Union's action with regard to the promotion of the right of people living with dementia to decide on medical treatment, it is essential to analyse what mechanisms are or can be put in place that provide an open and direct channel of communication between the EU and the Committee on the Rights of Persons with Disabilities. In this regard, the point is guaranteeing that such mechanisms assure as much as possible a pervasive penetration and prompt implementation of international principles on legal capacity in the geographical area governed by the EU. A good starting point in order to understand the issues on the table, is represented by the dialogue between the Commission and the Committee on the Rights of Persons with Disabilities in occasion of the EU progress report submission on the CRPD. In this section I will focus in particular on the relevant statements for the case of healthcare decisions of people living with dementia.

On a general level, the EU initial report puts emphasis on the fact that, in order to favour the cooperation between the Union and Member States and among Member States themselves the Commission has created the High Level Group on Disability (HLGD, also referred to as DHLG).⁸⁰ This permanent informal experts' group, working at the service of the European Commission is made of senior experts in disability issues nominated by Member States, meets regularly twice a year and issues to the Commission annual reports on the progresses in the implementation of the CRPD in Europe.⁸¹ This is one of the main ways in which the European Union can make use, in the context of disability policy, of the political mechanisms based on peer pressure which are at the centre of the Open Method of Coordination.⁸²

Another positive feature of the EU work in the field of disability, emphasised by the Initial Report, is the involvement of NGOs and organisations of disabled people. Indeed, the HLGD includes a number of such associations, guaranteeing that disabled people themselves can play a meaningful role in shaping the agenda of this body and

⁸⁰ EU, 'Initial Report', *above*, 9. See also the website of the group <<http://ec.europa.eu/transparency/regexpert/index.cfm?do=groupDetail.groupDetail&groupID=1259>> accessed 2 April 2017.

⁸¹ *Ibid.*

⁸² See *above*, Section 2.

in flagging the most urgent issues for them. Moreover, the Union provides financial support to many disabled people's organisations with the aim of strengthening their advocacy capacity and their 'ability to voice the concerns of national member organisations at an EU level'.⁸³ As noted by Lawson, European organisations of disabled people have played a crucial role in facilitating a rights and social model oriented EU disability policy.⁸⁴ In this regard, the ratification of the CRPD has encouraged a more intense involvement with the Convention of associations such as the European Disability Forum (EDF) who played a prominent role in the Ad Hoc Committee in charge of Drafting the CRPD and within the International Disability Alliance (IDA), which has been chaired by the EDF President between 2012 and 2014.⁸⁵ In this sense, the fact that such organisations are even financially supported by the EU is very positive also with regard to the field of healthcare decisions of individuals living with dementia, as it increases the capacity of such associations to put in place awareness raising campaigns on the right of these individuals to decide on medical treatment and to promote supported decision-making initiatives which can take place in various healthcare settings.

Another element bearing the potential of assuring a consistent compliance of EU law and policies with the CRPD is the fact that, the Convention, having been ratified by the Union, is part of its legal order, being positioned, in the EU hierarchy of laws, immediately after the Fundamental Treaties and the Charter of Fundamental Rights.⁸⁶ In this regard, the Union Institutions must always act in accordance with the Convention, whose norms prevail over non-compliant secondary legislation which can be invalidated by the EU Court of Justice.⁸⁷ In order to guarantee the respect of the Convention the Commission has created an 'Inter-Service Group on Disability' gathering together members of various departments.⁸⁸ In addition, the 'Operational Guidance on taking account of Fundamental Rights' requires an Impact assessment

⁸³ EU, 'Initial Report', *above*, 12-13.

⁸⁴ A Lawson, 'The European Union and the Convention on the Rights of Persons with Disabilities: Complexities, Challenges and Opportunities' in G Palmisano, V Della Fina and R Cera (eds), *The United Nations Convention on the Rights of Persons with Disabilities. A Commentary* (Springer 2015), 69-70.

⁸⁵ *Ibid.*

⁸⁶ This aspect is emphasised by EU, 'Initial Report', *above*, 8.

⁸⁷ *Ibid.*

⁸⁸ *Ibid.* 11.

before the publication of Commission initiatives, in order to check that they are compliant also with the CRPD.⁸⁹

With specific regard to Article 12 CRPD, the EU notes that it has no competence to regulate this area. However it has tried to promote the Convention principles through political channels within the HLGD by supporting NGOs and academics working in this area, for example by funding the PERSON Project co-ordinated by the National University of Ireland and focusing on increasing the capacities of organisations in the Balkans to advocate and monitor reforms affecting persons with psycho-social and intellectual disabilities.⁹⁰

The Committee on the Rights of Persons with Disabilities has recognised the value of such mechanisms for the promotion of the Convention principles. It has also welcomed the inclusion of disability in the European Union Communication on the post-2015 Sustainable Development Goals.⁹¹ However, it has expressed some general concerns.

First, the Committee notes, in its concluding observations on the EU, that the Union has failed to conduct a ‘cross-cutting, comprehensive review of its legislation’ relevant to the field of disability and does not seem to have an organic general strategy for the implementation of the CRPD.⁹² In fact, as it has also been seen above, in order to draw a general picture of the EU Policies in relation to one form of disability (dementia), it is necessary to put together a number of documents. In this regard, even the EU Disability Strategy, despite being a good starting point for the development of policy actions in this area, is far from taking into account all the principles of the CRPD and appears too vague on the specific measures that should be adopted by EU Institutions and Member States.

Partially, linked to this aspect is the preoccupation, expressed by the Committee, that the EU Competence Declaration, attached to the Union’s ratification act, does not mention all the disability relevant legislative and non-legislative measures put in place by the European Union.⁹³ With regard to legal capacity and dementia, for example, it

⁸⁹ Commission, ‘Operational Guidance on taking account of Fundamental Rights in Commission Impact Assessments’ (SEC(2011) 567 final 6 May 2011), 5 and 9 < http://ec.europa.eu/justice/fundamental-rights/files/operational-guidance_en.pdf> accessed 18 April 2017.

⁹⁰ EU, ‘Initial Report’, *above*, 22.

⁹¹ Committee on the Rights of Persons with Disabilities, ‘Concluding Observations on the Initial Report of the European Union’, 1 < <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/226/55/PDF/G1522655.pdf?OpenElement>> accessed 1 May 2017.

⁹² *Ibid*, 2.

⁹³ *Ibid*, 3.

does not mention the relevant principles contained in the EU Dementia Initiative or the Initiative on Healthy Aging mentioned above. In this way, it deprives the Committee of the opportunity of providing useful guidance with regard to such provisions.

These issues reflect also in the field of legal capacity. In relation to Article 12 CRPD, the Committee notes how ‘across the European Union, the full legal capacity of a large number of persons with disabilities is restricted’ and urges the EU to ‘take appropriate measures to ensure that all persons with disabilities who have been deprived of their legal capacity can exercise all the rights enshrined in European Union treaties’.⁹⁴ In this regard, the Union surely faces limitations deriving from the fact that the TEU and the TFEU do not recognise its specific competence to issue binding acts in the field of legal capacity. However, initiatives already undertaken in the areas of disability, aging and dementia, show how the Union can develop meaningful principles in this field.

In response to the concerns expressed by the Committee on the Rights of Persons with Disabilities, the Commission has published, on 2 February 2017, the Progress Report on the implementation of the European Disability Strategy.⁹⁵ Such a report had been requested also by the Committee which, in its Concluding Observations on the EU, had expressed concerns for the fact that the Union had not yet carried out its mid-term report on the Disability Strategy.⁹⁶ In its Progress Report, the EU provides an updated list of the legislative measures issued in relation to disability.⁹⁷ However, it fails once again to mention the initiatives cited above concerning people living with dementia. Moreover, it does not announce any organic CRPD implementation strategy involving all the aspects covered by the Convention. In relation to Article 12 CRPD, the report stresses how the Academy of European Law (ERA) is working on providing training to lawyers and professionals also on legal capacity.⁹⁸ However, it does not mention any specific action of the EU directed to put pressure on Member States to change their legislation or to clarify the sometimes evasive indications contained in the Disability Strategy.

⁹⁴ *Ibid*, 5.

⁹⁵ Commission, ‘Progress Report on the implementation of the European Disability Strategy (2010 - 2020)’ (SWD(2017) 29 final, 2 February 2017) <<http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=2725>> 1 May 2017.

⁹⁶ Committee on the Rights of Persons with Disabilities, ‘Concluding Observations’, *above*, 2.

⁹⁷ Commission, ‘Progress Report’, *above*, 158.

⁹⁸ *Ibid*, 136.

5. The EU and the Dissemination of Promising Practices

In its concluding observations on the EU, the Committee on the Rights of Persons with Disabilities indicates the area of European Structural and Investment Funds as one in which the mark left by the ratification of the CRPD is more evident. In this context, it notes how the provisions for the 2014-2020 programming period take into consideration the principles of the Convention and focus, among other things, on promoting equality, non-discrimination and accessibility for disabled people.⁹⁹ The European Disability Strategy 2010-2020 itself emphasises the necessity to ‘optimise use of EU funding instruments for accessibility and non-discrimination’ of disabled people.¹⁰⁰ The EU Initial report to the UN Committee affirms, with regard to Article 12 and legal capacity, the commitment of the Union to support projects in this area and the diffusion of promising practices.¹⁰¹

The potential of European funding schemes to contribute to the development and exchange of promising practices emerges from the Horizon 2020 programmes.¹⁰² As stated on the scheme website, this is the largest EU Research and Innovation programme with around €80 billion of funding made available over the period 2014-2020 and has the aim of promoting innovation and development.¹⁰³ In this context, a number of sub-schemes may provide a platform to promote promising practices in the field of supported decision making of people living with dementia. The section ‘Health, Demographic Change and Wellbeing’ focuses, among other goals on ‘personalising health and care’, supporting ‘older persons to remain active and healthy’ and testing ‘new models and tools for health and care delivery’.¹⁰⁴ In this regard, the EU is supporting the project ‘Patient Empowerment through Predictive Personalised decision support’.¹⁰⁵ The initiative focuses on developing ‘a personalised decision support system for chronic disease management’.¹⁰⁶ People with chronic conditions

⁹⁹ Committee on the Rights of Persons with Disabilities, ‘Concluding Observations’, *above*, 1-2.

¹⁰⁰ Commission, ‘European Disability Strategy’, section 2.2.2.

¹⁰¹ EU, ‘Initial Report’, *above*, 22.

¹⁰² <<https://ec.europa.eu/programmes/horizon2020/en>> accessed 30 April 2017.

¹⁰³ <<https://ec.europa.eu/programmes/horizon2020/en/what-horizon-2020>> accessed 30 April 2017.

¹⁰⁴ <<https://ec.europa.eu/programmes/horizon2020/en/h2020-section/health-demographic-change-and-wellbeing>> accessed 3 May 2017.

¹⁰⁵ For the summary of the project see <http://cordis.europa.eu/project/rcn/199900_en.html> accessed 3 May 2017.

¹⁰⁶ *Ibid.*

(including individuals living with dementia) are involved in any phase of the project, which designs the support system around their needs. The tool developed in this area will combine case-based reasoning with predictive computer modelling in order to ‘offer bespoke advice for self-management by integrating personal health systems with broad and various sources of physiological, lifestyle, environmental and social data’.¹⁰⁷

The Horizon 2020 funded project ‘Digital Environment for Cognitive Inclusion’ focuses on helping older people with cognitive impairments to manage and monitor their health through a system combining the action of formal and informal carers and the use of digital devices which help the person to understand when some of their health parameters signal a situation of potential risk.¹⁰⁸ In this way, an older person with cognitive impairment will be more able to assess their care needs, increasing the possibilities that they contact a care practitioner on time. Funding for similar projects is also provided through the ‘Cross-Cutting Activities’ sub-scheme, which includes a section on the ‘Internet of Things’ applied to healthcare.¹⁰⁹ In this context, support is granted to research groups and companies developing digital aids for healthcare such as tracking devices, digital tools reminding the person to take medications or external memory aids.

More focused on policy is the project ‘Shaping European policies to promote health equity’, which concentrates on detecting the obstacles, emerging in various European regions, preventing one or more categories of people from receiving quality care on an equal basis with others.¹¹⁰ In this context, it has the potential to unveil many of the environmental factors which often prevent medical professionals from putting in place a really person centred model of care and from engaging in supporting decision making with the person also in the case of dementia.

All these initiatives have a great potential to promote supported decision-making for people living with dementia. The financial support provided to them by the EU is probably one of the best examples of how a social institution can concretely help especially healthcare structures and professionals to be more responsive to the needs

¹⁰⁷ *Ibid.*

¹⁰⁸ For a summary of the project see < http://cordis.europa.eu/project/rcn/197186_en.html> accessed 3 May 2017.

¹⁰⁹ < <https://ec.europa.eu/programmes/horizon2020/en/h2020-section/cross-cutting-activities-focus-areas>> accessed 3 May 2017.

¹¹⁰ For a summary see < http://cordis.europa.eu/project/rcn/194060_en.html> accessed 3 May 2017.

of people living with dementia in relation to treatment decisions. However, such funding programmes still tend to focus mainly on one off projects, which may last even for several years, but are still destined to end, posing the risk that their positive impact will disappear after some time.

6. Conclusion

In conclusion, with regard to promoting the right of people living with dementia to decide on medical treatment, the EU surely faces limitations deriving from the resistance of Member States to a more active role of the Union in this area and from the fact that its fundamental treaties do not confer to it the specific power to emanate legislative acts in the area of legal capacity. Anyway, initiatives such as the EU Disability Strategy or the EU Dementia Initiatives, show that the Union can give a significant contribution in this context especially through policy work, and through its funding schemes.

However, the EU does not seem to have fully embraced the spirit of the CRPD in relation to legal capacity. Indeed, the policy lines expressed in this context often lack clarity, failing to indicate the specific measures that should be put in place by EU Member States. Moreover, some declarations issued by EU bodies still seem too compromised with an old fashioned, medicalised vision of dementia and mental disability. Finally, EU funding schemes in this area are still excessively focus of single, one off intervention, instead of aiming at supporting systematic, long term processes of change.

Therefore, it is necessary that activists and legal scholars continue to use the many channels of communication opened between EU Institutions and public opinion, in order to lobby for the adoption of a more convinced CRPD compliant approach to the problem of treatment decisions of people with mental disabilities like dementia and to assure that the Union action is really in line with the needs emerging from practice.

CHAPTER 7

Dementia and Promising Practices from Europe

1. Introduction

Gerard Quinn affirms, with regard to the UN Convention on the Rights of Persons with Disabilities (CRPD), that the main challenge today is transforming its ‘majestic generalities’ into a reality.¹ Also in relation to treatment decisions of people living with dementia, it is crucial to identify how principles affirmed at an International and European level can translate into concrete initiatives.

Hence, after having analysed relevant provisions of the CRPD on legal capacity and consent to treatment and having studied how the Council of Europe and the European Union can contribute to promote the practical realisation of such principles, this chapter considers promising practices, developed within Europe, which can be used to promote the right of people living with dementia to decide on healthcare matters and to support them in making their voice heard. In doing this, it makes a final step towards answering the research question of this thesis, as it identifies concrete initiatives which, embodying the values expressed in Chapter 3 and the spirit and provisions of the CRPD can create the conditions to better foster the right of people living with dementia to decide on medical treatment. Though starting primarily from initiatives developed with regard to choices on medical treatment, it also takes into account practices originated in different areas such as independent living, housing and banking and which provide inputs that can be used also in relation to healthcare choices.

The aim of this overview is not to provide an exhaustive analysis of all relevant initiatives emerging throughout Europe. Rather, it refers to some of them with the intent of giving a clearer idea of how a CRPD compliant practice in healthcare decisions could look like. Therefore, the principles of the CRPD, of the social model of disability, and of Fineman’s vulnerability theory, constitute the evaluative

¹ G Quinn, ‘Resisting the “Temptation of Elegance”: Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?’ in OM Arnardóttir and G Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009), 217.

framework of this chapter. In order to establish which behaviours and practices are in line with the evaluative framework I have compared the content of the documents concerning the various interventions with the indications and examples, sometimes rather specific, provided by the Committee on the Rights of Persons with Disabilities and various Council of Europe and European Union bodies, as to what means of support are coherent with the CRPD model of legal capacity.

The initiatives analysed in this chapter have been selected having in mind the barriers to the right of people living with dementia to decide on medical treatment studied in Chapter 2 and which are mostly caused by the prejudice of professionals or carers, the lack of human, physical or time resources to adequately assist the person, and the absence of a framework providing guidance on how to concretely support the individual in making healthcare choices. Therefore, I have considered as promising those practices which go in the direction of persuading professionals or members of the general public that even people living with dementia are often able to choose for themselves, or that provide training to medical professionals or caregivers on how to navigate choice making in dementia care and better communicate with the person, or that indicate a concrete model that could be used to provide the support that the person needs for a certain decision or to provide suggestions with regard to analogical or IT based tools to assist the person in the decisional process. Particular attention has been paid to projects putting at the centre the voice of people living with dementia and showing a move from a medicalised approach to this condition.² For this reason, the views of service users and formal and informal carers have been a key element in the assessment of the various practices.

In order to collect relevant material, I started from websites and databases such as the portals of Alzheimer Europe³ and the European Foundation Initiative on Dementia (EFID),⁴ the practices database of the ZERO Project,⁵ and the supported decision-

² These aspects are foundational to the general architecture of the CRPD (see Chapter 4) and to the work of scholars and activists who are advocating for the social model of disability in relation to dementia. In this regard see Mental Health Foundation, 'Dementia, Rights, and the Social Model of Disability. A new Direction for Policy and Practice?' (MHF 2015), 4-6 <www.mentalhealth.org.uk/content/assets/PDF/publications/dementia-rights-key-summary.pdf?view=Standard> accessed 12 November 2015.

³ <www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies> and <www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons> accessed 23 October 2016.

⁴ See <www.efid.info/eng/awards/> and <www.efid.info/eng/resources/mapping-dfcs/> accessed 16 February 2017.

⁵ <<https://zeroproject.org/innovative-practices/>> accessed 16 February 2016.

making resource library developed by the American Civil Liberties Union (ACLU).⁶ These collections, constantly updated, can be very helpful for everyone who wishes to keep informed on the topics relating to this Chapter. In addition, valuable information is contained in the final report of the EU ALCOVE project⁷ and the documents published by the Academic Network of European Disability Experts (ANED).⁸ Data emerging from these sources are complemented with those contained in studies and other websites of institutions and NGOs. In order to collect this material I have used online search engines (Google and Google Scholar) and platforms such as PubMed and HeinOnline. Employed key words included ‘dementia stigma’, ‘mental disability stigma’, ‘dementia awareness raising’, ‘mental disability awareness raising’, ‘dementia training’, ‘shared decision-making dementia’, ‘supported decision-making dementia’, ‘mental capacity advocacy’, ‘dementia advocacy’. A range of service providers have been considered including government bodies, health authorities, NHS Trusts, hospitals, care homes, charities and NGOs. In my work I relied mainly on documents written in English, German, Italian, French and Spanish. When it has been necessary to read material in other languages I have asked native speakers to translate to me essential passages, but this could have not enabled me to have access to the full range of materials published in these languages. Therefore, there will inevitably be projects which I am not aware of, as they have not been included in International reports or are mentioned in documents not written in the aforementioned languages. This does not diminish the value of this research which is in nature illustrative rather than exhaustive.

In summarising the promising practices emerging from such a research, the Chapter proceeds as follows. In Section 2, it focuses on actions targeting the general public which can contribute to challenge prejudice against people living with dementia. Section 3 analyses projects promoting a more positive perception of dementia among relatives and informal carers of people living with this condition. In addition, it considers practices aiming at fighting dementia related self-stigma. Section 4 focuses on training programmes directed at providing guidance to doctors, nurses, social workers, and other professionals on how to interact with people living with

⁶ <www.aclu.org/other/supported-decision-making-resource-library?redirect=supported-decision-making-resource-library> accessed 16 February 2017.

⁷ See <www.alcove-project.eu/index.php?option=com_content&view=article&id=9&Itemid=118> accessed 23 October 2016.

⁸ <www.disability-europe.net/> accessed 6 November 2014.

dementia and how to ensure that they are supported to make autonomous decisions. Section 5, analyses projects and studies shedding light on the potential of supported and shared decision-making in relation to care decisions of people living with dementia. In this context, it considers the strategies adopted in order to explain information to the person. Section 6 considers techniques used to overcome difficulties of communication with the person, to interpret the person's will and to remind them information they may not recall. In this context, it also refers to projects using IT and new technologies. Section 7 provides a brief overview on the actions put in place by authorities and NGOs in order to assure that people living with dementia receive an adequate level of support. In this context, I will also focus on the role of independent advocacy associations. The Conclusion emphasises once again how these practices can give an idea of how the vision of healthcare decision-making in dementia care can be translated into concrete behaviours and briefly reflects on how they can be further improved and spread.

2. Awareness raising and anti-stigma actions for the general public

As seen in Chapter 2, the negative impact of prejudice on the autonomy of people living with mental impairments like dementia is confirmed by a number of studies.⁹ For this reason, fighting stigma and making the general public aware of what living with dementia means seems the first step to promote the person's decisional power. Researchers and people with this condition identify the messages which should be spread in this regard.¹⁰ In particular, they emphasise the necessity of convincing people

⁹ The EU Fundamental Rights Agency notes that, because of stigma, mentally disabled people tend to be denied the right to choose where and how to live. FRA, 'The Fundamental Rights of Persons with Intellectual Disabilities and Persons with Mental Health Problems' (FRA November 2010), 1 <http://fra.europa.eu/sites/default/files/fra_uploads/1292-Factsheet-disability-nov2010.pdf> accessed 12 January 2017. SM Benbow and D Jolley, 'Dementia: Stigma and its Effects' (2012) 2 *Neurodegenerative Disease Management* 165, 169 note that the tendency to see individuals living with dementia as 'child-like incapable' leads to their voices not being heard. For a wider analysis on the impact of prejudice, preconceptions and stigma in treatment decisions of people living with dementia see Chapter 2.

¹⁰ In this regard a summary is provided by NL Batsch and MS Mittelman (eds), *World Alzheimer Report 2012. Overcoming the Stigma of Dementia* (Alzheimer's Disease International 2012), 9-10 <https://www.alz.org/documents_custom/world_report_2012_final.pdf> accessed 13 January 2017.

that life with dementia can still be meaningful, that individuals in this situation are often able to understand the reality around them and that they have preferences which should be respected.¹¹

Such themes are at the centre of many national dementia strategies. For example, the Dementia Plan for Flanders 2016 states: ‘we want people with dementia to “be part of society” [...]. We want them to feel that they are [...] able to lead the life they want’.¹² The Finnish National Memory Programme 2012-2020 emphasises how ‘what it is needed is an attitude check to allow people with cognitive problems and dementia to be included in society [...] and to make decisions about their lives independently’.¹³ The Italian Dementias National Plan (*Piano Nazionale Demenze*) affirms that ‘a person with a dementia diagnosis shall not be automatically considered incapable of exercising his or her right to choose’.¹⁴ These statements can significantly contribute to advance a culture of respect for people with dementia and their autonomy. Indeed, they are included in government documents setting out the official approach which should be followed at least by all public service providers.

However, it is also necessary to assure that these ideas truly penetrate in society, so that everyone has them in mind when eventually developing dementia or assisting a person living with this condition. In this regard, state agencies, charities and common citizens throughout Europe are carrying on anti-stigma campaigns, sending the general message that dementia does not ‘empty’ the person of their self and of the abilities necessary for a meaningful social life. For example, the Slovak Alzheimer Society (*Slovenska Alzheimerova Spolocnost*) is running the project ‘Together against

¹¹ *Ibid.* These themes emerge also from the analysis contained in Chapter 2.

¹² Vlaamse Regering, ‘Continuing to build a dementia-friendly Flanders together. Updated Dementia Plan for Flanders 2016 – 2019’ (Vlaamse Regering 2015), 15 <[www.alzheimer-europe.org/content/download/125432/784052/file/Flanders%20dementia%20strategy%202016-2019%20\(English\).pdf](http://www.alzheimer-europe.org/content/download/125432/784052/file/Flanders%20dementia%20strategy%202016-2019%20(English).pdf)> accessed 23 October 2016.

¹³ Finnish Ministry of Social Affairs and Health, ‘National Memory Programme 2012-2020. Creating a “Memory Friendly” Finland’ (MSAH 2013), 11 <www.alzheimer-europe.org/content/download/40967/269054/file/Finland%20National%20Memory%20Programme%202012-2020.pdf> accessed 23 October 2016.

¹⁴ Presidenza del Consiglio dei Ministri, ‘Piano Nazionale Demenze’ (Accordo 135/CU all A, Governo Italiano 2014), 7 <www.salute.gov.it/portale/news/p3_2_1_1_1.jsp?menu=notizie&p=dalministero&id=1836> accessed 3 November 2016. Similar statements are contained in other dementia strategies such as that of Norway (Norwegian Ministry of Health and Care Services, ‘Dementia Plan 2020. A More Dementia Friendly Society’ (MHCS 2015), 17-18 <www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/dementia_plan_2020_long.pdf> accessed 1 December 2016) and the one of Ireland (Department of Health, ‘The Irish National Dementia Strategy’ (Dep of Health 2014), 15 <<http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>> accessed 23 January 2017).

Dementia’, having produced leaflets and a website with informative material on what having dementia means.¹⁵ In addition, it organises a series of talks named ‘Days of Open Mind’.¹⁶ Similar initiatives take place, among others, in Austria,¹⁷ Belgium,¹⁸ Norway,¹⁹ Italy²⁰ and the UK.²¹ In Germany, the *Deutsche Alzheimer Gesellschaft* has created, in 2007, a website called ‘Alzheimer and You’, which aims to increase the awareness of young people in relation to dementia.²² The website contains videos, a forum, quizzes and suggestions on books and poems about this condition. As part of the website launch, the *Gesellschaft* organised a competition for youths aged 14-21, who have been invited to submit creative works on their experiences with dementia.²³ The willingness of spreading a positive idea of this dynamic is also at the basis of the website ‘Dementia Positive’, which has the aim of ‘celebrating the strengths, creativity and insights of people living with dementia’.²⁴ It is run by a former teacher and a clinical psychologists from Stirling (Scotland) and contains information on events, books and artistic material produced by or regarding people with dementia.²⁵

Among these campaigns particularly promising is the one launched by the First Dementia Plan for Flanders 2010-2014 with the slogan ‘Forget Dementia. Remember the Person’ (*Vergeet dementia. Onthou mens*).²⁶ The first point is that it is directly promoted by the government, showing a long-term commitment at a state level.

¹⁵ For an explanation of the project in English see < <http://alzheimer-europe.org/News/Members-news/Monday-14-March-2016-Slovakia-reports-on-its-campaign-Together-against-dementia>> accessed 1 December 2016. See also the website of Slovak Alzheimer Society <www.alzheimer.sk> accessed 1 December 2016.

¹⁶ The Society annual report 2015 shows how the number of participants in the campaign is constantly growing. Slovenska Alzheimerova Spolocnost, ‘Vyrocna Sprava’ (SAS 2015), 14 < <http://www.alzheimer.sk/media/110046/vyrocna.sprav.2015.def.pdf>> accessed 13 January 2017.

¹⁷ See the campaign run by *Aktion Demenz* < www.aktion-demenz.at/demenz-geht-uns-alle-an/plakate/> accessed 17 February 2017.

¹⁸ See the talks’ series organised by *Ligue Alzheimer* < www.alzheimer.be/activites/conferences/cycles> accessed 17 February 2017.

¹⁹ <<http://nasjonalforeningen.no/tilbud/demensvennlig-samfunn/>> accessed 17 February 2017.

²⁰ See the campaign recently launched by the Health Ministry <www.salute.gov.it/portale/temi/p2_6.jsp?lingua=italiano&id=170&area=salute%20mentale&menu=azioni> accessed 17 February 2017.

²¹ Examples can be found on the websites of Alzheimer Society UK < https://www.alzheimers.org.uk/info/20016/our_campaigns/242/campaign_reports> or Alzheimer’s Scotland < <http://www.alzscot.org/campaigning>> both accessed 17 February 2017.

²² More than 100 entries were received for the contest. See < www.alzheimerandyou.de/> accessed 25 November 2016.

²³ A brief summary of the project in English may be found in Batsch and Mittelman (eds), *above*, 59.

²⁴ See <www.dementiapositive.co.uk/> accessed 25 November 2016.

²⁵ *Ibid.*

²⁶ Vlaamse Regering, ‘Naar een dementievriendelijk Vlaanderen. Dementieplan Vlaanderen 2010 -2014’ (Vlaamse Regering 2011) < <http://www.jovandeurzen.be/sites/jvandeurzen/files/dementieplan2010-2014.pdf>> accessed 13 January 2017. The new Plan 2016-2020 provides for the continuation of this project. See Vlaamse Regering, ‘Continuing to build 2016’, *above*, 10.

Moreover, it stands out for the wide variety of communication means that it uses in order to reach the highest possible number of people, proposing ‘destigmatising counter-frames or different ways of looking at dementia that better reflect reality’.²⁷ In this context, surveys carried out in 2015 by the Flemish Dementia Expertise group show that now 80% of the respondents think that people living with dementia can still enjoy life, while 70% see them as full individuals with wishes and feelings.²⁸ Moreover, 1 of 3 respondents think dementia is not the end of one’s life, even though 55% of participants admit that it causes losses in identity and personality.²⁹ The positive opinions of individuals taking part in the project, give an idea of how this campaign is playing a crucial role in developing such levels of awareness.³⁰



Figure 1 Image from the 'Vergeet Dementia. Onthou Mens Campaign' (translation 'You may have Alzheimer but we have you')

The initiative consists of leaflets, posters, books, videos, exhibitions, talks and cultural events conveying a positive idea of dementia. Moreover, a website has been created with resources for people who work in the field of dementia care or who want to make their own campaign.³¹ They include stories of people living with this condition and their carers, statements of politicians or intellectuals, practical information for the person and their carers. The website has also a database of pictures showing people

²⁷ *Ibid.*

²⁸ Flemish Minister of Welfare, Public Health and Family and Flemish Dementia Expertise, 'Cijfers en feiten over dementie' (Vlaamse Regering 2015), 2 <http://jo.vandeurzen.cdenv.be/sites/jvandeurzen/files/Cijfers%20en%20feiten%20over%20dementie_0.pdf> accessed 13th January 2017.

²⁹ *Ibid.*, 2-3.

³⁰ For a collection of such opinions see <<http://onthoumens.be/in-de-media>> accessed 13 January 2017.

³¹ See <www.onthoumens.be> accessed 12 November 2016.

living with dementia in everyday life, intended to help challenge stereotypes. The fact that some of these materials comes from people living with dementia themselves is a particularly positive feature of the initiative. In fact, it complies with the principles of the social model of disability as it assures that the messages spread are in tune with what primary stakeholders think.

The active role played by people living with dementia is also a praiseworthy characteristic of the campaign ‘Forget the Stigma’ launched by Alzheimer Society Ireland in 2015. It consists of leaflets and posters with slogans such as ‘I have dementia, I am still me’. It includes video ads shared through social media, inviting people to learn ‘the facts of the condition, listening and empathising, and linking in with those with dementia to prevent isolation’.³²



Figure 2 Posters from the ‘Forget the Stigma Campaign’

In addition, the charity has launched a new YouTube Channel entitled ‘Alzheimer Talks’ (AlzTalks), containing videos of people living with dementia who tell their experience with the condition.³³ Here people living with dementia are even more protagonist than in the Flemish project, as they appear in person in the vast majority of materials, telling their experience and showing how much they are conscious of

³² Alzheimer Society of Ireland, ‘Forget Stigma Campaign Press Release’ (Alzheimer Society Ireland 2014), 1 <www.alzheimer.ie/Alzheimer/media/SiteMedia/Forget-The-Stigma-National-Press-Release_1.pdf> accessed 25 November 2016. For further information on the campaign see the website of the society <www.alzheimer.ie/Get-Involved/Campaigning/Past-Campaigns/Forget-the-Stigma.aspx> and its YouTube channel <www.youtube.com/channel/UCjdO3TY6WWZybV6p_AEvQYg> both hyperlinks accessed on 25 November 2016.

³³ See <www.alzheimer.ie/Get-Involved/Campaigning/Current-Advocacy-Campaigns/Alz-Talks.aspx> and <www.youtube.com/c/alztalks> both accessed 25 January 2017. By this date the channel had been viewed by 8.677 YouTube users.

their condition. This makes the messages of the campaign more powerful and difficult to ignore. A similar project is run by Dementia NI in Northern Ireland and supported by the Government and Health Ministers.³⁴ TV ads and documentaries on dementia are also produced by Alzheimer Croatia.³⁵

As noted by Smith, stigma is a relational dynamic which originates from a combination of factors which may not be intercepted by campaigns targeting the general public.³⁶ Therefore, while posters and ads can produce the ‘background noise’ essential for every change of mentality, they may not be enough to generate concrete change.³⁷ In this context, agreeing in principle with the declarations printed on a leaflet may be relatively easy, while really believing them may be a rather different matter. Therefore, initiatives based on talks, like those organized by the Slovak Alzheimer Association or *Ligue Alzheimer* (Belgium) offer a better chance to directly engage with people and making them aware of the biases they may not know they have.

Among these programmes, the UK Dementia Friends and Dementia Champions project appears to be the most extensive, successful and well structured, involving around 1.5 million people.³⁸ This initiative is part of the Dementia Friendly Community Programme launched in 2015 by Alzheimer’s Society UK.³⁹ The precise aim of this action is to achieve a better understanding of dementia within society and promoting a more positive attitude towards people living with this condition⁴⁰ through

³⁴ See <<http://dementiani.org/index.php/component/k2/item/39-dementia-ni-members-help-to-launch-still-me-campaign>> and <www.youtube.com/channel/UCqigMiyLjh0Lf980zWoeAmA> both accessed 25 November 2016.

³⁵ <www.alzheimer.hr/tv-emisije/> accessed 22 February 2017.

³⁶ M Smith, ‘Anti-stigma Campaigns: time to change’ (2013) *The British Journal of Psychiatry* 49, 50.

³⁷ *Ibid.*, 49, shows, in relation to anti-stigma initiatives in the field of mental health, how they may not only fail to produce a decrease in the number of discrimination cases, but also make it grow.

³⁸ See the EFID summary <https://ec.europa.eu/eip/ageing/commitments-tracker/d4/creating-dementia-friends-and-dementia-friendly-communities_en> accessed 17 February 2017. The project is described as an outstanding anti-stigma campaign in the report commissioned and developed by Mental Health Foundation, ‘Mapping Dementia-Friendly Communities across Europe’ (EFID 2016), 29 <www.nef-europe.org/wp-content/uploads/2016/10/Mapping_DFCS_across_Europe_final.pdf> accessed 17 February 2017. The value of the initiative is recognised also by foreign Alzheimer Associations. In this regard the chair of Alzheimerforeningen (Denmark) has explicitly recognised, in her speech at the Alzheimer Europe Conference 2016 in Copenhagen that ‘the Danish Alzheimer Association has in fact been both impressed and inspired [...] by the way in which the dementia friend concept is developed and unfolded in England’ see <<http://alzheimer-europe.org/Conferences/Previous-conferences/2016-Copenhagen/Videos-and-photo-gallery/Opening-ceremony/Birgitte-Voelund>> accessed 17 February 2017.

³⁹ Alzheimer’s Society, ‘Building Dementia-friendly Communities: A Priority for Everyone’ (Alzheimer’s Society 2015) <www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1236> accessed 10 March 2016.

⁴⁰ For a short summary on the structure and scope of the project see <www.dementiafriends.org.uk/WEBArticle?page=what-is-a-friend#.WInIiIXXLIU> accessed 14 January 2017.

the creation of a network of ‘dementia friends’ and ‘dementia champions’.⁴¹ In order to become a ‘dementia friend’ it is sufficient to watch the video posted online and then attend a one hour session in which dementia champions and people living with the condition explain what dementia is, what are the challenges of living with it and how everyone can help the person in facing such challenges.⁴² In order to become a ‘dementia champion’ it is necessary to attend a one day induction event.⁴³ Single induction sessions provide training on the principles of person centered care in dementia, the way in which one can understand the personality and feelings of the person and on the techniques through which the latter can be involved in the decisions about their life.⁴⁴ So far there are around 10,500 dementia champions in the UK.⁴⁵ The more promising aspects of the programme are its interactive nature and the fact that it provides the participants with an articulate ‘education pathway’ in which their skills are recognised by a certificate of ‘dementia friendship’ and ‘dementia championship’.⁴⁶ Moreover, those who take part are inserted in a network of friends and champions through which they receive constant inputs and information.⁴⁷

These projects appear to give a valuable contribution to dismiss the still frequent idea that people living with dementia lack a sense of self and cannot express their opinions, which is one of the great barriers to their involvement in decision-making also in relation to medical treatment.⁴⁸ However, they often seem to not make enough clear the link between respect of the person and promotion of their right to decide. Indeed, often they fail to state clearly that respecting the person with dementia means also promoting their rights and especially their power to decide. As stressed by Thornicroft, this issue is common to many anti-stigma campaigns in the field of mental health,⁴⁹ and causes the paradoxical situation according to which, despite the proliferation of initiatives, people living with dementia feel sometimes ‘used’ in a

⁴¹ <www.dementiafriends.org.uk/> accessed 14 January 2017.

⁴² *Ibid.*

⁴³ <www.dementiafriends.org.uk/WEBArticle?page=what-is-a-champion#.WInNOIXXLIU> accessed 14 January 2017.

⁴⁴ <www.dementiafriends.org.uk/WEBArticle?page=champions-training#.WInNX4XXLIU> accessed 14 January 2017.

⁴⁵ <www.dementiafriends.org.uk/WEBArticle?page=what-is-a-champion#.WInNOIXXLIU> accessed 14 January 2017.

⁴⁶ *Ibid.*

⁴⁷ *Ibid.*

⁴⁸ See A Jaworska, ‘Respecting the Margins of Agency: Alzheimer’s patients and the capacity to value’ (1999) 28 *Philosophy and Public Affairs* 105. See also Chapter 2.

⁴⁹ G Thornicroft, *Ignorance+Prejudice+Discrimination=Stigma* (MHF 2006), 18.

patronizing and tokenistic way by associations that claim they are working for including them.⁵⁰ Therefore, though they show a substantial progress, the campaigns cited above appear still partly influenced by the old medicalised approach to dementia. Indeed, messages of respect and inclusiveness tend still to be framed in the language of welfare/care rather than that of empowerment/rights.

In this regard, a pioneering role in spreading a human rights approach to dementia is played by Dementia Alliance International.⁵¹ This NGO based in America but operating also in Europe has adopted the motto of the disability movement ‘Nothing about us, without us’.⁵² With this spirit, since the World Health Organisation’s First Ministerial Conference on Dementia held in Geneva in March 2015 the association has been advocating for the effective application of the CRPD to people living with dementia.⁵³ In this context, it considers as its main mission that ‘people living with dementia should be empowered to use their undisputed right of access to this and to other relevant UN Human Rights Conventions, including a future Convention on the Rights of Older Persons’.⁵⁴ The activity of the association is of great importance even in the field of decision-making. Indeed, it’s among the very few which has embraced with decision a full disability and human rights approach to dementia and it is run directly by people living with dementia. In this regard, it is developing campaigns characterized by the fact of being entirely designed with and by people living with dementia, putting emphasis on recognising the rights and autonomy of these individuals, and stressing that all decisions in this field require the person’s involvement. In order to spread these messages and raise awareness on the CRPD, Dementia International Alliance has published various leaflets, videos and informative documents, including the guide ‘The Human Rights of People Living with Dementia: from Rhetoric to Reality’.⁵⁵ This publication clearly indicates how promoting the power to decide also on matters such as medical treatment is essential for really including people living with dementia in the society.⁵⁶ In addition, it organises talks,

⁵⁰ K Swaffer, *What the Hell is going on with my Brain?* (Jessica Kingsley 2014), 40.

⁵¹ <www.dementiaallianceinternational.org/> accessed 23 January 2017.

⁵² *Ibid.*

⁵³ <<http://www.dementiaallianceinternational.org/human-rights/>> accessed 23 January 2017.

⁵⁴ *Ibid.*

⁵⁵ DAI, ‘The Human Rights of People Living with Dementia: from Rhetoric to Reality’ (DAI 2016) <<http://www.dementiaallianceinternational.org/human-rights/>> accessed 23 January 2017.

⁵⁶ *Ibid.*, 11.

dementia cafes in which people living with this condition can share their experiences, and blogs written by people living with dementia.

The activity of Dementia Alliance International, provides an example of what all dementia awareness raising campaigns should be about. For this reason, it is a shame that its initiatives have not yet reached the scale and pervasiveness of the ones run, for example, in Flanders, Ireland, or by Alzheimer's Society UK. Moreover, no government has so far really embraced their approach. It would be extremely beneficial for people living with dementia if, putting together the strengths of the projects mentioned here, it would be possible to promote extensive campaigns through leaflets, TV programmes and ads that use creatively all the means offered by modern media, but really focus on rights and empowerment.

Besides that, there is the need of providing for systematic evaluation which clearly indicates if the path followed by the various associations is the right one. Indeed, in relation to many of the projects cited above there is a lack of data on how each of them has concretely contributed to challenge prejudice. Findings collected by Alzheimer's International show how generally the exposition of people to information campaigns can be quite effective in demolishing their preconceptions.⁵⁷ In this context, some people living with dementia, recognise that the situation 'it's getting better' and 'more people with dementia are being asked for their opinion'.⁵⁸ However, many other individuals living with this condition still tend to be marginalised and subject to commiseration, ignoring behaviour and even abuse.⁵⁹ The criticism brought forward by associations such as Dementia Alliance International is quite indicative of how the situation is still far from ideal. This appears even truer if one recalls that according to some studies, the impact of awareness raising campaigns in the field of mental health can appear quite dubious.⁶⁰ In this regard, activists and researchers are questioning the usefulness of concentrating excessively on campaigns, risking to waste precious resources that could be employed to put in place more concrete measures in favour of mentally disabled people.⁶¹ Moreover, empirical studies show how stigmatising and ignoring behaviour towards individuals living with dementia originates from the

⁵⁷ Batsch and Mittelman (eds), *above*, 13.

⁵⁸ *Ibid*, 27-29.

⁵⁹ *Ibid*, 24-32.

⁶⁰ See SE Estoff, DL Penn and JR Toporek, 'From Stigma to Discrimination: an Analysis of Community Efforts to Reduce the Negative Consequences of Having a Psychiatric Disorder and Label' (2004) 30 *Schizophrenia. Bulletin* 493.

⁶¹ L Sayce, *From Psychiatric Patient to Citizen revisited* (Palgrave 2016), 107.

challenging relational dynamics emerging in concrete cases.⁶² Therefore, the point often seems more offering support in the specific situation rather than focusing on educating people.

3. Actions challenging relatives' prejudice and the person's self-stigma

As shown by the Alzheimer Disease International report on stigma and dementia also the behaviour of family members is often influenced by prejudice and negative attitudes towards the condition.⁶³ Relatives of people living with dementia can feel ashamed of their beloved ones and think that the person, because of their condition, is incapable of understanding or deciding on anything.⁶⁴ This attitude is, most of the time, unconscious and is the result of general attitudes and expectations embedded in societal structures and values.⁶⁵ Nonetheless, it has a significant impact on the person's self-confidence and ultimately on their right to make decisions.⁶⁶

In order to address this issue, in a number of European countries hospital boards, health authorities and charities have developed guides for relatives of people living with dementia. These materials include tips on how to have a more positive approach to relational and emotional challenges relating to the management of this condition and how to communicate with the person.⁶⁷ They are often written by experts but, especially when published by private associations, they include, among the authors, also people with dementia, family members and activists. To this category belongs, for example, the advice page on the website of *Alzheimerforeningen* (the Danish Alzheimer association). This webpage recognises that 'in this situation it is natural that you could have a [negative] reaction. All the people who have a beloved one with dementia experience emotional difficulties' and 'it takes time to accept and

⁶² KL Smebye, M Kirkevold and K Engedal, 'How do Persons with Dementia participate in Decision Making related to Health and Daily Care? A multi-case study' (2012) 12 *BMC Health Services Research* 241.

⁶³ NL Batsch and MS Mittelman (eds), *above*, 24-25.

⁶⁴ *Ibid.*

⁶⁵ *Ibid.*, 10-11.

⁶⁶ *Ibid.*, 9-11 and 24-25. For a deeper analysis on how the attitude of family members impacts on the autonomy of people with dementia see above Chapter 2.

⁶⁷ The various communication strategies developed within medical and non-medical practice are analysed more in detail in Sections 5 and 6.

understand'.⁶⁸ Therefore, it encourages family members to seek assistance, be open and talk to people they trust about their issues.⁶⁹ A similar webpage, developed by Alzheimer Austria, urges family caregivers to 'promote for as long as possible the autonomy of the person concerned and provide them with the possibility of choosing'.⁷⁰ Its German correspondent, developed by the *Deutsche Alzheimer Gesellschaft* (German Alzheimer Society) states that: 'patients must be accepted as they are. You cannot change them. Relatives should learn to perceive and take into account the needs and wishes of the patients'.⁷¹

These advices have the merit of putting emphasis on the necessity of being respectful and promoting the freedom of choice of the person. However, because of the way in which they are expressed, they appear still trapped in a medicalised vision of dementia. Indeed, individuals with this condition are often still referred to as 'patients'. Moreover, the tone of some statements gives the impression that adopting a certain attitude towards the person is more a question of being professional and diligent in one's care duties, rather than building a meaningful relationship. In this context, conceding that negative reactions are normal in such a situation may have the undesired effect of confirming to some people that dementia is indeed a mainly tragic and hopeless state and that the only thing to do is simply being polite and carrying on. Therefore, while such declarations may change the negative attitudes of some relatives, in other cases they may cause an increase in the levels of dependence and domination to which the person is subject. In this regard, a vast literature in the field of disability studies and psychiatry, shows how it is easy to end up in situations in which the person's autonomy is apparently encouraged but substantially impeded by the fact that they feel intimidated.⁷²

⁶⁸ <www.alzheimer.dk/er-du-paaroerende/aegtefaelle-kaereste-eller-samlever/> accessed 14 January 2017.

⁶⁹ *Ibid.*

⁷⁰ <www.alzheimer-selbsthilfe.at/leben-mit-demenz/den-alltag-gestalten/was-konnen-sie-tun/> accessed 14 January 2017.

⁷¹ <www.deutsche-alzheimer.de/angehoerige/umgang-und-beschaeftigung.html>. Brochures with similar advice are provided, for example, by *Ligue Alzheimer* (Belgium) <www.alzheimer.be/infos-et-medias/ressources>; Italian local governments and hospitals such as Regione Emilia Romagna, 'Non so cosa avrei fatto senza di te. Manuale per i familiari delle persone con demenza' (SSR Emilia Romagna 2013) <www.ctr.it/back_end/files_news/1612.pdf> and Istituto di Cura Santa Margherita Pavia, 'Manuale per i caregiver di persone affette da Malattia di Alzheimer' (ASP Pavia 2008) <www.asppavia.it/shared/binary/24/Manuale%20per%20i%20caregiver.pdf>; and by the Finnish website <www.muistiliitto.fi/fi/aivot-ja-muisti/esitteet/>. All websites accessed 14 January 2017.

⁷² See for example JI Chalton, *Nothing About Us without Us* (University of California Press 2000). The effects of familial and professional deference in the case of people living with dementia are analysed also by Smebye, Kirkevold and Engedal, *above*.

The same problem emerges in relation to the courses for family members of people living with dementia organised by various charities. An example are the sessions within the already mentioned UK Dementia Friends project, in which families of people living with this condition are encouraged to take part.⁷³ Training events are also provided by the Alzheimer Federation Italy (*Federazione Alzheimer Italia*),⁷⁴ the association ‘*Approccio Capacitante*’ (Capacitating Approach)⁷⁵ and some local organisations.⁷⁶ However, though many of these courses still tend to concentrate on medical aspects of dementia and personal care, there are sessions focused on relational and emotional questions. For example, the courses proposed by CPL Servizi (Verona) include a session on ‘Relatives of Persons with Dementia: Difficulties and Emotions. Techniques of Emotion Management’.⁷⁷ Moreover, some events provide training on how to assist the person in everyday communication and empower them to make choices.⁷⁸

The positive characteristic of these courses is that through them charities and relatives of people living with dementia engage with relational problems relating to this condition. In this context, it is surely a good thing that here participants, instead of simply being passive recipients of indications written on a leaflet, can actively discuss the problems they face. Unfortunately, these courses do not normally include the presence of people living with dementia, which could be very helpful in order to give to attendees a deeper understanding of the questions at the centre of discussion.⁷⁹ In addition, on the websites advertising them a medicalised language still tends to be

⁷³ See above Section 3.

⁷⁴ See < www.alzheimer.it/index.html> accessed 23 January 2017.

⁷⁵ See < http://www.formalzheimer.it/index.php?option=com_frontpage&Itemid=1> accessed 23 January 2017.

⁷⁶ See for example the websites of Alzheimer Italia Bari < www.alzheimerbari.it/event/corso-di-formazione-per-familiari-prendersi-cura-del-malato-di-alzheimer-ogni-giorno/>; Associazione Familiari Alzheimer Pordenone Onlus <www.alzheimer-pordenone.org/attivita/programma-lua-2009/>; CPL Servizi Onlus Verona < www.cplservizi.it/corso-famigliari-di-malati-di-alzheimer-difficolta-ed-emozioni/> all accessed 23 January 2017.

⁷⁷ <www.cplservizi.it/corso-famigliari-di-malati-di-alzheimer-difficolta-ed-emozioni/> accessed 23 January 2017. See also the sessions provided by Alzheimer Bari < www.alzheimerbari.it/event/corso-di-formazione-per-familiari-prendersi-cura-del-malato-di-alzheimer-ogni-giorno/> accessed 23 January 2017.

⁷⁸ < www.formalzheimer.it/index.php?option=com_frontpage&Itemid=1> accessed 23 January 2017. For an explanation of specific communication techniques to support people in the decision-making process see Section 6.

⁷⁹ There are some limited and still sporadic exceptions. For example the events of the Dementia Friends Project involve sometimes people living with dementia. Also the courses of Alzheimer Bari sometimes, but still very rarely, are opened to people living with dementia. See < www.alzheimerbari.it/event/corso-di-formazione-per-familiari-prendersi-cura-del-malato-di-alzheimer-ogni-giorno/> accessed 23 January 2017.

used and it seems that these events are more about ‘managing’ the person than empowering them. Finally, there are no data available on the concrete impact of such initiatives on the behaviour of family members of people living with dementia.

In this regard a more promising project has been developed by the English Tide association, a UK based private network of dementia carers.⁸⁰ This organisation runs various initiatives which use ‘stories sharing’ to promote a better understanding of the life experience of the person living with dementia. The aim of such initiatives is to ‘educate, empower and enable in order to encourage and embrace relationships built on empathy’.⁸¹ The website of the group provides also a database of experiences which show how story sharing permits to understand that in interacting and making choices with people living with dementia there is more to be considered than their cognitive impairment.⁸² Such practices are praiseworthy because they put at the centre the experience of people living with dementia and encourage the person to tell their life experience. Moreover, it prioritises the development of meaningful human relationships between the person and their carer. Finally, and most importantly, here the family member can actively seek guidance on the issues he/she faces from his/her beloved one with dementia.

In one experience report, for example, a person with dementia describes his love for nature, how he likes to walk outdoors and explains that he considers essential for his life the relationship with his family.⁸³ Another report shows how story sharing has helped a dementia advocate to know more about the concerns of her cared for in relation to his problems of motility and communication.⁸⁴ Relatives who took part in the initiative found it very helpful. For example, one of them said ‘what difference has LSW (Life Story Work) made? It’s changed me a lot already. [...] It makes [my mum] feel good about herself. [...]. It’s given me positivity’.⁸⁵ An advocate involved in the project noted how story sharing can be helpful for her work in relation to decision-making:

⁸⁰ < www.tide.uk.net/ > accessed 23 January 2017.

⁸¹ <www.lifestorynetwork.org.uk/> accessed 26 October 2016.

⁸² <www.lifestorynetwork.org.uk/in-my-words/> accessed 26 October 2016.

⁸³ GA Moss, ‘A life story’ < <http://www.lifestorynetwork.org.uk/wp-content/uploads/downloads/2015/04/George-Moss-Life-Story.pdf> > accessed 24 January 2017.

⁸⁴ J Kendall, ‘Case Study from Dementia Advocacy Network’ < <http://www.lifestorynetwork.org.uk/wp-content/uploads/downloads/2014/02/Case-Study-Dementia-Advocacy-Network.pdf> > accessed 24 January 2017.

⁸⁵ Anonymous, ‘Time Flies’ <<http://www.lifestorynetwork.org.uk/wp-content/uploads/downloads/2015/07/I-Care-Worker-caring-for-Mum-Time-Flies.pdf>> accessed 24 January 2017.

‘advocates recognise the value of knowing something of a person’s past – when language and speech are affected as they are in someone with dementia, we rely on the past to tell us something of the person’s values and beliefs, what was important to them and therefore what might still be important. [...] I was intrigued to know more about Gordon [...]. I was passionate about doing something that would help others who might come into his life to know him and to value him [...]’.⁸⁶

Positive narratives are also at the centre of some publications by the Alzheimer Society of Finland targeting younger family members of people living with dementia. These fictional books for children, containing colourful illustrations, try to explain to their young readers the personal, emotional and relational dynamics related to dementia and memory loss.⁸⁷



Figure 3 Two pages from *Merihevesten saari*. *Olipa kerran kaukana, kaukana täältä aivan erityinen saari...* (Translation: *Sea horses island. Once upon a time far, far away from here a very special island ...*)

The *Deutsche Alzheimer Gesellschaft* provides a service of counselling for relatives and people with dementia, in which these individuals receive personalised advice on specific issues they may encounter in their everyday life.⁸⁸ Counselling services are also run by other charities around Europe such as, to name but a few, *Hrvatska udruga za Alzheimerovu bolest* (Croatian Association for Alzheimer's

⁸⁶ Kendall, *above*.

⁸⁷ See S Aavaluoma and H Härmä, *Merihevesten saari. Olipa kerran kaukana, kaukana täältä aivan erityinen saari...* (translation: *Sea Horses Island. Once upon a time far, far away from here a very special island ...*) (Muistilitto 2014).

⁸⁸ *Ibid.*

Disease)⁸⁹ Alzheimer Italia,⁹⁰ or Aktion Demenz (Austria).⁹¹ *Alzheimer Gesellschaft* organises also ‘groups of self-help’ for relatives of people living with dementia which are used by participants to ‘talk about their worries, fears and despair, but also to give mutual support, suggestions and tips and replenish the energy storage’.⁹²

Self-help groups like the German ones appear grounded on the concept of peer support. This practice consists in two or more people, who share the same life experience, providing emotional and practical help to each other.⁹³ Traditionally, it has been employed in the field of mental health services in order to fight stigma, discrimination and isolation and to support the journey of the person towards recovery. In this context, one of many successful initiatives is the ‘Next Steps Project’ (Ireland) which, through support groups, aims at providing ‘individualized support to people with intellectual disabilities so that they can live a life of their choosing.’⁹⁴ The good results achieved through this practice are extensively documented by medical literature.⁹⁵

These practices are applicable and have been applied to the field of dementia. Here, UK charities are at the forefront. Indeed, a number of them, use extensively this tool to support not only carers but also people living with dementia.⁹⁶ The promising characteristic of these practices is that they are means for providing support and advice in the specific situation. Therefore they are well placed to tackle what are the concrete causes from which stigma originates in the single case.

In the majority of cases, peer support is carried out in groups in which people living with dementia take part and that meet regularly (e.g. once a week). Here participants can exchange thoughts about their experience of living with the disease, their personal problems and even discuss their choices. In this regard, Health

⁸⁹ <www.alzheimer.hr/savjetovaliste/> accessed 23 January 2017.

⁹⁰ <www.alzheimer.it/contatti.html> accessed 23 January 2017.

⁹¹ <<http://www.aktion-demenz.at/angebote-fuer-betroffene.html>> accessed 23 January 2017.

⁹² <<https://www.deutsche-alzheimer.de/angehoerige/entlastungsangebote.html>> accessed 23 January 2017.

⁹³ S Mead, D Hilton and L Curtis, ‘Peer Support: A Theoretical Perspective’ (2001) 25 *Psychiatric Rehabilitation Journal* 134.

⁹⁴ See <<https://zeroproject.org/practice/national-federation-of-voluntary-bodies-providing-services-to-people-with-intellectual-disabilities-ireland/>> accessed 23 February 2017.

⁹⁵ I Davidson et al, ‘Peer Support among Individuals with Severe Mental Illness: A review of the evidence.’ (1999) 6 *Clinical Psychology: Science and Practice* 165.

⁹⁶ See for example the projects run by the Health Innovation Network South London <www.hin-southlondon.org/system/resources/resources/000/000/095/original/HIN_Interactive_Toolkit_September_15_LIVE.pdf>; Alzheimer Scotland <www.alzscot.org/services_and_support/peer_support>; Dementia without Walls <dementiawithoutwalls.org.uk/thinking-differently-about-dementia/peer-support/>. All websites accessed 20 January 2017.

Innovation Network (HIN) South London provide a range of peer support services, in order to fit different needs. Their ‘Peer Support for People with Dementia Resource Pack’ leaflet explains the spirit of dementia peer support and how this works in practice emphasizing how they are ‘proposing a whole system approach’ which meets the needs of the whole population of people with dementia’.⁹⁷ The components of this system include:

- Specialist peer support, usually for a time-limited period
- Dementia cafes where people can meet others who are in a similar situation on a more informal basis
- Community groups
- A network of Dementia advisers or navigators who are able to support people with dementia.⁹⁸

The success of these initiatives and the usefulness of peer support is demonstrated by the feedback coming from people living with dementia themselves. For example, a person from one of the groups in Oxfordshire explained how comfortable she felt in the group: ‘we’re all in the same boat and we don’t need to worry who is listening’.⁹⁹ A man from one of the groups run by HIN said that ‘you feel as you’ve got more freedom’, while a woman said ‘you know, we have hakes and pains and we can see it and you could say, well you can do this, you can do that’.¹⁰⁰ A facilitator involved in the same project declared ‘as well as laughing together and developing friendships they [people living with dementia] can also develop strategies because they are the people affected by dementia, that’s how they can learn from each other.’¹⁰¹

The issue of self-stigma is also at the centre of the Finnish National Memory Plan.¹⁰² In this context, the Finland Ministry of Social Affairs and Health has launched a website containing various kinds of materials.¹⁰³ These include short brochures aimed at explaining to the person and their carers the symptoms of the condition and

⁹⁷ HIN, ‘Peer Support for People with Dementia Resource Pack. Promoting peer support opportunities for people with dementia’ (HIN 2015) < http://www.hin-southlondon.org/system/resources/resources/000/000/095/original/HIN_Interactive_Toolkit_September_15_LIVE.pdf> accessed 20 January 2017.

⁹⁸ *Ibid.*

⁹⁹ < <http://dementiawithoutwalls.org.uk/thinking-differently-about-dementia/peer-support/>> accessed 20 January 2017.

¹⁰⁰ < <https://vimeo.com/123402358>> accessed 20 January 2017.

¹⁰¹ < <https://vimeo.com/138857697> accessed 20 January 2017.

¹⁰² Finnish Ministry of Social Affairs and Health, *above*, 11.

¹⁰³ See < www.muistiliitto.fi/fi/etusivu> accessed 25 November 2016.

various care strategies, a collection of stories and a ‘dementia glossary’. Interestingly, it comprises also a detailed section on the person’s rights, emphasising how it is the duty of everyone to listen to the individual and to respect their will. With regard to treatment decisions, this contributes to build first in the person, then in the relatives, the consciousness and confidence to resist situations in which doctors or nurses, following a paternalistic approach may try to put aside the wishes of the individual.¹⁰⁴

4. Training for professionals

The importance of specific training for doctors, nurses and carers is emphasised by many national dementia strategies. For example, the Norwegian Dementia Plan 2020 states that ‘it is important not only to know about dementia oneself, but also that others have the necessary knowledge’.¹⁰⁵ The Swiss National Dementia Strategy similarly notes that dementia-specific professional skills play a crucial role in guaranteeing an adequate standard of care to the person.¹⁰⁶ In this regard, with the authority typically characterising official documents of the Health Ministry, the plan urges medical professionals to adopt an ethically sensible and autonomy centred approach also when they are dealing with people living with dementia.¹⁰⁷

However, as noted by Kinderman,¹⁰⁸ in order to assure that doctors nurses and other practitioners really promote the autonomy and the right to make decisions of the person it is crucial that they are provided with specific guidance on how to act in concrete situations. In this regard, the kind of training delivered to professionals in the area of healthcare decisions needs to cover two aspects. On the one hand, it has to transmit the idea that people living with dementia, if adequately supported, are often able to participate in the decisional process. On the other hand, it needs to provide

¹⁰⁴ *Ibid.*

¹⁰⁵ Norwegian Ministry of Health and Care Services, *above*, 24.

¹⁰⁶ Federal Office of Public Health and Swiss Conference of the Cantonal Ministers of Public Health, ‘National Dementia Strategy 2014 – 2017’ (FOPH and SCCMPH 2014), 11 < www.alzheimer-europe.org/content/download/72425/451359/file/Swiss%20national%20dementia%20strategy%202014%20-%20summary.pdf> accessed 1 December 2016.

¹⁰⁷ *Ibid.*

¹⁰⁸ P Kinderman, ‘Embedding a Human Rights Based Approach to Dementia Care’ (University of Liverpool and Mersey Care NHS Trust 2014), 3 <<https://njl-admin.nihr.ac.uk/document/download/2007729>> accessed 26 January 2017.

specific instructions on what are the appropriate means of support in a certain situation and how they should be implemented.¹⁰⁹

The first channel through which such notions can be acquired by doctors, nurses, lawyers or social workers is through articles published in academic and professional journals. These publications are read regularly by healthcare and legal staff and play a valuable role in spreading new ideas among them. In this regard, the last two decades have seen a significant increase in the literature challenging the old prejudice that people living with dementia are completely unable to express indications on their care.¹¹⁰ Moreover, recent years have seen the publication of studies offering guidance on how to concretely assist the person living with dementia in deciding on their care.¹¹¹

Another way to provide training is through the organisation of courses and seminars. The Italian Dementia Plan provides for inserting, in the national training pathway for GPs, training on dementia and the management of problems of communication also in relation to consent to treatment.¹¹² This is a very important provision, as the training pathway for GPs (*'Specializzazione in medicina generale'*) is compulsory for all the graduates that want to become family doctors and will be the first person to be approached by individuals living with dementia in need of care. In addition to this, the Italian Observatory on Dementias (*Osservatorio Nazionale sulle Demenze*), local authorities and charities organise regularly conferences and training sessions on these topics in which the staff working in hospitals and care units has to take part in order to collect the credits necessary for being confirmed in their working position.¹¹³ Similar Provisions are contained also in the Spanish Plan for Neurodegenerative Diseases which urges local authorities to implement a programme of continued training for hospital staff on how to handle problems relating to the management of person centred dementia care.¹¹⁴ In addition, besides government actions, charities and NGOs throughout Europe have a rich calendar of activities in which medical and legal professionals regularly take part. It is not possible to name all

¹⁰⁹ The importance of these elements emerge from reports by NGOs such as Nuffield Council on Bioethics, *Dementia: Ethical Issues* (Nuffield 2009), 35-94.

¹¹⁰ These works are cited extensively throughout this thesis. Here I will only cite the particularly representative article by Jaworska, *above*.

¹¹¹ These works are analysed in Sections 5 and 6.

¹¹² Presidenza del Consiglio dei Ministri, *above*, 7.

¹¹³ See <<http://www.iss.it/demenze/index.php?lang=1&anno=2016&tipo=42>> and <www.alzheimer.it/corsi.html> both accessed 3 November 2016.

¹¹⁴ Ministerio De Sanidad, 'Estrategia en Enfermedades Neurodegenerativas del Sistema Nacional de Salud' (Sanidad 2016), 131 <<http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies/Spain>> accessed 26 November 2016.

of them here. Just as an example, I recall some of the largest and most well-known associations such as Alzheimer Europe,¹¹⁵ the Foundation Roi Baoudoin (Belgium),¹¹⁶ Alzheimer Society UK,¹¹⁷ Associazione Assostegno (Italy),¹¹⁸ *Alzheimer Gesellschaft* (Germany).¹¹⁹

Especially the initiatives developed by the Italian and the Spanish Health Ministries appear praiseworthy as in these cases attendance to courses is compulsory for all medical practitioners. However, the sessions dedicated on supported decision-making are still too limited in terms of time.¹²⁰ Moreover, no one of the programmes cited so far contemplates the involvement of people living with dementia. In this regard, the field of training for professionals in dementia appears as the one in which the principles of the social model of disability are the furthest from being implemented. The focus here is still very much on curing the person rather than respecting their rights.

A positive exception is represented by the French *Espace éthique Maladies neuro-dégénératives* (the Ethical Space for Neurodegenerative Diseases).¹²¹ The *Espace* has been created by the French Plan for Neurodegenerative Diseases. The plan focuses on the management of ethical problems related to medical treatment and dementia. In this regard, it dedicates one section to ‘*Faire des droits de la personne et de la réflexion éthique un levier de la conduite du changement*’ (Using the Person’s Rights and Ethical Debate as Means of change), referring to dementia as a ‘medicosocial’ problem and to the necessity of training carers especially on how to promote the autonomy of the person, as long as raising public awareness on dementia rights.¹²² For this reason, it has created a permanent forum which, through regular meetings, has the aim of promoting especially among medical practitioners a serious discussion and a better understanding of the reality which people living with dementia experience.¹²³ In this

¹¹⁵ <www.alzheimer-europe.org/> accessed 2 December 2016.

¹¹⁶ <www.kbs-frb.be/en/> accessed 2 December 2016.

¹¹⁷ <www.alzheimers.org.uk/> accessed 2 December 2016.

¹¹⁸ <www.assostegno.it/> accessed 2 December 2016.

¹¹⁹ <www.deutsche-alzheimer.de/> accessed 2 December. Other charities are mentioned throughout this chapter.

¹²⁰ In general a couple of hours in the entire course are dedicated to this issue. See for example <<http://www.iss.it/demenze/index.php?lang=1&anno=2016&tipo=42>> accessed 17 February 2017.

¹²¹ Ministère des Affaires sociales, de la Santé et des Droits des femmes, ‘Plan maladies neurodégénératives 2014-2019’ (Dicom 2014), <www.alzheimer-europe.org/content/download/86515/554682/file/2014%20Plan%20maladies%20neuro%20degenerati ves.pdf> accessed 24 October 2016.

¹²² *Ibid*, 76-78.

¹²³ For further information see <<http://mnd.espace-ethique.org/>> accessed 27 October 2016.

context, medical professionals learn how to handle ethical problems and how to promote the right to decide of the person living with dementia, through the debate with colleagues and service users.¹²⁴ These kinds of initiatives are very valuable for increasing the centrality of the person in medical care. Indeed, they involve primary stakeholders in the debate. In addition, mechanisms like the *Espace étique* offer precious opportunities for care workers to discuss their problems and dilemmas with colleagues and feel more supported.

A promising example of training programme outside the context of healthcare is the one developed in the UK by the Liverpool Housing Trust (LHT) in cooperation with Dementia Action Alliance, a group formed mainly by people living with dementia.¹²⁵ This project originates from the increased consciousness that many applicants or tenants have dementia or similar cognitive impairments. Therefore, the initiative aims at training staff to identify the kind of assistance needed by these individuals and to ensure that they receive the right type of support in order to maintain their own independence.¹²⁶ The programme includes courses conducted by members of Alzheimer Action Alliance on how to recognize the symptoms of dementia, how to deal with difficulties of behaviour or communication and raising awareness on the fact that people living with dementia are human beings with the right of being helped in carrying on their lives.¹²⁷ In addition, people from the Alliance assist the Trust staff in their everyday work, providing advice on how to deal more effectively with dementia related problems that may come out.¹²⁸ This is a very praiseworthy characteristic of the project. Indeed, here training is provided with regard to specific situations, giving the possibility to explore the concrete and sometimes unexpected issues which characterize everyday practice in every sector.

5. Supported decision-making techniques

The ‘Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities’ refers to supported decision-making as the action put in place by one

¹²⁴ Ministère des Affaires sociales, de la Santé et des Droits des femmes, *above*, 77-78.

¹²⁵ <http://www.dementiaaction.org.uk/members_and_action_plans/1479-liverpool_housing_trust> accessed 14 January 2014.

¹²⁶ *Ibid.*

¹²⁷ *Ibid.*

¹²⁸ *Ibid.*

or more individuals who explain a series of issues to the person or, when necessary, interpret their words and behaviour in order to identify their preferences.¹²⁹ These two components of assistance/explanation and interpretation emerge from the various initiatives focusing on helping mentally disabled people in general and people living with dementia in particular to exercise their legal capacity.

In this regard, relevant practices have been emerging in various contexts. Healthcare is one of the sectors in which a higher number of projects has been developed on a European scale.¹³⁰ Indeed, as already seen in Chapter 1, because of their old age, people living with dementia need often medical assistance. Moreover, decisions in this field are often ethically sensible, inducing doctors to make every attempt to seek the person's opinion.¹³¹ Practices in this area are generally referred to under the label 'shared decision-making'.¹³² Nonetheless, interesting ideas come also from projects focusing on non-medical decisions. It is the case of initiatives developed within the context of 'dementia friendly community' programmes. This concept refers to actions aiming at removing the obstacles preventing people with dementia from living a fulfilling life and be included in society.¹³³ In this context, for example, valuable projects have been developed with the aim of assisting the person in doing shopping or managing their bank account.

With regard to healthcare, associations of medical professionals like the European Association for Palliative Care (EAPC) and the UK Royal College of Ophthalmologists (RCO) have issued official guidelines on shared decision-making in dementia. These documents are a very positive step towards a better promotion of the right to decide on medical treatment of individuals living with this condition. Indeed, for the first time authoritative bodies, with whose directives medical professionals are

¹²⁹ UN-DESA and OHCHR, *From Exclusion to Equality. Realizing the Rights of Persons with Disabilities. Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities* (UN 2007) 89-90, available at < www.un.org/disabilities/default.asp?id=242> accessed 10 March 2016.

¹³⁰ For information on the scale of the debate in medical practice see LM Miller, CJ Whitlatch and KS Lyons, 'Shared Decision-Making in Dementia: A Review of Patient and Family Carer Involvement' (2016) 15 *Dementia* 1141.

¹³¹ See Chapter 1.

¹³² See among others CH Braddock, 'The Emerging Importance and Relevance of Shared Decision Making in Clinical Practice' (2010) 30 *Medical Decision Making* (Supplement); A Coulter and A Collins, *Making Shared Decision-Making a Reality. No decisions about me without me* (The King's Found 2011), vii; RM Epstein and RL Street, 'Shared Mind: Communication, Decision Making, and Autonomy in Serious Illness' (2011) 9 *Annals of Family Medicine* 454.

¹³³ See < <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities>> accessed 3 December 2017.

required to comply, state clearly that people living with dementia should be supported and involved in the decisional process rather than substituted. The recommendations on shared decision-making by the EAPC, which is made of practitioners and common citizens from 48 European countries and associations from 32,¹³⁴ are contained in a wider guide on the treatment of older people and people living with dementia.¹³⁵ In this context, eleven scenarios and fifty seven recommendations are identified.¹³⁶ Among them, particularly relevant are those emphasising how the person and their family members have to be involved in the decisional process on medical treatment (recommendation 2.2).¹³⁷ Moreover, the document affirms that perceived problems of care should be seen from the person's perspective, prioritising relational aspects as much as care ones (recommendation 2.1).¹³⁸ Finally, it asks the doctor to inform, educate and emotionally support family members, in order to avoid that their sense of burden and stigma impacts negatively on the person (scenario 9).¹³⁹ Similar principles are affirmed by the RCO.¹⁴⁰ In this context, the College requires all ophthalmology departments to make sure they have members of staff specifically trained in communicating with people living with dementia (quality statement 1).¹⁴¹ In addition, it encourages professionals to work in partnership with carers or advocacy services, to explain information in a way that is understandable to the person and to make sure that they are following the reasoning (quality statement 2).¹⁴² Finally, it urges departments to provide individuals living with dementia with longer appointments and the possibility of rescheduling the session if that day they seem agitated or lost (quality statements 3 and 4).¹⁴³

While acknowledging the potential of the declarations cited so far, it has to be admitted that formal documents clearly in favour of shared decision-making in

¹³⁴ < www.eapcnet.eu/Corporate/AbouttheEAPC.aspx> accessed 19 January 2017.

¹³⁵ EAPC, 'Recommendations on Palliative Care and Treatment of Older People with Alzheimer's Disease and other progressive Dementias' (June 2013) < www.eapcnet.eu/LinkClick.aspx?fileticket=xhe-DLmfNb4%3D> accessed 19 January 2017.

¹³⁶ *Ibid.*

¹³⁷ *Ibid.*, 4-5.

¹³⁸ *Ibid.*, 4.

¹³⁹ *Ibid.*, 14-16.

¹⁴⁰ The Royal College of Ophthalmologists, 'Quality Standard for People with Sight Loss and Dementia in an Ophthalmology Department' (RCO 2005) < www.rmib.org.uk/sites/default/files/Quality-standard-for-people-with-sight-loss-and-dementia-in-an-ophthalmology-department.pdf> accessed 30 November 2016.

¹⁴¹ *Ibid.*, 6.

¹⁴² *Ibid.*, 7-8.

¹⁴³ *Ibid.*, 9-12.

dementia care do not seem to have been issued by other professional bodies. Moreover, also in the cases reported above language (e.g. the use of the word ‘patient’) shows how the medical model is still exerting its influence. Also, though they are developed taking into account the opinions of service users, people living with dementia are not involved in the drafting of these documents. Finally, there are still no official data on how many doctors and nurses are applying the principles under discussion and how they really work in practice.

In this regard, an idea of how such statements may be implemented is given by the experiences of *équipes* from Dutch,¹⁴⁴ British,¹⁴⁵ Norwegian¹⁴⁶ and Italian¹⁴⁷ hospitals and nursing homes.¹⁴⁸ All These experiences make use of support networks made up by the person, their relatives and the doctor, following what recommended by the EAPC. Anyway, though the fact that they are taking place is an encouraging signal, studies such as the review published by Miller, Whitlatch, and Lyons show how these practices are still not widespread and they often encounter the scepticism and prejudice of medical professionals.¹⁴⁹

Among these initiatives, particularly promising is the one carried on by Mariani et al, in a Dutch and an Italian Nursing home.¹⁵⁰ It stands out because it uses the action of each member of the support group in order to balance and complement that of the others.¹⁵¹ In addition, it considers also the impact of the social and cultural environment. Finally, it includes a structured preliminary training session for healthcare professionals. Indeed, the staff of the two structures involved was invited to take part in a communication skills course featuring elements of role-playing technique.¹⁵² Then, they had to conduct discussion sessions with people living with

¹⁴⁴ L Groen-van de Ven et al, ‘The challenges of shared decision making in dementia care networks’ [2016] *International Psychogeriatrics* 1; E Mariani et al, ‘Shared Decision-Making in Dementia care planning: barriers and facilitators in two European countries’ (2017) 21 *Aging Mental Health* 31.

¹⁴⁵ See, among others, G Livingston et al, ‘Making Decisions for People with Dementia who Lack Capacity: qualitative study of family carers in UK’ (2010) 341 *British Medical Journal* 1; R Daly, F Bunn and C Goodman, ‘Shared Decision-Making for People living with Dementia in Extended Care Settings: protocol for a systematic review’ (2016) 355 *British Medical Journal* 1.

¹⁴⁶ KL Smebye, M Kirkevold and K Engedal, *above*, 241.

¹⁴⁷ Mariani et al, *above*.

¹⁴⁸ The name and exact location of the care structures involved in the cited studies is not disclosed for reasons of research ethics.

¹⁴⁹ Miller, Whitlatch and Lyons, *above*.

¹⁵⁰ Mariani et al, *above*, 32.

¹⁵¹ This practice is endorsed by A Larke, EJ Hanson and H Ross, ‘Seeing the Person Behind the Patient: Enhancing the Care of Older People Using a Biographical Approach’ (2003) 12 *Journal of Clinical Nursing* 697; CG Shields et al, ‘Influence of Accompanied Encounters on Patient-Centeredness with Older Patients’ (2005) 18 *Journal of the Administrative Board of Family Practitioners* 344.

¹⁵² *Ibid*, 31.

dementia and their relatives and draft an agreed care plan for the person.¹⁵³ In this regard, the role of the family caregiver is described as really important in understanding the needs of the person. However, especially in the Italian context, there is often the risk that the family caregiver tries to substitute themselves to the person.¹⁵⁴

In this regard an Italian professional affirms:

‘During some interviews, the family caregivers supported us and suggested issues to discuss. We have learnt a lot from them [...] but sometimes family caregivers want to substitute themselves to the residents, and answer in their place. This does not facilitate the discussion with residents.’¹⁵⁵

In these cases the care professional may counterbalance the disruptive action of the relative, as explained by another Italian nurse:

‘During one interview, the family caregiver wanted to focus on a topic that was different from the question addressed to the resident. However, the resident kept repeating the same answer, meaning that for her the topic was important. Thus, the psychologist reassured the resident, who consequently started feeling more at ease, and that she had a leading role in the situation. In fact, [at the start of the interview] the resident was really agitated and had spasms, whereas, at the end, she was quiet and peaceful. The family caregiver then understood that the topic was important for her mother’.¹⁵⁶

The risk of undue interference and the importance of the balancing role of each member of the network is emphasised also by Smebye, Kirkevold and Engedal in relation to the Norwegian context.¹⁵⁷ The researchers show how there are situations in which doctors and professional carers fail to challenge the preconceptions of family members.¹⁵⁸ In this regard, an issue characterising all the experiences analysed so far is that the support network does not include an independent advocate, which promotes the will of the person in situations where professionals and family members share

¹⁵³ *Ibid*, 32.

¹⁵⁴ *Ibid*, 38-39.

¹⁵⁵ *Ibid*, 36.

¹⁵⁶ *Ibid*.

¹⁵⁷ Smebye, Kirkevold and Engedal, *above*, 250.

¹⁵⁸ *Ibid*, 246-247.

interests which are conflicting with that of the individual living with dementia. The opposite problem has come out in the Dutch context. Here it has emerged how sometimes family members are not willing to be involved in the support network, frustrating the process.¹⁵⁹

Anyway, with regard to the British context, Livingston shows that when the discussion within the support network is conducted properly and everyone is involved, the result can be quite satisfactory.¹⁶⁰ In this context, a relative of a person living with dementia affirmed:

‘We weren’t in agreement with each other...whether to have an heart operation...with hindsight...it was the right decision...he decided...it made his mental abilities much worse, but physically, he’s much better.’¹⁶¹

With regard to specific support techniques, according to medical literature on shared decision making explanation and simplification are among the most important actions to achieve a meaningful communication with the person interested by a certain treatment decision.¹⁶² In this regard, a promising practice is the one developed in Norway by Smebye, Kirkevold and Engedal.¹⁶³ They have developed a shared decision-making procedure which provides that family members actively explain the information to the person and indicate how they have to proceed. The Norwegian researchers report that:

‘Family carers and professional caregivers ensured that persons were informed and checked to make sure that they understood what the information meant in their situation. [...] Stating possible alternatives in a clear and concrete manner was at times necessary. Failing memory was compensated with aids/props to make options clearer. Narrowing the range of available choices because of limited powers of concentration and deliberation reduced confusion and promoted autonomous decision making’.¹⁶⁴

¹⁵⁹ *Ibid*, 36.

¹⁶⁰ Livingston et al, *above*. See also T Hope, A Slowther and J Eccles, ‘Best Interests Dementia and the MCA 2005’ (2009) 35 *Journal of Medical Ethics* 733.

¹⁶¹ Livingston et al, *above*, 6.

¹⁶² Epstein and Street, *above*, 457.

¹⁶³ Smebye, Kirkevold and Engedal, *above*.

¹⁶⁴ *Ibid*, 245.

The opinions of caregivers involved in the experience show that often these techniques lead to an improvement of the ability of the person to decide on medical treatment.¹⁶⁵ However, there are also cases in which, despite the aid provided, the person appears not capable of understanding what disclosed, as the cognitive impairment is too extensive.¹⁶⁶

Projects inside and outside the healthcare sector focus on providing accessible information to the person. This sort of practice is endorsed also by the Committee on the Rights of Persons with Disabilities who, among the possible forms of supported decision-making mentions providing information in an understandable format.¹⁶⁷ The importance of accessibility in healthcare information is emphasised also by ANED in various national reports, on the accessibility of health information and data for mentally disabled people in general.¹⁶⁸

In this context, a praiseworthy initiative is the one promoted by the Dementia Engagement and Empowerment Project (DEEP), which published a guide on how to write ‘dementia friendly information’.¹⁶⁹ This guide appears a very valuable tool in order to understand how to support people living with dementia in making decisions. It provides a clear list of what characteristics make a document more accessible. In addition, it is drafted by people living with dementia themselves, making sure that the principles affirmed really match the needs of service users.¹⁷⁰ In this regard, tips provided by DEEP include presenting information ‘logically, one piece at a time’, keeping language simple, writing concisely and using quotations and examples in order to help the person understand the main points.¹⁷¹ In addition, they suggest to make use of pictures, distinguish sections by using different colours, and prefer bold to italics.¹⁷²

¹⁶⁵ *Ibid.*

¹⁶⁶ *Ibid.*, 246-247.

¹⁶⁷ Committee on the Rights of Persons with Disabilities, ‘General Comment No. 1 (2014). Article 12: Equal recognition before the law’ (CRPD/C/GC/1 30 March–11 April 2014), 4 <<http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>> accessed 26 January 2015.

¹⁶⁸ See <www.disability-europe.net/theme/health> accessed 3 December 2016.

¹⁶⁹ DEEP, ‘Writing dementia-friendly Information’ (DEEP 2013) <<http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf>> accessed 21 February 2017.

¹⁷⁰ For information on the composition of the group see <<http://dementivoices.org.uk/>> accessed 21 February 2017.

¹⁷¹ DEEP, *above*, 2.

¹⁷² *Ibid.*, 3.

Similar indications emerge from the NHS Accessible Information Standard.¹⁷³ This document ‘aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand’.¹⁷⁴ Its provisions have to be applied by ‘all organisations that provide NHS care or adult social care’.¹⁷⁵ In this context, in relation to mentally disabled individuals, the Standard’s Implementation guide includes communication tips such as, for example:

- ‘Identify yourself clearly [...]
- Keep your face and lips visible [...]
- Use gestures and facial expressions to support what you are saying.
- If necessary, repeat phrases, re-phrase the sentence or use simpler words or phrases.
- Use plain, direct language and avoid using figures of speech [...]
- Check if the person has understood what you are saying.’¹⁷⁶

The guide also states that it is crucial to keep on the person’s record a note of their communication needs and of all the conversations between them and their doctors so that such exchanges of information are easier to recall when needed. These records have to be made available to the person.¹⁷⁷

This initiative undertaken by NHS England appears really promising. Indeed, the above mentioned Accessible Information Standard is binding for all service providers under the NHS England.¹⁷⁸ Therefore, it stands good chances to be applied extensively in hospitals throughout the country.¹⁷⁹ For this reason, it represents an example which should be followed by other health authorities in Europe.

Outside the healthcare sector the goal of providing accessible services and support for people living with dementia is pursued also by Lloyds Bank within its Disability and Dementia friendly policy. In this context, apart from aids specifically concerning banking services, the company provides support means which can be used also in other contexts. These include, providing informative material on single products which is

¹⁷³ See <<https://www.england.nhs.uk/ourwork/accessibleinfo/>> accessed 14 January 2017.

¹⁷⁴ *Ibid.*

¹⁷⁵ *Ibid.*

¹⁷⁶ NHS England, *Accessible Information: Implementation Guidance* (NHS 2016), 15.

¹⁷⁷ *Ibid.*, 25-26.

¹⁷⁸ <www.england.nhs.uk/ourwork/accessibleinfo/> accessed 21 February 2017.

¹⁷⁹ Unfortunately there are still no data on the extent to which the principles of the standard are applied in practice.

understandable by a person with dementia, disclose openly when a certain product is not appropriate for people living with this condition or suggesting to the person where to get further assistance if they are trying to go for a potentially dangerous choice.¹⁸⁰ An important provision is the commitment to review constantly the support means the bank offers in light of the feedback from clients with dementia, in order to respond to emerging needs.¹⁸¹

6. Supported decision-making and management of communication problems

As shown by a number of studies, problems of communication are among the main practical barriers to support in decision-making of people with dementia.¹⁸² In this context, particularly difficult to handle appear the memory lapses that the person shows and the fact that he or she often struggles to find the right words.¹⁸³ Another relevant issue is the fluctuation of the person's cognitive abilities and the fact that he/she tends to change his/her opinions.¹⁸⁴

In order to address such issues, a number of researchers have been focusing on how to build a more effective dialogue with the person, which can be carried on continuously day after day. Muramoto stresses how the progressive nature of dementia requires a vision of treatment decisions as a process which goes on for several years and during which the person's memories fade away.¹⁸⁵ The researcher, proposes that this loss of memories is counteracted through the action of the relatives and close friends of the individual with dementia, who can act as 'an external memory', reminding him/her the elements he/she does not remember anymore.¹⁸⁶ This idea appears quite promising as it suggests a specific use of networks of support in order to

¹⁸⁰ < www.lloydsbank.com/accessibility.asp#tab-row-5 > accessed 15 January 2017.

¹⁸¹ Alzheimer Society and Lloyd's Bank, 'Dementia-Friendly Financial Services' (AlzSoc 2013) 7-9 < www.dementiafriends.org.uk/servlet/servlet.FileDownload?retURL=%2Fapex%2FWEBArticle%3Fpage%3Ddementia-friendly-communities&file=00P2000000quqLwEAI > accessed 17 January 2017.

¹⁸² See for example DT. Maust et al 'Treatment Decisions Regarding Hospitalization and Surgery for Nursing Home Residents with Advanced Dementia: the Care AD Study' (2008) 20 *International Psychogeriatrics* 406.

¹⁸³ *Ibid.*

¹⁸⁴ M Giampieri, 'Communication and Informed Consent in Elderly People' (2012) 78 *Minerva Anestesiologica*, 236.

¹⁸⁵ O Muramoto, 'Socially and Temporally extended End-of-Life Decision-Making process for Dementia Patients' (2011) 37 *Journal of Medical Ethics* 1.

¹⁸⁶ Muramoto, *above*, 3.

solve one of the most urgent issues emerging in everyday practice. The study cited above does not report empirical data or practical experiences. However, this use of networks of support emerges in some of the experiences I have been referring to in previous sections. For example, one of the facilitators from the peer support network organised by HIN South London, stresses how the network is often used by the person to recall information and experiences.¹⁸⁷ In addition, Smebye, Kirkevold and Engedal report an episode, from their experience in a Norwegian nursing home, in which the carer acts as a reminder for the person in relation to daily personal care, saying, for example:

‘It is Friday today and on Fridays we have an agreement about showering. Look at your plan for the week written on your board. Come let me help you!’¹⁸⁸

Apart from that, the idea of ‘external memory’ has inspired many practices which use analogical or digital memory aids. Clark and Chalmers show how it can be very helpful that the person keeps a notebook, so he/she can record experiences, facts and notions, and can retrieve the information when needed. This arrangement is recommended by studies and charities.¹⁸⁹ Some private companies are starting to sell memory bank DVDs for people with dementia, on which the person or his/her relatives can record notions that need to be remembered.¹⁹⁰ Similar aids are developed in the area of telecare, in which products such as watches or other digital tools are sold in order to remind the person of taking medications or going to appointments with his/her GP.¹⁹¹

Information technology permits to go even beyond simply sending reminders. Some groups of researchers have developed IT tools for supporting people with dementia in the decision-making process using. For example, an *equipe* of Dutch experts have developed DEcideguide, ‘an interactive web tool (in development) that case managers can use in facilitating shared decision making in care networks of

¹⁸⁷ < <https://vimeo.com/123402358> > accessed 20 January 2017.

¹⁸⁸ Smebye, Kirkevold and Engedal, *above*, 247.

¹⁸⁹ A Clark and D Chalmers, ‘The Extended Mind’ (1998) 58 *Analysis* 7, 12-13. See also Alzheimer Society, ‘The Dementia Guide. Living Well after the Diagnosis’ (AlzSoc 2015), 43 < www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2240&pageNumber=2 > accessed 30 November 2016.

¹⁹⁰ See for example < www.alzproducts.co.uk/memory-bank-dvd-resource-pack-for-dementia-alzheimers.html > accessed 23 February 2017.

¹⁹¹ See among others < <http://hivinsite.ucsf.edu/InSite?page=kb-04-01-03> > accessed 23 February 2017.

people with dementia'.¹⁹² It consist in a chat room in which the person with dementia can freely interact with other members of his/her support network, an application through which the members of the network can discuss the different stages of a certain decision, and a tool which permits to the person to isolate and analyse his/her feelings on certain aspects of his/her choice.¹⁹³ This programme can be very helpful, especially in case of younger people with dementia who have more familiarity with IT, in order to guarantee a constant interaction of the person with his/her support network.¹⁹⁴ The team which created this tool is still working in order to make it more accessible, following the advice of users themselves, who suggested to simplify the graphic interface and the language used.¹⁹⁵

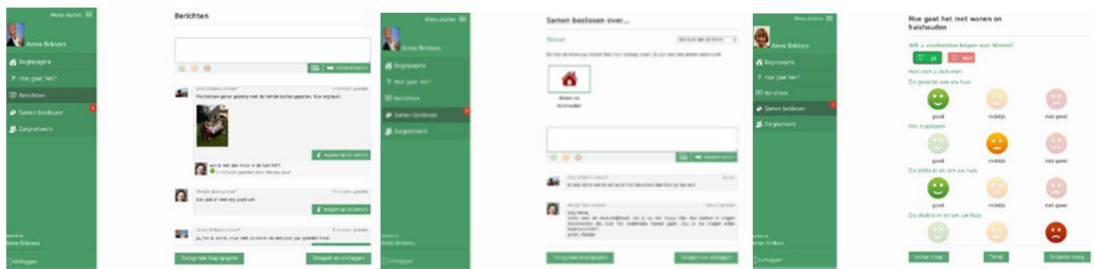


Figure 4 Screenshots of the DDecideguide

As stresses by Fritschy, Kessels and Postma, the technological aids mentioned above open very promising perspectives especially with regard to the goal of providing better assistance to people living alone or in isolated areas.¹⁹⁶ In particular, they can be of great help in relation to treatment decisions, as they can be used by the person to record his/her will on medical treatment or his/her opinions on certain medications. However, they are often expensive and require a level of technological literacy which often people with dementia do not have because of their age.¹⁹⁷ A possible way to solve this problem could be, of course, trying to modify the interface of such tools. This solution, for example, has been tried with success in the case of people with cerebral palsy by Confederación ASPACE and Vodafone Spain Foundation.¹⁹⁸ In this

¹⁹² M Span et al, 'Developing a Supportive Tool to Facilitate Shared Decision-Making in Dementia' (2015) 7 *Frontiers in Aging Neuroscience* 253.

¹⁹³ *Ibid* 254-255.

¹⁹⁴ *Ibid*.

¹⁹⁵ *Ibid* 256.

¹⁹⁶ EP Fritschy, RF Kessels and A Postma, 'External memory aids for patients with dementia: a literature study on efficacy and applicability' (2004) 35(6) *Tijdschrift voor Gerontologie Geriatrie* 234.

¹⁹⁷ *Ibid*.

¹⁹⁸ For a summary of the project see < <https://zeroproject.org/practice/using-ict-to-empower-persons-with-cerebral-palsy/>> accessed 23 February 2017.

context, hardware and apps have been developed which permit to enter text through voice or adapted keyboards (with pictograms, enlarged keys, etc.).¹⁹⁹

In addition to such issues, we need to consider that many of these applications imply the storage a huge amounts of sensible data, requiring to seek previously the consent of the person. As shown by Batchelor et al, making sure that a person with dementia, especially in an advanced stage is really in the position to consciously consent to the use of his/her personal data could be extremely challenging²⁰⁰

Other researchers and charities are focusing on solving communication problems by creating a better environment for the person. Giampieri, in relation to his experience with older people in an Italian hospital, stresses that supported decision-making may also consist in trying to overcome possible difficulties of communication.²⁰¹ In this context, doctors, nurses or relatives have to identify the moments in which the person appears more lucid, making him or her feel at ease during the conversation and assisting him/her with words or concepts that may not come immediately to mind. In fact, one of the main source of difficulties when trying to communicate with a person with dementia and obtaining from him/her a decision on medical treatment is the psychological pressure that the individual feels.²⁰²

On how to manage the communication with the person with dementia concentrate some projects outside the area of healthcare. For example, Alzheimer Scotland has recently launched a programme aimed at making shops around the country more dementia-friendly.²⁰³ In this context it has issued instructions to retail shops on how to favour the information exchange with the individual.²⁰⁴ Such guidelines have been elaborated in cooperation with people with dementia, their carers and medical experts,

¹⁹⁹ *Ibid.*

²⁰⁰ R Batchelor et al, 'Challenges of ethical and legal responsibilities when technologies' uses and users change: social networking sites, decision-making capacity and dementia' (2012) 14 *Ethics and Information Technology* 99.

²⁰¹ Giampieri, *above*.

²⁰² See JM Chalmers, 'Behaviour Management and Communication Strategies for Dental Professionals when Caring for Patients with Dementia' (2000) 20(4) *Special Care in Dentistry*, 247; R O'Halloran, L Hickson and L Worrall, 'Environmental factors that influence Communication between People with Communication Disability and their Healthcare Providers in Hospital: a review of the literature within the International Classification of Functioning, Disability and Health (ICF) framework' (2008) 43(6) *International Journal of Language & Communication Disorders*, 601.

²⁰³ See <http://www.alzscot.org/dementia_friendly_communities> accessed 23rd January 2017.

²⁰⁴ Alzheimer Scotland, 'Building a Dementia-Friendly Community. Tips for Shops and Businesses' <http://www.alzscot.org/assets/0001/2870/Hints_and_Tips_for_Shops_and_Businesses.pdf> accessed 23rd January 2017.

on the basis of everyday life experience.²⁰⁵ In this regard the association recommends the following steps:

1 Speak clearly. Speak clearly, calmly and slowly to allow the person time to understand information. Use simple short sentences and avoid direct questions. Keep choices to a minimum and don't raise your voice. [...] If the person finds it difficult to find a word, then you could suggest one... but be careful not to interrupt or finish the sentence for them!

2 Body language. People with dementia may find it difficult to understand what is being said but can be quick to interpret the message on people's faces and may still be aware of body language. Smile warmly, make eye contact, make sure you are at the person's level, use a friendly tone and respect personal space.

3 Listen. Listen carefully to what the person has to say, giving plenty of encouragement, whilst looking out for other clues of what they might be trying to communicate.

4 Show respect and patience. Adapt what you are saying if the person with dementia does not understand it. Allow them time to find the words to tell you what they want. Don't rush and try to go at their pace.

5 Noise. A person with dementia may have difficulty listening if there are a lot of different noises around them. Reduce unnecessary noise or move to a quieter area.

6 Lighting. Make sure the lighting is sufficient so the person with dementia can see you and everything around them clearly. Turn up the lights or move to a well-lit area.²⁰⁶

At the moment there are no surveys reporting the opinions of people with dementia in these projects. However, in relation to the Scottish project, material relating to the development of the initiative in some communities show that that shop owners consider it a successful and helpful initiative.²⁰⁷ Moreover, the fact that the number of retail companies that decide to join the project can be considered as a confirmation of the satisfaction of customers with dementia.

²⁰⁵ Alzheimer Scotland, 'Dementia is Everyone's Business. Building Motherwell's Dementia Friendly Community' < http://www.alzscot.org/assets/0001/4677/Dementia_Everyone_27s_Business.pdf> accessed 23rd January 2017.

²⁰⁶ Alzheimer Scotland, 'Building a Dementia-Friendly Community', *above*, 1-2.

²⁰⁷ Alzheimer Scotland, 'Dementia is Everyone's Business', *above*, 24-27.

Giampieri focuses also on the aspect of the interpretation of the person's will.²⁰⁸ In this context the role of the supporter would consist in trying to resolve possible contradictions in the person's statements, even by asking him or her for further clarifications. Moreover, he or she may also be required to identify the utterances which do not have to be taken into account, being the result of misunderstandings or moments of distress.²⁰⁹ Finally, the work of the interpreter may also include taking into account statements of the person not regarding directly the treatment decision that may nonetheless be useful for reconstructing the person's opinions.²¹⁰ These sort of aid is in line with the general principles of shared decision-making, in particular with that of shared decision.²¹¹

Smebye, Kirkevold and Engedal, describing some of the promising practices observed in their research summarise quite well how all these techniques fit together in shared decision-making with people with dementia:

It was typical that there was an exchange of information and a questioning and answering pattern in the dialogue. Helpers who were aware of how important it was to ensure the flow of information, enquired about the person's views, checked to make sure they understood the information and waited for answers. Questions were also used to remind persons of their options'.²¹²

7. Monitoring of the quality of support and protection from undue influence

Scholarly works and experience in everyday care practice show that supported and shared decision-making are valuable means to promote the autonomy of people with mental disabilities like dementia, but, if not correctly applied, can turn into forms of hidden substituted judgement or undue influence.²¹³ Therefore it is crucial to put in

²⁰⁸ See Giampieri, *above*.

²⁰⁹ *Ibid.*

²¹⁰ *Ibid.*

²¹¹ See *above*.

²¹² Smebye, Kirkevold and Engedal, *above*, 247.

²¹³ See A Ho, 'Relational Autonomy or Undue Pressure? Family's role in Medical Decision-Making' (2008) 22(1) *Scandinavian Journal of Caring Sciences* 128. Situations in which relatives and doctors fail to support the person with dementia in his/her decision-making, rather substituting him/her are reported by Smebye, Kirkevold and Engedal, *above*, 250.

place strategies to assure the person is adequately supported and that his or her will is always put at the centre of the decisional process.

In this context, in many European countries there are authorities with the specific role of monitoring what happens inside care settings also with regard to consent to treatment. One of these is the English Care Quality Commission (CQC).²¹⁴ The Commission is the independent regulator of health and adult social care in England. Also thanks to its local divisions spread throughout the country it constantly monitors GPs, hospitals, care homes and other care services providers, collecting feedback sent directly from service users and having the power of inspecting care structures.²¹⁵ The main goal of this body is ensuring that care services comply with fundamental standards of care which include the respect of person centred care principles, of the dignity of the person and of his or her autonomy and consent.²¹⁶ The CQC plays an important role on holding accountable service providers for their failures in promoting the autonomy of mentally disabled people. In this context, through its periodical reports, it constantly stigmatises situations in which the voice of individuals with cognitive impairments like dementia is not given adequate consideration in choices regarding healthcare.²¹⁷ However the structural characteristics of this monitoring mechanism make it a good tool to promote improvements on a macro-level and in the long term, rather than preventing single situations of abuse, which normally are reported by the CQC once they have already happened.

A valuable means in order to react to situations in which the person's will is disregarded is independent advocacy. This concept, widely employed in mental health, refers to a series of actions aimed at promoting and defending the rights and dignity of mentally disabled individuals.²¹⁸ This service is often provided by charities and NGOs which, apart from running awareness-raising and anti-stigma campaigns intervene in single situations in order to advocate for the person interests when they are at risk of

²¹⁴ <www.cqc.org.uk> accessed 20 January 2017.

²¹⁵ <www.cqc.org.uk/content/who-we-are> accessed 20 January 2017.

²¹⁶ <www.cqc.org.uk/content/fundamental-standards> accessed 20 January 2017.

²¹⁷ See among others CQC, 'Monitoring the use of the Mental Capacity Act Deprivation of Liberty Safeguards in 2011/12' (CQC 2013) <www.cqc.org.uk/sites/default/files/documents/dols_report_-_main_-_final.pdf>; CQC, 'Better Care in My Hands. A Review of how People are Involved in their Care' (CQC 2016) <https://www.cqc.org.uk/sites/default/files/20160519_Better_care_in_my_hands_FINAL.pdf> accessed 20 January 2017.

²¹⁸ WHO, 'Advocacy for Mental Health' (WHO 2003) 2.

being neglected. However the role may be played also by a trusted family member.²¹⁹ An advocate can be appointed by the person, or, in certain cases provided by the law, *ex officio*.²²⁰ Within the context of mental health one of the many associations providing this service is ‘Mind’ a British organisation which, through its local groups spread around the UK, provides volunteer advocates to people with any mental or cognitive impairment.²²¹

An independent advocacy service addressed also to people with dementia is run by Leeds based Advonet.²²² This organisation provides advocates on request of the person or his/her family members or friends. These individuals make sure that the people they assist ‘have a voice’ making sure that when ‘they are speaking themselves are heard’ and that ‘the rights and the likely preferences of people who can’t speak for themselves re respected’.²²³ In this context the goal of every advocate is making sure that people with dementia:

- play a full part in decisions about everyday matters affecting their lives;
- play a full part in major life decisions, for example, about moving home;
- obtain outcomes that they want;
- prevent outcomes that they do not want;
- ensure their needs are met;
- protect their rights and secure their entitlements;
- promote their wellbeing;
- improve their quality of life’.²²⁴

In order to provide more incisive assistance to people with dementia in case of abuses many charities run a helpline service. In this context, people with dementia, their relatives and their carers may contact an association specialised in dementia care in case of emergencies or because mistreatment is taking place.²²⁵ The call centre then gives to the person the indications he or she needs and in case sends volunteers to deal

²¹⁹ *Ibid.*

²²⁰ *Ibid.*

²²¹ See <www.mind.org.uk/information-support/guides-to-support-and-services/advocacy/finding-an-advocate/#.WJRvfaNFCUk> accessed 21 January 2017.

²²² <www.advonet.org.uk/> accessed 21 January 2017.

²²³ <<http://www.advonet.org.uk/advocacy-in-leeds/a-z-directory>> accessed 21 January 2017.

²²⁴ *Ibid.*

²²⁵ See for example <http://www.alzscot.org/services_and_support/dementia_helpline> accessed 21 January 2017.

with the situation. In Europe services like this are run, to name but a few, by Deutsche Alzheimer Gesellschaft,²²⁶ Alzheimer Iceland,²²⁷ or Alzheimer Croatia.²²⁸

8. Conclusion

From the overview contained in this chapter a picture emerges characterised by light and shadow. In various European countries governments, hospitals, care homes, charities and citizens seem to increasingly understand the necessity of supporting people with dementia in being included in society and in deciding on their medical treatment. In this regard, we can see a relatively significant number of initiatives being developed throughout the continent. However, despite the encouraging trend, the coverage of such practices is still far from being extensive. In fact, they are often limited to single care structures or local areas.

This perception may be in part due to the practical and language limitations of this research, disclosed in the Introduction. However, the existence of this patchwork-like scenario is also confirmed by other studies and international reports.²²⁹

To be more precise, with regard to anti-stigma actions targeting the general public, relatives of people with dementia and people with dementia themselves, we can find successful campaigns in a vast number of European countries. However, they often fail to stress that including the person in society implies also respecting his or her decisions on medical treatment. Finally, still too few awareness raising campaigns in relation to dementia stress the importance of the UNCRPD.

In relation to training programmes for dementia care professionals, it is positive that governments and charities are putting increasing efforts in their development. Moreover, training programmes appear still too focus on medical aspects and often fail to include sessions in which participants can actually discuss with people with dementia.

In the area of specific support techniques, practices developed inside and outside the healthcare sector propose really interesting ideas. However, the occasions in which

²²⁶ <www.deutsche-alzheimer.de/unsere-service/alzheimer-telefon.html> accessed 21 January 2017.

²²⁷ <<http://www.alzheimer.is/>> accessed 21 January 2017.

²²⁸ <<http://www.alzheimer.hr/>> accessed 21 January 2017.

²²⁹ See Alzheimer Disease International, 'World Alzheimer Report 2012', *above*; Miller, Whitlatch and Lyon, *above*.

such proposals are actually applied in practice are still quite rare. Moreover, especially in the context of technological aids there are still obstacles to their diffusion on a vast scale.

Finally, on the problem of guaranteeing the quality of supported decision-making, the adopted measure still appear too weak in many states also because the use of tools like independent advocacy still tend to be limited to countries in Northern Europe such as England.

To sum up, though it's positive that increased effort is put into promoting the dignity and autonomy of people with mental disabilities like dementia, we should continue to stress the necessity to build on existing promising practices and most importantly to 'institutionalise them' so they are available to everyone.

CHAPTER 8

Conclusion

1. Introduction

This thesis has attempted to analyse the barriers faced by individuals living with dementia in exercising their right to decide on medical treatment, and to study how they can be overcome or attenuated through an alternative model of healthcare decision-making, which moves away from the approach characterising current legislation, policies and practices, which is still based on substituted and surrogate decision-making.

In this regard, it has adopted a vision of the person living with dementia which, building on the ideas of the social model of disability and of Fineman's vulnerability theory, focuses on what society and the people around the individual can do to promote their right to decide. Indeed, from this point of view, dynamics of disability and vulnerability are seen as caused not so much by the person's impairment, but rather by the way society accommodates or fails to accommodate their needs. For this reason, also in relation to treatment decisions of individuals living with dementia it is necessary to adopt an approach based not on deprivation of the capacity to decide, but rather on the responsibility of state and society to actively engage in creating the necessary conditions for the person to fully express their will.

Starting from this perspective, the thesis has explored how Article 12 CRPD provides a normative framework embodying such values and a model of legal capacity and decision-making which permits to overcome the barriers faced by people living with dementia in deciding on medical treatment. Then it has studied how the action of regional organisations such as the Council of Europe (CoE) and the European Union (EU) can contribute to promote the principles of Article 12 CRPD among Member States and citizens and how initiatives emerging in national jurisdictions can give an idea of how these provisions can be translated into concrete practices.

Through the analysis of principles, policies and practices developed at an International, European and national/local level, this work has demonstrated that a new legal policy and practice approach to healthcare decision-making, based on the recognition of the person's capacity to consent and on supported decision-making,

allows to remove or greatly attenuate the barriers preventing people living with dementia from exercising their right to decide on medical treatment. However, this work has also shown how much more needs to be done by European regional organisations, governments, healthcare structures, professionals and informal carers to realise the principles of Article 12 CRPD. Indeed, CoE and EU institutions have issued a series of documents advocating for the implementation of Article 12 principles in relation to people living with mental conditions and cognitive impairments. However, the indications contained in such sources often lack the necessary level of detail on how such provisions should translate in terms of specific rules. Moreover, recent initiatives such as the Draft Additional Protocol on Involuntary Treatment and Involuntary Commitment to the Oviedo Convention on Human Rights and Biomedicine, appear to take a step backwards compared to the innovations proposed by the CRPD, thus sending confusing messages to policy makers and professionals. Finally, though the CoE and the EU offer useful channels for spreading promising practices and providing training to medical professionals, they often seem unable to sustain such initiatives with adequate economic contributions. In addition, when funds are available, mostly through the EU, they are instead allocated to temporary projects which are useful in spreading new ideas and ways of working with people living with dementia, but lack the necessary continuity to promote a long term change of approach. Promising practices are also emerging in single European countries but also here they tend to appear still as isolated initiatives carried out by good-willed professionals and activists, which often lack systematic support from the state or other social institutions.

This chapter provides a final overview of the arguments developed in the thesis and of its main messages. Therefore, Section 2 summarises how the various chapters contribute to answering the study research question. Section 3 identifies the main final messages of the thesis. Section 4 then focuses on what it has not been possible to explore in this work, providing some recommendations for future research. Finally, the Conclusion further underlines the overall message emerging from the thesis.

2. Answering the research question

The thesis has addressed the problem of how to create the conditions for people living with dementia to make decisions about their medical treatment, by indicating as

a solution a model of legal capacity based on a more inclusive vision of the individual such as that proposed by Article 12 CRPD and by looking at how such a model can be realised through the action of CoE and EU institutions and through promising initiatives developed at a national level.

Chapter 2 has made a first step towards addressing the research question, identifying the barriers faced by people living with dementia in exercising their right to decide on medical treatment. In this regard, it has shown that while the person's impairment plays a role in creating such obstacles, what really prevents people living with dementia from deciding on medical treatment are contextual factors rather than their impairment. Indeed, these individuals are often subject to stigma, prejudice and negative attitudes which induce doctors, relatives and carers to automatically disregard their opinions even when they appear well grounded and articulate. In addition, conversations on care choices are often conducted in a way that does not take into account the specific characteristics and needs of people living with dementia, so that the person struggles to participate in conversations with doctors and carers. Such problems appear to be partially aggravated by the current legal approach to capacity to consent and healthcare choice-making. Indeed, in all European countries, legislation still subordinates the possibility to make valid healthcare decisions to the presence in the person of a set level of mental capacity, increasing in this way the risk that people living with a condition like dementia are deprived of their right to choose. In addition, the emphasis on mental capacity leads to see all decision-making issues arising in this context as caused by the person's brain, providing no basis for addressing their needs for support and adjustments. Finally, with regard to the last stages of dementia, current legal approaches propose tools such as advance directives, surrogate decision-making, substituted and best interests judgement which can often be paternalistic, morally controversial and difficult to apply in practice.

Chapter 3 claims that the inadequacy of current legal, policy and practice approaches to healthcare decision-making of people living with dementia is mainly due to the fact that they are based on a too narrow and exclusive vision, which sees such individuals as by definition incapable and devoid of their self. In doing this they ignore how many of these people, despite their condition, appear able to develop opinions, have values, and to live a meaningful life. Therefore, this chapter suggests to adopt an alternative view of the person living with dementia informed by the social model of disability and by Fineman's vulnerability theory. The social model looks at

disability and chronic conditions such as dementia as dynamics originating from the interaction between the person's impairment and societal barriers, showing how policies and practices on disability should shift to focusing on the removal of societal barriers impacting the life of disabled individuals. Therefore, it also creates grounds for the argument that in relation to treatment decisions of people living with dementia the focus needs to be on removing the obstacles preventing the person from making choices about their care, rather than on their cognitive deficits. Vulnerability theory extends the message of Fineman's social model with regard to legal personality and to the role of the state and social institutions in removing societal barriers oppressing individuals in a position of disadvantage. Indeed, it claims that not only disabled people or individuals living with dementia, but all human beings are to a certain extent vulnerable and incapable due to their fragile bodies and because of the way society is organised and poses obstacles to them. Therefore, it is necessary to move away from the utopian notion of the perfectly autonomous liberal individual, which still underpins our social structure and legal systems, and put at the centre of legal and political discourse the vulnerable subject. Adopting this perspective leads to abandon the binary distinction between capable and incapable individuals which still characterises regulations on healthcare decision-making and which puts people with dementia at risk of being deprived of the possibility to choose their care. Instead, it states that state and social institutions have to take action in order to remove the societal barriers preventing disabled people and individuals living with dementia from exercising their right to decide on medical treatment, and to accommodate their needs as much as possible.

Chapter 4 shows how Article 12 UN Convention on the Rights of Persons with Disabilities provides a model of legal capacity which substantially embodies the ideas of the social model of disability and of Fineman's vulnerability theory. In this regard, it makes a further step towards addressing the thesis research question as it identifies a normative framework which permits to remove or attenuate the barriers faced by people living with dementia in exercising their right to decide on medical treatment, providing a legal tool to create better conditions for these individuals to make legally valid healthcare choices. Indeed, by qualifying legal capacity as an inalienable human right and recognising the power to make decisions to all individuals, including those with severe cognitive impairments, it issues a powerful statement against behaviours in which the opinion of the person living with dementia is disregarded because of

stigma, prejudice and labelling. Moreover, Article 12(3), states that if a disabled individual like a person living with dementia struggles to make decisions, the preferred course of action should be to help the individual through supported decision-making. In this regard, it advocates for an ‘active’ approach to legal capacity in which the person is supported and empowered in expressing their will rather than being substituted by a legal representative or guardian. Article 25 CRPD further clarifies how these principles also apply in relation to healthcare choices, as it affirms that disabled people such as individuals living with dementia must always be guaranteed the right to consent to or refuse a medical treatment and that they should be helped to express their will through a communication and consultation style which takes into account their needs and specific characteristics. In this way, the Convention provides a legal basis for policy initiatives and practices which really address the issues emerging in medical and legal practice relating to healthcare decisions of people living with dementia, proposing an approach which better enables the person to make their voice heard.

Chapter 5 further contributes to answering the thesis research question by showing how the realisation of the messages and provisions of Article 12 CRPD can be fostered through the action of the Council of Europe. Such an organisation has already shown a commitment to promoting the principles of this Article of the CRPD among single citizens and Member States through policy documents such as the CoE Disability Action Plan 2006-2015 and Disability Strategy 2017-2023. In these recommendations, the Council of Europe issues powerful statements in favour of the respect for the right of disabled people to make decisions also in the context of healthcare. Moreover, it urges Member States to implement a legal capacity model based on supported decision-making. In addition, the CoE has also shown potential to valuably contribute to the implementation of CRPD principles through the case law of the European Court of Human Rights. The judgements delivered by the Court with regard to legal capacity are still limited in number, but show nonetheless how this body can play an instrumental role in forcing States to change their legislation also with regard to healthcare decision-making. Finally, a significant contribution in supporting the implementation of principles such as those of the CRPD can also be given by monitoring bodies such as the European Committee of Social Rights, which can advocate for putting in place appropriate person-centred health services, and the European Commissioner of Human Rights, which, having the power to visit and

inspect care facilities, can closely monitor whether such principles are really applied in everyday healthcare practice. However, the chapter also shows how recent initiatives such as the issuing of the new Draft Additional Protocol on Involuntary Treatment and Involuntary Commitment to the Oviedo Convention have posed doubts on the seriousness of the CoE commitment towards the realisation of CRPD principles.

Chapter 6 shows how valuable help in spreading a new CRPD-oriented model of legal capacity can also be given by the EU, which in this field can complement the action of the Council of Europe. This organisation has also undertaken policy initiatives urging Member States to implement the principles of Article 12 CRPD, such as the European Disability Strategy 2010-2020. In addition, the EU has released documents specifically focusing on the care and rights of individuals living with dementia and older people living with cognitive impairments such as the European Initiative on Alzheimer's Disease and other Dementias (2009) and the Guiding Principles on Active Aging (2011). While EU documents often contain less detailed and extensive instructions to Member States compared to those issued by the CoE, they include provisions specifically advocating for the right of individuals living with dementia and of older people living with cognitive impairments to be supported in expressing their will on medical treatment. In addition, these policy documents are subject to more structured monitoring processes, so that in the future, EU policy initiatives might have an even greater potential than the ones put in place by the CoE to generate change in the field of healthcare decision-making by people living with dementia. In this regard, what adds strength to the EU's action is that this organisation has a significant financial budget at its disposal which can be used to support promising practices promoting the empowerment of disabled people and individuals living with dementia in healthcare decision-making.

Finally, Chapter 7 concentrates on initiatives and promising practices which are emerging in single European countries, and, which aim to promote the right of people living with dementia to decide on medical treatment and which function to support them in expressing their will on such a matter. In this way, it makes a final step towards answering the thesis research question as it provides examples of how the principles of Article 12 CRPD could potentially translate in practice, identifying concrete means to create the conditions to better allow individuals living with dementia to make decisions on medical treatment. An initial step which can be undertaken in this area is constituted by awareness raising and anti-stigma campaigns spreading a positive

image of people living with dementia and advocating for the respect of their right to make decisions for themselves, hence diminishing the risk that these individuals' opinions on care are disregarded due to prejudice and stigma. Equally important are training programmes for medical professionals and family members put in place by health authorities, governments, and private associations which give these stakeholders tools and strategies for effectively communicating with people living with dementia and how to effectively handle consent procedures involving these individuals. A crucial role in concretely enabling people living with dementia to make healthcare choices is also played by the various projects and processes put in place by European hospitals, care structures, health authorities and charities which utilise shared decision-making and analogical or digital aids to support people living with dementia in making healthcare decisions. These support means can significantly enhance the extent to which a person living with dementia is able to exercise their right to make decisions on medical treatment. If not only governments but also organisations such as the CoE and the EU, as well as single people involved in the care of individuals living with dementia really commit to ensuring a wide and systematic use of these means of supported decision-making, it will be possible to realise a model of healthcare decision-making which matches with the expectations and innovative principles set up in the CRPD and that avoids many of the issues posed by current legal, policy, and practical approaches in this area.

3. The Thesis Main Messages

In light of the summary provided in the previous section, four main messages emerge from this thesis. The first message recognises the potential of Article 12 CRPD and of a vision of the person living with dementia grounded on the social model of disability and Fineman's vulnerability theory to remove or at least attenuate the barriers faced by people living with dementia in exercising their right to decide on medical treatment. The second contribution emerging from this research is a series of indications on how such a model of treatment decisions can translate into concrete initiatives and practices. The third message concerns the fact that regional organisations such as the CoE, and the EU, national governments and social institutions have a great deal of (still unexploited) potential in promoting a new approach to treatment decisions which really empowers the person to fully express

their will. However, and this is the fourth message emerging from the thesis, such state and social institutions need to do more work in institutionalising the promising practices and initiatives emerging in single countries and to provide individuals living with dementia, medical professionals, and carers with the physical, human, social, ecological and environmental resources necessary to make the Article 12 model of legal capacity a reality.

Towards a new approach to dementia and treatment decisions

This thesis confirms that, as also shown by a number of empirical studies and experiential accounts, what really prevents people living with dementia from fully exercising their right to decide on medical treatment are contextual factors and barriers such as stigma, prejudice, medical consultation styles not taking into account their needs, a lack of adequate communication training for carers and medical professionals, and legislation on legal capacity and capacity to consent which is focused on hypercognitive assessments rather than support. A system based on a conceptualisation of people living with dementia which is in line with the social model of disability and vulnerability theory such as the one proposed by Article 12 CRPD overcomes such barriers.

Indeed, by affirming that legal capacity is a fundamental right which needs to be recognized to everyone and that even individuals living with serious cognitive impairments cannot be deprived of their decisional power, this model challenges the widespread prejudice informing the conduct of medical and legal professionals, carers and relatives, who, assuming the person incapable to consent, tend to automatically disregard their wishes. In addition, Article 12 leads to a system which avoids the problem of establishing when a person living with dementia becomes incapable to consent through discriminatory, controversial, and often impractical mental capacity assessments. Indeed, by affirming that ‘persons with disabilities enjoy legal capacity on an equal basis with others’ it puts these individuals on the same level as others, rejecting any distinction between legally capable and incapable people on the basis of mental abilities.

Instead, by requiring that 'States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity' (Article 12(3) CRPD), the Convention advocates for an approach in which the person is supported in making their choices by professionals or next of kin

who can explain to them elements they may not understand, help them in analysing the various nuances and implications of a decision, interpret their statements when unclear, create a network of people which monitor potentially abusive behaviours, and gather complete information regarding the person's wishes in preparation for the time at which they will be unable to communicate with the people around them. The model emerging from Article 12 CRPD, which embraces the vision of disability as a social construction elaborated by the social model, provides a legal basis for grounding the right of people living with dementia to have access to the support means that they need to make their voice heard with regard to healthcare. The model also advocates for the removal of the barriers they face in making decisions on medical treatment. In this regard, the principles of Article 12 CRPD must also be viewed as a call to governments and social institutions to be more responsive to the needs of people living with dementia, reiterating the ideas of Fineman's vulnerability theory. Indeed, it also requires states and social institutions to actively engage and invest financial resources in creating the conditions for these individuals to exercise their right to decide on healthcare matters by making sure that care staff is properly trained to communicate with people living with dementia, that there are adequate spaces to talk with the person about their health care, and that staff of hospitals, care structures, or local practices has the time to do so.

Realising a support-based model of treatment decisions in dementia care

In its second part, the thesis provides a series of indications on what concrete actions and practices could be put into place at a European and national or local level in order to realise the model of legal capacity and treatment decisions of individuals living with dementia emerging from Article 12 CRPD.

The first type of actions required in this regard are initiatives which ensure that people living with dementia are recognised as having the right and the capacity to decide on medical treatment at all times and in all environments. A first contribution in this sense comes not only from authoritative policy documents such as the CoE Disability Action Plan 2006-2015, the CoE Disability Strategy 2017-2023, the EU Initiative and European Parliament Resolution on Alzheimer's Disease and other Dementias, but also from some judgements of the ECtHR and several national dementia strategies, which contain powerful statements in favour of the right of disabled people and people living with dementia to decide on their life and care, and

statements demonstrating the need to recognise that they are equal in dignity to others. Moreover, awareness-raising and anti-stigma campaigns which are put in place especially by charities and NGOs in various European countries, have a crucial role in spreading a more positive view of individuals with this condition and in challenging the negative prejudice against them. Such initiatives ensure that people living with dementia are increasingly viewed as individuals who still have meaningful opinions to voice and that, with some help, are often still able to manage their life. Therefore, such initiatives also guarantee that lay people, doctors, nurses, carers and legal professionals cease to consider people living with dementia as inherently unable to make choices about their treatment, avoiding situations in which they are deprived of their capacity to consent on the basis of their impairment.

A second crucial factor in realising a support-based model of treatment decisions in dementia care is to make sure that in addition to awareness-raising and anti-stigma campaigns, medical professionals, carers, and family members benefit from specific training which improves their ability to promote the right of the person to decide on medical treatment. In this way, it is possible to guarantee that the people around the individual living with dementia are fully prepared to satisfy the person's needs for support and that they will concretely know how to promote their right to decide on medical treatment. This will specifically overcome one of the most frequent obstacles that people with dementia encounter on making choices for themselves. Such initiatives can be put in place by CoE and EU institutions, as well as by governments and private organisations. In this regard, it has been shown in Chapters 5.3 and 6.3 that the CoE and the EU regularly organise or fund conferences, public events, and networks especially dedicated to healthcare and legal professionals which focus on themes of disability rights, legal capacity, supported decision-making and rights-based approaches in dementia care. Chapter 7.4 showed that some national dementia strategies have incorporated sessions on the ethical dimension of dementia care in compulsory training pathways for healthcare professionals. Such initiatives provide valuable occasions of reflection and exchange on legal problems relating to consent to treatment of individuals living with this condition. In addition, Chapter 7.3 showed how certain organizations, namely, national charities and NGOs have put in place various sensibilisation campaigns, meetings, and discussion groups for carers and relatives of individuals living with dementia. Such initiatives accompany the family members and people involved in providing support to the person in their journey with

their condition and help them to adopt a more positive, empowering approach to dementia as well as with providing advice on how to handle the communication and relationship with the person. In this way, these campaigns, meetings, and discussion groups address another set of barriers which prevent people living with dementia from getting adequate support in expressing their will on medical treatment. These barriers stem from relatives' tendencies to discourage the person, their lack of knowledge, or their fatigue in handling situations alone for which they are not entirely equipped or comfortable. Stigma, frustration, and inefficacy on the part of the relatives ultimately lead to their inability to take adequate action when the person living with dementia requires it.

A third crucial level of action entails making sure that the person actually receives appropriate support when they are in the situation of having to decide on their care and medical treatment. Through its analysis of promising practices developed at a national-local level, Chapter 7 provided examples of how the person living with dementia can be concretely supported in this case. The chapter showed that in some care structures, the application of shared decision making in its triadic form including the person, their doctors, and their family and friends permits to make use of the network of relationships around the individual in order to help them understand information on medical treatment and communicate their wishes. It is a tool with which healthcare professionals and carers are often familiar and that can be used as a scheme through which they may have the possibility to explain relevant information in an accessible and simpler manner, reminding the person of elements they may not recall, and guiding the person to the exploration of alternatives. Also, this tool allows for the gathering of information about the person's wishes which will be useful in the final stages of their condition when they are absolutely unable to communicate with the outside world. Next, the network around the person, which may include advocate or members of associations for the rights of individuals living with dementia, can also be used to ensure and monitor that everyone provides high quality support and to prevent situations of abuse and undue influence through mutual supervision of its members. In addition, Chapter 7 showed that guidelines provided by public bodies such as the NHS or guides issued by NGOs regarding accessible information standards for disabled individuals or people living with dementia can play a valuable role in enabling the person living with dementia to voice their opinion on medical treatment. Finally, IT tools produced in even greater quantity by specialised companies or research institutes

which help the person to navigate decisional processes to keep in touch with their care staff and to remember relevant elements for their decision also appear promising.

The initiatives and tools analysed in this thesis do not exhaust the full range of available possibilities with regard to support in decision-making for people living with dementia. However, they provide an idea on how regional institutions, governments, NGOs and other social bodies may contribute to removing the barriers preventing people living with dementia from making choices about their medical treatment and how to be more responsive to the needs of these individuals.

The potential of CoE, EU and nation-level actions

The policy initiatives, legal and policy documents, and promising practices reviewed in this thesis show how organisations like the CoE and the EU, national governments, NGOs, hospitals, care homes, health authorities, and other social institutions have significant potential in attaining positive change in the area of treatment decisions of people living with dementia. As shown in Chapters 5 and 6, the statements contained in CoE and EU policy documents on disability, dementia and old age have played a valuable role in spreading the messages of the CRPD with regard to legal capacity, contributing to reform processes in various European countries. ECtHR judgements in this area have produced immediate changes in the legal sphere of the applicants and have forced governments to change their legislation and practices in this specific area. The existence of a body dedicated to the promotion of social rights such as the European Committee for Social Rights and the powers of inspection of monitoring bodies such as the European Commissioner of Human Rights constitute good channels for the cooperation between CoE, governments, local authorities, single care structures and other social institutions in creating the conditions necessary for adequate supported decision making. Such cooperation channels also enable stakeholders to make sure state and social institutions are particularly responsive to the needs of individuals living with dementia and really engage in removing the barriers preventing these individuals from deciding on medical treatment. In addition, EU funding schemes already support projects which provide support to disabled people and individuals living with dementia in making everyday life and care decisions. These projects have helped spread promising practices which range from awareness raising campaigns, to IT-based decisional aids, to shared decision-making and care support schemes. Many individuals living with dementia, their family members, and carers

who have taken part in the reviewed initiatives put in place by public authorities, hospitals, medical teams, and NGOs have confirmed that such promising practices have been paramount in enabling the person to decide on their health care.

However, though these actions signal a positive move towards a model of treatment decisions of people living with dementia which is more in line with the vision of the social model, Fineman's vulnerability theory, and Article 12 CRPD, they are still far from sufficient to promote a general, structural change of approach in this area. Indeed, even though the EU and the CoE have shown a commitment to promote the great messages of the Convention, they have not been able to go beyond statements of principle or to provide a rigorous roadmap for the implementation of such an approach. ECtHR litigation, though constituting a promising channel to achieve improvements in individual situations is still scarcely used, as for many potential appellants it is a costly mechanism which often requires several years to lend results. The not binding nature of the jurisprudence and reports by the European Committee for Social Rights and the European Commissioner of Human Rights still pose the risk that once the attention triggered by the publication of the document as died down all the commitments made by governments, care structures and local professionals vanish. Moreover, since these bodies have the task of monitoring complex dynamics in forty seven countries, they often lack the capacity to provide rigorous analyses and adequate follow-up to their enquiries. In addition, the potential for change of EU funding programmes is hindered by the fact that such resources are almost entirely employed for supporting one-time initiatives rather than sustaining long-term processes of structural change. Finally, initiatives such as anti-stigma campaigns, training programmes, practices utilising supported and shared decision-making in care settings are still not widespread, rather appearing as the result of the isolated efforts of good willing professionals or officers. In this regard, much more work still needs to be done in order to 'institutionalise' these promising practices so that every person can benefit from them and not only those who happen to live in a certain area or are treated in a particularly innovative care structure.

Furthermore, one of the most striking elements emerging from this study is that despite the fact that governments and also regional organisations such as the CoE and the EU have shown a willingness to be more responsive to the needs of individuals such as people living with dementia, by endorsing and-or ratifying documents such as the CRPD, they still do not appear to have completely embraced the mission of putting

such declarations in practice. Indeed, no European government has really made a serious commitment towards investing the necessary economic resources to provide supported decision-making to people living with dementia on a vast scale. However, such an investment is a fundamental prerequisite for the realisation of the approach to treatment decisions of people living with dementia which is analysed in this thesis. As a matter of fact, seen in Chapter 2 shows that one of the main factors preventing these individuals from expressing their will on medical treatment is the actuality that medical practitioners and formal and informal carers are often not given the resources, infrastructure, and time to properly interact with the person and help them in making choices by their institutions and governments.

Unfortunately, at the moment, public health policies in Europe seem to go in an opposite direction. Many countries have enforced strict austerity policies which have diminished the amount of financial resources available for health and care services, putting increasing pressure not only on the staff of hospitals and care structures but also on the relatives of people living with dementia. Such policies have caused protests and resentment, especially among those with lower socioeconomic status and have particularly worsened the situation of individuals such as people living with dementia. Realising an approach to legal capacity and treatment decisions really based on supported decision-making requires at least the partial reversal of such austerity policies. However, this is far from an easy task. Because of the quantitative dimension of the ‘dementia phenomenon’, it seems utopian to think that the issues analysed in this study can be addressed solely through the investment of public resources. Consequently, this thesis also gives attention to practices of supported decision-making which utilise the action of people who are already involved in the care of the person living with dementia, limiting the costs. Nonetheless, it is still crucial that the state uses its regulatory power to ensure that possibly scarce resources are used strategically and, most importantly, that they are used to empower people living with dementia to decide on their care.

A call to action for regional organisations and governments

In light of the considerations reported above, what emerges from this thesis is also a call to organisations like the CoE or the EU and to states to take more decisive and incisive action to promote an approach to legal capacity and treatment decisions which

is in line with Article 12 CRPD and with the values advocated by the social model of disability and by Fineman's vulnerability theory.

A first contribution can come from CoE and EU institutions in the form of a development of clearer guidelines on how Member States should reform their legal capacity legislation. Such guidelines should require the elimination of legal rules which reserve the power to make decisions on medical treatment for those with a certain mental capacity level. In addition, they should require that national legislation explicitly recognises the right of each person to receive the support they need in deciding on medical treatment and mandates that before resorting to forms of surrogate decision-making, doctors and carers should make every possible effort to explain relevant information to the individual and enable them to make the decision for themselves.

CoE institutions and NGOs in the field of disability and dementia advocacy can also contribute to further unlocking the potential for change of ECtHR litigation in the area of legal capacity and the right to decide of individuals living with dementia. In particular, they can provide funding for covering the legal expenses related to bringing a case in front of the Court and can enact pro bono schemes in which potential appellants receive free legal assistance. Organisations for the rights of disabled people and individuals living with dementia can use strategic litigation to develop a body of judicial principles and ECtHR precedents which are binding for CoE Member States. These organisations can also contribute to the establishment of a new system based on supported decision-making in regards to treatment decisions of people living with dementia.

The EU can also improve its action with regard to the promotion of supported decision-making. Its work in this area can become more effective and impactful if the EU creates more long-term or even permanent funding programmes to support national, publicly funded, and high quality healthcare services and supported decision-making schemes. Such funding would need to be subject to stringent conditions, requiring that governments and healthcare structures use it to build capacity and create opportunities to help people with dementia in expressing their views on medical treatment. The funding should also be accompanied by clear guidelines applicable to all care structures and institutions of the Member States, which make sure that uniform and systematic supported decision-making procedures are in place everywhere in the Union.

Not only national governments, but also individual care institutions can contribute to put into practice the alternative approach to legal capacity and treatment decisions analysed in this thesis by approving reforms that are in line with the provisions of Article 12 CRPD. Moreover, they can use national dementia strategies to include more extensive sessions on ethical and legal issues related to consent to treatment of individuals living with dementia in training pathways for medical and legal professionals. However, the most important contribution would be ensuring that adequate resources are available to fund the support practices which need to be put in place in hospitals and care structures, which would give medical professionals the necessary time and space to really sit down and assist the person in developing their opinions on medical treatment.

4. Study limitations and directions for future research

This thesis has focused on studying how to create the conditions for people living with dementia to exercise their right to decide on medical treatment, adopting the perspective of the social model of disability and of Fineman's vulnerability theory, and applying the principles of Article 12 CRPD. Therefore, its main aim has been to propose a new general vision which better addresses the issues emerging from practice in this area, linking the debate on healthcare choices of individuals living with dementia to the ideas of the social model of disability and the ideas of vulnerability theory, as well as studying how the principles of the CRPD can play an important role in enabling the person to voice their will on care. By highlighting these links, the thesis contributes to advancing current research and policy in this area. Indeed, these ideas and principles have only quite recently started to be applied to the case of people living with dementia. These individuals have often remained at the margins (or have even been excluded altogether) of the disability movement and of the great policy process resulted in the entering into force of the CRPD. Thus, these individuals remain far from a position in which they could fully benefit from the liberating and revolutionary potential of its provisions. This work sets out to fill this gap. In order to fill the gap as best as possible, the thesis has concentrated on the possible general implications of the new model of legal capacity and decision-making proposed by Article 12 of the Convention, and on understanding how it could be realised in practice. In doing this, the thesis has analysed, without any attempt to be exhaustive, initiatives and promising

practices put in place at a CoE, EU and national-local level, which show how the vision of the social model, Fineman's vulnerability theory, and the principles of Article 12 CRPD can be translated into concrete policies, as well as legal and practice initiatives in the field of healthcare decision-making of individuals living with dementia.

The chosen focus allowed the analysis of how different social institutions and levels of governance can play a role in advancing the right of people living with dementia to decide on medical treatment and in promoting supported decision-making. However, it has not been possible to analyse in depth the nuances and problems relating to the implementation of specific provisions and support means in the various countries included in this study. Additionally, because the thesis essentially relies on white and grey literature written in English or in the main European languages, it is possible that practices not mentioned in such documents, or not accounted for in the main repositories and databases, or described in reports written in languages not known by the author of this work have been missed.

For these reasons, it is important that more research is conducted which adopts a more narrow focus and uses empirical field-based methodologies, so that it may study the specific problems faced by people living with dementia, carers and medical and legal professionals more closely. In particular, there is a need for studies which involve the largest number possible of stakeholders within a certain geographical area, asking them to provide a detailed account of the various support techniques used and to express their opinions on them. In this way, it will be possible to obtain a complete view of what is working and what can be improved with regard to healthcare decision-making processes for people living with dementia. In this process, special attention will need to be paid to countries such as those of Eastern Europe on which we have fewer data.

Another area which requires further research is that of the political, economic and social conditions which need to be in place for supported decision-making to be realised and in order to guarantee that people living with dementia are fully enabled to decide on medical treatment. In this thesis, it has been argued that what often creates barriers to the exercise of the right to decide on healthcare matters of people living with dementia is that hospitals, care structures, professionals and carers are not given the resources and infrastructure necessary to assist the person in expressing their will. Because of the significant number of people living with dementia and the scarcity of available resources, reversing this situation is not easy. It requires the development of

sophisticated and innovative solutions which combine careful policy planning, a mix of public and private funding and resources, and an approach to care in which the action of healthcare services is complemented with the efforts of informal carers. Therefore, there is also a need for more research in areas outside legal studies such as health economics, health governance, analysis of health systems, sociology of health, which thoroughly analyse the dynamics surrounding consent procedures for people living with dementia and which play a significant role in the success of supported decision-making practices.

5. Conclusion

Despite being generally considered inherently incapable of making healthcare choices, people living with dementia are often able to express their will on medical treatment. However, they continue to face barriers in the development and expression of said will such as stigma and prejudice, the lack of support means to help them make choices, doctors and carers who are not properly trained to respond to their needs, and an approach to legal capacity and capacity to consent which tends to deprive them of their right to decide instead of providing a legal basis to remove the obstacles which prevent them from making decisions. This thesis has argued that by adopting an alternative approach to legal capacity and healthcare decision-making which embraces the ideas of the social model of disability and of Fineman's vulnerability theory and that is in line with the principles affirmed by Article 12 CRPD, it is possible to remove and avoid such barriers. In this regard, it has shown how in some European countries, hospitals, care structures, NGOs, and groups of professionals and carers have already developed initiatives which are in line with the principles of the CRPD and are making considerable impacts in empowering the person to choose on their care.

Nonetheless, we are just at the beginning of the journey towards a more inclusive and empowering model of healthcare decision-making for people living with dementia. There is still much work to do in order to ensure that principles such as those of Article 12 CRPD are systematically embraced by healthcare institutions, professionals, carers and lay people. In this regard, this thesis has argued that not only CoE and EU Institutions, but also national governments and local actors have significant potential to promote the implementation of such provisions in relation to treatment decisions of individuals living with dementia. However, this potential is still

significantly unexploited. I hope that this work can contribute to providing ideas on how governing bodies and social institutions at a European, national, and local level can be more effective in promoting the right of people living with dementia to decide on medical treatment.

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LIST of ABBREVIATIONS

APA	American Psychiatric Association
BGH	Bundesgerichtshof
CQC	Care Quality Commission
CRPD	UN Convention on the Rights of Persons with Disabilities
CoE	Council of Europe
EU	European Union
ECHR	European Convention of Human Rights
ECtHR	European Court of Human Rights
HLGD	High Level Grup on Disability
MCA	Mental Capacity Act
OMC	Open Method of Coordination
UN	United Nations
WHO	World Health Organisation