The experiences of family carers of people with learning disabilities: a participatory action research study

By:

Rachael Black

A thesis submitted in partial fulfilment of the requirements for the degree of
Doctor of Philosophy

The University of Sheffield
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Acknowledgments

Abstract

Very little is known about family carers' experiences of providing life-long care. Limited research suggests family carers struggle with accessing services (Neary, 2013), with judgement (Tozer & Atkin, 2015), marginalisation (Twigg & Atkin, 1994), and the burden of co-ordinating multiple services (Hubert, 2010). Participatory Action Research (PAR) is research *with* rather than *on* participants (Kindon et al 2007). Very little participatory research has worked with family carers as co-researchers.

The overall aim of this study is to use PAR to understand the experiences of family carers of adults with learning disabilities (LD). Further aims are to: 1) identify the research agenda of family carers of adults with LD; 2) conduct a collaborative research study and 3) disseminate the findings.

In Phase 1, family carers were recruited to form a research group. We set the research agenda for Phase 2, identifying four themes in discussions: 1) lack of carer power; 2) caring for an adult with learning disabilities; 3) what's not being said and; 4) impact on siblings.

In **Phase 2,** these themes informed a collaborative research study, to investigate interactions between family carers and service providers. Two online co-produced surveys were completed by 116 family carers and 51 service providers and then co-analysed. The surveys demonstrated the burden placed on family carers, and the lack of understanding by service providers who often perceived disengagement by carers. Carers reported that services were not on their side and that they were not treated as equal partners in supporting their loved one. Results highlight the power imbalances underpinning relationships and carers' fear of practical consequences resulting from any complaint. The findings were disseminated at a co-produced event to enable collaboration between service providers and carers.

PAR focused the project on carers' priorities: new knowledge was created about service-carer relationships. PAR also ensured the relevance and reach of the surveys produced. As a result, the project has important implications for policy and for service providers, demonstrating the reform needed to improve partnerships with family carers.

Table of Contents

List of Tables

List of Figures

Chapter 1
Introduction

This introductory chapter gives an overview of who 'family carers' are and of the research method underpinning the study, Participatory Action Research (PAR). I discuss my rationale for embarking on this study and for selecting this research method. The study aims are presented, with a brief consideration of its significance in relation to wider policy and research. The chapter concludes with a summary of the structure of the thesis and a brief description of each chapter.

1.1   Who are Family Carers?

Research shows that some parent carers of people with learning disabilities would rather their child died before they did, so acute is their lack of trust in support services (Bibby, 2013; Bowey & McGlaughlin, 2005; Dillenburger & McKerr, 2010). This is despite policy that aims to facilitate partnership between family and service providers:

> Carers need to be recognised and valued. Carers need access to information and support to provide the best care they can. Carers need to be helped to balance their caring responsibilities with their own employment and to preserve their personal health and wellbeing (Department of Health and Social Care, 2018).

Carers' rights are legally recognised in the Care Act 2014 and government policy states that service providers should be engaging with carers as "expert care partners" (Department of Health, 2010: 5). Carers are people who provide unpaid care, from a few hours a week to the majority of the day. They may or may not live with the person they care for (Carers UK, 2015a). There are 6.5 million carers in the United Kingdom and the figure is rising, with an 11% increase between 2001 and 2015 (Carers UK, 2015a). Of these, 14% (approximately 840,000) care for a person with learning disabilities (Carers Trust, 2018). It is estimated that the unpaid work carried out by carers saves the NHS in England £119 billion per year (Carers UK & University of Leeds, 2011). Caring can impact on a carer's ability to work, with consequences for household finances and economic hardship (Carers UK, 2014). Caring can also impact on both the physical and mental health of carers, with high levels of stress and anxiety reported (Carers UK, 2015b).

Caring for a person with a learning disability is a lifelong role that can continue well into old age (Bowey & McGlaughlin, 2005). Thirty eight percent of people with a learning disability, known to social services, live within the family home (Mencap, 2012b) and have been largely ignored by service providers (Walker & Walker, 1998). Previous research indicates that carers do not feel that they are treated as equals in their interactions with service providers (Tozer & Atkin, 2015; Twigg & Atkin, 1994). Instead of alleviating their caring responsibilities, paid services can cause

them increased stress (Beresford, 1994; Neary, 2013; White & Hastings, 2004). Family carers report feeling judged by services and reluctant to engage (Baxter et al, 1990; Hubert, 2006; Tozer & Atkin, 2015). Sixty percent of carers who care for a person with profound and multiple learning disabilities (PMLD) report engaging in caring tasks for over 10 hours of the day (Mencap, 2001). Carers for people with PMLD are woken, on average, three times during the night, yet this lack of sleep was not taken seriously by service providers (Mencap, 2001).

There is a gap between policy, stating carers should be equal and included, and practice which sees carers feeling judged and excluded by service providers. There is a paucity of research about the support needs of carers of people with profound disabilities and about how carers interact with formal services (Kyzar et al., 2012 Mencap, 2001a). More research is needed to explore both the needs of family carers and how their role is understood and supported by service providers. This would increase understanding of how services could alleviate, rather than contribute to, carer stress and thus provide better, more joined up support for people with learning disabilities and their families.

1.2   What is Participatory Action Research?

Action research is a broad term that covers a range of approaches and is therefore described as a "family of practices" (Reason and Bradbury, 2008: 1). This family includes participatory action research, cooperative inquiry and emancipatory research. Action research approaches are underpinned by three components "research, action and participation" (Greenwood & Levin, 2007: 5). Researchers seek to work collaboratively with stakeholders invested in the research to explore practical solutions and meaningful change. Increasing knowledge is not enough there needs to be action and solutions.

Participatory action research (PAR) is an umbrella term covering a range of approaches and methods (Kindon et al., 2007). However, they all must consist of action-focussed research conducted collaboratively with groups rather than on them (Kindon et al., 2007). Previous research with carers shows that PAR increased the relevance of a study for the groups being researched, (Turnbull, Friesen, & Ramirez, 1998) empowered carers and increased their voice (Santelli et al., 1998). This study uses participatory action research methods, including the validity measures defined by Heron and Reason in their approach cooperative inquiry (Heron & Reason, 2006). These measures have been defined to ensure the research remains robust while still grounded in the theoretical underpinnings of participatory action research (Heron & Reason, 2006).

1.3 Research Aims Objectives and Approach

The research aims of this study are to:

1. Gain a rich understanding of the experiences of carers of people with learning disabilities using methods that are participative and solution focussed.

2. Identify the research agenda of family carers of people with learning disabilities around understanding the needs of people with learning disabilities and their carers

3. Use the identified research agenda to conduct a research study and disseminate findings in line with participative research methodology.

This study is in two phases. In Phase 1 I recruited family carers to work with me as co-researchers. We used unstructured, audio recorded group discussions to identify the issues that were of significance to them. In Phase 2 we used these issues and themes generated by our discussions as the basis of a research study. The co-researchers were invited to participate in all stages of this research from design to dissemination. Using PAR increased the relevance of the study and ensured it remained grounded in the carers' own experience and priorities. As this was an action research study, I worked with the group to explore potential outputs from the study that could be utilised by either service providers or carers to improve carers' experiences.

Neither the outputs nor the Phase 2 research questions were identified prior to Phase 1. This was to ensure the research focus came from the co-researchers and their own experiences, to facilitate a true collaboration.

1.4 Significance of Study

This study makes an important contribution to the current research knowledge because carers' own experiences are at the centre of the project. Phase 1 developed in-depth knowledge of carers' perspectives and priorities. Phase 2 built on this by demonstrating how carers view their interactions with service providers negatively. This impacts future interactions. This has not been examined in detail in relation to this population before.

Using PAR with this demographic is innovative. It advanced understanding of how to engage with carers in research and how best to support them to take a lead in designing and conducting research. PAR enabled a deeper appreciation of carers' every day experiences and the impact this has on their wellbeing. Carers feel unable to express their frustrations with service providers and therefore these are unrecognised by providers. PAR delivered a means by which to

understand the misaligned experiences of carers and service providers; with providers reporting positive relationships with carers and carers expressing dissatisfaction and anger.

By combining the skills and knowledge of the carers and the initiating researcher we were able to conduct a research study that was both rigorous and relevant. This increased the impact it could have and its potential for change. This study has implications for service provision. This study shows that carers recognise tokenistic attempts at collaboration as 'paying lip service' and this increases their feelings of exclusion. To work more effectively with carers, service providers, need to recognise, and address, the power imbalance that exists between the two groups and the difficulties carers have expressing their dissatisfaction. They need to include carers in the planning and delivery of support and maintain open communication.

1.5 Personal Motivation for Conducting the Study

This study was motivated by my experiences as a support worker for adults with learning disabilities. I have worked with people in their homes, at day centres, and attending community events and health appointments. My experience has remained professional, despite coming to care very deeply about some of the people I have worked with. I do not have family with learning disabilities.

I struggled greatly with some of the poor services I witnessed and the lack of opportunities and choices available for people with learning disabilities, in particular, for those with profound and multiple learning disabilities (PMLD). I witnessed people being talked over, having their meal fed to them by someone disengaged and standing up, or having their wheelchair pushed without a word from the person pushing. During my eight years as a support worker, I worked with many family carers. I had some very positive working relationships with family carers, and others where interactions and partnership were challenging.

On leaving support work, I started working as a research assistant, which introduced me to research methods and also highlighted the gap between research and practice. Research was rarely referred to during my time as a support worker and research was never utilised to design services. Some of the research articles I read related to my experiences working in social care, but these were not accessible to or shared with care workers. Designing and conducting a research study was fascinating to me but equally I was mindful of the need to make research accessible to practitioners and families outside of academia.

When I began this PhD I started to explore issues around social inclusion for people with PMLD and I considered interviewing carers to gain their experiences. However, in 2012 I attended the

Raising Our Sights Conference, at Nottingham. This conference was to explore the report into services for people with PMLD by Jim Mansell (2010). In the report he featured case studies of individuals with PMLD who were receiving a good quality of care. One of the young men featured in the report and his mother attended the event. The mother told the delegates that she had just been informed that her son's continence pad allowance was going to be reduced, a decision she disagreed with. This information caused me to rethink my whole study plan. I had intended to ask carers about social inclusion when some of them were struggling to have their child's most basic physical needs met. It made me realise that despite working with people with learning disabilities, I understood very little about the experiences of carers. I was able to leave work at the end of the day whereas they would be caring into the night and over the weekends. I started to investigate research methods which would enable me to gain a much deeper understanding about what carers experience and what their priorities were. Rather than plan a study that may not be relevant, I wanted to work with carers in partnership every step of the way to ensure that our research questions, aims and methods genuinely had the potential to improve experiences for carers. This led me to participatory action research which would include a group of carers at every stage in the study, grounding it in what mattered to them.

1.5 Structuring the Thesis

This thesis contains a further nine chapters.

Chapters 2 & 3: Literature Review

Here I present the current literature of both the experiences of family carers and participatory action research methodologies. In Chapter 2, I discuss the history of services for people with disabilities and how this has come to be understood as a social rather than an individual issue. I will then explore how the role of family carers has moved from being excluded from their relative with disabilities to being primary carer until well into old age. I will then explore the literature about family carers including carers from Black and Minority Ethnic communities, older carers, sibling carers and carers of people with PMLD. I will also examine the role of formal support providers in the lives of family carers. In Chapter 3, I look at the history of the PAR approach, the challenges of using such a method and the validity measures necessary to ensure rigorous research. I will then bring together PAR methods with disability studies to explore how the method has been used in studies involving people with disabilities or their carers.

Chapters 4 to 8: Method and Results

Over these four chapters, I present the method and results of the two phase study. Chapter 4 explores the pilot study and details how this influenced the design of the PhD study. Chapter 5 explores the process of recruiting a group of family carers to work collaboratively as co-researchers. I describe the six group meetings that form Phase 1. I summarise each meeting and the main topics of discussion. In Chapter 6 I explore the thematic analysis of the Phase 1 discussions and the key themes identified. These discussions yielded rich, qualitative data about the nature of carers' relationships with service providers and their interactions with them. Chapter 7 considers the process of moving the study from discussion to action: How we worked as a group to move the Phase 1 discussions into the Phase 2 collaborative research study. Here I reflect on my own place in the group as initiating researcher and my role in shaping this process. I describe how the group used the themes from the first phase to determine our research questions and method. I discuss how we co-designed and shared two surveys; one for family carers and one for service providers. In Chapter 8, I describe the co-analysis of the Phase 2 survey data and our findings.

Chapters 9 and 10: Reflection, Discussion and Concluding Comments

In Chapter 9, I present the co-researchers' reflections on the research process, as well as my own reflections as initiating researcher based on field notes and my research journal. Chapter 10 is the discussion chapter in which I demonstrate how this study addressed the research aims and critically reflect on contribution to the wider research literature. I then discuss the implications of the study for both research and practice. I consider the benefits and challenges of using PAR methods, the limitations of the design, and make concluding comments.

Chapter 2
Disability and the Family Carer Literature Review

2.1 Introduction

2.1.1 Definition

The cross party White Paper Valuing People (Department of Health, 2001) defines a learning disability as:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development (2001: 14).

Learning disabilities can occur prenatally, for example as a result of a chromosomal abnormality, during birth due to a lack of oxygen or can occur in childhood as a result of illness, neglect, malnutrition or abuse. Often there is no clear cause for a learning disability. In 2014/15 there were 252,446 people with a learning disability recorded on the General Practitioner learning disability register, this is an increase of 4.4% on previous years (Public Health England, 2016).

2.1.2 A Note on Terminology

I will be using people first language throughout the thesis, for example people with disabilities rather than disabled people. People first language originated from the self-advocacy group The Campaign for People with Mental Handicaps (CMH) in North America to highlight the individual before their disability or condition (Atherton & Crickmore, 2012; Goodley, 2011). However, some people with disabilities do not appreciate being described as a person with a disability as they consider themselves to be disabled by the society in which they live and are therefore disabled people (Goodley, 2011). Whilst appreciating the relevance of this argument I have adopted people first language in an attempt to highlight the humanity of the person before their disability or impairment. This language was developed by people with learning disabilities and important to them in recognising their identity and contributions not just their impairment (Atherton & Crickmore, 2012).

Valuing People (Department of Health, 2001) differentiates between the term learning disability and learning difficulty, with learning difficulty being more widely used in education policy and including conditions such as dyslexia (Department of Health, 2001). The term used most often

internationally is intellectual disability (Mansell, 2010). However, throughout this thesis I will use learning disability because it is still the term most widely used locally and the term most familiar to the families I have worked with.

2.2 The Social Model of Disability

2.2.1 Introduction

This section explores the Social Model of Disability and the ways in which adults with learning disabilities and their families continue to face discrimination and poorer life chances (Emerson, Hatton, Robertson, & Baines, 2018; Khalifeh, Howard, Osborn, Moran, & Johnson, 2013; Mazars LLP, 2015).

2.2.2 The Social Model of Disability: Origins and theory

Michael Oliver first coined the terms individual model and social model of disability in 1981 in a collection of papers edited by a practising social worker, Jo Campling (Oliver, 1981). He explored this further in *The Politics of Disablement* (Oliver, 1990) in which he drew a distinction between disability and the impairment.

The individual, or medical, model of disability depicts the person with disabilities as in need and requiring care (Atherton & Crickmore, 2012). In this model people with disabilities, including those with learning disabilities, are represented as passive, weak and vulnerable (Atherton & Crickmore, 2012). This model locates any issues and difficulties people with disabilities face within their own individual pathology rather than as a result of attitudes or prejudices (Atherton & Crickmore, 2012). A serious consequence of perceiving people with disabilities as deficient is that it results in health and social care services being designed to address this individual deficit (Oliver, 1990). This reinforces the status of people with disabilities as inadequate and impaired (Oliver, 1990) rather than challenging it. The medical model poses serious threat to the human rights of people with learning disabilities (Degener, 2014). It pathologises the individual, regardless of whether they need medical treatment, and then enables individuals to be excluded from society in the name of treatment, for example in special education, hospitals or assessment and treatment units (Degener, 2014).

Whereas by using the social model to define disability; an individual may be impaired but it is society, both environmentally and in the attitudes held, that disable a person (Oliver, 1990). This distinction is based on the work in the 1970s of the Union of the Physically Impaired Against Segregation (UPIAS) (Oliver, 1990). The prevalent view in medical services is that disability is a

"personal tragedy" (Oliver, 1990:1) that befalls an individual, with policy then developed to counteract this individual tragedy. This fails to address the social causes that have a disabling effect on an individual. For Oliver (1990), in western society, it is economic factors that influence how an individual is viewed. The emergence of a capitalist society meant that an individual's worth was judged by their physical ability to carry out labour (Oliver & Barnes, 2012). It created impairment as an individual's problem; those that could carry out the labour were able; therefore those that could not carry out the tasks required were *dis*abled (Oliver, 1990). The individuals who could not participate in this capitalist activity were viewed as lacking and at the same time became increasingly dependent on the state for welfare and housing (Oliver, 1990; Oliver & Barnes, 2012). This reliance on welfare creates a notion that people with disabilities are dependent, rely on others for their care and income and cannot contribute to society (Oliver, 1990). By placing such an emphasis on being employed, society fails to appreciate the other ways in which people with disabilities can contribute to the economy, such as employing one to one workers and using aides and adaptations that have to be designed and manufactured (Atherton & Crickmore, 2012; Oliver, 1990). The view is that people with disabilities are entirely dependent without considering the many contributions people with disabilities make to the economy.

Imbalances of power remain despite a move away from residential institutions (Oliver 1990). Despite being based in the community, power in these services is retained by the professional staff (Oliver, Sapey, & Thomas, 2012). The services are still organised institutionally, for example with specialist transport, and with rigid timetables and activities that are decided by the staff not the individuals who attend (Oliver, 1990). This imbalance of power reinforces the view that people with disabilities are dependent and therefore legitimises the professional's role (Oliver, 1990). To Oliver (1990), dependency is a created state that is caused by economic factors, social policy and power imbalances between professionals and people with disabilities. The failure of services to meet the needs of people with disabilities is highlighted by services' interests in promoting independence (Oliver, 1990). Staff and people with disabilities have very different ideas about what independence means (Oliver, 1990). For staff priority is placed on individuals being able to demonstrate self-care and carry out household tasks. For people with disabilities the priorities are being in control and making their own decisions (Oliver, 1990). The former does not place any challenge on the power of the professional whereas the latter does.

Societal assumptions about people with disabilities and social policy rarely challenge the prevailing view that people with disabilities are passive, dependant and tragic (Oliver & Barnes, 2012). Policy by either side of the political spectrum does not help people with disabilities; on

the right, policy is often to cut services to decrease dependency, whereas the left seek to increase spending and therefore the number of services available without addressing the disabling issues in society or challenge what society considers "normal" (Oliver, 1990).

Erving Goffman attempts to understand the oppressive nature of a disabling society (namely in the USA where he is based) in his book of essays *Stigma* first published in 1963 and reprinted in 1990 (Goffman, 1990). In it, he explores the various ways in which stigmatized individuals navigate a hostile world and how they construct their identity in the face of this hostility (Goffman, 1990). Along with the stigmatized individual, Goffman (1990) identifies a group he calls "wise" (1990:43). These are people who do not carry stigma as individuals but by their association with a stigmatized person. To Goffman (1990), this can result in their own stigmatisation albeit to a lesser degree. One such group is relatives of people with disabilities who are also subjected to the impacts of an oppressive society.

In 2011 Mark Neary, father to Steven a young man with Autism and Severe Learning Disabilities, took the London Borough of Hillingdon to court. Steven had been admitted to respite in 2009 while his father was ill and Hillingdon Local Authority refused to allow him to return home (Neary, 2011). The judge ruled that Steven was unlawfully detained and he returned home. Neary has written about the experiences of the court case in *Get Steven Home* (Neary, 2011). In 2013, he published a collection of his blogs detailing his experiences of dealing with adult social care services (Neary, 2013). He describes the inaccessible information he is expected to make sense of, the hostility he experiences, and the fact that his issues and anxieties relate not to the care of his son but the trying to navigate intimidating services. As he describes it:

> Caring for a disabled son is an absolute piece of piss when compared to attending multi-disciplinary meetings; trying to decode the strange language endemic in the system; or having to manage a care package when all you really want to do is flop on the sofa with The Expendables (Neary, 2013: 3).

Oliver criticises Goffman's depiction of stigma (Oliver, 1990). He acknowledges that it seeks to explore interactions and the social context, rather than merely individual bodies (Oliver, 1990). However, he criticises the methodology, mainly that much of the information came from secondary sources and that it "was ultimately reducible to the individual" (Oliver, 1990:66).

It is the individual who carries the stigma and therefore their responsibility to adapt to fit in. Oliver (1990) notes that it is never considered that an individual may not merely wish to cope with their stigma. They may choose to "confront, reject or ignore as a deliberate strategy" Despite such criticisms Goffman's work remains an "inspiration" to researchers in disability

studies (Goodley 2011: 53). By moving the problem from the individual to the sociological Goffman's work radically challenged how disability was viewed (Goodley, 2011).

As well as his work on stigma, Goffman (1991) explored the role of institutions in his work *Asylums* published in 1961 and reprinted in 1991. This work, and his ethnographic studies into asylums took place in the USA, namely Maryland and Washington. Goffman (1991) describes what he calls a "total institution" (1991:11), in particular the "mental asylum" (1991:11). Here all aspects of life exist in one building; work activities, leisure, sleep and meals. As with *Stigma* (1990) his essays focus on the presentation of the individual within these oppressive institutions. He identifies the ways individuals adopt the role of "lowly" (Goffman, 1991: 30) for example being made to eat meals with a spoon like a child (Goffman, 1991). They may be forced to adopt physical and verbal responses to show their lower status to the staff members employed in the institutions. He gives such examples as having to refer to staff as "sir" (Goffman, 1991: 31) and humbly requesting a light for a cigarette or a drink (Goffman, 1991). The individual becomes required to act like the person the institution requires them to be. This necessity to behave in a certain way, a way which may be against their own wishes, enacts physiological stress on individuals (Goffman, 1991: 68).

Licia Carlson (2010) explores the way institutions for people with learning disabilities were conceived as the total institutions Goffman (1991) describes. To explore the power imbalance in such institutions she uses the work of Michel Foucault, particularly *Madness and Civilisation* (1961) and *Discipline and Punish: The Birth of the Prison* (1975, reprinted in 1991). She takes his description of disciplinary power (Carlson, 2010) and applies it to institutions. Institutions use surveillance, assessment and expectations of behaviour to exercise control rather than force or violence (Foucault, 1991). The way individuals are expected to behave in environments such as prison, school and institutions is so embedded in society that inmates adopt these behaviours unconsciously (Foucault, 1991). Carlson (2010) describes the ways institutions employed a range of tools and techniques to discipline and punish. They took over responsibility for all aspect of a person's life; what they ate, how they behaved and what activities they engaged in. This was all with the aim of creating "useful human beings" (Carlson, 2010:27).

These institutions, as with the mental asylums described by Goffman (1991), reinforce the power of the staff employed in them and the otherness of the people who reside there. People become less competent and more isolated (Goodley, 2011) by behaving in the ways expected of them from the institutions and the staff who worked there. Carlson (2010) asks "to what extent

did the structure of institutional life create their feeble minds rather than improve them (2010:44)"?

Yates (2005) also applies Foucauldian theory to an English care home setting and how people with learning disabilities understand their role within it. There are rigid expectations on their behaviour and how they must act (Yates, 2005). Residents come to understand themselves as a person with learning disability and act in certain ways based on their understanding of this role (Yates, 2005). The participants he interviewed could list the ways in which they were expected to behave and be a "good boy" (Yates, 2005:71), using the word "you" to describe how they are expected to behave "you're supposed to just take what they give you, and not say no" (2005: 72). They are not simply referring to their individual experiences but the experience of living in care accommodation more generally. They understand where their own behaviour fits within the rules of a care home.

Yates (2005) also explores the role of the researcher in uncovering the power imbalances that exist in such settings. Where Foucault championed working with the individuals in these powerless positions he warned against taking up an issue on someone's behalf (Yates, 2005). He advocated instead for the oppressed individual to challenge the power dynamics (Yates, 2005). However, to Yates (2005) researchers have a responsibility to problematise these relationships and highlight the power imbalance otherwise they can be considered the natural and the only option. To Yates solutions:

> lie not in the formulation of programs by academics on behalf of other people. The role that the researcher should play lies in working with people who live in care in order to bring to light the actions of power and subjectivity that they experience and, in turn, problematize those actions (2005: 75-76).

2.2.3 Criticisms of the Social Model

There are criticisms of the social model of disability. Tom Shakespeare and Nicholas Watson (2002) question the simplicity of the impairment and disability distinction. They ask where impairment ends, and disability begins. To them society cannot be expected to make all the adaptations necessary for everyone, regardless of impairment, to be able to access every part of it:

> If someone has a significant intellectual limitation, how can society be altered to make this irrelevant to employment opportunities, for example (Shakespeare & Watson, 2002:18)?

Shakespeare and Watson (2002) also criticise the ways in which the social model has become so dominant. To them it has closed down discussion about how disability can be understood and the potential impact this could have on the lives of people with disabilities who do not wish to

14

be seen as political or activist but to be accepted into a mainstream society (Shakespeare & Watson, 2002). It also does not account for the multifaceted nature of an individual's identity such as their gender, sexuality, ethnicity or religion (Shakespeare & Watson, 2002). For Shakespeare and Watson (2002), the social model rejects the notion that people may identify more strongly with other aspects of their identity. It is too simplistic to believe that all medical intervention is negative, they point out that an impaired person may require medical support and while they acknowledge social change is important medical care is still a necessity; one cannot replace the other (Shakespeare & Watson, 2002).

Goodley (2001) questions the definition of impairment within the social model of disability. He argues that it too is a socially constructed state rather than an "isolated, individual pathology" (Goodley, 2001: 225). He also explores the many ways in which people with learning disabilities are ignored within the social model (Goodley, 2001). Within disability activism he argues that people with learning disability are still encouraged to focus on their own impairment and not the societal factors that impact on them (Goodley, 2001). He calls for a move on from the social model of disability to a "mutually inclusive social theory of disability and impairment that are open and inclusive to people who have been labelled as having 'learning disabilities' (Goodley, 2001: 225)".

In *The Politics of Disablement*, Oliver (1990) makes some reference to what he refers to as the "mental handicapped" (1990:15) but does not refer specifically to people with PMLD or severe learning disabilities. In *The New Politics of Disablement*, Oliver and Barnes (2012) update the terminology they use "learning difficulties" (2012: 36) but there is still no reference to PMLD. People with severe learning disabilities have been largely ignored within explorations of the social model (Goodley, 2001). Where consideration in literature has been made as to how the social model works for people with mild learning disabilities (Goodley, 2001), people with severe disabilities have been "left in the realms of static, irreversible, individualised biology (2001: 213)". To Goodley (2001), a social theory with people with learning disabilities at the centre is a necessity.

In The *New Politics of Disablement*, Oliver and Barnes (2012) address some of the criticisms of the social model. Their argument is that the distinctions between impairment and disability should be used as a call to action and change (Oliver & Barnes, 2012). They acknowledge it is an over-simplified distinction but an effective one to challenge the personal tragedy theory (Oliver & Barnes, 2012). They state that, as Shakespeare and Watson (2002) suggest, the social model is not to imply that people with disabilities never require medical intervention (Oliver & Barnes,

2012). Their argument is that it should not be the *only* intervention they receive (Oliver & Barnes, 2012). Oliver and Barnes (2012) address the criticisms by highlighting the fact that the Social Model of Disability was never intended to be a social theory but a means of understanding disability that could be used to influence law, policy and research. They also highlight its effectiveness in giving people with disabilities a basis by which to organise themselves and verbalise the barriers they face in terms of environment and patronising attitudes (Oliver & Barnes, 2012).

The Social Model has resonated with people with disabilities. Pippa Murray (2004) explored the models of disability in her project with a group of young people about their access to leisure facilities in England. While she noted that they did not use the term 'social model' they demonstrated an "intuitive grasp" (Murray, 2004: 28) of its key principles. The group recognised the ways in which their access to leisure was restricted and that this was the fault of inaccessible leisure centres, restrictive rules and attitudes rather than their own impairment (Murray, 2004). They could identify examples of society being inaccessible to them, such as one boy being denied access to a swimming pool because of his support needs (Murray, 2004).

The social model challenges the ways disability is understood. Not as an individual's problem that exists fully formed and waiting to be fixed or treated, but as an oppression on the rights, access and life chances of people with impairments. The personal tragedy model results in people with disabilities being seen as less than people without disabilities and therefore subject to poor treatment and limited support (Oliver, 1990). This can be seen in the Mazars (2015) report which highlighted that people with learning disabilities are expected, by health professionals, to die younger and their deaths are not subjected to scrutiny. Despite its critics, the social model of disability continues to provide a necessary challenge to the prevailing idea that disability is the problem of the individual. Drawing on the work on several theorists, this section explored the many ways in which society can impose a disabling affect not just on individuals with disabilities but also on their carers. The expectations on their behaviour, the inaccessible information they receive, and the attitudes they face means that people with disabilities and their families continue to be seen as other and offered poor quality services and insufficient support.

2.2.4   Human Rights Model and Approaches

The Human Rights Act 1998 incorporates the rights set out in the European Convention on Human Rights (ECHR) into British law. These rights include a right to liberty, to marry, to start a family and protection from discrimination. This, combined with the United Nations Convention

on the Rights of Persons with Disabilities (CRPD) which was adopted in 2006, has seen a call for the social model to be developed into a human rights model of disability (Degener, 2014; Umeasiegbu, Bishop, & Mpofu, 2013). It is recognised that people with learning disabilities are subjected to abuse of their human rights which proponents of the human rights model seek to address (Duffy, 2003; Greenhill & Whitehead, 2011; Hall, 2013; Redman, Taylor, Furlong, Carney, & Greenhill, 2012).

Degener (2014) identifies ways in which the human rights model can potentially build on the social model, rather than replace it. She identifies that the human rights model places a moral expectation that people with disabilities will be treated equally which the social model does not do. Though the social model does refer to the rights of disabled people it is not fundamentally a rights-based model and focuses more on social relations and attitudes. To Degener (2014), the human rights model addresses those criticisms of the social model that state that the distinction between impairment and disability are too binary (Shakespeare & Watson, 2002). In a human rights model impairment does not reduce or remove the human rights of the individual. It is a more inclusive model that acknowledges the impact impairment can have not only on how people are viewed in society but in how individuals understand and experience their own bodies (Degener, 2014). The human rights model also allows for other aspects of individual identity to come to the fore (Degener, 2014). Where the social model is criticised as neglecting identity politics (Shakespeare & Watson, 2002) the human rights model acknowledges the many layers of identity a person with disabilities may inhabit beyond their disability such as their gender, sexuality or race (Degener, 2014). In addition to this it acknowledges that there are many identities within that of 'person with disabilities' for example recognising the cultural and communication needs of deaf and deaf blind people (Degener, 2014)

Understanding human rights has been identified as a means to improving the quality and access to support for people with learning disabilities. Redman et al (2012) call for human rights training to be delivered to both health care staff and people who use services. They developed a Human Rights Quiz which 23 staff members from a UK based Community Learning Disability Team completed before and after being trained in human rights (Redman et al., 2012). The training impacted on the staff members' knowledge of human rights legislation but did not change their attitudinal score results. The authors acknowledge that to change staff practice both knowledge and attitude need to change (Redman et al., 2012). However, this was only a small sample size and he quiz had not been standardised therefore more work needed to be done on the measures (Redman et al., 2012). Duffy (2003) describes people with learning disabilities as "treated like objects, controlled by others" (Duffy, 2003: V) which reduces the

power they have to exercise their human rights. In his book, written for people with learning disabilities, he identifies the six factors to support people with learning disabilities to achieve their rights to be full citizens (Duffy, 2003). These are self-determination, direction and goals, access to community life, a home, support and access to and control of money (Duffy, 2003). To Duffy (2003) this notion of full citizenship ensures people with learning disabilities are treated as equals and taken seriously.

Greenhill and Whitehead (2011) recognise a tension between the need for service providers to safeguard and the human rights of people with learning disabilities. They identify the key concepts in a human rights based approach (HRBA) to developing risk assessments which are that where possible the measures in place for managing risk should be proportional and proactive (Greenhill & Whitehead, 2011). The humans rights of the individual being assessed should remain at the forefront of the risk assessment process and people with learning disabilities should be involved in developing their own risk assessments (Greenhill & Whitehead, 2011). However, the authors acknowledged this may require balancing their rights with others, for example staff members and others using the service (Greenhill & Whitehead, 2011).

The human rights model seeks to extend the social model of disability by linking back to the rights of people with disabilities and understanding the intersectional ways in which impairment and other types of identity can impact on the individual. Human rights training and approaches are being increasingly recognised as necessary for improving services for people with disabilities and the quality of support they get. Knowledge of human rights is not only important for paid support staff but also people with learning disabilities and their allies.

2.3   Family Carers in Research

This section summarises the research involving family carers of people with learning disabilities as participants focussing on ten key areas 1) the caring role of parents of people with PMLD; 2) parents and services; 3) parental experiences; 4) physical and mental health needs of parent carers 5) older parent carers; 6) sibling carers; 7) carers from black and minority ethnic communities: 8) parent carers of people with challenging behaviour; 9) and support for families.

2.3.1   The caring role of parent carers of people with PMLD

In 2001 Mencap conducted research, in England, with 76 parents of people with PMLD. This research highlighted that many (60%) of these parents cared for their sons and daughters for over 18 hours a day (Mencap, 2001). Over two thirds (78%) of parents received either no support or less than 2 hours a week support with caring tasks (Mencap, 2001). Of those surveyed 61%

18

had received no support to plan for their child's future, for example support to move out of the family home (Mencap, 2001). The research also reported on the parents' dissatisfaction with services, the strain caring placed on their family and social life and the negative impact it had had on their careers (with 78% of those that had worked before their child's birth having to give up work) (Mencap, 2001). The report depicts a very negative situation with parents feeling isolated, suffering from ill health and disappointed in their local services. However, the report does highlight the love and affection these parents feel for their son or daughter with PMLD; they are a valued member of the family:

> They are like anyone else, just as obnoxious and just as loving, and it's wonderful when you get a beam or a cuddle. Sometimes she will look at you, right into your soul (Mencap 2001: 18).

2.3.2   Parent Carers Collaboration with Services

Research investigated the collaboration between parents and services (De Geeter, Poppes, & Vlaskamp, 2002; Jansen et al., 2013). De Geeter et al explored the idea of the parent as expert (2002). The notion of parent as expert is found in UK social policy which states that "carers will be respected as expert care partners" (Department of Health, 2010: 5). This includes not only being an expert in the needs of the person they support but also in the needs of carers generally to ensure new support services are more "inclusive and...supportive" (2010: 35).

Historically, parents were viewed by services as "laymen" (De Geeter et al 2002: 443) in contrast to the expertise of staff and medical professionals. Now research recognises the expertise held by parents (De Geeter et al., 2002). This expertise develops as a result of the high amount of time they spend with their child and the bond they share with them (De Geeter et al 2002). However, parents perceive that they are not treated as an expert, and resentment is caused by a mismatch between their experiences and what is written in policy (Graungaard & Skov, 2007). The role of expert can also bring additional demands on parents (De Geeter et al 2002). It requires knowledge about what is available in terms of care and support as well as persistence and time to find out about different resources (De Geeter et al., 2002). Parents need information about what is available and what is appropriate to enable them to make the decisions they are now expected to make (De Geeter et al 2002). De Geeter et al (2002) sent questionnaires to 723 parents of children with PMLD who attended special schools in The Netherlands. Parents rated on a Likert scale how included they were in their child's education and therapy. The majority of parents reported they were satisfied with the level of collaboration between themselves and staff at their child's school (De Geeter et al., 2002). Their opinions were listened to and they were included in decisions about therapies. This differs quite considerably from the Mencap

(2001) report which highlighted the vital role parents played in supporting their child but reported that many parents felt this was not taken in to consideration by staff:

> The way they deal with carers is appalling - they don't show respect for relatives. They don't respect carers for the knowledge they have gained over the years. (Mencap 2001: 24).

The differences in these findings from parents could be due to location (the Netherlands and the UK) or age of offspring (parents of children and parents of adults). The involvement of parents in the services for their sons and daughters may change as their children move from children's to adult services. It could also be due to survey bias, with dissatisfied parents using the survey as an outlet to express this.

2.3.3 Experiences of caring

Studies have looked at how factors such as the age of child, the severity of disability or maternal education can affect parental experiences of raising a child with disabilities (Chen, Ryan-Henry, Heller, & Chen, 2001; Jansen et al., 2013; Saloviita, Itälinna, & Leinonen, 2003). However, only one study looks at this in relation to parents of children with PMLD (Jansen et al., 2013). Saloviita et al., (2003) invited parents of people with PMLD in Finland to take part in their research but the response from this group was only 4% of the 258 returned questionnaires. This was an underrepresentation compared to the general population (Saloviita et al., 2003). This could be because parents of children with PMLD have demanding caring responsibilities and are unable to commit the time to complete the questionnaire. The parents were asked to rate their child's level of disability themselves. Therefore, some may have selected other options (for example severe) rather than rate their child's disability as profound. Jansen et al (2013) used surveys to explore what parents of children with PMLD considered important and whether this was affected by characteristics such as age of child, gender of child, gender of parent and parental education amongst others. In their study in the Netherlands 100 parents rated the quality of care their child received on a 7-point scale using a Dutch version of the Canadian Measure of Processes of Care (MPOC) (Jansen et al., 2013). Non parametric tests examined the differences in scores based on child and parent characteristics, for example the child's age, gender, type of disability, the parent's gender, education or involvement in services (Jansen et al., 2013). Only one category produced statistically significant differences and this was the difference in responses between parents of children aged six to twelve and parents of those aged seventeen and over (Jansen et al., 2013). Parents of children aged six to twelve were significantly more satisfied with how services shared information than parents of people aged seventeen and over (Jansen et al., 2013). One explanation could be that parents of younger children have less

experience of care services and therefore less negative experiences (Jansen et al 2013). There were no significant differences between any of the other characteristics (Jansen et al., 2013). Most of the parents were satisfied with the support they received, however a significant minority (18.8%) of the parents were not and rated the support they received at the lower end of the scale (a grade of 5.5 or less) (Jansen et al., 2013). Again these findings differ to the Mencap (2001) report in which the majority of parents were unsatisfied with the services they or their child received.

Kyzar et al (2012) reviewed literature published in English but from several countries between 1990-2010. The literature focussed on family support and family outcomes for families that include a child with moderate or severe disabilities. They found that parents caring for people with severe disabilities experience unique issues that are not as keenly felt by parents of a child with mild disabilities (Kyzar et al., 2012). Issues included affording good quality care, finding qualified staff and getting sufficient rest (Kyzar et al., 2012). Kyzar et al (2012) also highlight that they are unable to synthesise the experiences of family carers of people with PMLD due to a lack of research in this area.

2.3.4 Physical and mental health needs of parent carers

Much of the research into caring for a person with disabilities addresses the physical and mental health needs of parents. Some research has shown that parents of people with learning disabilities are more likely to have mental health issues such as depression and more likely to report poorer physical health (Mencap, 2001). These issues are said to increase the longer the carer is caring for (Carers UK, 2012). This can be a result of the carers' own declining health, a lack of support for older carers compared to younger carers and the increasing needs of the person they care for as they age (Minnes & Woodford, 2005).

In contrast, other studies have found no differences between parents caring for a child with disabilities and the rest of the population. This could be because the studies have taken place in different countries, or because they focus on the general learning disability population rather than specifically those with PMLD. Chen et al (2001) found that both middle aged mothers (aged 55 to 64 years) and late aged mothers (aged over 65 years) in the US who cared for a son or daughter with learning disabilities did not rate their physical or mental health as any different from the rest of the US population. In fact, the middle aged mothers rated their mental health as better than the rest of the population (Chen et al., 2001). The characteristics of their adult children with learning disabilities made no difference to the mother's health (Chen et al., 2001). For younger mothers being in employment was shown to have a positive impact on their physical

health (Chen et al., 2001). This issue was also explored by Chou et al (2010) who asked working aged mothers in Taiwan to rate their quality of life using the World Health Organisation Quality of life scale. The mothers were all primary carers of an adult with learning disabilities (Chou et al., 2010). This research found that mothers in full time or part time employment rated their quality of life as higher (93.65 and 94.04 respectively) than those not in employment (90.90) (Chou et al., 2010). Although all of the participants in the study rated their quality of life as lower than the national average (Chou et al., 2010). This finding supports earlier research that suggests that for mothers of children with disabilities going to work can be a therapeutic experience that enables them to take a break from caring and increases their social networks (Beresford, 1994).

2.3.5 Positive caring experiences

In many of these studies parents also highlight the positive aspects of caring for a son or daughter with disabilities. They provide companionship (Cairns, Tolson, Brown, & Darbyshire, 2013) and, in some cases, as the carer gets older they provide reciprocal care (Bibby, 2013). Carers describe the love they feel for their child and the satisfaction caring brings:

> I've brought her up to the best of my ability and seen her grow and develop…it's a real pleasure. Every day I see her and she's my ray of sunshine. She's a joy to be with (Mrs Smyth) (Cairns 2013: 79).

In the Canadian study conducted by Jokinen et al (2005) into the quality of family life parent carers describe themselves as "pioneers" (2005: 791) and express great pride in their achievements in challenging and changing services (Jokinen & Brown, 2005).

Cairns et al (2013) criticise research which has not highlighted these benefits and only described the stress and burden of caring for a child with disabilities. This contributes to what they call the "deficit model" (2013: 74). Kyzar et al (2012) call for more positive interpretations of caring for a family member with disabilities using a "support paradigm" (2012: 41) which focuses on the strengths and needs of the whole family rather than individual, sometimes negatively perceived traits such as severity of disability (Kyzar et al., 2012).

2.3.6 Older parent carers

As more people with learning disabilities live at home and people are living to a greater age, many people with learning disabilities are now living with elderly carers (Bowey & McGlaughlin, 2005). Mencap (2002) identified that 29,000 people with learning disabilities were living with a carer over 70. A reoccurring theme in research with older carers is a lack of future planning and a fear of the future (Bibby, 2013; Bowey & McGlaughlin, 2005). In particular, what will happen

to their son or daughter if they outlive their parents? As medical care means that people with disabilities are living longer this generation has been identified as the first to face this dilemma (Jokinen & Brown, 2005). In several research studies, parents express it may be preferable if their adult child dies before them (Bibby, 2013; Bowey & McGlaughlin, 2005; Dillenburger & McKerr, 2010). This way they do not need to worry about who will care for and advocate for their family member after they have died. Those parents of people with more severe disabilities and/or no verbal communication have the added concern that the person needs higher levels of support and are unable to verbally express their needs:

> If she could speak, it wouldn't bother me half so much, I know all the signs, it takes
> a long time to find out what she wants. If she could talk and tell people, it wouldn't
> be so bad (Mary, dual carer) (Bowey and McGlaughlin 2007: 50).

This fear of the future and what will happen when they are no longer able to care combined with a perceived lack of suitable services means that many carers have not made any plans for the future. The risk here is that the situation could reach crises (in the event of a carer's death or deteriorating health) and solutions will need to be found at very short notice. Some parents, when they are no longer able to care, had planned that another family member, usually the disabled person's sibling would take over the care (Dillenburger & McKerr, 2010). However, many were reluctant to ask their other children to do this as it could impact negatively on the siblings' lives (Dillenburger & McKerr, 2010; Jokinen & Brown, 2005).

In some cases, the lack of future planning comes from a reluctance to live apart from their disabled son or daughter. For some this is because their adult child has taken on a caring role of their own and now cares for the parent (Bibby, 2013) or because they provide the parent with company which they worry they would not have otherwise (Hubert, 2006). Parents can be influenced by previously negative experiences of services, mainly respite services, and a lack of information about the options available (Bowey & McGlaughlin, 2005). Bowey and McGlaughlin (2005) surveyed 62 family carers in Ireland (including parents, siblings, aunts and grandparent) aged 70 and over about their plans for the future. One barrier to making future plans was negative experiences of services, particularly respite care (Bowey & McGlaughlin, 2005). This was many carers only experience of housing services and therefore they surmised that other residential care would also be low quality (Bowey & McGlaughlin, 2005).

The research focussing on the future planning needs of older carers all highlighted the need for accessible information about what is available (Bibby, 2013; Bowey & McGlaughlin, 2005; Cairns et al., 2013) and for services to be proactive yet sensitive in initiating future planning (Bowey & McGlaughlin, 2005). However, as parent carers in the UK save the NHS a considerable amount

of money, approximately £119 billion (Carers UK & University of Leeds, 2011) Dillenburger and McKerr (2010) suggest that the drive for future planning will need to come from families themselves as there is little incentive for services to initiate future planning and support the person with disabilities to move out of the family home.

2.3.7 Sibling Carers

As the life expectancy of people with learning disabilities increases so does the possibility that they will outlive their parents. In some cases, the role of carer then falls to the sibling of the person with disabilities (Bigby, 1998) despite parents' fears that this could be a burden on their children without disabilities (Dillenburger & McKerr, 2010; Jokinen & Brown, 2005). The role of adult siblings has not been as widely explored as the experiences of siblings during childhood (Bigby, 1998). Bigby (1998) sought to address this gap in the research by identifying 62 people with learning disabilities in Australia who had lived with parents until they were at least 40 years old, but had since left the parental home, and were now aged over 55 years. Bigby (1998) interviewed people they had close personal relationships with including siblings and friends, the service providers who had identified the individuals and in 51 out of 62 cases the individual with disabilities themselves. The interview data was collected as part of a wider project exploring future planning in Melbourne Australia but was re-analysed specifically to explore the role of sibling carers (Bigby, 1998). In this study, the main role the siblings played was to manage the care their sibling with disabilities received, for example by liaising with service providers (Bigby, 1998). A smaller proportion provided the primary care; such as living with the person and providing personal care (Bigby, 1998). Those that did this tended to be single and they did so for a shorter period of time (mean 6.3 years) than their parents had (Bigby, 1998). Twenty six siblings provided primary care immediately preceding the person with disabilities leaving the parental home but in most cases this was a short or medium term situation (Bigby, 1998). This study is twenty years old and some of the research methods are outdated, for example the service provider decided whether or not the person with disabilities had sufficient communication skills to participate in an interview rather than more inclusive methods being explored. It also does not explore the emotional response siblings have to taking on the caring role. However, it does highlight that often plans had not been made for when the person with disabilities leaves parental care and therefore it falls to siblings to step in even if only in the short term (Bigby, 1998). Siblings could have their own family commitments or health issues so this situation can be far from ideal (Bigby, 1998). Tozer and Atkin et al (2013) explored the experiences of adult siblings of people with severe autism and learning disabilities. They conducted semi structured interviews with 21 siblings and twelve people with autism and a

learning disability living in England (Tozer et al., 2013). The authors highlighted the complex relationship adult siblings can have with their sibling with autism in which they may be trying to balance the support their sibling requires with caring for their own children, caring for elderly relatives and career responsibilities (Tozer et al., 2013). There is also a lack of recognition in policy about the role of adult siblings. Tozer et al (2013) identify, as did Bigby, (1998) that young carers and siblings in childhood are a much more recognised group. This lack of recognition can lead to siblings feeling invisible and ignored by services and anxious about a lack of clarity regarding their legal status (Tozer et al., 2013). The interviews explored the siblings' childhood and their current relationship with their sibling with autism and learning disabilities (Tozer et al., 2013). Many of the participants recounted memories of parental stress, taking on caring responsibilities when they were young and negative responses from others as part of their childhood (Tozer et al., 2013). However, they could also identify positive aspects of their childhood with a sibling with autism (Tozer et al., 2013). The siblings continued to feel a sense of responsibility for their sibling with disabilities and the impact caring for them had on their parents (Tozer et al., 2013). Nearly half had sought counselling in an attempt to understand their childhood and many described mental health conditions such as depression (Tozer et al., 2013). Many siblings wanted to offer support to their sibling with disabilities but in a flexible way, they did not want to be relied on as the only carer for their sibling (Tozer et al., 2013). This flexibility was viewed by the participants as more in keeping with a 'normal' sibling relationship (Tozer et al., 2013). This study, as with many others about caring, featured predominantly white and female participants from a higher socioeconomic background. All of the participants were already engaged in an advocacy group so were not a hard to reach or disengaged group. None of them lived with their sibling which may give a different dynamic to the relationship.

As part of a wider study Tozer and Atkin (2015) interviewed 12 social care staff in England along with the siblings and adults with autism, examining the ways in which adult siblings and service providers work together (Tozer & Atkin, 2015). The siblings could remember negative experiences with service providers from their childhood and for many this resulted in viewing service providers with mistrust (Tozer & Atkin, 2015). They felt they had been previously excluded from their siblings' care and a third felt judged by providers, for example for not visiting very often (Tozer & Atkin, 2015). Many siblings recognised there may be a time when they needed to take on more caring responsibilities, for example when their parents die, but they were frustrated by the lack of planning from services (Tozer & Atkin, 2015). This is similar to the findings of Bigby (1998) that often siblings step in and become primary carers, at least for the short term, when their parents are no longer able to assume this role (Bigby, 1998). The twelve

service providers recognised there was more they could do to include siblings but were concerned about forcing contact where it was not wanted or where the sibling may need support beyond what they could provide (Tozer & Atkin, 2015). Some practitioners described siblings as "unreliable" (Tozer & Atkin, 2015:348) as they would become involved in care at times of crisis but then back off again, confirming siblings' fears that they are being judged (Tozer & Atkin, 2015). For practitioners they worry that what they perceive as unreliable may be upsetting for the sibling with autism but for the sibling this is a flexible relationship in keeping with 'normal' sibling relationships (Tozer & Atkin, 2015). Despite the limitations mentioned previously (for example the lack of diversity of the participants) this study highlights an important gap in services understanding of how best to engage with siblings and their capacity to support the sibling relationship.

2.3.8 Carers from black and minority ethnic communities

As well as research that focused on older parents, research has also focused specifically on the needs of carers from black and minority ethnic (BME) communities. In many ways their needs are the same as those of all parent carers (Hubert, 2006). However, there are specific challenges faced by carers from a BME background, the key one being communication (Hubert, 2006; Joseph Rowntree Foundation, 1999). If the carer does not speak English they may find it difficult to initiate communication with service providers, understand written information or find information about available services (Hubert, 2006). This can result in the family becoming isolated and not receiving services they are entitled to (Hubert, 2006). Although most of the carers in Hubert's (2006) study conducted in South London, England, reported they had not experienced prejudice, some did feel that prejudiced attitudes resulted in them receiving less support and being treated dismissively by service providers. This discrimination can be a result of a power imbalance between service providers and BME families and an expectation that black families will be "submissive and accepting" (Baxter, Poonia, Ward, Nadirshaw, 1990: 20). This can be exacerbated by cultural stereotypes employed by service providers (Baxter et al., 1990; Hubert, 2006). One stereotype is that families from South Asian background have large, supportive families who live in close proximity and can offer support to the families. In Hubert's (2006) study of 30 BME families living in South London she found that this was not the case and in fact social isolation was an issue for most of her participants. Only one described having a lot of informal support and only one reported a full social life (Hubert, 2006). These stereotypes can result in families not being treated as individuals but receiving support based on cultural assumptions. Hubert (2006) suggests a solution to some of these issues would be a named social worker who knew the family and visited them at home.

2.3.9 The impact on parent carers of caring for someone with challenging behaviour

Challenging behaviour is defined as:

> Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities (Emerson & Einfield, 2011: 4).

Much of the research about the impact of challenging behaviour on parents and carers focuses on parents and carers of children (Doubet & Ostrosky, 2014; Hassall, Rose, & McDonald, 2005; McConkey, Gent, & Scowcroft, 2013; Wodehouse & McGill, 2009). There is literature about the impacts of children's challenging behaviour on the family (Doubet & Ostrosky, 2014), on access to services (McConkey et al., 2013) and on the services that parents and carers perceive as being useful (Wodehouse & McGill, 2009). There is also a strong association between challenging behaviour and higher parental stress (Hassall et al., 2005) and poor parental health (Gallagher & Whiteley, 2012). There is very little research that focuses on the parents and carers of adults with challenging behaviour. This could be because services for adults are not as coordinated and it is not as easy to identify parents and carers of adults with challenging behaviour. It could also be that challenging behaviour can exist alongside other health and support needs and therefore they are the focus of the research rather than the challenging behaviour.

Daley, Weisner and Singhal (2014) found that challenging behaviour was one of the main factors preventing people with autism attending structured activities outside the home. Daley et al. (2014) interviewed and surveyed 52 families living in New Delhi, India and surrounding areas who cared for an adult with autism at home. Families were recruited through the Action for Autism database and autism services in Delhi (Daley et al., 2014).

Families in this study came from a range of backgrounds and some had experience with formal services whereas others did not. Most were financially well off and 67% had household servants either full or part time (Daley et al 2014). The parents were all interviewed in their home and left with a set of questionnaires to complete on their own. The results from one of these questionnaires, Parent Stress Index-Short Form (PSI-SF) is reported in the study (Daley et al., 2014). The PSI-SF is a 5-point Likert scale in which parents are asked whether they agree or disagree with various statements about parenting. The parents reported that nearly half (n=22) of the people with autism they care for had no structured day time activity (Daley et al., 2014). The main reasons parents gave for this were 1) the person did not want to go out 2) there were a lack of suitable activities, and 3) they were prevented by behaviour that challenged including:

hitting, throwing objects, pushing, removing clothes, sexual behaviours and vomiting, as well as seizures, other medical problems, and not being toilet trained (Daley et al 2014: 146).

However, the results from the questionnaires show that parents and carers of children who were in the house all day did not report themselves as more stressed than parents and carers of those children who went out (Daley et al., 2014). The biggest impact on parental stress levels was whether the mother in the family worked, which impacted on both mothers' and fathers' stress levels, perhaps because the mothers tended to be the primary care giver and therefore balancing the responsibilities of the home and work caused an increase in stress levels (Daley et al., 2014). This was a mixed method study (combining interview and questionnaire data). This can give more rounded results as the quantitative results of the questionnaire can be expanded upon using the qualitative responses of the interviews. It can add a narrative to the data obtained from the questionnaires. The families in this study were financially comfortable, as indicated by their use of household help and their monthly income. Parents and carers of adults with autism who earn very little or nothing at all could have very different experiences. In this study the support needs of the adults with autism were very wide ranging; some were working or studying whereas others needed extensive physical support (such as support with toileting). This wide range of skills and needs means that the family experience could vary greatly.

The study by Daley et al (2014) looked at the impact of challenging behaviour on access to services. Lunsky et al (2014) also explored this in their review of literature. They aimed to find out which system-wide information needed to be collected about families to improve the quality of learning disability services (Lunsky et al., 2014). They conducted a scoping review of the literature using 56 databases and the following categories "population of interest (e.g., developmental disabilities), family experiences (e.g., carer, parent), age groups (e.g., adult, transition age), and services (e.g., support services) (Lunsky et al. 2014: 9)". Articles were excluded if they focussed on children with learning disabilities (rather than adults), did not discuss carer or service need, the focus of the study was parents and carers *with* disabilities rather than parents and carers *of* people with disabilities or they evaluated a service without discussing the need for that service (Lunsky et al., 2014). A total of 87 articles were included in the literature review. The results were organised under three headings 1) service use; 2) service need/waiting for services and 3) permanency planning (Lunsky et al., 2014). Lunsky et al (2014) found that challenging behaviour was associated with unmet services needs including psychological support and vocational training. However, the presence of challenging behaviour was also associated with increased service use particularly social services (Lunsky et al., 2014).

This suggests that although people with challenging behaviour access more services there is still more support they need. Their complex needs may mean they need a wider range of services. The studies described focus on the negative experiences that parents and carers face when caring for a child or adult with learning disabilities and challenging behaviour. Hubert (2010) conducted an ethnographic study of 20 families living in one county in South England. Ethnography is a research method that explores real life experiences through participant observations (Atkinson, Coffey, Delamont, Lofland, & Lofland, 2001). This is often combined with other research methods such as in-depth interviews and focus groups to explore the findings from the observations with the participant (Atkinson et al., 2001). The participants in this study were parents and carers (mainly mothers) of children aged 15-22 years who had severe or profound disabilities and severely challenging behaviour (Hubert, 2010). Professionals such as teachers, social workers and psychologists were asked to identify people who may meet these criteria (Hubert, 2010). Other professionals were then consulted to reach a consensus about whether or not the child had the requisite level of disability and challenging behaviour (Hubert, 2010). Once an agreement was reached families were approached (Hubert, 2010). Hubert (2010) used participant observation and unstructured interviews to gain an insight in to the carers' experiences. The study took place over two years and between eight and 33 hours were spent with the families (Hubert, 2010). Hubert (2010) found that the parents she observed and interviewed took a lot of pride and felt a great deal of love for their offspring with severe disabilities and challenging behaviour. She found that for many of the parents their disabled child was the most important person in their life (more so than spouses, friends or other relatives) (Hubert, 2010). Most were unwilling to contemplate a time when they could not care for their child and as a result 15 out of 20 expressed a hope that their child would die before they did (Hubert, 2010). Where these parents expressed frustration and dissatisfaction it was with services rather than the person they cared for (Hubert, 2010). Many felt that the quality of services had deteriorated as their child moved in to adult services (Hubert, 2010). They found them unreliable and disorganised (Hubert, 2010). They also found the impact of the child's challenging behaviour increased as the child got older; violent behaviour was harder to control and some had started to exhibit overt sexual behaviour (Hubert, 2010). However, even with these frustrations and struggles the mothers enjoyed the role they had in caring for their son or daughter (Hubert, 2010). These more positive experiences provide a counter balance to the very negative experiences described by many studies. It could be that the ethnographic methods used and the extended time spent with the families enabled a wide variety of experiences to be witnessed which included both the positive and negative. A survey or structured interview does

not allow for such a rich and in-depth window in to these families lives. However, this study has limitations. The participants were all known the services; though it is not clear from the study if they were all accessing services at the time. Families who are not well known to services may have very different experiences. The families that agreed to participate in the ethnographic study may be those who feel more comfortable letting someone in their home. This may be because they were in a relatively stable position and not in a crisis situation. Therefore, their experiences at that time may be more positive.

2.3.10 Identifying sources of carer stress

Boehm, et al (2015) explored the quality of life of parents and carers of people with learning disabilities aged 13 to 21. They recognise that transition in to adulthood can be particularly stressful for families of children with learning disabilities and also that much of the learning disability research focuses on parents of much younger children (Boehm et al., 2015). They surveyed 425 parents and carers of transition aged children with learning disabilities or autism who resided in one state in the United States of America (Boehm et al., 2015). The parents and carers were recruited through various organisations including schools, religious groups and sports groups (Boehm et al., 2015). Families who expressed an interest in participating were sent a range of questionnaires in the post along with a stamp addressed envelope to return the completed forms (Boehm et al., 2015). Family Quality of Life (FQoL) was measured using the Beach Centre Family Quality of Life Scale (Boehm et al., 2015). This measure is a 5-point Likert scale on which the participant rates their satisfaction with various aspects of family life including family interaction and physical and material wellbeing (Boehm et al., 2015). The parents and carers completed demographic information about their child including information about the nature of their disability and how often they exhibited challenging behaviour outside the home (Boehm et al., 2015). They also rated their child's level of support need across various domains using a 5 point Likert scale ranging from no support needed to total support needed (Boehm et al., 2015). The domains included home living, social activities and health and safety activities (Boehm et al., 2015). Boehm et al (2015) found that the overall FQoL ratings were quite high (m=3.99 SD=0.63) and parents and carers rated themselves most highly in terms of their physical and material wellbeing. However, the factors that had the most negative impact on FQoL was having children with higher support needs and having children who exhibit challenging behaviour (Boehm et al., 2015). Parents and carers who stated their child did not exhibit challenging behaviour were more satisfied across the domains than parents and carers who stated that their child did (Boehm et al., 2015). This study approached parents and carers through various different organisations in an attempt to reach a wide range of people. However,

the fact that the parents and carers rated themselves as satisfied with their physical/material wellbeing suggests that it may be more solvent and physically healthy people responded. Those parents with poor physical health or financial issues may have different experiences to the parents in this sample. All these parents were from one state in America (Tennessee). This state may have particularly well-resourced learning disability and transition services which account for parents and carers in this study being fairly satisfied. This may not be the case in other states or other countries. As with many studies of parent and carers experiences the majority of participants were mothers (87%). Mothers may have a different view of family life to fathers but the father's view is not as well represented. This study does not compare how maternal and paternal views differ. The surveys sent to parents were approximately 15 pages long. This may have been off putting to people who have low literacy or do not speak English as a first language. This may have impacted who completed the forms and their levels of education.

The study by Boehm et al (2015) supports the research conducted by Walden et al in 2000. Walden et al. (2000) surveyed 62 parents and carers of adults with learning disabilities. The parents and carers were known to services as they used respite services in two London boroughs, England (Walden et al., 2000). The parents and carers had to be the primary carer of someone with learning disabilities who was over 18 years but no further inclusion criteria were used (Walden et al., 2000). The researcher in this study visited the participants at home and went through a range of self-report scales and interview questions (Walden et al., 2000). The tools used were the Scales of Psychological Wellbeing, Positive Affect Scale, the short form of the Questionnaire on Resources and Stress, Symptom Checklist 90 Revised, Degree of Dependency Scale, the Checklist of Challenging Behaviour (Walden et al., 2000). Parents and carers were asked about the support they received. This was divided in to three types of support 1) formal; 2) informal and 3) emotional. The participants were also asked an open question: "how different do you think your life would be if (name) was not living at home" (Walden et al 2000:66)? Their responses were recorded verbatim. Parents in this study reported higher levels of stress than previous studies of parents and carers in the US and Republic of Ireland (Walden et al., 2000). Challenging behaviour was the factor most strongly associated with parental stress, anxiety and depression (Walden et al., 2000). The most positive impact of carer well-being was having access to informal support (friends or family who could offer support such as sitting with their son or daughter while the carer goes out) (Walden et al., 2000). In this study the participants were asked to rate their experience over several rating scales which gives a range of responses covering many domains. However, the researcher sat with the participant as they completed their ratings. This could have impacted on how honest they felt able to be. The

participants in this group all used respite services. Those parents and carers who receive no support or who are not known to services were not represented in this study. Their experiences could be very different to this group who have access to respite. As with the study by Boehm et al (2015) the parents in this group were mainly mothers (93%), mainly in good health (90%) and mainly financially stable (77%). This could mean that certain groups (fathers, those in poor physical health and those with financial worries) are not well represented.

The impact of socio economic status on carer well-being is explored in a qualitative study by Hatton et al (2010). They interviewed seven minority ethnic parents and carers and seven majority ethnic parents and carers of people with learning disabilities who lived in the same town in England (Hatton et al., 2010). The parents and carers were identified using the local NHS primary care database of teenagers and adults with learning disabilities (Hatton et al., 2010). All of the people on the database had either used specialist services at some point or had been referred by General Practitioners (Hatton et al., 2010). The families were visited by a researcher to gain informed consent and then to complete interviews lasting between 45 minutes and 2 hours (Hatton et al., 2010). This data was then translated (minority ethnic participants spoke Urdu, Punjabi or Gujarati), transcribed and analysed using Interpretive Phenomenological Analysis (IPA). Findings from the interviews show that families all reported problematic behaviour exhibited by the person with disabilities and that this behaviour impacted on family life (Hatton et al., 2010). Some of this behaviour matched the definition of challenging behaviour (such as physical violence and self-injury) however, while other behaviours such as starting arguments, needing a structured routine or avoiding family life did not (Hatton et al., 2010). All families identified some problematic behaviour, not just those where services had identified challenging behaviour (Hatton et al., 2010). Whether or not the person had service defined challenging behaviour did not impact on how negative or positive the parent or carer found the caring experience (Hatton et al., 2010). This study used the participants' postcodes and the English Index of Multiple Deprivation to rank their socio economic status (Hatton et al., 2010). Most of the participants (n=11) lived in an area rated as deciles 1 or 2 (a ranking scale where 1 is most deprived and 10 is least deprived). Although the sample in this study was small (n=14) there was some suggestion that those living in more deprived areas had more negative family experiences than those in the less deprived areas (Hatton et al., 2010). In fact, this was more relevant than whether or not the person with disabilities showed challenging behaviour (Hatton et al., 2010). Those from the minority ethnic communities also had more negative experiences than those in the majority ethnic communities (Hatton et al., 2010). However, those from minority ethnic communities but less deprived areas reported more positive experiences

suggesting that socio economic status has a greater impact that ethnicity (Hatton et al., 2010). This study used in depth interviews to get to the root of these carers' experiences. The semi structured interview meant that the participants could discuss the topics that they found important in as much detail as they wanted. However, the sample was small so the conclusions must be treated cautiously. The study was also funded by the local NHS Primary Care Trust which could have influenced some of the responses. Participants with negative experiences of NHS services may have used the interview to express their dissatisfaction. It may have resulted in people with negative experiences being more likely to take part in the study.

2.3.11 Support for families

Much of the research focuses on characteristics of the family or the individual with disabilities (age, ethnicity, type of disability). Kyzar et al (2012) describes a shift in how intellectual disabilities have been defined from an "individual capacity" model (2012: 32) where the disability is situated within the individual to a model of "support" (2012: 32). There is a greater understanding of how environmental factors can be disabling and that people have "support needs" (Kyzar et al 2012: 32) to overcome some of these barriers. With this is an increased understanding about the impact of disability on the family and an acknowledgement that families will also have support needs (Kyzar et al., 2012). The authors also recognise that although the necessity of family support is documented in US policy, actual implementation of family support remains low (Kyzar et al., 2012). For many families informal support is viewed as highly beneficial and has been identified as a major factor in reducing parental (particularly maternal) stress (Chou et al., 2011; Saloviita et al., 2003; White & Hastings, 2004). Informal support can be spousal support, support from family and friends, and support from the wider community such as neighbours or religious groups (White & Hastings, 2004). In their UK study White and Hastings (2004) asked 33 parents of adolescents with moderate to profound disabilities to quantify the amount of informal support they had and rate how helpful it was. Helpfulness was rated in terms of practical support such as someone to provide childcare or support with chores and emotional support such as someone to talk to (White & Hastings, 2004). White and Hastings (2004) found that it was not the size of this support network that reduced stress but how helpful the carers perceived to be. In contrast formal support was not identified as something that reduced stresses or improved parental quality of life. In fact it is sometimes seen as factor that increases stress levels (White & Hastings, 2004). Beresford (1994) identified from the literature several ways in which formal support could increase parental stress. Formal support can be inflexible and can therefore leave carers feeling as though their needs are still not being met (Beresford, 1994). Interactions with professionals can be stressful for parents and

also accessing services can be a difficult experience (Beresford, 1994). Formal service can also be viewed as something to be accessed in times of crisis and therefore associated with difficult situations (Beresford, 1994). However, Kyzar et al (2012) noted that many of the studies they found in their review focussed on informal support and not formal support. They suggest that more research is needed before the role of formal support can be fully understood (Kyzar et al., 2012).

2.3.12 Summary

This section aimed to synthesise some of the findings from research in which the participants were family carers of people with disabilities. It focussed on ten key areas 1) the caring role of parents of people with PMLD; 2) parents and services; 3) parental experiences; 4) physical and mental health needs of parent carers 5) older parent carers; 6) adult siblings; 7) carers from black and minority ethnic communities: 8) the impact on parent carers of caring for someone with challenging behaviour; 9) and support for families. The review of the literature has shown a shift in the way that research with parents is interpreted and conducted. The more recent research tends to include more positive experiences of being a parent carer, rather than focusing on the negatives. However, the majority of the research still focuses on the burden of the carer role and the stress associated with individual character traits such as the age of the carer, their ethnicity and the severity of their child's disability. There is little research that explores the stressors external to the person being cared for, such as carers needing to navigate formal services. Stress is still assumed to come from the individual needing care. Informal support, such as friends, relatives and neighbours, are often identified as a means of reducing some of this stress. Full or part time paid employment can also reduce carer stress and improve carer wellbeing. Despite adult siblings wishing to be involved in the care of their sibling with disabilities they are still largely excluded by services and ignored in policy and research. There is limited research focussing on the needs of parents of people with PMLD, even though they are identified as a group that have unique support needs (Kyzar et al., 2012) and are at risk of being marginalised (Mencap, 2001).

2.4 Learning Disability History and the Changing Role of the Family Carer

2.4.1 Introduction

As a group, people with learning disabilities became visible during the time of the Industrial Revolution (Oliver, 1990) when the increasing complexity of work related tasks meant that not

everyone was able to complete them. This section explores the history of people with learning disabilities in the United Kingdom and the changing legislation relating to their treatment, care and support. It also looks at the history of the family carer and their changing and increasingly varied role.

The section explores the legislation relating to adults with learning disabilities rather than children. Support services for children with learning disabilities have been governed by legislation relating to education such as the Education Acts in 1944 and 1970 and The Children and Families Act, 2014.

2.4.2   History of Learning Disability Services

While current government policy and legislation refers to 'personalisation' and 'citizenship (Department of Health, 2009) the fact remains that people with learning disabilities are still not enjoying the same access to social opportunities (Milner & Kelly, 2009), employment (Emerson et al., 2018) and health (Emerson, Hatton, Robertson, & Baines, 2016) as adults without disabilities.

Segregated learning disability services started at the time of the Industrial Revolution, around 1760 (Atherton & Crickmore, 2012; Malin, 1995). Prior to this many people with learning disabilities resided in the places where they had been born and could participate, if not fully, in the agricultural work that dominated at this time (Oliver, 1990). Although they may have been subjected to exploitation or abuse, people with learning disabilities were not considered harmful to the local community (Malin, 1995). The Industrial Revolution brought the need for skilled workers who could adapt to using new, complex, technologies (Oliver, 1990). This increased the status of the skilled worker and also the need for skills such as reading and writing (Malin, 1995; Oliver, 1990). During this time many people with learning disabilities were housed in Poor Houses along with other people deemed unable to work (Barnes, & Oliver, 2012). It highlighted people with learning disabilities as a group in a way they had not been previously (Atherton & Crickmore, 2012).

In the late 19th century the Eugenics Movement started to gain momentum, a term first coined by Francis Galton in his book Hereditary Genius in 1869 (Atherton & Crickmore, 2012). This movement went on to gain popularity in the early decades of the 20th Century (Atherton & Crickmore, 2012). Galton's theory was that human beings have an innate intelligence that is passed, unaltered, through generations of families. If this intelligence was low then this, along with this other social problems, would be passed to the next generation, thus weakening society

as a whole and leaving it poor, sickly and immoral (Atherton & Crickmore, 2012). There was no significance placed on environmental factors such as access to education. In eugenics the condition was inherent and could not be altered, therefore improvements to education and wider society would not be prudent. Instead the solution was "systemic actions, whether decisional or programmatic, that serves to minimise the spread of deleterious genes in society (Atherton & Crickmore, 2012: 37)". In the UK the systemic action adopted was the creation of legislation and institutions that could label, detain and control these individuals, other Western countries adopted programs of sterilisation and in the case of Hitler's Germany, genocide (Bashford & Levine, 2012). The Eugenics Movement was not solely aimed at those with learning disabilities; it was also directed at immigrants and people from lower classes. However, those with a learning disability were classed as an even greater threat as there were no physical signs of disability and therefore the person could integrate and potentially procreate without others knowing (Atherton & Crickmore, 2012).

The legislation to support this movement came in the form of the 1913 *Mental Deficiency Act* which categorised people with learning disabilities as idiot defective, imbecile defective, feeble minded and moral defective. It also legalised the compulsory certification and the confinement of said 'defectives' in local authority run facilities (Olubokun, 2007). Doctors would assess a person as defective and detain them under local authority care. The structure of institutions was based on a model of farming and industrial colonies (Olubokun, 2007). This was followed by the 1927 *Mental Deficiency Act* which added that disease or injury could be a cause of deficiency as long as it occurred before the age of 18 years. The effect of these acts is shown by the number of inpatients increasing sevenfold between the war years (Race, 1995). The institutions were situated away from towns and cities and were very isolated, with very few opportunities for social inclusion and community involvement (Race, 1995).

After the Second World War, the Eugenics Movement lost its popularity (Atherton & Crickmore, 2012). The association with the acts committed within Nazi Germany meant that many now distanced themselves from it yet this did not mark the end of the institutions (Atherton & Crickmore, 2012). In 1948 the National Health Service was established and the colony style institutions became hospitals run by the Ministry of Health. Around this time, research was conducted that called to question the necessity for people to be segregated and to challenge the notion that people could not work or learn. Researchers such as Tizard, O'Connor and Clarke and Clarke carried out studies which showed those labelled as defective were able to marry and had higher than expected IQ levels (Race, 1995). By the mid-1950s, there was increasing concern about the shocking physical conditions within the institutions, including overcrowding, a lack of

storage and poor washing facilities (Race, 1995). This, along with an increasing concern about the wrongful detainment of people with disabilities, gave the impetus for change. However, when it came, the change was not seen to be radical enough. The 1959 *Mental Health Act* abolished the compulsory certification and confinement of those who were now labelled by the act as mentally disordered. However, the dominant place that a person with learning disabilities lived was still to be an institution, the only other alternative was remaining with family members. Through the 1950s, 1960s and 1970s research continued to be carried out which showed that people in the institutions were living in very poor conditions (Race, 1995). This research also showed that, contrary to previously held beliefs, people in these institutions were capable of learning new skills (Race, 1995). However, this had little impact in the short term on the care that was offered and the living situation of people with learning disabilities remained fairly unchanged (Race, 1995).

The 1959 Act made very little reference to how people in the institutions should spend their time; however, it did refer to the 1948 *National Health Service Act* which mentions training and occupation. The responsibility to provide this fell to the local health authority that tended to set up adult and junior training centres which were on the grounds of the institution. The increasing research and debate about services for people with learning disabilities continued with more people calling in to question the appropriacy of the large hospital settings, even though this continued to result in little change in the services that were actually provided (Race, 1995). The 1971 white paper *Better Services for the Mentally Handicapped* made the case for more community-based services and a decrease in the number of hospital beds. Though like *the Mental Health Act* it was not considered radical enough to exact any real change.

During the mounting criticism of the institutions, the Normalisation principle started to gain popularity. Originally developed in Scandinavia in the late 1950s several versions of Normalisation were developed in the Western world (most noticeably by Nirje in Sweden in 1969 and by Wolfensberger in the USA in 1972). Nirje's theory came from a perspective of Human Rights (the United Nations made the Declaration of Human Rights in 1948 and the Declaration on the Rights of Mentally Retarded in 1971). The aim was for total social inclusion of people with learning disabilities that included the right to experience a 'normal' life cycle, a normal day and a normal year. Nirje stated that people with learning disabilities should have their choices and wishes respected (Perske, 2004). Wolfensberger was aware that as a group people with disabilities were not valued by society and so developed a theory of normalisation (later known as Social Role Valorization (SRV)). He believed that if people had roles that society valued they would be accepted and their social status would improve:

Wolfensberger shifted focus from a human-rights based policy to a system based upon social manipulation (Atherton & Crickmore, 2012: 69).

There were other versions of normalisation, but these are the most widely referred to. Normalisation became a prevailing theory in the delivery of support and services to people with learning disabilities. As the institutions closed and people moved in to smaller community based accommodation the principles of Normalisation continued, particularly in the area of age appropriacy (Coupe-O'Kane & Goldbart, 1996). This came from Wolfenberger's view that people with learning disabilities were viewed as the eternal child (Wolfensberger & Tullman, 1982) and therefore not respected by society. The theory was that by dressing, behaving and undertaking routines that correlate to people of their age then they would be accepted and respected by other members of society. Normalisation has since come under criticism, particularly Wolfenberger's model, as it calls on the person with learning disabilities to adapt and change to appear 'normal' rather than society to be more accepting (Culham & Nind, 2003). However, it cannot be denied that normalisation and SRV has been a dominant force in social care policy (Culham & Nind, 2003).

In 1990, the *National Health Service and Community Care Act* placed the care and support of people with learning disabilities within the remit of local authorities. This meant that long stay hospitals were to be closed and people supported to live and have leisure opportunities within a community setting. This was followed in 1995 with the *Disability Discrimination Act* which made it unlawful to discriminate against anyone on grounds of disability. The Act specifies that people with disabilities (learning and physical disabilities) must have the same access to education, transport and employment as those without disabilities. Government policy has continued to support the right that people with learning disabilities are equal citizens in society and governed by the same human rights laws and protection as those without (Department of Health, 2009). The White Paper *Valuing People: A New Strategy for Learning Disabilities in the 21st Century* (Department of Health, 2001) made the commitment that "the Government's objective is to enable people with learning disabilities to have as much choice and control as possible over their lives and the services and support they receive (Department of Health, 2001: 4)". The paper was significant as it was the first White Paper that focussed specifically on learning disabilities for 30 years (since *Better Services for the Mentally Handicapped* in 1971). The message from *Valuing People* (Department of Health, 2001) was reinforced by the 2009 follow up strategy entitled *Valuing People Now: a new three-year strategy for people with learning disabilities* which highlighted the expectation that people with learning disabilities will

be fully active members of their community including access to employment, engaging in meaningful relationships and having a family life (Department of Health, 2009).

2.4.3 Personalisation

In 2003, In Control, a charity founded in 2003 and inspired by the Independent Living Movement, began a pilot scheme in Wigan to support people with learning disabilities and their families to exercise greater control over their own lives. This was achieved by the means of Self Directed Support (now known as Personalisation) in which people received Individual Budgets (now known as Personal Budgets) to spend on the support they needed. The results from the pilot influenced government policy and in 2007 *Putting People First* announced that:

> Personal Budgets will ensure people receiving public funding use available resources to choose their own support services – a right previously available only to self-funders. The state and statutory agencies will have a different not lesser role – more active and enabling, less controlling (Department of Health, 2007: 2).

There is still on-going debate about how effective the introduction of Personalisation has been. It is argued that the complicated systems that have been implemented mean that it is not particularly effective and that many decisions are now made with the goal of saving money rather than really enhancing support (Duffy, 2012). Despite being an original developer of Self Directed Support Simon Duffy (2012) now argues that personalisation has been used as a system with which to offer people services, rather than what it originally set out to do which was to support people to access resources to enable them to become citizens. The 2014 Care Act (Department of Health, 2014), enforced in 2015, places a great emphasis on personal budgets, prevention and tighter regulation of service providers. It also enshrined in law the rights of not only those people who use social care but their carers. Carers are now entitled to an assessment and access to support services. Oliver et al (2012) are critical of the increasing legislation to support carers as it further embeds the image of people with disabilities as dependent and in need of care. Oliver et al (2012) recognise the lack of health and social care services that requires family carers to fill this gap. However, this legislation focuses on solutions and support for carers rather than attempting to remove the disabling barriers that prevent people with disabilities being independent (Oliver et al., 2012). The laws also fail to recognise and account for potential conflict between the priorities of carers and the people they care for (Oliver et al., 2012).

2.4.4 The Human Rights of People with Learning Disabilities in the 21st Century

Despite continued efforts to highlight the human rights of people with learning disabilities and their families in national and international legislation people with learning disabilities are still disadvantaged in society. They have lower life expectancies (Emerson, Baines, Allerton, & Welch, 2011) and higher chances of being the victim of violent crime (Khalifeh et al., 2013). As Oliver's (1990) social model of disability shows these disadvantages stem from the attitudes of society. These attitudes continue to pervade and recent examples of this inequitable treatment include the Winterbourne scandal in 2011 and the death of Connor Sparrowhawke. In 2011 an undercover reporter secretly filmed the appalling treatment of people with learning disabilities in Winterbourne View, a private hospital in Bristol. Sparrowhawk was an 18- year-old man with autism, learning disabilities and epilepsy. In March 2013 he was admitted to the Short Term Assessment and Treatment Team Inpatient Unit run by Southern Health NHS Foundation Trust. In July 2013 he drowned after having a seizure in the bath (justiceforlb.org n.d). In an attempt to get some recognition and justice for their son's preventable death Sparrowhawk's family launched the campaign *Justice for LB*, LB being an abbreviation of Connor's nickname Laughing Boy.

Initially Connor's death was recorded by Southern Health as natural causes. This was dismissed by the coroner and an inquest was ordered. The inquest jury found the negligance of Southern Health contributed to Connor's death and NHS England commissioned an investigation. Mazars LLP (2015) conducted the investigation and found that between 2011 and 2015 there were 722 unexpected deaths of people in Southern Health's care. Only 272 (37.5%) were investigated further and only 1% of deaths of people with learning disabilities were investigated at all. The report concluded that people with learning disabilities cared for by this trust died earlier than people with learning disabilities nationally (56 years compared to 59 years old) and that the Trust did not make any use of data to monitor mortality (Mazars LLP, 2015). The report highlighted poor leadership by the executive board and trustees (Mazars LLP, 2015). It also mentioned the inadequate consultation with families and carers when investigating deaths (Mazars LLP, 2015).

The family campaigned for five years to have Southern Health held accountable for Connor's death. In March 2018, Southern Health was fined £2 million, the largest fine of an NHS trust following a prosecution by the Health and Safety Executive (Halliday, 2018). A month before this, in February 2018, a Medical Practitioners Tribunal Service (MPTS) ruled that Dr Valerie Murphey should be suspended for one year after finding her "directly responsible for Connor's death"

(). Murphey had failed to complete risk assessments and made the decision that Connor should only be checked every 15 minutes while in the bath rather than 10 minutes a decision that was not agreed with his family (justiceforlb.org n.d.).

The campaign for LB highlighted a lack of accountability in unexpected deaths of people with learning disabilities. This was also found in the Mencap reports *Death by Indifference* (Mencap, 2007) and *Death by Indifference 74 and Counting* (Mencap, 2012a) which highlighted that people with learning disabilities receive poorer care from the NHS than people without disabilities. Lower receipt of screening tests and fewer health investigations were reported. There was a belief amongst practitioners that this was acceptable as people with learning disabilities are expected to die younger (Mencap, 2007). These reports and the case of Connor Sparrowhawk demonstrate the failings of large organisations to report and investigate the deaths of people with learning disabilities and a lack of willingness to engage with family carers. The tireless campaigning of Connor's family and supporters resulted in the prosecution of Southern Health, however without this campaigning it is unlikely that the negligence surrounded Connor's death and the fact it was entirely avoidable would have been acknowledged by Southern Health NHS Foundation Trust at all. This could be due to people with learning disabilities not being considered fully human (Carlson, 2010). Society create a 'them' and 'us' which allows space for people with learning disabilities to be treated as other than human (Carlson, 2010). This lack of humanity results in people with learning disabilities being treated differently; for example, given a low priority by health professionals (Mencap 2007).

2.5   The Changing Role of Family Carers

The closure of long stay institutions resulted in many families taking on the long term care of their relatives (Jones & Campling, 2002). Increasing life expectancy means that this caring responsibility can be lifelong and well into old age (Bowey & McGlaughlin, 2005; Coyle, Kramer, & Mutchler, 2014). In the 1930s, the life expectancy of someone with genetic disabilities, such as Down Syndrome was 18.5 years, it is now closer to the general population (Coyle et al., 2014). As a group the needs of family carers have only recently started to be recognised in law with the 1995 Carers' Act (Department of Health, 1995). This was the first-time informal carers (as opposed to those offering paid care) were recognised in law and provides an assessment of the carers needs.

The move to providing care in the community means that carers and service providers need to work more collaboratively to support the person, especially since many people with learning disabilities reside in the family home (Public Health England, 2016). It is estimated this saves £27

billion annually for the UK economy (Dillenburger & McKerr, 2010). The move to personalised support and personal budgets mean the role of the family carer has changed. As well as providing physical care support to the person while they are at home, up to 18 hours a day for those with the most profound needs (Mencap, 2001), they now need to take on the role of employer (Larkin & Dickinson, 2011), managing finances and coordinating multiple services (Glendinning et al., 2009). Glendinning et al. (2009) investigated the impact on carers of the person they care for receiving an individual budget in England, as part of a wider randomised control trial (RCT) on the impact of the Individual Budgets (IB). They conducted structured interviews with carers in the IB group and carers in a control group and conducted more in-depth interviews with a small number of the carers in the IB group. They interviewed staff from the pilot sites who had responsibilities for "carer issues" (Glendinning et al., 2009: 12). The report focuses on the experiences of carers of people with learning disabilities and carers of older people, though the RCT also included carers of people with physical disabilities (Glendinning et al., 2009). They found individual budgets could actually mean carers spent more time caring as they supported the person they care for to attend leisure activities rather than the person attending a specialist service such as a day centre or respite service (Glendinning et al., 2009). This can have an impact on carer health either due to the physical and emotional stress of caring or because they do not have time to seek medical support (Glendinning et al., 2009). Although in some ways individual budgets and personalised support have brought increased responsibilities for carers such as paper work and management, carers of people who received individual budgets were more satisfied and experienced a higher quality of life (Glendinning et al., 2009). In semi structured interviews they reported having more choice and control, they could employ someone to carry out the caring tasks they had previously been responsible for (Glendinning et al., 2009). However, Glendinning et al (2009) did find that carers of people with learning disabilities were less satisfied than carers of older people. For these carers personalised support had not delivered what had been promised and they did not feel well supported. By having more control about what support was given, the carers felt less guilty, for example a person could use their individual budget to go to Centre Parcs rather than the local respite unit which they had not enjoyed (Glendinning et al., 2009). The carer could then enjoy the respite without the guilt of knowing the person was not happy (Glendinning et al., 2009). Although carers of people with learning disabilities did not necessarily see the value of individual budgets for themselves, they could see it for the person they supported; they were more independent, could have support workers their own age and felt more able to express their preferences (Glendinning et al., 2009). One risk identified by Glendinning et al (2009) was

that carers could often underestimate their own needs and focus on the needs of the person they care for therefore missing out on support they needed for their own wellbeing. The number of carers taking part in structured interviews across both groups was 129 which was not as many as the researchers intended to recruit (Glendinning et al., 2009). The sample were mainly white and female so their experiences may not be representative of male carers or those from BME communities (Glendinning et al., 2009). This evaluation, of which the carer study is one part, is credited with being a critical piece of research in getting government to commit to personalised support (Duffy, 2018).

Larkin and Dickinson (2011) explore how third sector organisations, in the UK, need to understand the role of carers to successfully implement personalisation. As service users come into contact with a wider range of service providers the carer provides the continuity and coordination (Larkin & Dickinson, 2011). However, Larkin and Dickinson (2011) found in their review of literature the impact of personalisation on carers was not widely explored. Lack of research regarding the impact of personalisation on carers is at odds with a growing recognition over the last two decades about carers' needs in policy (Larkin & Dickinson, 2011). Larkin and Dickinson (2011) use real life case studies to identify the new roles carers may need to undertake under personalisation, including supporting service design for the person they care for, employing personal assistants and managing budgets and paperwork. There can be an emotional impact where a family carer who has provided emotional and physical support now feels pushed out and not needed (Larkin & Dickinson, 2011). Larkin and Dickinson (2011) explore ways in which carers can be supported through access to resources and support groups as well as service providers being more understanding. Carers are crucial to personalisation being deliverable and reaching its potential to increase the choice and opportunities for people receiving social care (Larkin & Dickinson, 2011). Due to the lack of evidence this report uses real life case study examples. However, it is not clear from the report where these case studies are sourced from and what consent has been given to use them therefore, it is not clear how much is accurate and how much has been changed (Larkin & Dickinson, 2011).

The visibility of people with learning disabilities in society has changed considerably as society moved from agricultural to industrial. Their families have moved from being side-lined or excluded to central to supporting the person, often well into old age. The majority of people with learning disabilities live with family and the move to personalisation and personal budgets has seen family carers become employers, care coordinators and managers. Their role has changed dramatically since the closure of the large institutions and where policy and legislation

has started to recognise the role and needs of carers there is still a way to go to ensure the quality of support is consistent and the needs of carers are fully understood.

2.6 Summary

This chapter demonstrates the changing, multi-faceted and often lifelong role of family carers of people with learning disabilities. Historically people with learning disabilities would have resided in institutions whereas now a large proportion remain living with parent carers who need to plan for the possibility of their child outliving them. Although carers' rights are now protected by law, carers still do not feel well supported and formal support services can be a source of increased stress. The Social Model of Disability, and current events such as the Winterbourne scandal and death of Connor Sparrowhawke, highlight the many ways in which society continues to discriminate against people with disabilities. This review shows the ways in which this discrimination extends to the families trying to provide care and support.

Chapter 3
Action Research Methods Literature Review

3.1 Introduction

This chapter will explore the concept of action research, starting with the history of this approach. This is followed by a detailed discussion on co-operative Inquiry (CI); a participatory research methodology developed in the 1970s which falls within the action research "family of practices" (Reason & Bradbury, 2006: 1). The chapter will focus on the theoretical perspectives underpinning CI and consider the implementation of the methodology. It will then discuss participatory action research and disability studies and studies that employ carers as researchers.

Action research proponents define action research as research with rather than on people (Reason & Bradbury, 2006) where researchers and non-researchers come together to form a group of co-researchers. As a paradigm it sits in opposition to positivist methods (Brydon-Miller, Greenwood, & Maguire, 2003; Heron, 1996). Positivist research methods seek to understand the facts that exist in the world and do not tend to explore social influences on these facts (Reason & Bradbury, 2006). It is associated with quantitative, scientific research in which the researcher is detached from the process and seen to be objective. Qualitative research covers a broad range of methodologies that seek to understand the human condition through such methods as interviews and focus groups to gain a more in-depth appreciation (Dawson, 2009). This methodology is mainly used in social sciences and education research (Berkovich, 2018). There is some debate as to whether qualitative research is positivist or not and Berkovich makes the case that "positivist qualitative research" (Berkovich, 2018:2063) should be viewed as a unique and legitimate branch of qualitative research methods. In some definitions of research methods, action research is viewed as a type of qualitative research (Dawson, 2009) however, this chapter will explore why action researchers reject that categorisation. For advocates of action research, it is the commitment to action and collaboration, not necessarily features of qualitative research, that make their approach distinct (Brydon-Miller et al., 2003).

3.2 Action research

Action research is varied and has been applied within many disciplines using different theories. However, there are several key components that link these methods. These are; 1) collaboration between researcher and participant; 2) a desire to stimulate change and; 3) a commitment to "human flourishing", both for individuals and entire communities (Reason & Bradbury, 2006: 1).

According to Reason and Bradbury (2006) individuals need to be able to understand their environment and the way it impacts on them and to develop practical ways of making changes in order to flourish. By developing this understanding individuals can adapt and change their ways of living to enable entire communities to flourish (Reason & Bradbury, 2006). Greenwood and Levin (2007) state that action research should still be "identified as scientific knowledge generation" (Greenwood & Levin, 2007: 53) and therefore should be conducted to rigorous standards. The action and the research need to have equal status. Participatory Action Research is a range of methods and approaches, within the action research family, in which research is conducted *with* rather than *on* the groups being researched (Kindon, Pain, & Kesby, 2007).

Action research is a democratic experience where researchers and participants collaborate as equals throughout the research process from defining questions to carrying out actions based on their experiences. The aim is that as a result of the process the stakeholders involved are in a more positive and empowered situation than they were before. The fact that action research can have such a significant impact on people's lives means that the knowledge generated, and acted upon, needs to be valid. Therefore, action research still relies heavily on rigorous and well-founded research practices. The broad range of applications of action research means that it is described in various ways; as an "orientation to inquiry" (Reason & Bradbury, 2006: 1), a "family of approaches" (Reason & Bradbury, 2006: 7), a set of "collaborative ways of conducting social research" (Greenwood & Levin, 2007: 1) and as a "methodology" (Dawson, 2009: 17).

Despite such variation contemporary action research comprises of "research, action and participation" (Greenwood & Levin, 2007: 5). The different ways in which action research is practised could be as a result of its evolution. Contemporary action research is influenced by a number of disciplines, the history of which is explored in the next section.

3.2.1 History of action research

Given the heterogeneity of how action research is implemented a single linear history is difficult to describe (Greenwood & Levin, 2007). Three key movements in the history of action research are; Industrial Democracy, Participatory Action Research and Co-operative Inquiry (Greenwood & Levin, 2007). Industrial Democracy has been traced back to German-American psychologist Kurt Lewin who is said to have coined the term action research in the 1940s (Greenwood & Levin, 2007). However, his use of the term bears little resemblance to what is seen as action research today. Lewin used the term to apply to research that is carried out in a naturalistic setting (such as the participants' own homes or place of work) and also one in which theory can be expressed in an action (Gustavsen, 2006). However, this original description lacked a key

element of contemporary action research; participation. Whereas Lewin conducted research in people's own homes, the method, research questions and analysis were all determined and conducted by external researchers (Gustavesen, 2006). Lewin's thinking and approach to research was then adopted for use in various industrial settings including the Norwegian Industrial Democracy project. They used Lewin's three stage social change concept in their own work. Lewin believed change happened by first unfreezing (releasing people from current ways of working and acting), carrying out change and then freezing the new ways of working in to a permanent state (Greenwood & Levin, 2007). This was an attractive model as it allowed for short term interventions with the belief that this was all that was needed for the situation to be completely changed. However, this has since been evaluated as a limited approach, given it does not allow for continuous change and development of participants, nor on-going learning or empowerment (Greenwood & Levin, 2007). When the theory has been developed in isolation from the participants it can be difficult to apply to a practical setting (such as a workplace). The participants (such as the workforce) are excluded from the process (Gustavsen, 2006). Although some of Lewin's work has since been criticised, where it does remain relevant to action research is in the redefining of the researcher's role. In Lewin's research the researcher is not a distant observer but central to problem solving in 'real world' settings.

Participatory action research was initially developed by working with oppressed groups (Greenwood & Levin, 2007). Again, the methods used are varied and multi-disciplinary but are linked by liberationist aims. This is viewed as an "inherently political activity" (Greenwood & Levin, 2007: 32) as the work is usually completed in collaboration with the oppressed people (and therefore at odds with those in a position of power). It works to educate, enable and empower groups, such as: women, subjects of racism, people with disabilities and the elderly (Greenwood & Levin, 2007). A key researcher is Orlando Fals Borda, a Columbian researcher who is considered one of the founders of PAR (Greenwood & Levin, 2007). Fals Borda's development of PAR in the 1970s came from a dissatisfaction with the traditional role of researcher (aloof and detached) and the conditions he witnessed around him including economic exploitation (Borda, Fals, 2006). As a researcher he did not feel able to continue to silently witness these conditions, but he needed to act. Fals Borda (2006) believed there needed to be a coming together of research and action that focussed on local issues and was "emancipatory, educational, cultural and political" (Fals Borda, 2006: 28).

Paulo Freire also contributed to the field of participatory action research, calling for a new 'Critical Pedagogy' in his work *Pedagogy of the Oppressed* (1968, translated to English in 1970). In this new pedagogy students are not viewed as receptacles to be filled by the teacher

(described by Freire as "banking education" (Freire, 1970: 53)) but co-creators of knowledge. In this libertarian education, teachers and students should not be separate beings but should be "simultaneously teachers and students" (Freire 1970: 53). Freire's *Pedagogy of the Oppressed* is considered "one of the most widely read AR books ever published" (Greenwood and Levin, 2007: 178) as it describes a culture of silence that prevents oppressed people from changing their position or challenging their oppressor. To Freire, education was not about a traditional classroom environment, but it was an empowering act that gave voice to the oppressed (Greenwood and Levin, 2007).

Co-operative inquiry (CI) was first described by John Heron, Peter Reason and John Rowan in their research group New Paradigm in 1977 (Reason & Rowan, 1981). The key principle for this approach was that it was research with people rather than on people. The originators of CI defined a set of validity procedures to ensure the research and the participation had equal weighting. CI is explored in more detail later in the chapter.

3.2.2   The theoretical perspectives of action research

Researchers writing about action research highlight the differences between the approach and more traditional, positivist, research methods. This research is described as either research on people (quantitative research) or research about people (qualitative) (Heron, 1996). In both practices, the researcher designs and conducts the research project. They then go on to analyse the data and draw conclusions. The problem with both these methods, according to Heron (1996), is that they oppress the participant. The researcher is a self-directing being whereas the participants are not; they are under the control of the researcher. It also results in the knowledge gathered from the research being ungrounded due to the separate roles the researcher and the participant are cast in. The researcher has determined the issue to be researched but they do not have any experience of it and the participant may have the experience, but they have not been involved in designing the research study. Their experiences have been framed and constructed by the external researcher and not by the participants themselves. Therefore, a gap exists between the experience of the participants and the way the researcher has constructed this experience. Traditional social science studies are also different from action research projects in the way they separate action and theory. Action research primarily works towards outcomes whereas "normal science and academia" (Reason and Bradbury, 2008:5) prioritises theory generating. However, as an alternative position Arksey and Knight (1999) question if action research's focus on outcomes can result in "all action and no research" (1999: 44)? Reflection is vital for ensuring there is both action and research in any action research project. Without this

reflection, and ultimately the development of new understanding, the process is "blind" (Reason & Bradbury, 2006: 2). The cycle of action and reflection will be explored in more detail in relation to Co-operative Inquiry.

Due to the broad nature of action research the theoretical perspectives that underpin the approach can also vary. However, some approaches are regularly referred to by practitioners in action research. One is Pragmatism, which is traced back to the work of John Dewey, an American philosopher. Where Dewey's work is relevant to action research is in his belief that thought and action should not be separated (Greenwood & Levin, 2007). He believed that knowledge should be used as an instrument for action, rather than knowledge production being an outcome in itself. He also disagreed with the practice of dividing education as vocational versus academic. He believed that the purpose of schools was to provide active learning environments where the student can develop the skills to engage in scientific judgement. The separating of education into academic and vocational was, in his view to weaken the opportunities for young people to be involved in knowledge generation (Greenwood & Levin, 2007). However, Pragmatism is just one approach said to influence the development of action research. Others include "social and experimental psychology, community development and adult education, industrial democracy work, human inquiry, action science, action learning, reflective practice, participatory rural development, and liberation theology" (Greenwood and Leven, 2007: 2).

Action research can be grouped in to the following types of practice:

First Person action research involving only the researcher. The researcher looks at actions, thoughts and responses in their everyday life and considers them more critically. This research can result in the researcher seeing their actions and the world around them, in new previously unconsidered ways. Judi Marshall (2006) has made this a particular focus of her work. She has written about this in what she calls Self Reflective Inquiry Practices, where self-reflection is considered a formal research discipline where findings from it are recorded (Greenwood & Levin, 2007; Marshall, 2006)

Second Person action research is face to face research with another person, or group of people, which focuses on an area of joint concern for example changing their work practice. The basis

of second person research is "interpersonal dialogue" (Reason and Bradbury, 2006: xxvi) and can develop in to wider inquiry groups.

Third Person action research aims to take first and second person approaches to a wider audience. Here wider communities of inquiry are developed. This may use other forms of interaction (such as report writing) as the group may be geographically dispersed.

Action research which uses all three strategies is seen as more valid than those which only employ one (Reason & Bradbury, 2006). In order to have a wide impact it needs to be larger than just first person research. However, without grounding in first person reflection the researcher may not have the ability to critically consider their own values, ideas and actions. The third person research could become distorted without first person reflections (Reason and Bradbury, 2006).

3.2.3 Why use Action Research?

Advocates of action research reject the notion that issues relating to humans can be explored using the same methods as are applied to the natural sciences (Brydon-Miller et al., 2003). For action researchers acknowledging the knowledge of groups and individuals about their own situations not only strengthens the opportunity to create changes but increases the impact of the research (Brydon-Miller et al., 2003). Action research maintains a focus on challenging power imbalances by giving voice to oppressed people and equally increasing social justice. This is achieved through understanding groups by working alongside them and making a commitment to action rather than just knowledge generation (Brydon-Miller et al., 2003).

3.2.4 Rigour in Action Research

Although a focus on social justice and change is laudable action research still needs to prioritise good, quality research. However, action research is often criticised for not being sufficiently rigorous and only producing "good stories" (Levin, 2012: 135) rather than scientific knowledge. Levin (2012) describes a process for ensuring integrity and rigour in action research. Firstly the process itself must be grounded in the researcher's commitment to seeking practical solutions to issues. The next step is that findings and solutions must be shared locally with those experiencing the problems in a way they can access and utilise (Levin, 2012). The final stage is to take a step back and consider the scientific presentation of the research (Levin, 2012). This requires the researcher to reflect critically on their involvement in the process and understand the phenomena being explored. However, to Levin (2012) it is important that the researcher, although critically reflective in their involvement, does not seek to remove themselves entirely

from the process. They need to understand their role in it and how this affected the outcome (Levin, 2012). To ensure this rigour Levin identifies five key components that action researchers must not only be aware of but address in the presentation of the work. These are:

- Research partners-this can enable researchers to consider the implications of any decisions they make which can, by the nature of action research, have real world implications. It can also allow for the discussion and reflection that come from alternative viewpoints.

- Awareness of own biases-these should be made explicit, not necessarily to the research group or stakeholders but in the researchers own research journal or field notes. This enables the researcher to check against these and ensure they are not influencing the collection or analysis of the data.

- Standardized methods-in action research any method, qualitative or quantitative, can be utilised as long as the researcher is aware of the limitations of the methods selected. The analysis of data gathered using these methods needs to be appropriate to the data being collected.

- Alternative explanations-by exploring alternative explanations the researcher can distance themselves from the process and ensure that the data does support the findings claimed.

- Trustworthiness-the researcher and the findings they share must be trustworthy. For the sake of the rigour of action research as a whole and also to ensure the most accurate representation of the stakeholders involved in the process (Levin, 2012).

Participatory action research has the potential to enable individuals to understand their own experience and empower them to enact change. However, this potential is undermined by a lack of scientific rigour (Langlois, Goudreau, & Lalonde, 2014). For Langlois et al (2014) rigour in the case of PAR relies on critical collaboration before any action or change is attempted. It is difficult for individuals to understand the situation they are in as they rarely critically reflect on it. Therefore, creating space for this to happen is a vital first step to ensuring the rigour and legitimacy of the findings (Langlois et al., 2014)

3.3 Co-operative Inquiry

Co-operative Inquiry (CI) is a second person research methodology of action research which includes a range of validity measures that ensure the research remains both collaborative and robust. It works on a cycle of action and reflection in which a group of co-researchers work

together to address issues that are of mutual interest to them. As part of the cycle may involve observing each other, the co-researchers may also become co-subjects.

3.3.1   John Heron and Peter Reason

CI was developed by the New Paradigm Research Group in 1977 and has since been written about extensively by two of the developers; Peter Reason (1981, 1988, 1994, 1997, 1999, 2006, 2008) and John Heron (1996, 1997, 2006, 2008). They have developed a practical framework for conducting CI projects and a set of validity measures to ensure the quality of the findings. This section uses the work of Heron and Reason to define CI, explore the theoretical perspectives behind it and outlines the process that they consider all CI projects should follow. At the very centre of CI is a participatory worldview (Reason, 1988) which rejects the view that any facts can genuinely be considered objective. Heron (1996) asserts that all facts are subject to the values of the researcher. He warns that any statement of fact is actually a theory-laden and value-laden statement which represents the theories of the researcher and the values that lie behind them (Heron, 1996).

Much of Heron and Reason's writing is devoted to criticising what they consider traditional, positivist research methods, both qualitative and quantitative. They believe that these methods are fundamentally unable to really understand human behaviour. Firstly, with the role of the researcher, Heron (1996) writes that while the researcher decides the research question, methods and draws conclusions from the data they cannot fully represent the participants. He states that this form of research is oppressive, it imposes the values of the researcher on those being studied and therefore cannot truly represent them; it can only represent them through a filter of the researcher's own values (Heron, 1996).

Another area of traditional research which is criticised by proponents of cooperative inquiry is what they consider the prioritisation of theory generation over action in academia. However, a prioritisation of action can only be validated by being grounded in forms of knowing. CI rests on developing an extended or radical epistemology. One that cycles between four different ways of knowing which are described by Heron and Reason (1997, 2006, 2008,) as:

Experiential knowing: a tacit and pre-verbal understanding of the world that is gained through lived experience. In CI this forms the base of a pyramid of knowing. Without this form of knowing it can be tempting to move too quickly in to the generation of theories. This kind of knowing

represents the participatory worldview as people should feel engaged with the environment around them (Heron and Reason, 2008).

Presentational knowing is the way in which these experiences are presented. It can be through dance, visuals and music. Reason and Heron warn about the "conceptual power of language" (Reason & Heron, 2008: 371) as by expressing our knowing in language a layer of interpretation is added. They encourage researchers to find alternative ways of presenting their knowing.

Propositional knowing: through ideas and theories is deemed the "main kind of knowledge accepted in society" (Reason & Heron, 2008: 374) in the fields of academia, politics, marketing and management. However, Reason and Heron (2008) advise it should be handled cautiously. Where it should be carefully handled is in adding to this kind of knowing in traditional ways in which the participant remains passive and the researcher in a powerful position. Using CI should be an empowering process for all involved as everyone is working collaboratively therefore they should develop in all four areas of knowing including but not prioritising propositional (Reason & Heron, 2008). As CI is a cyclical process any propositional knowing should be rooted in experiential knowing and tested through action. The propositional knowledge gained should not be the overall aim of the project but it is a necessary component. In fact, Reason and Heron (2008) believe it has the potential to be "liberating" (2008: 179) as it can provide the means with which to understand the world in new ways.

Practical Knowing: Practical skills, knowing how to do something. According to Reason and Heron (2008) this is the apex of a pyramid that can only be validated when it is grounded in the three previous types of knowing. To act intentionally in relation to something it needs to be experienced, expressed and understood.

The work of Scottish philosopher John Macmurray influenced Heron and Reason (Reason & Heron, 2008). In his work Macmurray describes how people are objectified and therefore seen as a means to an end. Macmurray feels that the cause of this objectification is distinction between body and mind (Pring, 2012). In his 1957 Gifford Lecture, *Self as Agent*, Macmurray criticises what he saw as the dominance of the theoretical and called for the "primacy of the practical" (Pring, 2012: 756). He stated "it is the practical that is primary. The theoretical is secondary and derivative" (Macmurray 1957 cited in Reason 1998: 13). A system that prioritises theory will value propositional knowing rather than knowledge generated by action or by interaction with others (Pring, 2012). Whereas a research process that cycles through the four stages of holistic knowing will be transformative (Reason & Bradbury, 2006). It is not focussed solely on generating theory or engaging with participants as subjects but in working

collaboratively with the participants and prioritising the practical (although ensuring this practical is validated by other forms of knowing).

A participative approach is more in line with a person's human rights than other methods (Heron 1996). Heron (1996) states that a human being's right to participate in a political institution should be extended to "every social situation of decision making" (1996: 16). He acknowledges that this right is currently applied, in many countries, to national and local government but not to other social areas such as research (Heron, 1996). There is a contradiction as people have a right to decide to take part in a research project but not what methods will be used or how the data will be interpreted and disseminated (Heron, 1996). Co-operative inquiry addresses this imbalance by involving people in all elements of the decision-making process.

The New Paradigm research group was based on dissatisfaction with more traditional research methods. This has been critiqued by Greenwood and Levin (2007) who said the group "probably had a clearer picture of what they wanted to get away from than a clear vision of where they would go" (2007: 32). It is clear in Reason and Heron's work that they were attempting to describe a research methodology which did not resemble traditional approaches. Their focus on participation and action is directly in contrast to what they consider dominant, positivist research. However, Reason and Heron (2006) do state clearly how a co-operative inquiry project should be conducted. They describe four phases which should be cycled through (Heron & Reason, 2006). These phases are discussed in the next section.

3.3.2   Co-operative inquiry in Practice

In practice Reason and Heron (2006) describe a four phase cycle that CI projects will move through which should contain a balance of action and reflection.

Phase 1

In this phase of co-operative inquiry a group of researchers convene and agree the issues they wish to explore. They will develop questions and agree the actions they will undertake in the following phases. They will agree on procedures for observing and recording their experiences. Some CI groups are created by an initiating researcher, whereas others come together more spontaneously and learn about the approach through their reading and research.

Phase 2

This is the first action phase of the cycle. Here the group will apply their agreed actions and record their observations. In the early stages of the research the action may just be to observe

their ordinary responses and reactions to events. In later stages there may be a new action or behaviour they will try. Again, there are decisions to be made about how these action phases can be conducted. There can be inside inquiries in which the actions are carried out in the same space, with the entire group present or there can be outside inquires where the group separate and then reconvene to discuss their experiences.

The action phase could also be closed boundary where only the co-researchers are involved or open boundary where others are invited to participate. Inviting external people to participate can be beneficial as it stops the group getting too insular and offers an alternative perspective. However, if external people are being used as participants, for example taking part in interviews, then care must be taken. A key feature of CI is that people develop their own knowing and understanding through their actions. If people are interviewed, their data is then brought back to the group and the interviewee has no further involvement then this is no different to traditional research methods. It is equivalent to an external researcher taking data off a subject and the subject having no say in how it is used. Some solutions to this issue are a) to have representatives in the inquiry group; b) set up mini CI where the participants and the co-researchers engage in further inquiry or; c) set up sibling groups, for example if a group of potential participants are identified by the researchers they could set up their own inquiry group (Heron & Reason, 2006).

Phase 3

Phase 3 is described as the period of the "deep experiential engagement" (Heron & Reason, 2006: 146) in which the researchers become immersed in their observations and actions. They may forget in this phase they are taking part in an inquiry. In this phase co-researchers may see the world in a new way and deepen their understanding of it (Heron & Reason, 2006). This can also be a phase of uncertainty as the researchers start to challenge their own preconceptions and may become anxious about the process they have started (Heron & Reason, 2006). Hilary Traylen (1994) describes an eight month study with health visitors in England which consisted of six co-researchers; five heath visitors and the initiating researcher (Traylen, 1994). The health visitors identified issues of hidden agendas and confrontation; how do they raise sensitive issues such as drug addiction, incest and abuse with the families they are working with (Traylen, 1994)? The individuals in the group outlined a plan for how they were going to be more direct and assertive with certain families and tackle the issues they had previously avoided (Traylen, 1994). In the third phase the group fed back how this had gone and for all of them being more open had resulted in increased confidence and reduced their stress as conversations they were

previously anxious about having were not as difficult as they feared (Traylen, 1994). However, along with these positive reflections the third phase was also the most challenging for the group (Traylen, 1994). The work they had been doing with families highlighted to the group a lack of certainty about the health visitor's role and their own competence in delivering it (Traylen, 1994). Traylen (1994) considers whether the groups' keenness for action had meant they had bypassed discussions that should have been had earlier in the process thus masking ongoing issues about how health visitors understand their own profession. This is a detailed account of the cooperative inquiry study combining the health visitors and the initiating researcher's reflections and actions. It addresses a gap in the literature as prior to this much that had been written about CI focussed on theory and not on how to deliver an inquiry and some of the issues initiating and co-researchers may face (Traylen, 1994). Traylen (1994) addresses the successes and the limitations of the inquiry such as running out of time and focussing too much on action and not on reflection. She also acknowledges where time constraints meant that she had to take a lead, for example in writing the research report, although shared with the group regularly the majority of the report was written by her (Traylen, 1994). This highlights where the external pressures, such as time, can result in the actual process differing from the ideal.

Phase 4

This is a phase of reflection. The group will reunite to discuss their experiences of the previous three phases and how the actions they engaged in have affected their thinking and behaviour. The group will also make plans for the cycle to repeat again. CI is a flexible process so at this phase the question may be altered or the actions changed. CI should engage in several cycles. This ensures that there is opportunity for both reflection and action.

3.3.3   Validity Measures

CI involves people examining their own behaviour and experiences in collaboration with others who have encountered similar experiences or who are in similar positions. The validity of the end action needs to be grounded in the three forms of knowing (experiential, presentational and propositional). If this is not the case then the end product may not be valid and may not fully represent the co-researchers involved. Therefore, a series of validity procedures have been developed to ensure the end findings are robust: research cycling, developing critical attention, authentic collaboration, dealing with distress and chaos and order (Heron, 1988).

Research Cycling

This is the cycling between reflection and action that comprises the four stages of the CI process. This can enable the participants to look in new and different ways at their experiences and practice. It gives time and space to reflect upon what is happening and make changes if necessary. Research cycling should also enable the group to find the right balance of action and reflection. Reason warns that "too little experience is armchair theorizing...too little reflection is mere activism" (Heron and Reason, 2006: 151). Therefore, an appropriate balance between the two is required and it will be up to the group to find this balance.

Developing Critical Attention

Critical attention is the ability of the members of the inquiry group to view and reflect on their own experiences openly and honestly. If they are too attached they will be unable to do this and will misinterpret their responses to them. A solution to this could be to use a Devil's Advocate Approach (Heron, 1988) where each member of the group makes a statement about their assumptions and other members take the opposing view so that the group have to justify their assumptions (Heron, 1988). This process is associated with another validity procedure 'avoiding consensus collusion'. The forms of collusion that can develop include being fixated on false assumptions which can distort the inquiry and a lack of rigour. There must be an awareness that this can happen and strategies developed to overcome it.

Authentic Collaboration

All members of the group must feel able to be heard and express their voices, if only one or two members dominate then it is not authentic collaboration. This could be overcome by engaging in practices like having a different group leader every time the group meets.

Dealing with Distress

It is likely that by paying close attention to their experiences co-researchers may become distressed by something they reveal about themselves or their situation. The group need to have tactics for addressing and acknowledging distress. Without these strategies the anxiety and distress can distort the group's experiences and reflections.

Chaos and Order

Groups need to be open to and tolerant of chaos and unpredictability. The risk otherwise is that the group will prematurely attempt to 'tidy up' the chaos and as a result start to make

assumptions and conclusions too early (Heron, 1988). Rather it is better to let the chaotic periods reach a natural conclusion.

Reason (1988) identifies the end of a cooperative inquiry group as the "most difficult" (1988: 39) due to the fact that it is an intense experience and not all members of the group will be fully satisfied with the outcome (Reason, 1988). The measure of success of a cooperative inquiry group is that it "lives on" (Reason, 1988: 39) not only in the written outputs but in the lives of the co-researchers. In practice CI has often been used by groups of medical professionals seeking to change or further understand their own practice.

3.3.4 Co-operative Inquiry in Research

Increasingly providers of health services have been expected to involve service users in the development of their services, starting with the 1990 *National Health Service and Community Care Act* (Carr, 2004). The same applies to Health and Social Care related research in which emphasis is placed on "putting people more… in control of the policy setting process" (Department of Health, 2006: 14) and in all aspects of the research process including design, analysis and reporting. The democratizing (Hostick & McClelland, 2000) of both health care provision and health care research has led to calls for a new research paradigm (Ridley & Jones, 2001; Simonds, Wallerstein, Duran, & Villegas, 2013; Stone & Priestley, 1996). One that is emancipatory, rejects the notion of objectivity and actively challenges oppression (Stone & Priestley, 1996). Co-operative inquiry fits this search for an alternative research paradigm and has therefore been used increasingly by researchers keen to explore the experiences of practitioners and patients in health professions. It has not been utilised as much in other fields such as production or manufacturing but has remained predominantly in the health services (Greenwood & Levin, 2007). This section explores how CI has been used in research and some key themes that have emerged from adopting a CI methodology including 1) ethics; 2) exploitation and 3) the phases of the research cycle.

Ethics

Much of the literature about co-operative inquiry focuses on the process of gaining ethical approval and the ethics of working collaboratively with people classed as vulnerable (Brydon-Miller, 2008; Hostick & McClelland, 2000; Tee & Lathlean, 2004). A review of literature was conducted into research involving mental health service users and co-operative methods to explore the ethical issues these researchers faced (Tee & Lathlean, 2004). The main issue identified was that ethics boards often require detailed research proposals at the start of the

project, before being able to obtain ethical approval. However, CI is an emergent process so it is difficult to define the research design and question until the group have convened and made these decisions (Tee & Lathlean, 2004). One solution to this could be to provide a risk assessment instead which details possible risks and solutions to demonstrate that these issues have been considered (Tee & Lathlean, 2004). Hostick and McClelland (2000) describe the need to attend the local ethics committee in person to explain their project and the safeguards they would take. The difficulty in granting ethical approval came, they felt, from their inability to provide great detail about the research methods, as these would be agreed upon later. Also around issues of consent and conducting research with a group identified as vulnerable (in this case mental health service users) (Hostick & McClelland, 2000).

However, although many CI researchers have had difficulty gaining ethical approval it has been argued that CI can in fact be *more* ethical than traditional, positivist method (Brydon-Miller, 2008). The Helsinki Declaration, a set of ethical principles regarding research with human participants (adopted in 1964 and amended in 2004) lists its three main principles as:

> Respect for the persons
> Beneficence
> Justice (Brydon-Miller, 2008: 200).

Brydon-Miller (2008) argues that the way these have been traditionally translated by ethics committees can result in the maintenance of power by academic institutions who work in a paternalistic way to decide what is risky and what is beneficial for other people. Far more beneficial, and just, is for members of a community to decide what is risky and beneficial for themselves and decide on their own research topic and how it should be shared. However, simply engaging in action research does not ensure research is ethical (Brydon-Miller, 2008). Discussion and understanding of the ethical issues is still vital (Brydon-Miller, 2008). If it is done ethically, action research:

> Opens up possibilities for a significant shift in who owns and controls the knowledge generated through research… opens up the possibility for the democratization of knowledge (Brydon-Miller 2008: 208).

Exploitation

In their Norwegian study, Hummelvoll and Severinsson (2005) identified five ethical issues which they felt were prominent in action research, (1) informed consent, (2) privacy, (3) respect for personal integrity, (4) harm, and (5) exploitation. (Hummelvoll & Severinsson, 2005:185). These authors state that the participative nature of their research means exploitation was not a relevant issue (Hummelvoll & Severinsson, 2005). However, it is not necessarily the case that

including co-researchers removes the risk of exploitation. In fact it has been argued that it could actually be more exploitative as an initiating research attempts to encourage and make changes that a community may not be ready for or may have unintended consequences (Swantz, 1996), The integrity of the researcher and the use of the validity procedures outlined by Heron (1988) should reduce these risks, for example using authentic collaboration to ensure everyone feels heard.

Phases of the research cycle

Much of the writing about co-operative inquiry focuses on the initial start-up of the project and the reflective phases, for example when the group meet to share their experiences. Less emphasis is given in what is happening in the action phases and therefore what changes are being made. This can make it difficult to assess the findings from the research as only half of the cycle is reported. An example of this is the paper by Hostick and McLelland (2000) where they report on an inquiry group involving mental health service users and mental health nurses. They note that although it is clear that the group are using the group meetings to reflect it is "unclear what action takes place in between, if any" (Hostick & McClelland, 2000: 311). Many of the articles focus on data gathered during these reflective phases or gathered by the initiating researcher (such as research journals and field notes). However, some projects describe a variety of methods used to generate data, including ethnographic observations, questionnaires, multi stage focus groups and interviews (Hummelvoll & Severinsson, 2005; Whitmore, 1994). To ensure that the inquiry group remains fully collaborative, decisions around the interview schedule, how to analyse the data and how it should be disseminated, should be decided as a group.

3.4   Participatory Action Research and Analysis

McTaggert (1991) identifies the ways in which data can be collected during participatory action research including observation, interviews and field notes. The data then needs to be validated through co-researcher confirmation, triangulation and testing the argument (McTaggart, 1991). To ensure that the research remains participative co-researchers should be included throughout the research process (Kindon, Pain, & Kesby, 2007). This includes the analysis; the analysis should not be a separate act that takes place away from the research group by an expert (Cahill, 2007). To enable non-academic co-researchers to engage in the analysis the approach used needs to be accessible (Whitmore & McKee, 2006). Braun and Clarke's (2006) model of thematic analysis is an easy to learn and uncomplicated method. Therefore, supporting others to learn and start using the method does not need to be time consuming (Braun & Clarke, 2006). Braun

and Clarke (2006) identify the method as a useful one for working in a participatory paradigm within a group and that the analysis produced lends itself to policy development. Therefore it is an appropriate method for an action research study with its commitment to producing change, not just generating knowledge (Greenwood & Levin, 2007).

However, thematic analysis has been criticised for focussing too much on what people say in a group and not attempting to use the data to gain a deeper understanding of their social worlds (Silverman, 2011). For Silverman (2011), a constructionist method that seeks to analyse the interactions within a group is more appropriate than thematic analysis. He uses a focus group about women's reactions to their diagnosis of breast cancer to demonstrate his point. He takes the example that one woman in the group becomes upset and the others implore her to think positively (Silverman, 2011). Silverman (2011) feels that a thematic analysis of this data would identify a theme of 'positive thinking' whereas a constructivist approach would identify this not as positive thinking but as the necessity for cancer sufferers to display positivity whilst in public. Silverman (2011) concludes that a constructivist view may give researchers a deeper understanding into the interactions within a focus group. However, he highlights this is still constructed data. His preference is for researchers to seek out naturally occurring interactions and discussions (Silverman, 2011). Braun and Clarke (2006) recognise these disadvantages and highlight that the researcher needs to ensure that; 1) the thematic analysis is of good quality, they identify fifteen criteria the analysis should meet, and 2) that it is the right analysis to answer the research question. This requires the researcher to allow their method of analysis to be guided by their research topic and question and not to commit to one method regardless of whether or not it is most appropriate (Braun & Clarke, 2006).

Kindon et al (2007) describes the different ways analysis can be conducted within a participatory action research study; 1) by the initiating researcher; 2) by some of the group; 3) by all of the group and; 4) the findings can be verified by the group. If an individual conducts the analysis, findings from this must be verified by the rest of the group (Pain et al., 2012). Group analysis should be emergent and involve reflection from both the initiating and the co-researchers (Cahill, 2007). This constant reflecting enables the status quo to be challenged and to make "visible the invisible" (Cahill, 2007: 187). Whitmore and McKee (2006) describe a participatory project in which they worked with a group of young people and staff to evaluate a youth drop in centre in a Canadian city. The research group consisted of two staff members, six young people and an external evaluator. The group agreed their own ground rules and spent many weeks building trust and rapport with team activities and outings. The group then co-designed an evaluation using surveys, semi structured interviews and group mapping (Whitmore &

McKee, 2006). To analyse the open responses from their data the group used an iterative process. They worked in pairs to describe and summarise this data and came back to the whole group to agree on themes (Whitmore & McKee, 2006). From this, the group produced a range of resources including 'The Kit' for other youth evaluators, a formal report and presentations. Whitmore and McKee (2006) describe this process as enabling the young people in the group to have ownership and pride over the outputs from the evaluation. The authors reflect on their learning from the project that evaluation tasks need to be set within the capabilities of the research group (Whitmore & McKee, 2006). They identified that the group gained skills and expertise in analysis including identifying themes, agreeing findings and drawing conclusions (Whitmore & McKee, 2006). The authors do not name the methods they use to analyse their qualitative data with the group nor do they provide much information about the analysis process. This makes it difficult to know if the method was the most appropriate or rigorous. However, the fact that the group remained engaged, when earlier in the evaluation process they had started to lose interest (Whitmore & McKee, 2006), suggests the process of analysis was an interesting and meaningful one for them.

3.5 Participatory Research and Disability

There is an ongoing debate about the role of the researcher when researching the lives and experiences of people with disabilities (Goodley, 2011). Goodley (2011) summarises the main three approaches to research with or on people with disabilities on a continuum from non-participatory through participatory to emancipatory (Goodley, 2011). Non-participatory is researcher led, participatory is by researcher invite and emancipatory is initiated and conducted by co-researchers (Goodley, 2011). For Goodley (2011) the key to studying disability is in what is being prioritised. Is it to understand the disabling nature of society or is it to measure impacts of impairment? The priority will then influence the methods and measures used to answer the research question. An example he gives is the 1984 Office of Population Census and Survey (OPCS) of adults and children with disabilities. The questions used in these surveys demonstrate a deficit model understanding of disability, for example:

> Can you tell me what is wrong with you?
> Does your health problems/disability prevent you from going out as often or far as
> you would like? (Goodley, 2011: 25).

No attempt is made in these questions to explore the ways in which societal attitudes and prejudices impact on the lives of disabled people. For Goodley (2011) the research paradigm

used is not as important as exploring the relationship between the impairment and the impact and restraints of contemporary society on people with disabilities.

For Oliver (1997) participatory and action research do not go far enough to challenge the power imbalance between researcher and participant. While it may challenge the social relationships involved in research by inviting participants to be more fully included it does not challenge the issue that resources necessary to conduct research still lie in the hands of academics and powerful organisations including the NHS and funding bodies (Oliver, 1997). Even though Oliver (1997) recognises that many funding organisations now specify public engagement and participant involvement in their funding criteria, the studies they fund still favour traditional research models and the panels who decide how funding is allocated rarely include people with disabilities. Even in participatory research studies it is still the researcher rather than people with disabilities who benefit. He proposes that research should be emancipatory; it should not merely include people with disabilities but fundamentally seek to change the research process so that people with disabilities are not excluded in the first place (Oliver, 1997). Oliver (1997) suggests six ways in which emancipatory research can challenge oppression of people with disabilities:

1) a description of experience in the face of academics who abstract and distort the experience of disabled people
2) a redefinition of the problem of disability
3) a challenge to the ideology and methodology of dominant research paradigms
4) the development of a methodology and set of techniques commensurate with the emancipatory research paradigm
5) a description of collective experience in the face of academics who are unaware or ignore the existence of the disability movement; and
6) a monitoring and evaluation of services that are established, controlled and operated by disabled people themselves (Oliver, 1997: 20).

He acknowledges the challenge of emancipatory research is that it is not something you can decide to "do" on a group of people as that is not emancipatory (Oliver, 1997). Emancipatory research needs to start with the oppressed group. However, he argues that these difficulties do not mean researchers should not continue to strive for change (Oliver, 1997). He calls on researchers to be continually reflexive even if it means they must face the uncomfortable truth that they are the main beneficiaries of their work (Oliver, 1997).

Inclusive research with people with learning disabilities began in the late 1980s (Walmsley & Johnson, 2003) and is increasingly recognised as an important shift to emphasise the voice of this particularly marginalized group (Walmsley & Johnson, 2003). An example of this early inclusive research is Atkinson's (1986) study to explore how people with learning disabilities

coped with the move from long stay hospitals to community living. In this study Atkinson (1986) scrutinised social worker notes and hospital records to understand the support networks people with learning disabilities relied on to cope with community living. In this study people with learning disabilities were interviewed and asked to identify the people they spent time with (Atkinson, 1986). This research is inclusive rather than participatory or emancipatory as the marginalized people (those with learning disabilities) were not included as co-researchers or involved in research design. However, by interviewing people with learning disabilities rather than those who supported them it enabled people with learning disabilities to have a voice in research in a way they had not previously. Exploring methods to enable people with learning disabilities to contribute to research studies continued through the 1990s, Booth and Booth (1996) highlighted the paucity of studies that included people with learning disabilities as informants. They identified the issues that can make it difficult to include people with learning disabilities as research informants such as "inarticulateness; unresponsiveness; a concrete frame of reference; and difficulties with the concept of time" (Booth & Booth, 1996: 65). However, they highlighted the need for researchers to find solutions to this. They described a case study in England with a young man, Danny, who was almost entirely mono syllabic (Booth & Booth, 1996). They explored different methods to enable him to share his story, for example asking fewer open questions. They spoke to him in different environments including at home and with his peers in college to see if that made him more talkative (Booth & Booth, 1996). They conducted interviews over several hours to enable him time to open up (Booth & Booth, 1996). Again, Danny is not a co-researcher but the researchers' willingness to reflect and try various ways to enable Danny to participate in the study is a step towards more inclusive practices that recognise value in making research studies accessible to people with learning disabilities. Walmsley and Johnson (2003) argue that a central element to inclusive research should be what matters to people with learning disability. Without this focus, as has happened in the past, people without disabilities can pursue their own agendas which can lead to oppressive acts such as the IQ testing in the early 20th century (Walmsley & Johnson, 2003). However, the onus cannot be placed purely on people with learning disabilities to initiate research. Researchers may need to identify where there could be gaps in knowledge for example, the needs and experiences of people with PMLD (Walmsley & Johnson, 2003). Walmsley and Johnson (2003) also emphasise, as Oliver (1997) does, the barriers to accessing research resources that prevent people with learning disabilities initiating and conducting research. Walmsley and Johnson (2003) and Goodley (2011) both explore the issue of researchers without disabilities. Should only people with disabilities conduct research about disability? For Walmsley and Johnson (2003) the answer

is no because this would mean that people with profound needs would be excluded from research. Goodley (2011) explores a range of viewpoints on this but ultimately concludes that it is the intent of the researcher that is important. Their desire to uncover injustice and enact change must take priority over developing their own career and interests (Goodley, 2011).

3.6 Parent Carers as Researchers

Although it has been identified that carers play a key role in the support of their sons and daughters with PMLD there is a lack of research that addresses the needs of parents of people with PMLD (De Geeter et al., 2002; Jansen et al., 2013; Kyzar et al., 2012). This paucity of research needs to be addressed to avoid parents of people with PMLD and their sons and daughters becoming further marginalised (Mencap, 2001).

The majority of the research with parents of people with learning disabilities has involved the parents in the role of participants in which they complete questionnaires or take part in interviews or focus groups. However, there is a small amount of research in which the parents also take on the role of researcher; this is known as participatory action research (PAR). Turnbull et al (1998) described the benefits of this for family members as:

> a) increased relevance of research to the concerns of family members; (b) increased rigor of research; (c) increased benefit to researchers in minimizing logistical problems; (d) increased utilization of research by families; and (e) enhanced empowerment of researchers, families, and other stakeholders. We anticipate future research that will explore these advantages empirically (Turnbull et al., 1998: 178-179).

Since this article was published there have been studies where parents have worked as co-researchers. Walmsley and Mannan (2009) worked with a group of five parents in Ireland. These parents attended a half day training session about facilitating focus groups (Walmsley & Mannan, 2009). The parents were involved in designing the study, with support from the initiating researchers, and then collecting the data (Walmsley & Mannan, 2009). They conducted seven focus groups with other carers to gather their experiences of family support; two further focus groups were facilitated by the initiating researcher only (Walmsley & Mannan, 2009). The initiating and co-researchers asked five open ended questions to gather their information:

> Tell us about what life is like as a family for you?
> Tell us about instances when things have gone really well for you in terms of 'family support' and 'family needs'?
> Tell us about instances that have been especially tough within the context of 'family support' and 'family needs'.
> If you had a choice what one change would you make for your family to have a good time?

> What would be the one thing you would do differently for your family to have a good time (Walmsley & Mannan, 2009: 273)?

To evaluate the impact of being a co-researcher individual interviews were conducted with the parent researchers six months after the last focus group. Parents in the focus group described their frustration with the "set menu" (Walmsley & Mannan, 2009: 274) offered by services in which the needs of the individual come second to what services can provide. The majority of this article focused on the impact on co-researchers rather than the findings from the focus groups (Walmsley & Mannan, 2009). The parent researchers found the experience empowering; they described feeling like a role model to other parents and enabling the focus group participants to be more open by sharing their own experiences (Walmsley & Mannan, 2009). One parent implicitly criticised the project for lacking action and involving too much talking (Walmsley & Mannan, 2009). She described a group she attended where service providers were also present and she felt this resulted in more action (Walmsley & Mannan, 2009). To this carer, the focus groups including only parents lacked "energy" (Walmsley and Mannan 2009: 275). At the end of the project a group of the parent researchers gave a presentation to service providers (Walmsley & Mannan, 2009). The authors of this paper identified this as evidence of PAR methods being able to increase parents "voice" and "expand their sense of collective power" (Walmsley & Mannan, 2009: 275).

Santelli et al (1998) initiated a PAR project that explored the impact of the *Parent to Parent* programme in 5 states in the USA. The project brought together parents who worked on the programme and researchers based at universities in the USA (Santelli et al., 1998). The *Parent to Parent* programme supported parents of children with disabilities, including learning disabilities, chronic illnesses and other needs (Santelli et al., 1998). This article explores the critical moments and challenges of carrying out a PAR project. These include ensuring there are clearly defined roles for everyone involved, that all members of the group have an opportunity to contribute and that the outputs from the project (for example articles and presentations) are available to and include everyone from the research team (Santelli et al., 1998). The benefit of working with parent researchers was the different perspectives the parents brought to the project which enabled the research team to develop a study that was "meaningful and relevant to the parents" (Santelli et al., 1998: 222). The parent researchers described the experience as powerful as they were valued and respected (Santelli et al., 1998). These studies show that working with parents as co-researchers can be beneficial to both the project, by ensuring it is relevant, and to the parents who can find the experience empowering. Participative research

can increase parents voices and enable them to express their views in front of service providers which could change how services are developed and delivered (Walmsley & Mannan, 2009)

3.7 Summary

Action research is a family of approaches that prioritise action, participation and collaboration. Co-operative inquiry and participatory action research are two approaches within this family. Co-operative inquiry groups comprise of co-researchers and co-subjects who work in cycles of action and reflection to address concerns relevant to them all. The developers of this approach, Heron and Reason, critiqued traditional research methods which they claimed were oppressive and emphasised the importance of working collaboratively. To them learning must be grounded in experiential knowing that is transformative as opposed to simply informative. PAR seeks to give voice to oppressed groups by working in collaboration with them. Many of the research projects that have used participatory methodologies have been in health services where researchers have sought to engage with practitioners and patients not just as participants but also in the design and dissemination of the research. Increasingly health researchers are encouraged to engage patients and service users in the research process and participatory methods fit neatly with this need. In the field of disability research inclusive and participative research has gained in popularity since the late 1980s and is now recognised as a legitimate method to increase the voice of disabled people. However, Oliver (1997) argues, there is still work to be done to ensure it is disabled people, and not researchers, who benefit from this work. There is relatively little research in which parents are included as co-researchers. The research there is identifies this as a positive experience for both the parents and the initiating researcher as it can be empowering for the former and provide a different perspective for the latter.

Participatory action research is grounded is collaboration, a desire to create change and a commitment to action. Therefore, it can serve as an appropriate method to enable underrepresented groups to critically reflect on their own experiences and understand ways in which they can enact change, sometimes with the support of an initiating researcher. As the previous chapter demonstrated, despite increasing protection from legislation, people with learning disabilities are still subject to human rights abuses and their families are often left uninformed, ignored by service providers and stressed. Therefore, PAR is a fitting method to engage with family carers to understand their experiences, explore what they would like to see change and consider implications for service provision. By using this method it ensures the problems being explored are those that are relevant and important to family carers. By structuring the study to enable time for discussion and reflection before committing to an action

we can enhance the rigour of the study (Langlois et al., 2014) and base any material or methods in the carers own priorities. Recent scandals involving people with learning disabilities has highlighted a need for services to change and engage with carers more fully. Using PAR focuses this study on creating change that could improve outcomes for carers and the people they care for.

Chapter 4
Developing Participatory Action Research with Family Carers of People with Learning Disabilities

4.1   Introduction

This chapter describes a pilot study which was used to develop the method used in Phase 1. It describes the learning from the pilot phase and how this informed the development of the main study. The pilot study took place from November 2013 to April 2014 with the aims of:

1) Explaining the concepts of a PAR study and how this may differ from other research or consultations they may have participated in

2) Investigating if family carers were interested in participating in PAR; and

3) Exploring if individuals were willing to discuss their caring responsibilities in a group.

4.2   Recruitment

Family carers were approached via a contact at Mencap. Mencap runs services for adults with learning disabilities and their carers including information sessions and day trips. Mencap was approached as it is one of the largest organisations in the local area providing support for carers. Staff members and carers from Mencap has undertaken research with the department on previous occasions and therefore I had contacts I could approach to discuss and sense check the study. I met with staff at Mencap in November 2013 to explain the study and to distribute information sheets (Appendix A). This was kept deliberately brief and not too detailed to try and encourage potential co-researchers to read it. A more detailed Information Sheet (Appendix B for this) was shared during the meeting in February and again with the group in the main study. Staff at Mencap then contacted family carers to determine their interest in participating in the pilot study. The contact details of carers who expressed an interest were passed on to me and I contacted them to introduce myself. At this stage I also offered to meet with the carers one to one to give them more information about the study but none of them accepted this offer before the first meeting. Although I had asked for the information sheets to be shared with family carers of people with PMLD I did not set any other inclusion criteria. Anyone who expressed an interest in attending the first meeting was invited to attend. I was concerned that carers may find the time commitment too onerous and therefore not wish to be involved in the study therefore I was not particularly strict about inclusion criteria as my main priority was to recruit a large enough group to enable discussion and reflection.

4.3   Participants

Five carers expressed an interest in participating in the pilot study; two were staff members at Mencap as well as family carers. The family carers group consisted of four mothers and one father of adult offspring. All but one carer had their adult child living at home with them. The carers are listed in Table 1 along with details about the person they support. The family carers provided all the information about their family member(s) and the services they used. Pseudonyms are used in all cases. Ethical approval was granted in February 2014; for more detail on this see section 5.2.3 in Chapter 5. This was after the first meeting which was considered an introductory meeting to enable people to find out more about the study.

Table 1 Carers in the research pilot group

Name	Who they care for
Dave	Adult daughter with learning disabilities and limited vocabulary. Lives with family.
Trisha	Adult son with profound and multiple learning disabilities. Lives with family.
Ellen	Adult son with profound and multiple learning disabilities. Lives with family.
Zainub	Adult son with profound and multiple learning disabilities. Lives with family.
Jenny	Two adult sons with autism-live in supported living and residential care
Nicky	Adult daughter who lives in supported living (joined the group after the first meeting had taken place).

4.4   Measures

No formal measures were defined before the pilot study group met; this was to ensure that the research was participative and not pre-defined by me. There was no audio recording during the pilot study so data was collected from detailed written notes taken during the meetings and field notes recorded after each meeting. I wanted the group to get to know each other and feel comfortable before introducing an audio recorder so I decided not to use one in the pilot phase.

4.5   Analysis

As this pilot phase was explore the feasibility of a participatory action research study with a group of family carers there was no data collected or analysed. My own notes and reflections

were used to consider the potential of such a study and what needed to be amended or taken into consideration for the main study.

4.6   Summary of Pilot

Once the group was recruited to the pilot study the next stage was to arrange a meeting in a convenient place, in terms of location (transport links, parking etc) and comfort. A priority was a place where the group felt comfortable to participate fully in discussions. The Mencap building was selected as it was familiar to all of the carers. The meeting date was set for January 2014. To try and ensure that participating in the pilot study was not too costly for the carers I offered to pay for public transport or petrol costs, this offer was reiterated in the main study.

First meeting January 2014

Four carers attended the first meeting; Zainub could not attend. I had taken drinks and snacks to ensure the participants were as comfortable as possible. It was clear as the carers arrived that they were familiar with each other and also familiar with attending meetings, as they referred to other meetings they had attended recently. They used the opportunity of being together to discuss their thoughts on these meetings and share their experiences of local services, such as the local respite facility. I found it difficult to break up these discussions and introduce the study as the conversations were obviously interesting to the group. Trisha ended the discussion so that I could introduce myself. I took this opportunity to introduce the pilot study and give a brief description of PAR and how it differed from other research. I emphasised that two main differences between this methodology and other research methods were that the carers and I would be co-researchers on the study and that there will be an output at the end of it (to be decided by the group). Two of the carers particularly liked the idea of an output and reflected that in a lot of the meetings they attended there was no outcome.

Trisha and Ellen shared that they had been involved in long term research studies and neither had ever found out what the research was for or how the data was used. By sharing these examples, they seemed to understand how this study would differ from other projects in which they, as participants, were given very little information. The carers asked questions about the research. Trisha asked whether or not the study would be endorsed by the University. I explained it would as anything that was produced as a result of the study would need to be approved by the University. Trisha felt that would add value to what the group was saying. At the end of the meeting the group arranged another meeting date (for February 2014). I was positive about this as it showed they were interested in continuing with the meetings.

After the first meeting

After the meeting, I recorded field notes in which I explored what had happened, via the written notes I had taken in the meeting. I also added to this my own thoughts and feelings. I compiled some meeting minutes to send to the group. The group were invited to make amendments or additions to the minutes to ensure they felt completely involved and that the conversations had been recorded accurately. No-one contacted me with amendments.

In the four weeks between the two meetings, I was given the contact details of two more carers by my contact at Mencap. They were Nicky, a parent carer, and a sibling carer. Nicky requested to meet on a one to one basis. The one to one meeting took place at the Mencap premises but Nicky did not go on to attend any of the meetings during the pilot study. The sibling carer was contacted by email but then decided she would not be able to commit to the study.

Second meeting: February 2014

Five carers attended the meeting in February, the four carers from the January meeting plus Zainub. Zainub had requested help in organising and paying for transport so I arranged a taxi. I was concerned about how Zainub would feel about joining a group who had already met. However, she knew members of the group well so seemed comfortable in the group. This meeting started with two members of the group (Trisha and Dave) feeding back from a meeting they had just been to as well as general discussions about services, mainly the respite unit that four of the carers use. Most of the group were engaged in the discussion but they were aware of my presence and Trisha apologised for going off track. Again, I felt torn between directing the discussions too much and leaving the conversation to flow. If the research is to be participative then the group need to be able to have open discussions so I was reluctant to make the meeting too structured. As with the first meeting, the conversations flowed easily. The group seemed comfortable to share their experiences of being carers and their experiences, and frustrations, of interacting with services such as respite, day services and residential services.

At the end of the second meeting I went round the group asking about ideas for research questions. Dave suggested exploring communication between, 1) services and carers and; 2) between services and people with disabilities. He felt it was impossible to separate out the person with disabilities from their carer, particular those with more complex needs such as no or limited verbal communication. Ellen had read the research articles I had distributed at the first meeting and asked some questions about the research based on what she had read. For example, would they be able to approach other carers to take part in the study. She was

concerned services would feel criticised. One suggested solution was that the group could invite staff members to participate in the research as well as carers. Dave was unsure if this was the remit of the study or if we should focus only on the carer's perspective. The group raised other questions such as where participants could be recruited from and whether it would be ethical for the carers to use their own contacts to find potential participants. At the end of the meeting we booked a third meeting for April 2014. I also discussed and distributed consent forms to be read at home and returned to me at the next meeting. The carers were told to contact me in the meantime if they had any questions about the study or the consent form.

After the second meeting

After this meeting I again sent out meeting minutes to summarise the discussions that had taken place and invited the carers to make amendments; none of the carers made any. The third meeting was scheduled for the first week in April. However, I had to start my maternity leave a week early at very short notice. I contacted the carers by email to explain this and to cancel the third meeting. I explained that I would be in touch towards the end of the year to try and arrange a meeting.

I contacted members of the group in September 2014 in an attempt to arrange a meeting in November. Four members of the group replied. Nicky said she did not feel able to commit to attending meetings but would still like to receive emails. No date for a meeting could be agreed upon so I contacted the group again in December to suggest a meeting in January 2015. Only two of the group responded, Trish and Jenny. I explained that they were the only two people to respond but suggested we meet anyway to discuss inviting other people to join the study. Trish replied to say that her son had been ill and that she would no longer be able to take part in the study.

I returned to the study in March 2015 and sent emails to Nicky, Ellen, Dave and Jenny to see if they still would like to be involved in the study. Ellen and Nicky did not respond. Dave and Jenny replied to say they would still like to be involved. I explained that I would contact organisations to find more group members and that I would get back in contact once I had some more participants. Once I had recruited more participants this represented the start of the main study as it was a new group of carers.

4.7   Researcher Reflections

The pilot study showed this group of family carers was used to attending meetings and expressing their views. They were comfortable to share experiences and would say if they did

not agree with each other. This was positive as it meant that their conversations provided rich data and insight in to their experiences. The difficulty I faced was understanding my own role within the group. I was not a family carer so could not join in with the conversations on that level, nor did I want to constrain the flow of the conversation by imposing too much of a structure or agenda. However, I was aware of the fact that I had invited carers to participate in a research study and therefore, at some point, these discussions should be formed in to research aims and questions. I did not want to rush this process, as the discussions were important and helped the group to get to know each other. If I rushed through the early discussions, then I risked dominating the study and not being truly participative.

This pilot study highlighted how quickly the circumstances of family carers can change making it difficult to commit to a long term study. Therefore, the study needed to be accessible and flexible for example visiting carers at home or one to one if they could not attend meetings. The co-researchers needed to feel able to miss a meeting and know they would be welcome at future meetings. Building a relationship with the co-researchers was vital in encouraging them to be invested in the study and to express if they are finding it too onerous. Building this relationship could be done through regularly keeping in touch, honouring special events, like birthdays, and allowing time in the meetings for more sociable discussion.

4.8   Conclusions from the Pilot

The pilot study aimed to address three questions 1) are family carers in interested in participating in PAR; 2) are individual carers comfortable discussing their caring responsibilities in a group and; 3) can the group understand the aims of concepts of a PAR study and how this may differ from other research or consultations they may have taken part in? These shall be explored in turn.

Are family carers interested in participating in PAR?

The pilot study showed that carers of people with learning disabilities were interested in PAR and taking part in a research study, not all these carers cared for someone with PMLD. Originally this study had sought to work with carers of people with PMLD only but as the response had not been very high only including carers of people with PMLD may have resulted in a very small or unsustainable group. This was a small group and participants situations could change quickly. When recruiting to the group it was difficult to find the balance between leaving the outcomes of the study open for the group to decide and providing sufficient information to make the study

appealing for potential participants. Unlike other studies it was difficult to define a timescale or end date for the study.

Are individual carers comfortable discussing their caring responsibilities in a group?

These carers were happy to discuss their experiences openly and honestly. During our discussions we covered various topics including how labels, such as 'autistic' and 'challenging behaviour', can be used to make assumptions about the kind of support people need. We discussed poor communication between services and carers and how carers often felt excluded or dismissed. We also discussed the quality of staffing and service provision of several local organisations. For some carers they were torn between needing to use the services, such as respite, to have a break from caring but knowing it was a place their sons or daughters did not enjoy spending time in. They were a group of carers who were comfortable attending meetings and expressing their views. This may not be the case for all family carers and could limit who would want to participate in the main study.

Can the group understand the aims of concepts of a PAR study and how this may differ from other research or consultations they may have taken part in?

The group indicated they understood that this study would be different to others they had participated in, for example, referring back to previous research. That said the content of these pilot meeting tended to focus on frustrations with services. The pilot highlighted the role of the initiating researcher in providing a balance between discussing ongoing issues with services and exploring how these issues and frustrations could be adapted in to a research question. Unless I mentioned it the group did not refer to research suggesting they may not be familiar with it. When I did mention it they showed knowledge and understanding of research methods as well as some of the ethical issues associated with research.

The pilot study demonstrated that family carers of people with learning disabilities were interested in participating in a research study. Previous research, with carer co-researchers, identified the experience could be empowering for those involved for example, enabling them to present at conferences and meetings (Walmsley & Mannan, 2009). Having carers as researchers can encourage other carers to share their own experiences, via interviews and focus groups, as they are interacting with someone who understands their experiences (Walmsley & Mannan, 2009). Working with carers as co-researchers reduces logistical issues in research as carers have contacts with organisations which could support recruitment and dissemination (Mannan et al., 2011). Previous research shows that carers involved with participative studies

like to see an outcome as a result of their involvement or they can feel like the experience has been all talk (Walmsley & Mannan, 2009). Walmsley and Mannan (2009) questioned whether service providers should be included in participative studies to hear what carers are saying, this was briefly discussed in the pilot with the group having differing views.

Learning from the pilot study and previous research was vital in ensuring the study was relevant and useful for family carers who care for people with learning disabilities. This included utilising their knowledge and experiences of local services, discussing with the group if they would like to include service providers in the discussions and ensuring the carers felt there is a positive outcome from the study. The pilot highlighted how situations for family carers can change and result in them no longer feeling able to participate. I needed to be mindful of this for the main study and consider other ways the carers could participate for example one to one meetings or online forums. Maintaining regular contact was important for ensuring carers felt invested and included in the study. This contact could be via email, telephone or social media. Discussion about the groups' preferred communication was important.

There was an interest in this type of research but carers need support to consider how their own day to day experiences could be utilised in a research study. The pilot highlighted that my role would need to be multi-faceted; I needed to be able to join in and encourage discussions with the group whilst at the same time considering the wider research issues and how the group may address these. In conclusion, the pilot study highlighted the need to:

- Maintain regular contact between meetings
- Enable time for social discussion to bond the group
- Consider other ways to enable participation for example one to one meetings or sending information by email
- Be mindful of my role in drawing the discussions back to research
- Use the contacts of carers for recruitment and dissemination
- Regularly discuss the end outcomes and what these may be so the group can see how these meetings differ to other meetings they attend
- Provide empowering opportunities for the carers such as attending conferences or delivering presentations.

Chapter 5
Phase 1 Method

5.1 Introduction

This chapter presents the Phase 1 method. During this phase a research group was recruited, data collected on the experiences of being a carer and the research priorities of the group were explored. Phase 2 (detailed in Chapters 7 and 8) was a collaborative research study based on some of the themes from Phase 1.

5.2 Forming a Group

5.2.1 Recruitment for Phase 1

The first phase of this study was to recruit and meet regularly with a group of family carers of people with learning disabilities. The phase started when I returned from maternity leave in March 2015. Although this study originally intended to explore the experiences of carers of adults with PMLD there was a low response from carers of people with PMLD. Therefore, I expanded the inclusion criteria to include all carers of people with learning disabilities. The lack of participatory action research about carers of adults with learning disabilities more generally meant that this was still an underrepresented group whose needs were underexplored.

Members of the pilot group were invited to continue to participate in the study. Two members, Dave and Jenny, expressed an interest in continuing. The pilot study had been an opportunity to gauge interest and increase my understanding of the process and practicalities of bringing together a research group. It had not been a means of generating data or testing hypothesis. Therefore, Dave and Jenny's presence in the main group would not skew any existing data as we had not collected any. I did need to be mindful of confidentiality and ensure we did not share information about the pilot study group with the new group.

To increase the group size, we approached new family carers via contacts at Mencap, Inspired by Kim (IBK) Initiatives and the Parent Carer Forum. All these organisations run services for people with learning disabilities and their carers such as training courses, social groups and other activities. I met with staff from these organisations to explain the study and distribute information sheets. Staff from the organisations then shared the information sheets via meetings with carers and social media. My contact details were on the information sheets and I invited potential participants to contact me to learn more about the study. Three carers, Sharon, Ayesha and Joanne, contacted me by telephone to find out more about the study. They were all

invited to attend a meeting in June 2015. One carer, Ayesha, asked to meet me before this date on a one to one basis. We met at the University in May 2015 where I explained more about the study and the possible outcomes from it. Four participants, Dave, Sharon, Jenny and Joanne, attended the first meeting in June 2015, at the Department of Human Communication Sciences. Ayesha sent her apologies and was unable to attend.

5.2.2   Participants

Table 2 describes the five family carers, who contacted me before the first meeting, and the person they care for. The carers provided information about the person they cared for and the services they accessed.

Table 2 Co-researchers in the research group

Name	Who they care for
Dave	Adult daughter with severe learning disability and limited vocabulary. Lives with family.
Jenny	Two adult sons with autism-both live in their own homes with support
Sharon	Adult son with downs syndrome and autism. Lives with family.
Ayesha	Adult brother with profound and multiple learning disabilities. Lives with family.
Joanna	Teenage son who lives with family. He has autism and behaviour that challenges.

Joanna only attended the first meeting. I made several attempts to contact her by telephone and email to invite her to other meetings and to try and arrange a one to one meeting but she did not respond. Ayesha attended one group meeting at the University and participated in one meeting at her home. Ayesha contacted me by email in early February 2016 to say that she was unable to continue with the study due to health issues. Therefore, the majority of the study consisted of me and three family carers, Dave, Jenny and Sharon**.**

5.2.3 Ethical Approval

Ethical approval was obtained from ethical review panel at the Department for Human Communication Sciences. Ethics for Phase 1 was approved in February 2014 (see Appendix C). The application addressed the issues of confidentiality, consent and co-researcher distress.

Confidentiality

During the study, co-researchers would be discussing the people they cared for, as well as the services they used, including individual support staff. Therefore, it was important to be clear how to maintain confidentiality. I discussed the importance of this during the meetings and explained that although we wanted to be able to speak openly, we also needed to be aware of not sharing confidential information outside of the group meetings. I explained verbally and on the information sheet how I would store their information; including meeting recordings and transcriptions, so they could be sure their own information was secure. Electronic audio data was removed from the recorder, immediately after the meeting and stored on the university network drive; this was based on advice received by the Corporate Information and Computing Service (CICS) at the University. Written and transcribed data did not include any names and was stored electronically on the university network drive. The co-researchers were informed that only I had access to the passwords.

Consent

Co-researchers were asked to sign a consent form after attending two of the meetings. This gave the group members' opportunity to learn about the study before they signed the consent form. I produced an accompanying information sheet written in plain English to provide further information (see Appendix D for the Consent Form). During the meeting, I read the forms to the group and answered their questions as they completed it. I explained that they were welcome to leave the study at any time and for any reason.

Co-researcher Distress

As this is a study where co-researchers may be reflecting on their own lives and actions there was a risk they may become distressed. To minimise this risk, I made it clear that co-researchers do not have be involved in any discussions where they did not feel comfortable. They could take time away from the group and spend some time alone or talking one to one with another member of the group. The co-researchers could decide at any time if there was something they did not wish to be included in the study.

The research group had my contact details in case they needed reassurance or to reflect on the discussions. To manage my own well-being I had regular supervisions with my supervisors where I could reflect on the meetings and discuss any difficult topics. I was also aware that I could make contact with my supervisors in between these meetings if I needed further support.

5.3 Collecting data on experiences of being a carer

The group met every four to six weeks at the University. I asked the group if they would prefer to meet elsewhere but they expressed that they were happy to continue to meet in the Department of Human Communication Sciences. The Phase 1 meetings were held between May 2015 to December 2015; these were meetings where the majority of the discussions centrered around the co-researchers' own experiences of caring. The meetings held after December 2015 focussed more on the methods for the collaborative research study so these have been classed as Phase 2. Table 3 summarises each of the meetings in Phase 1.

After each meeting I recorded field notes. These served three main purposes; 1) they enabled me to reflect on my own role and anything I could do differently at future meetings; 2) as a record of interesting topics that emerged that could be explored further at future meetings and 3) a way to note potential research questions. The field notes were either written or audio recorded and then transcribed.

Table 3 Phase 1 Meeting Summary

Date	Length	Main Discussion Points	Attendance*	Audio recorded?
18th June 2015	2 hours	*Summary of meeting:* The meeting started with introductions. Then moved on to discussing frustrations with service providers and the carer having to join up the services. Joanne gave an example of sourcing a respite service for her son, liaising with schools so they were aware but no-one then informing community transport who were unable to take him to respite. She had to involve her member of parliament to resolve the issue. There were discussions about the value of labels with some of the group finding them useful and some finding them unhelpful. Sharon described that since her son had received his diagnosis of autism, in adulthood, he was treated with more understanding. His behaviour and the way she supported it was now seen as part of his diagnosis and not poor behaviour that she pandered to. The group also discussed what would happen to their children when they died. They were concerned that this could place the burden of care of their other children. We also discussed how service providers often mention the cost of the persons support package as though they are taking more than their share. The group felt this was a way to make them feel guilty and stop them asking for anything more even though it is funding they are entitled to. *Researcher Reflections:* In the field notes I reflected on how nervous I had felt at the start of this meeting. I also considered whether I should add more structure to the meetings. The group was very comfortable sharing their experiences so this took up most of the time. Joanne had to leave to collect her son and asked what would happen next. As she needed to leave my description of the research study felt rushed and poorly explained.	Dave, Sharon, Jenny and Joanne	No
16th July 2015	2 hours 10 minutes	*Summary of meeting:* We discussed various types of communication a) between the person with learning disabilities and the people who support them b) between service providers and carers and c) vice versa. Dave expressed frustration that many carers will not complain to service providers for fear of making the situation worse. Sharon raised the issue of accessible information where pictures are used in letters. However, her son does not understand the content of these letters and it feels like a tick box exercise. This led onto a discussion about how her son gets all his mail directly to him. However he neither shares this information with his parents nor knows how to act on the content of the letter.	Dave, Sharon and Jenny	No

		This issue felt like a policy in which people receive their own mail because they are adults but it does not take into account the support needs of the person. Jenny and Dave both described meetings with social workers who they considered to be good quality. We discussed what made a good social worker. It was someone who listens and may have to go on to explain that they cannot deliver what is requested but do not dismiss the carer's suggestions as unreasonable. Someone who doesn't mention money. *Researcher Reflections:* As with the first meeting I felt nervous before this meeting. Without the introductions to start the meeting off I was struggling to know how to begin the discussions. I tried during this meeting to raise with the group some of my concerns about how to make the meetings meaningful and useful to them. By sharing these concerns I attempted to give them some ownership of the study and try and find out what they wanted to get out of participating.		
21st September 2015**		MEETING CANCELLED BY ME DUE TO ILLNESS		Not Applicable
12th October 2015	2 hours 45 minutes	*Summary of meeting:* It had been difficult to arrange a meeting after I cancelled the previous one. I was very concerned about losing momentum so offered one to one meetings so that the co-researchers still felt involved in the study. This meeting was with Dave. Dave was very open in this meeting in describing his mental health problems and how he managed them. When Dave arrived today he was stressed because he had failed to submit a timesheet for one of his daughter's support workers and they had not been paid. It emphasised that carers are taking on more responsibilities now that they are managing direct payments and employing staff. *Researcher Reflections:* Dave became quite upset while describing his mental health and the stress he was under. It made me reflect on what I was asking people to share and how this could be difficult for people. Dave also shared that he preferred to be out of the house as his anxiety increases when at home. I wondered whether this is why he chose to participate in the study.	Dave (one to one meeting)	Yes
22nd October 2015	1 hour 15 minutes	*Summary of meeting:* Ayesha has not yet been able to attend a group meeting. I arranged this one to one meeting to keep her engaged in the study and describe the discussions and process so far. Ayesha is a sibling carer and she feels side lined in this role. She is not able to sign consent forms in hospital on her brother's behalf. She feels ignored both as a carer and as her brother's advocate. She has been told	Ayesha (one to one meeting)	No

| | | she "baby's" him which she feels is an unfair description as she wants what is best for him. She described the feeling she gets about certain staff members and whether they interact well with her brother. She can see in his reaction to them if they interact well or not. Dave also covered this when we met.

Researcher Reflections: Ayesha has completed a PhD and is involved in research so it was enjoyable to discuss this element of the study with her. However, I reflected that she referred to the study as "mine" and I was concerned that there was not a buy in from the rest of the group that the study also belonged to them. | | |
|---|---|---|---|---|
| 9th November 2015 | 2 hours 32 minutes | *Summary of meeting:* As this was Ayesha's first group meeting I suggested we all introduce ourselves to each other again. Ayesha added a new dynamic to the group and gave insights from the perspective of a sibling carer rather than a parent carer. Sharon described people with disabilities as "public property" in that they had to justify how they spent their money and how they behaved. They had to prove themselves in a way people without disabilities did not. Jenny highlighted the unique nature of caring for a person with learning disabilities. It is a lifelong responsibility and also the person was born with the disability or had it from a young age so the carer has not had a relationship with person prior to becoming a carer.

Researcher Reflections: During the introductions I asked the group to say what they hoped to get from the study. Framing the discussions around research in this way helped to focus some of the discussions on research. I reflected that maybe I should open future meeting with a question or discussion point. Due to Ayesha coming to this meeting for the first time it felt like we were going over some discussions again. I reflected in my field notes about how we start to build on the discussions and not repeat them. | Dave, Sharon, Jenny and Ayesha | Yes |
| 14th December 2015 | 1 hour 37 minutes | *Summary of meeting:* I started this meeting with a description of research methods and some suggestions about what, as a group, we might like to achieve. For example presenting our findings to service providers and other carers, creating a training video etc. However, I expressed the fact I was conscious that what happens next needs to be decided by the whole group and not just me. I fed back about a book I had read (Twigg & Atkin, 1994) which described a philosophy in adult learning disability services around independent living that could result in carers being side-lined and excluded. The group agreed that this did happen and they were then labelled as over protective as their concerns | Dave, Sharon and Jenny | Yes |

| | | did not fit with the services' aims for their sons and daughters. We also discussed how the caring role increases when people become an adult as there is no one coordinating care like they did in school so it becomes the carer's role.

Researcher Reflections: My field notes from this meeting mainly focus on the fact that I directly asked the group how we were going to move the meetings forward and use what we have discussed so far as the basis for a research study. I had felt quite nervous about this in case the group felt rushed but they made some suggestions about what we could do next and also let me know what would be useful for them. For example, a list of themes from the meeting so far. The meeting felt more jokey and relaxed than previous meetings and it felt like the group, and I, were becoming more comfortable in each other's company | | |
|---|---|---|---|---|

*I attended all the meetings so have not listed myself in this chart

**No meetings were arranged over the summer holidays as Joanne's son was still in school and she could not attend meetings in the school holiday

More detailed descriptions of each meeting are provided in Appendix E.

5.4   Data Analysis Meetings and Field Notes

The audio recorded meetings and field notes were transcribed using speech to text software Dragon Naturally Speaking Home Edition. This software was selected to speed up the transcription process as there were several hours of recorded material to transcribe. The type of transcription used was verbatim transcription. This is transcription in which the text is written up exactly as it was said, including pauses, fillers or false starts. Two of the meetings were transcribed by an online transcription service UK Transcription. Where meetings were not recorded, extensive notes were taken during the meeting.

Figure 1 Sample of transcription from Meeting in January 2016

600.	S: What you mean when you say it gets in the way?
601.	J: For {*names son*} the philosophy is "that everyone should live in their own community if possible in their own house on a normal street" why should they? If it doesn't suit them.
602.	S: Yes, so they're subscribing to something that they've read or heard about.
603.	J: It's the thing that he should be as independent as possible everything is up to him, up to him without taking into account of the fact that he will say anything to get rid of them or to have the least fuss possible.
604.	R: I think that's the thing when we've talked before that it can drive a wedge because some of that does not fit in with you saying "actually that's not safe" "ahh mum's being overprotective again and closing down having a job" or whatever.
605.	S: It comes down to the way they interpreted though doesn't it?
606.	R: Yes
607.	J: Because a lot of it I wouldn't actually disagree with actually in terms of being able to have the choice of have the independence about you put that into practice. A lot of people need support to be independent even if it means "I've always got to be with you so that you can be independent".
608.	R: Yes
609.	S: That make sense? Yes?
610.	R: I think it means
611.	S: (*talking at the same time*) It doesn't mean being thrown into the swimming pool and left to swim
612.	R: That's it isn't it? And it's whether independence is the most important thing isn't it? It's like if we start to say "everybody should be able to live independently" do we actually lose an awful lot of what is the give someone a good life? And that might not necessarily be living in their own house in a normal street.
613.	J: A good life is way, way more important than normal or independent way more important.

I read the notes and transcriptions several times to familiarise myself with them and to see if there was anything that should be picked up by the group in the next meeting. For example, at my one to one meeting with Ayesha she expressed an interest in hearing about the groups' experiences of communicating with medical professionals, so I ensured this was covered at the next group meeting. I analysed the field notes, meeting notes and transcriptions using Braun and Clarke (2006) approach to thematic analysis. They describe six stages of thematic analysis:

1) Familiarise yourself with the data (involving repeated reading of the data, searching for meanings and patterns.
2) Generate initial codes
3) Search for themes
4) Review themes and determine if they work. If they do not then rearrange them
5) Defining and name themes
6) Produce the report that goes beyond simply describing the data but makes a strong argument (Braun & Clarke, 2006: 87).

I selected this method, and Braun and Clark's (2006) model, for its clearly demarcated structure and its theoretical flexibility. Thematic analysis as described by Braun and Clark (2006; 2013) has many advantages including allowing for summarising large amounts of data. My meeting transcriptions, notes and field notes resulted in large amounts of data that had to be summarised, synthesised and shared with the group in an accessible way. It is also an appropriate method for producing data that can inform policy development (Braun & Clarke, 2006). Therefore it is an appropriate model for a PAR study and its commitment to producing change not just generating knowledge (Greenwood & Levin, 2007). Kindon et al (2007) describe the different ways analysis can be conducted within a PAR study; 1) by the initiating researcher; 2) by some of the group; 3) by the entire group and; 4) the findings can be verified by the group. Pain, Whitman et al (2012) state that "depending on the sorts of data and methods of analysis needed, you may delegate this to one person or just a few people. They should report back clearly on what they have done" (Pain et al., 2012: 7).

For Phase 1 of the study, I conducted the thematic analysis using NVivo. The first read of the data generated initial codes in a process known as open coding (Fielding & Thomas, 2001). Following this the transcribed data was re-read to generate axial codes, during this process I explored the relationships between the codes generated during open-coding (Fielding & Thomas, 2001). Where open coding can be said to fragment the data by breaking it down axial coding starts to bring it back together in a "web of relationships" (Fielding & Thomas, 2001: 247). These are presented in Appendix F. The relationships between the initial codes need to be meaningful, moving beyond merely grouping them together (Fielding & Thomas, 2001).

The data generated in Phase 1 described two phenomena, one related to the experiences of being a family carer to an adult with learning disabilities and the second related to the PAR process. The themes related to the first phenomenon were presented back to the family carers for discussion as they were the basis of the second phase research study. The themes that focussed on the research process were used by me, as initiating researcher, to understand the support the group needed and to address Aims 2 and 3 of the study:

2. Identify the research agenda of family carers of people with learning disabilities around understanding the needs of people with learning disabilities and their carers

3. Use the identified research agenda to conduct a research study and disseminate findings in line with participative research methodology.

The open coding of the data described many instances that could broadly be described as commination-the lack of communication from service providers, the overly complex and jargonistic language that is used, the necessity for the carers to adopt similar communication styles to get the support their relative needed. These many instances of failed communication spoke to a power imbalance between carers and service providers. Family carers are forced to adopt the style of the service provider rather than vice versa. The lack of communication or the difficulty getting the information they needed left them feeling isolated and not a true partner in the process of providing care.

There were a series of codes that related to caring for an adult with learning disabilities (as opposed to caring for a child or a person with other support needs). They described the lifelong nature of the care that gets harder as the person ages. Services providers were less effective and joined up as the person reached adulthood. Overlapping with this were the difficulties described by carers when they described navigating all the very many services they interacted with.

Some of the themes overlapped. Where carers described meetings in their home that felt intrusive they were describing the power imbalance (for example describing it as an "invasion") whilst also feeling that there were hidden agendas that were nor being shared with them, mainly around saving money or cutting services.

The large amount of data and time constraints meant it was not practical to carry out all the analysis collaboratively. Therefore, I conducted thematic analysis and shared the themes with the group. Then as a group we were able to discuss the themes I had identified and decide which felt more important and potentially the basis of a research study. The group members validated

the themes and made changes to them that they felt were appropriate. Although the group was not directly involved in all steps of the analysis of the data at this stage they were involved in validating and sense checking the themes. They also contributed to defining and naming the themes. These themes are presented and discussed in Chapter 6. The topics we covered remained similar throughout, interactions with service providers, the insufficient support they deliver and the carers increasing role as the person they care for reaches adulthood. Therefore, it did not seem that more meetings were necessary for Phase 1 as the group members' returned to these topics regularly suggesting they were the topics of priority to the group. The names of the themes were agreed with the group to be; 1) Lack of Carer Power; 2) Caring for an adult with learning disabilities; 3) What's Not Being Said and; 4) Impact on Siblings.

5.5 Summary

These six meetings formed Phase 1 of this research study. They provided an opportunity to fully explore and understand the day-to-day experiences of family carers. The meetings provided rich qualitative data that formed the basis of a collaborative research study (Phase 2). Without this phase, the collaborative study would not have been grounded in the carers' lived experiences. These meetings also enabled myself and the carers to get to know each other so that we could work closely together in Phase 2. The group needed to feel safe to make suggestions and disagree with each other and the time spent together over these meetings enabled that. These six meetings started to encourage the group to take ownership of the study; I was able to reiterate to them that I would not be making decisions about the collaborative study and that these decisions would be made as a group. I also came to understand my role as initiating researcher more clearly. I realised that we all brought different experiences to this study and that I needed to be comfortable using my research background to suggest how the study could be designed, conducted and analysed.

Chapter 6
Phase 1 Results: Understanding the Carer Experience

6.1 Introduction

This chapter explores the results from the first phase of the study; the unstructured group discussions with the co-researchers.

I shared these themes at the meeting in January 2016; they formed the basis of our Phase 2 collaborative research study. The group discussion about these themes is covered in more detail in the next chapter. These themes have been honed and renamed since the earlier discussions. I will present these findings and discuss them in relation to the literature.

6.2 Lack of Carer Power

During the Phase 1 group discussions, the co-researchers' expressed frustration about the way they felt perceived by service providers and the lack of power carers had. To them service providers were forced to interact with carers but did not truly value their views nor see them as equal partners in delivering care:

> I mean, they've got to take our views into consideration, but that still feels very much as if, "Oh, we've got to do that, so we'll ask them" (Sharon 14th December 2015).

The co-researchers did not feel genuinely included in decision making about their relative's care. When they were it was because service providers felt obliged to, rather than recognising the value of carers' expertise. Interactions with service providers were "condescending" (Dave 14th December 2015) and "tokenism" (Sharon 14th December 2015). Rather than being part of a team offering support, they felt like outsiders raising issues that were inconvenient to service providers. As a result, the co-researchers were dismissed as over protective:

> When I have raised the issue with them they have turned around and said "you're babying him, you need to, you know, back off, you need to give him independence, he needs his autonomy". I am actually safe guarding him, I am trying to prevent things from reaching a point where I... have to take time off work because he's ill (Ayesha 9th November 2015).

Ayesha was employed as a researcher and was the only carer in the group still working, this may be why she adopted official terms such as "safeguarding". Another reason may be that, as many of the group discussed, they were often conscious of using the right terms in front of service providers to access the support their family member needed. They may have internalised some

of the terms used in these meetings in other settings. Dave described interactions with social services as:

> A game, and if you don't know the rules, you're lost, because there's a way of talking to Social Services (Dave 14th December 2015).

Co-researchers were speaking on behalf of the person they cared for but also trying to reduce the risk for themselves or their family. To the research group, service providers did not take the safety of their relatives seriously enough as they were too governed by philosophies such as independent living and normalisation. Jenny reported that her son had to demonstrate steps to independence, despite this not being a meaningful outcome for him. She felt him having a good life was much more meaningful than his independence:

> You want people to have a good life; that might not be the absolute maximum independence they can be. It might not be living in what other people think of as the local community. It might just be a good community for them that gives them a good life (Jenny 14th December 2015).

Jenny's son lived in a purpose built community, known as intentional communities, for people with learning disabilities in which accommodation and other community resources such as shops and a social space were in the same grounds. These communities have often been ignored in policy or criticised for not encouraging integration between people with learning disabilities and those without (Lyons, 2015). To Jenny it was the best place for her son to have his needs met. She felt service providers' preoccupation with living in mainstream communities was neither person-centred nor in her son's best interests. Despite their lack of power the co-researchers viewed themselves as advocates standing separate from service providers and offering another point of view, though that point of view was not always considered. They feared the time they could no longer act as an advocate for their relative:

> The thing I worry about when I'm not here, because they've got this philosophy, and when you're not there to shout for the person themselves then it is about the philosophy and not about the person and what's best for them (Jenny 29th January 2016).

Again, Jenny is discussing the philosophy of independent living. She fears that her son's bespoke and, as she had been informed, expensive placement would be removed from him if she is not able to fight for it. This need to fight really coloured their interactions with service providers. They approached meetings with anxiety as they felt they would need to be on the defensive and fighting for the people they cared for.

6.3 Caring for an Adult with Learning Disabilities

Caring for an adult with learning disabilities, rather than caring for a child or a person with different needs, is unique role. It is lifelong and does not end until the carer or the person being cared for dies. Due to the co-researcher's misgivings about the quality of services offered, the responsibility for caring would never reduce, even if the person stopped living with them:

> The thing is, if you've got a person, certainly with a learning disability, you never leave that responsibility. It is there until the death of one of you. Because even if they go into independent living, you've still got it (Dave 12th October 2015).

Dave was reflecting here on a time when his daughter may move into independent living accommodation. He felt he would still have a central role in her care. This view reflected Jenny's actual experience. Jenny's two sons with learning disabilities lived away from her but she still felt she was required to be very involved in their care, for example taking her son to buy a new mobile phone despite the fact that should be the support provider's role "they're supposed to be responsible for that stuff" (Jenny 9th November 2015).

Another unique factor was there had been no relationship with the person before becoming their carer, unlike caring for a parent or spouse who becomes ill. It also differs from being a parent to a person without disabilities:

> I mean, to a certain extent, you've always got it with children. We have it with our daughter; we've got it with our son. But they're not constantly on your mind thinking "are they all right?" But you're always there if occasion requires it. But with (*our daughter with disabilities*), we're always there because we know she can't... she hasn't got the ability to look after herself in any aspect (Dave 12th October 2015).

> Every other sort of carer is different from us because if you're looking after a partner you know you had a life with them probably before they got sick...if you're looking after a parent you can probably see the end of it at some point. Whereas we have it from when our children were born, we know that is it for the rest of our lives (Jenny 9th November 2015).

However, the caring role was more straightforward when the person was a child because services naturally defer to the parents of a child regardless of disability. It becomes much more complex when the person being cared for becomes an adult. Not only with regards to the relationship with service providers but also for the co-researchers' relationship with their adult child. Caring responsibilities increase as the person they care for reaches adulthood. Before this, their relative had been in an education system, but once they leave education the care falls to the co-researchers. At the same time, their role as a carer becomes more ambiguous:

My role is completely changing now or growing now instead of getting smaller as they get older, it goes the other way (Sharon 9th November 2015).

During the study the *Care Act* (Department of Health, 2014) was introduced which gave carers the same right to support and assessment as the people they care for. Although some of the group had made use of this legislation by participating in an assessment, the overwhelming feeling was that if services were fit for purpose the carers would not need an assessment. To the co-researchers the greatest stress associated with caring was dealing with service providers. The carers expressed a preference for services providers to proactively engage with each other and do what they say they will rather than spend resources assessing carers.

This heightened stress was demonstrated during my one to one meeting with Dave in October 2015. Dave was under great strain, some equipment his daughter relied on had broken over the weekend and there was no one to fix it outside of work hours and he had forgotten to send one of the support worker's timesheets to her agency therefore she had not been paid. Dave was acting as a carer and an employer as well as dealing with his own ill health, his daughter's bespoke equipment and an application to change the type of funding his daughter received. Dave was the only carer whose daughter had mobility issues so this added another set of services that he needed to engage with:

> Yes. I am supposed to fax them today. But there's so many things that's gone wrong this week. I forgot to send the PA's timesheet. Never even picked up that the payslip didn't arrive (on) Thursday (Dave 12th October 2015).

6.4 What's Not being Said?

Interactions with service providers were stressful for the co-researchers mainly due to the perceived hidden agenda of service providers. To them service providers were driven by a need to save money or cut services but did not express this in meetings. In an attempt to highlight that the support was necessary the co-researchers had to describe their loved one in the most negative terms. This felt disloyal "if you beef up the bad side, you could have a feeling of guilt that you have failed" (Dave 14th December 2015). These exchanges left the co-researchers feeling dismissed or ignored. They recounted examples of not being included in conversations and not being given information they needed, for example if a staff member left an organisation. This lack of interaction from service providers had a negative impact on their relatives as they did not know the people offering support or they did not know where their previous support worker had gone:

Sometimes they just disappear! And (*names son*) had huge problems with loss at one point because they just, they plucked in and plucked out of there (Sharon 9th November 2015).

Sharon stated on several occasions when she called the providers who support her son, she imagined they were pretending to be away from their desks to avoid speaking to her. She would leave messages and they rarely called back. She felt deliberately ignored.

6.5   Impact on Siblings

Caring had an impact on all family life with consequences for their other children. Dave described the ways they had to moderate their behaviour around his daughter including keep their voice low and not asking her direct questions. He also described the impact of having support workers in his home, how they would move their property around and he did not feel he had space in the house belonging to him.

> And they've got to respect that it's our house as well. They can't just say, "I want things to be done this way." Because we find that if they've picked something up they'll put it where they want to put it. And then we spend about two hours looking for where it is (Dave 12th October 2015).

During the time of the study, his daughter started to have support workers at home 24 hours a day. After years of waking throughout the night with their daughter, this was necessary for Dave and his wife but would mean there were always paid support staff in their home. This would affect their privacy and their time together as a family. It also gives their house a dual purpose; not only is it their home but it is also someone's place of work. Dave struggled with the fact there was always someone in his home "no matter how good they are there's always the resentment that it's people there" (Dave 12th October 2015).

The co-researchers expressed concern about the impact of their children with disabilities on their other children. None of them wanted their other children to take the level of caring responsibility they had once the carers died:

> I mean, my number one goal is ...for things to be as settled as possible. (*Names daughter without disabilities*) she'll still be their sister and I hope she'll still see a lot of them. Obviously, she's going to be responsible to some extent, in the future, but it's for that to just be as minimal as possible, really (Jenny 14th December 2015).

> They've got their own lives and you can't predict what happens. In my other son's life, he has his own set of personal difficulties, so it is not an easy equation, is it? (Sharon 14th December 2015).

As a sibling carer Ayesha was keen to reassure the other co-researchers that she felt no resentment for the caring responsibility; her frustrations came from the fact her rights as a carer were not recognised rather than the caring itself:

> I've just taken it on without actually seeming like I've taken something on. It's just a natural, natural thing for me... I have to emphasise sometimes that I'm not making a sacrifice, to me it's not sacrifice. A lot of people see it as and, I know it's a worry for older parents, to actually think about what's going to happen when they get ill, that they'll be unable to take care. That's where looking at services is a big part of thinking about the future for your children... but again services and service providers often don't accredit me with the same authority as if I were a parent (Ayesha 9th November 2015).

However, Dave felt that his daughter's siblings did feel ongoing resentment for the amount of support they had given to their disabled sister as children "even though the younger daughter was helping to care for (*names daughter with disabilities)* ... I don't know whether (*names wife*) is aware that there's resentment there, but I know there is" (Dave 14th December 2015).

6.6   Discussion

The themes from Phase 1 of the study add to the existing evidence that carers of adults with learning disabilities can feel side-lined by service providers (Twigg & Atkin, 1994), stressed from their interactions with service providers (Beresford, 1994) and anxious about what happened when they are no longer able to care (Bowey & McGlaughlin, 2005). The carers in this group found that service providers' preoccupation with independent living meant that this was valued over the person having an enjoyable life. As with previous research the carers found negotiating with services one of the most stressful aspects of caring (Beresford, 1994). The discussions in this phase highlighted the many strategies that carers used during their interactions with service providers including being conscious of saying the right words and terms and emphasising the negative aspects about the person they care for. This came at a cost to the carers who then felt guilty on behalf of their adult child. This phase uncovered the huge lack of trust the carers view service providers with, they are constantly attempting to uncover what is not being said and understand what the service provider's motives are. For the carers in the group the caring role felt more difficult as their child reached adulthood. Hubert (2010) found that physical care could be more difficult as people with severe disabilities got older due to their increased size and potential to exhibit sexual behaviour but my co-researchers did not refer to physical support. They found caring for an adult harder as they were no longer recognised by services as being responsible for the person and that there was no single organisation to coordinate their care so this became the carers' role.

Originally this phase was envisaged as a pre cursor to developing a collaborative research study. However, the discussions the group had yielded a large amount of data covering a wide range of issues that it had implications for service provision. These were not only discussions about developing a collaborative research study, and the practicalities of this, but also discussions about how carers feel perceived by service providers and what they would like to see changed. These findings could be shared and disseminated as a study in their own right and with this in mind I will now present some of these implications along with the limitations of this phase of the study.

The unstructured and open group discussions enabled the group to get to know each other and explore their own experiences as a group. By allowing the conversations to flow naturally it resulted in a range of topics relating to caring being covered. As I was not related to any particular service the group could be open and not fear repercussions for themselves or their family. My previous experience as a support worker meant that I only had a one-sided view of carer experiences. I needed to take time to listen and reflect with the group. I could not have understood what mattered most to carers without this first phase as my experience as a paid carer meant I had a very different understanding of the situations they would describe.

This phase demonstrates the need for service providers to improve how they include and interact with carers. The carers view services with suspicion and question their motives. Service providers need to approach carers with honesty and engage with them from the outset, engagement with carers should not be an add on. The carers in this group had been engaged with service providers for their son and daughters' entire life and intended to keep on doing this, service providers need to acknowledge this lifelong commitment and appreciate how many different service providers' carers interact with and coordinate on a regular basis.

The limitations of this phase were that the majority of these carers were retired and had adult children. Thus attending regular meetings may have been easier for the members of the group that someone who worked or had school aged children. As it was a long running project, some people were unable to complete it due to their own health needs. This group were clearly able to express themselves and felt able to share their experiences; they were used to attending meetings. Those carers who were satisfied with the support they received or those who were less confident or well engaged may have felt less desire to participate in the study. It could have been these carers' dissatisfaction with service provision that made them more likely to participate in the study.

The themes identified in this phase were not all incorporated in the second phase study. In the meeting in January the group identified that the key issues they wanted to explore further centred on interactions with service providers. Namely the power imbalance in these interactions and the perceived hidden agenda. These were the main focus of our Phase 2 study as they felt most pertinent to the research group's own experience.

6.7   Summary

Phase 1 showed the pressure that carers are under and the impact caring can have on their family life. The co-researchers felt side-lined by service providers and did not feel included in the support of their relative. They reported that they did not always get the information they needed and felt service providers often had hidden agendas during their interactions. This supports previous research which claims formal support can add to carer stress (Beresford, 1994; White & Hastings, 2004). It also adds new evidence of the strategies carers employ in their interactions with service providers.

Chapter 7
PAR in focus: The process of co-production with family carers

7.1   Introduction

In this chapter I will describe the process of moving from discussion to action and my role in this. I will then explore the action phase of this study in which the group defined a research question and co-designed, shared and analysed two surveys; one for family carers and one for service providers.

7.2   Moving from discussion to action

I recorded field notes after each meeting in Phase 1 to reflect on both the content of the discussions and my own feelings during the group meetings. This enabled me to assess my own role within the group and how to guide the discussions from Phase 1 into a research study. Some of my reflections relate to the research process of the study, how the meetings changed from experiential to practical and what worked well for the group. During meeting in December 2015, I asked the group to describe what would assist them in starting to design a research study and how best to use the Phase 1 discussions in this process. This shaped the following meetings which marked the start of the second phase. Sharon expressed that it would be useful to have a summary of the topics we had covered during the previous five meetings "perhaps, just on a sheet of paper, when we come next time, the sorts of things… You highlighted some of the threads that were coming out" (Sharon 14th December 2015). Therefore, we decided to take the themes as our starting point for developing the research study. The group was aware that the study needed action but needed support to understand what that action might be. I conducted the thematic analysis (Braun & Clarke, 2006) of the Phase 1 data over December 2015 and took the themes to the next meeting on 29th January 2016.

The move to Phase 2 meant that the meetings became more structured than in Phase 1, for example I would email the group prior to the meetings to suggest activities or tasks we could conduct in the meeting such as plotting a time line. The learning from the Pilot was that the carers valued the notion of creating an output from the study that could be shared and thus I was conscious of finding ways to support the group to do this. The six meetings between June 2015 and December 2015 were unstructured as the group decided the content of the discussions

and I would contribute whereas after this time the meetings were more practical and sometimes an agenda or task would be set in advance.

7.2.1   Determining the group's research priorities

One of the original aims of this study was to co-design and complete a collaborative research study. However, concerns about how to support the group to do this was a recurring theme in my field notes. I would question how much I should enable the conversation to flow and how much I should try and direct it. I had originally envisaged that the group would start to move onto discussions about research spontaneously. However, it became clear that this would not happen without some support from me:

> I do think that the group may need more support than I originally thought they did. Their comfort with talking about their experiences does not translate to a knowledge of research which is fine and that is fair enough but maybe I overestimated what they would already know (field notes 29th January 2016).

In the meeting in January 2016 we discussed the themes that I had identified from the Phase 1 discussions. The themes were on individual pieces of paper which the group moved around on the table to see how they linked and which they felt were the most important. I took photographs of these as visual aids for future meetings.

Jenny felt that the philosophy of learning disability adult services (Twigg & Atkin, 1994) which prioritised independent living dominated all of the themes as it coloured how services interacted, or did not interact, with carers. In my analysis I had broken interaction down in to three types:

- Interaction with statutory services
- Interaction with private service providers
- Interaction with medical professionals.
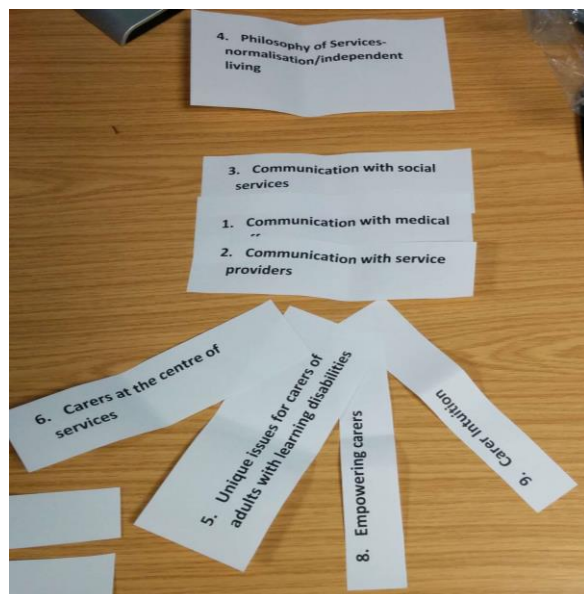
Figure 2 Discussing the Phase 1 themes 29th January 2015

Although the group acknowledged that Ayesha had a difficult experience with medical professionals, which she had shared at a previous meeting, Dave, Sharon and Jenny did not feel that their experiences with medical professionals had been as difficult as they had been with other professionals. Therefore, this theme was not seen to be as important as some of the others. At a previous meeting Jenny had expressed an interest in exploring not just their interactions with service providers but how service providers perceived carers' and how they saw themselves working with carers:

> If we're talking about communication, I think it's a lot about how we're perceived as parents of adults with disabilities, how people communicate with us, and how, in their minds, we fit into the picture (Jenny 14th December 2015).

Although the group were satisfied that the themes identified via the thematic analysis represented their own experiences they expressed concern that they could not speak for all carers and potentially other carers had different experiences to them. Dave suggested a survey as a means of gathering the opinions of other carers:

> We will need to have proof that whatever we want to concentrate on is relevant to the outer public so an initial questionnaire going out to try and obtain that proof might be a good idea (Dave 29th January 2016).

To which Sharon followed up with the suggestion that a second questionnaire be developed for service providers as well:

Also, interesting that might be to send that questionnaire with the same or a similar set of questions to people who provide the services... "what in your perception is the role of the carer" a general one perhaps and then further on "which way do you feel that the carer's unique situation feeds into the support that you offer" (Sharon 29th January 2016).

This would also fit with the comment she had made in the previous meeting about wanting to understand how service providers viewed carers and their role. I identified one theme as 'carers at the centre of services'. The carers did not feel this was the case. I explained what I meant by this; carers often had to coordinate services and pull them together. They agreed with this but not my wording. They felt that 'carers as coordinator of services' was more appropriate. Therefore, as a group we decided that we would take the themes from Phase 1 and incorporate them into two surveys; one to be completed by family carers and one to be completed by service providers.

7.3   Developing and piloting the survey

7.3.1   Aims and Objectives

During our discussions about the survey I emphasised that we needed to keep the aim of the survey in mind while designing the content. This would enable us to ensure the questions we were asking addressed our aims. We agreed that the aim of the survey was to gain insight into how carers and service providers perceived their interactions, and whether this differed. We also wanted to know how carers and service providers felt these interactions could be improved and whether this differed. I wrote these aims up and shared them with the group. We agreed that the aims of the surveys were to:

1) Investigate carers' experiences and perceptions of their interactions with service providers.

2) Consult carers about strategies and changes for improving interactions between carers and service providers.

3) Investigate service providers' perceptions about how they and their organisations work with carers

4) Consult service providers about strategies and changes for improving interactions between carers and service providers.

The group also defined further questions they would like to explore from the data:

1) Does the age of the person being cared for affect carers' perceptions of service providers?

2) Do the responses from the local area differ from those from other areas?

7.3.2 Design of Instrument

The surveys were designed collaboratively within the research group via face to face meetings and email. We discussed the survey over six months from January to June 2016. I would create a version in Survey Monkey and email it to the group for comments. If we were struggling to reach an agreement via email I would suggest resuming the discussion at our next meeting.

Through group discussion we generated draft questions and I inputted these into Survey Monkey, an online survey builder. During discussions about the survey design, my role was to give examples of what kind of questions were available (for example likert scales, rating scales, multiple choice questions) and to encourage the group to think about how we might ensure the survey was appealing to potential participants. For example, using an online survey to minimise time spent on data entry (Watt, Simpson, Mckillop, & Nunn, 2002) and to enable us to reach a wider range of potential participants. I also advised on how to structure the survey and which information we should provide alongside the surveys such as ensuring participants of their anonymity and sending out reminders (Nulty, 2008). I would also give examples about how responses could be analysed to answer the research questions such as using chi squared analysis and T Tests to compare the responses from different groups such as those who care for an adult and those who care for a child. Fowler (1995) describes a good question is one which "produces answers that are reliable and valid measures of what we want to describe" (1995: 2). Therefore, by thinking about the analysis and end outcomes when designing the survey, we could ensure the questions we asked provided the information we needed to complete the analysis.

In between the meetings, links to the surveys were shared by email with the co-researchers and they were invited to give feedback. The co-researchers would suggest amendments and I would make these changes and share the link again. Sometimes the feedback was contradictory, for example, one member of the group feeling a question was fine and another feeling it needed to be changed. When this happened, I would bring my laptop to the meeting and we would discuss issues with particular questions in face-to-face meetings. This meant the issue was cleared up more quickly than via email. The survey was discussed in six meetings from January to June 2016. This meant it was shared later than originally planned but it did mean that every member of the group had inputted into the survey. It also ensured that we had given ourselves plenty of time to guarantee it included the right questions to cover our research aims.

The feedback from the group while developing the survey focussed on the following issues:

Terminology

We discussed the terminology used in the survey in detail. It was important to establish a clear shared understanding of key terms included. For example, "services" may be taken to mean "paid services" then this may exclude reflections on social or education services because they are not billed. We decided in the end to define "services" as something other than support provided by friends and family. We also discussed the language we used to describe the people who were cared for. In an early version of the survey, we categorised disability (e.g. moderate, mild) however, Sharon fed back that:

> I would find it difficult putting my son into any of these categories and am wondering what information you need. Do you think the severity of the disability might affect the quality of the service/ support? (email received 14th March 2016)

> It just sounds like we are putting people in boxes and as that's often part of the problem with services I think we may be adding to it (email received 14th March 2016).

It was important to Sharon that as a group we should be creating something that sounded different to the documents developed by service providers. In previous discussions she raised that she often felt that she had to label her son and it was to his detriment and the benefit of services:

> I mean, I can remember somebody saying to me that my son was SLD (*severe learning disabilities*) and this was a way of playing the system. I said, "Oh, I thought he was given MLD (*medium learning disabilities*) once before, so he'd been demoted or something." They said, "Well, actually, you get more money, in terms of education, if you've got SLD, so that will help him." I said, "Oh, well, call him what you like. He's still the same person." It actually does influence people's perceptions. (Sharon 14th December 2015).

Therefore, she did not want our survey to ask other carers to label the people they cared for.

Clarity of questions

We made many changes to the questions over the six months we developed the survey. In an early version of the survey the likert scale ran from "strongly agree" to "strongly disagree". Jenny fed back that this was problematic and unclear because "I deal with so many different people and the experience can be different every time" (email received 23rd March 2016). She suggested that instead of agreeing or disagreeing with the statement, carers should be able to indicate how frequently they felt a certain way. She felt that a scale of frequency would be more appropriate as the quality of services could vary, depending on staffing and management, and

therefore something could happen some of the time but not all. She was able to use her experiences of interacting with services to edit the wording of the survey.

Carer experience of completing a survey

Again, the carers brought their own family experiences to this issue. Jenny raised the fact that she had two sons with a disability so would she complete the survey with both in mind, or would she complete the survey twice (once for each son)? She felt the former would be very difficult as their needs means she deals with different types of services and in different ways. We decided to highlight in the information sheet that carers of more than one person could complete the survey more than once.

Who is the survey for?

The group felt strongly that the survey should be completed by carers of adults or children with learning disabilities. Although they acknowledged there would be overlap in the issues faced by carers more generally, there were enough differences that they did not feel comfortable speaking for all carers. They expressed they had designed the survey based on their experiences as carers of people with learning disabilities specifically. I suggested that both surveys start with a question that would help the group identify if the participants completing the survey were the right ones for the study. In the Family Carers Survey the question was: Are you a family carer for someone with a learning disability? In the Service Provider Survey, the question was: Do you work for a service that supports people with learning disabilities and/or their carers? If anyone selected "no" in response to these questions their responses were excluded, as they did not fit our inclusion criteria. Although all responses were read in case they had selected no in error.

Service Providers were asked to rate their experiences of interacting with family carers on a 5-point likert scale from 1 (strongly agree) to 5 (strongly disagree). We discussed strategies to ensure that service providers read the questions and did not select 'strongly agree' for everything. We decided to include questions in the survey that were more negative in tone towards family carers such as "family carers are not always the expert" and "family carers are not always the best people to make decisions for the person they care for". This was to encourage the participant to read all of the questions carefully to make a more considered selection. We did not ask participants to identify which organisation they worked for in an attempt to allow them to answer more honestly. We included the question "Do you think there is anything that family carers could do to work more effectively with your organisation?" in order

to acknowledge carers' roles in interactions. It was important to the group that the survey did not have a negative tone towards service providers.

7.3.3 Structure of the Survey

To ensure the rigour of an action research study the qualitative and quantitative methods employed need to be applied appropriately and correctly (Langlois et al., 2014). For this study that meant utilising good practice when designing the survey and analysing the responses. Surveys are an effective method of looking for trends (Lauer, McLeod, & Blythe, 2013). The co-researchers in this group acknowledged that their experiences may not be representative of all carers. A survey would enable the group to explore if carers more generally faced the same issues and anxieties around engaging with service providers.

A key necessity when designing a survey is being clear what the aims of the survey are and what questions need to be answered (Bell, 2005). Constantly referring to the survey's aims ensures the questions selected are appropriate and will answer the questions. Another key consideration is clarity of questions and using accessible language (Bell, 2005) as without this participants may not engage or complete the survey. Careful testing of the survey by piloting it is vital to ensure it is accessible to potential participants. The surveys designed by the group were piloted and amended following feedback. This is discussed in Section 7.3.5: Pilot.

Another decision to be made was the method of sharing the survey. This could have been done via post, telephone interviews or online surveys. All come with benefits and difficulties. Postal surveys can reach large numbers of individuals, but they tend to have low response rates (Simmons, 2001) and they would require access to potential participants home or work addresses. They also have a cost involved as postage and pre-paid return envelopes need to be paid for. They are also more time consuming as the written responses would need to be transferred to a computer for analysis (Simmons, 2001). Telephone interviews enable some flexibility, for example questions can be reworded or explained further to enhance accessibility (Simmons, 2001). However, they are more time consuming and would again require access to telephone numbers. Although the group may have contact numbers for carers who were friends and acquaintances it would not be a large or particularly representative sample. We felt decided to share the survey using an online survey builder. This would enable us to send the survey, for free, to a key contact and ask them to share it on our behalf. This negated the need for us to have access to personal email addresses. Links to the survey could also be shared on online forums and social media so did not need to be sent directly to named individuals. However, we did recognise that online surveys required access to the internet and technology, so we also

offered to send printed, paper copies if organisations felt this would be more appropriate for their beneficiaries. Online surveys have been identified as being reliable tools as they are anonymous and there is no interviewer effect (Ramo, Hall, & Prochaska, 2011). The participant does not feel the need to modify their response to make it more socially acceptable as they are completing the survey alone. Using Survey Monkey meant the surveys are stored online. The participant does not have to email it back to the researcher therefore none of their identifying information needs to be linked to the survey unless they want it to be (for example by completing questions relating to contact details or demographics).

Simmons (2001) identifies eight considerations when developing a survey. I will consider each of these in turn in relation to the surveys developed by the research group.

- Relevance to participants; the potential participants need to have the information necessary to answer the questions and be willing to share the information being asked of them. In our discussions about the survey we decided to focus on carers of people with learning disabilities. Although the group acknowledged an overlap in the experiences of carers more generally they did not feel certain the questions would be relevant to all cares. This led us to include a screening question at the start of both surveys to find out if the participant cared for, or was paid to support, a person with learning disabilities. However, this was the only question we made compulsory. If a participant did not find the question relevant to them, or they were not comfortable sharing the information, they did not need to complete the question.

- Clarity; Simmons (2001) identifies this as a difficult balance. Complex language and jargon can alienate potential participants, but overly simplistic language could be interpreted as patronising. As a group we grappled with terms such as "service provider", "services" and "funding". We had to decide if we defined them or used them at all. In some cases, we provided a definition, such as for "services" and for some we did not. We used the Pilot to explore the language we used and see if it was accessible enough. As well as this we proof read the survey to ensure categories did not overlap such as the question about age. We did not want there to be two potential options the participant could select.

- Leading Questions; these should be avoided and questions presented more objectively (Simmons, 2001). One way to do this is use open questions to allow the participant to recount their own experiences in their own words. As a group we discussed the tone of our surveys, particularly the service provider survey. The group were aware of their own bias against some service providers and we did not want the survey to feel negative

towards providers. This could put participants off and therefore they would not engage. Equally we did not want family carers to feel they needed to respond in certain ways to the questions. We made it clear in the information sheet that we were not aligned to any services and that their responses in the survey would not impact on any services they received. The question that requires service providers to consider what carers could do differently was an attempt to ensure the survey did not appear too bias towards carer experiences. We made use of open questions in both surveys. In both we asked, using an open question, participants to reflect on their last interaction with each other. This was to enable the participants to provide detail but also to stop this question being leading or make assumptions that the interaction would have been negative. It was a more objective way of presenting the question.

- Double-barrelled questions; these are when two questions are rolled into one so that it is not clear which part of the question the participant is answering. We ensured our survey did not include these. However, our pilot showed some overlaps in the categories we were using that needed to be amended. For example, we asked participants to select the type of care they provided from a list of options. Support with shopping was included in more than one category and this was confusing so needed to be removed.

- Hypothetical questions; Simmons (2001) states that these should be avoided. They were not included in our survey.

- Secondary information; again something that should be avoided (Simmons, 2001). We did ask for some secondary information as we asked carers to report the type of support the person they cared for needed. The person with learning disabilities may have disagreed with what the carer selected here. As this survey was from the carers perspective it was the support they perceived the person needed. However, we must acknowledge this means that the responses should be taken as the carer's opinion and not factual.

- Periodicity; terms such as 'frequently' or 'regularly' are vague and subjective (Simmons, 2001). As a group we did decide to use these terms in the family carer survey as they seemed more applicable than 'agree' or 'disagree'. The carer may be reflecting on their experience of several different service providers and a scale of agree to disagree may be too simplistic. However, we did not know how often the participants interacted with service providers so that made it difficult to be more specific on the periodicity.

- Sensitivity; care needs to be taken when asking participants to report on sensitive issues. There is a risk they over report activities that are deemed to be positive and under report

those deemed to be negative (Simmons, 2001). Previous studies have shown that online surveys reduce the risk of over or under reporting (Ramo et al., 2011). However, as a group we did still consider the risk of over reporting. Service providers will be aware of the expectation to work collaboratively with family carers. Therefore, we assumed they would report that they proactively included family carers in their response to the survey. To attempt to ameliorate this we included two questions that were more negative about family carers. This was an attempt to at least ensure they read all the questions carefully and gave a more considered response. The surveys could be completed anonymously in an attempt to enable all participants to be transparent in their responses. We deliberately did not ask for details of organisations that participants were employed by nor services they used. Only the first, screening, question was compulsory. This was intentional so that if a question was too sensitive for the participant they were not obliged to answer it.

Other considerations when developing a survey are the order of the questions and the length of the survey (Dawson, 2009). The group's own experiences of completing several surveys meant that we were keen to keep it as short as possible but also be transparent in the information sheet about the time it would take. We did not want to risk losing participants if the survey took longer to complete than we had stated. We discussed the types of questions and for some open questions were the most appropriate however, we acknowledged they took longer to complete. Therefore, where appropriate we used closed questions that were quick to complete. We were also aware that not all the questions were relevant to all participants, for example a carer could not give their opinion on charity run services if they did not use them. Therefore, we made it clear in the descriptions for each question that they could be left out if they were not applicable.

When deciding the order of the survey we included the easiest questions first, this enables the participant to move quickly through the survey and makes them more likely to compete it (Dawson, 2009). In both surveys we started with closed questions (tick boxes and likert scales) before moving on to a series of open questions. Both surveys ended with closed questions relating to the participants personal information (gender, age, location). We included this at the end so that if the participant ran out of time and did not complete the survey we would still have the responses related to their behaviour, attitudes and beliefs (Simmons, 2001). The aim of the survey was to understand how carers and services providers perceived their interactions with each other and how these could be improved. The likert scale questions in both surveys tapped in to the concept of how central family carers were, or not, to the work of service providers. The open questions enabled these concepts to be explored in more detail. They also moved into

looking at how the situation could be improved. This was a new concept that answered the two of the original research aims:

1) Consult carers about strategies and changes for improving interactions between carers and service providers.
2) Consult service providers about strategies and changes for improving interactions between carers and service providers.

7.3.4 Ethics

Ethical approval was obtained from the Department for Human Communication Sciences, ethical review panel in September 2016. The full application form and participant Information Sheet are included in the appendices (Appendix G).

The ethics application addressed the issue of consent; the participants were not given a separate consent form to complete but it was made clear to them that completing the survey was considered consent. This was highlighted in the information sheet that accompanied the survey and also on the first page of the survey with the statement:

> I understand that by completing the survey I am consenting to having my answers analysed and possibly used (anonymously) in presentations or reports.

The ethics application also gave details about how participants' responses would be kept confidential. The information sheet detailed how responses would be stored to ensure confidentiality such as saving them to a password protected computer and shredding any responses that had been printed off for group discussions. The ethical panel requested clarification that the carers who were in the group would not be permitted to complete the survey. They required further information about how I would ensure anonymity of participants. The response I gave to this was:

> Pseudonyms will be used throughout (including for members of the research group). They will be used for the participants and the person they care for (if they refer to them). If a service or location is referred to this will be replaced by descriptive terms such as "supported living service in a Midland town" (taken from my Ethics Application Responses September 2016).

7.3.5 Pilot

In June 2016, we piloted the surveys and feedback was collected verbally, via SMS or email.

Family Carers Survey

The Family Carers Survey was sent by email to the co-researchers' own network of people they knew who were carers and who might be willing to pilot the survey. Four people were asked to complete the survey, see Table 4 for further information about this group.

Table 4 Information about carers invited to pilot the survey

Carer details	Feedback
Carer 1: Friend of one group member	Completed the survey but did not give feedback, this may be because they did not understand that they were required to give further feedback. The group member approached them to complete the survey, so I am not sure what information the friend was given.
Carer 2: Spouse of one group member	Gave feedback verbally
Carer 3: Spouse of another group member	Gave feedback verbally
Carer 4: Previous member of the group who is no longer involved in the study	Did not respond to email asking to pilot the survey

The two people who gave feedback did so verbally to the members of the group that they knew, one of these was Jenny's husband and the other was Sharon's husband. This was then written down and discussed with the rest of the group. The group had the survey in front of them on the laptop while they received the feedback. They then discussed the feedback and decided whether to make changes to the survey.

Feedback on the Pilot

The feedback to this survey was mainly about the wording of the questions and the clarity of the questions. An example of this is that participants are asked what support the person they care for needs. They are asked to choose from a list of different types of support, for example support with eating and drinking. However, some of the list items overlapped, for example support with shopping was included in both Support with Eating and Drinking and Support Around the Home. We amended the list so that all of the items were separate items. There was also some confusion over what was meant by the word "services" in the question "does the person you care for use any services to support their needs?" This also highlighted some discrepancies within the research group's understanding about the word "services" so it was useful to discuss it further. As a group we decided to amend the wording of the question to say "does the person you care for use any services to support their needs (other than that provided by friends and family)?" to make it clear that we were referring to services that are either paid for or funded rather than provided by unpaid carers. Some of the issues raised during the piloting phase related to the survey tool, Survey Monkey, so these could not be changed.

Service Providers Survey

I sent this survey to two former colleagues; one who currently works for the local Day Services and another who works for Day Services in a neighbouring local authority. I worked with them when we all worked for Day Services. I requested their help in piloting the survey. One of these read through the survey and also sent the link to the survey to two colleagues. She then wrote down their feedback and sent it to me by SMS. Information about this group is presented in Table 5.

Table 5 Information about paid staff invited to pilot the survey

Person	Feedback
Person 1: Initiating researcher's former colleague	Did not respond to email
Person 2: Initiating researcher's former colleague	Read through the survey but felt no changes were needed
Person 3: Current day service worker	Completed the survey and provided verbal feedback
Person 4: Current day service worker	Completed the survey and provided verbal feedback

Feedback on the Pilot

We discussed the feedback as a group and made changes to the survey in the meeting. We added spaces for comments, as suggested. Another piece of feedback was that some of the points listed on the likert scale (which runs from strongly agree to strongly disagree) could instead have a simpler yes or no response. We discussed this as a group and felt that we preferred the likert scale as it gave participants a wider range of responses to select from. Therefore, we made no changes to the survey based on this feedback. One person who piloted the survey felt the survey was too long, possibly because they were completing it on a mobile phone with a small screen. The initiating researcher's former colleague had completed the survey on a laptop and reported that it did not take a long time to complete. The group felt that they did not want to remove any questions but understood that this might mean participants skip questions or finish the survey before they had reached the final question. There was a query about the statement "family carers should be considered expert." The term "expert" was not clear, so the research group discussed how to make it clearer. The group decided to change the wording to "family carers should be considered to have expert knowledge in the person they

care for" to highlight that their expertise is in the person they care for rather than issues around caring more widely. After reviewing the feedback from the people who piloted both surveys, I made changes and emailed links to the surveys to the rest of the group. All three members of the group emailed back to say they were happy with the changes that had been made and did not wish to make any further changes.

Piloting the survey was very useful as it highlighted which areas of the survey were difficult to understand. It also demonstrated that some of the group understood the questions differently to others. It gave the group an opportunity to discuss these and make sure all members were happy with the content of the survey and what was being asked of participants. One of the Day Service Workers who piloted the survey commented that carers needed to be "educated" around service provision. This annoyed the carers as they did not feel it was their responsibility to seek education about services. Their response to this answer highlighted that some responses may be difficult for the carers to read. They may feel offended by them. It was a timely reminder that I needed to be sensitive to this and how I shared the responses with the research group. A table showing the changes we made to the survey following the group discussions and pilot is shown in Appendix H.

7.4   Recruitment and Selection

Once we had agreed the final version (see Appendix I), we shared the survey with organisations who either worked with carers or people with learning disabilities via email link or uploaded to forums. The group suggested contacts and organisations I could approach both at the meeting and in between meetings via email. I made contact with all of the suggestions; having a named individual to email lead to more responses than general organisation-level emails. The contacts of the co-researchers meant that I could approach individuals directly. The co researchers would also follow up in person with people they met, for example at the family carers' meetings at Mencap. As well as asking organisations to share the survey link I asked if they would prefer paper copies of the survey or if they would like the survey to be translated. None of the services took up either offer. The table in Appendix J shows the organisations I contacted to share the Family Carers Survey. I emailed each organisation a short description of the study and some text they could copy and paste into an email to colleagues or carers they worked with. I also sent a second email to ask services to complete the Service Provider Survey. I sent two separate emails to avoid confusion and ensure it was clear which survey link related to which survey. I attached

information sheets to each email. Appendix K shows the service providers contacted to share the Service Provider Survey.

After the closing date there were no responses from the local City Council. We were unsure if the survey links had been sent to the local City Council staff so they were approached a second time to try and increase response rates from the local area. I received no response from these emails so Dave contacted the service providers. The day he emailed them they responded to me and Dave to say they would be sharing the survey. This resulted in a further nine responses to the Service Provider Survey. We tended to get no response when I emailed a generic address rather than approaching a named person.

7.4.1   Inclusion and Exclusion Criteria

As the group had previously expressed that the survey should be for carers of people with learning disabilities, rather than carers more generally, we included a screening question at the start of each survey. As some of the organisations we approached were for carers generally, rather than specifically for carers of people with learning disabilities, we could not be sure that they were only being shared with carers of people with learning disabilities. Therefore, these questions enabled us to check who the responses were coming from. There were no other exclusion criteria.

7.5   Analysis

The closing date of the survey was 31st December 2016. By this date we had received:

- 151 carers survey responses
- 51 Service Provider Survey responses.

It is difficult to calculate the response rate because we relied on people sharing the survey on our behalf, therefore we do not know exactly how many were distributed. We also used online forums to share the survey so do not know how many people viewed and access it from there. In the Ethics Application I submitted I specified that we aimed to get 100 responses from carers and 50 from service providers so we exceeded our original target.

7.5.1   Quantitative Analysis

The group were invited to participate in all aspects of the analysis. Many of the questions which required a tick box response yielded quantitative data. This data was analysed using descriptive and statistical analysis. This was completed using statistical analysis software SPSS 23. None of

the group chose to participate in the analysis of the quantitative data. As the group had not completed this type of analysis before they may not have felt confident to participate in this analysis. We decided that I would complete the analysis of the quantitative data and bring it back to the group for discussion. From here we would decide what, if any, further analysis still needed to be done. Due to the group's lack of experience in statistical analysis I took the lead in suggesting what type of analysis could be completed. Initial descriptive analysis of the data was completed; the data was then saved as graphs and shared with the group. Statistical analysis using parametric tests such as ANOVA's and T Tests were conducted to compare the responses from carers of adults and carers of children and carers from the local area and carers from other parts of the country.

7.5.2   Qualitative Analysis

There were five questions in the survey that produced qualitative responses

1) Please think about the last interaction you had with services (this could be any of the services you or your family use). The interaction could be by email, telephone or face to face. Use the box below to complete the following sentence. My last interaction with services left me feeling.....

2) In what ways do support services make your life easier?

3) In what ways do support services make your life more difficult?

4) In what ways could support services be improved?

5) Is there anything else you would like to tell us?

The responses to these questions were co-analysed by the group using thematic analysis described in Chapter 4. Due to the collaborative nature of this study the priority was to select an accessible method of analysis that could be used by people who were not familiar with research and could be conducted as a group therefore thematic analysis was the most appropriate and well suited to these aims (Braun & Clarke, 2006). I printed out and cut up the qualitative responses. This enabled us to read and reread the responses. We sat round a table so we could move the responses around and see which responses were similar to each other. I coded the responses as we read them (see Appendix L for lists of codes). We then grouped the questions in to themes on an A1 piece of paper and labelled them. I photographed these as a record of our discussions. We spent six meetings conducting qualitative analysis. To support the group to familiarise themselves with thematic analysis we started by coding responses from one question at a time and we grouped the responses under simple headings such as 'positive' or 'negative'.
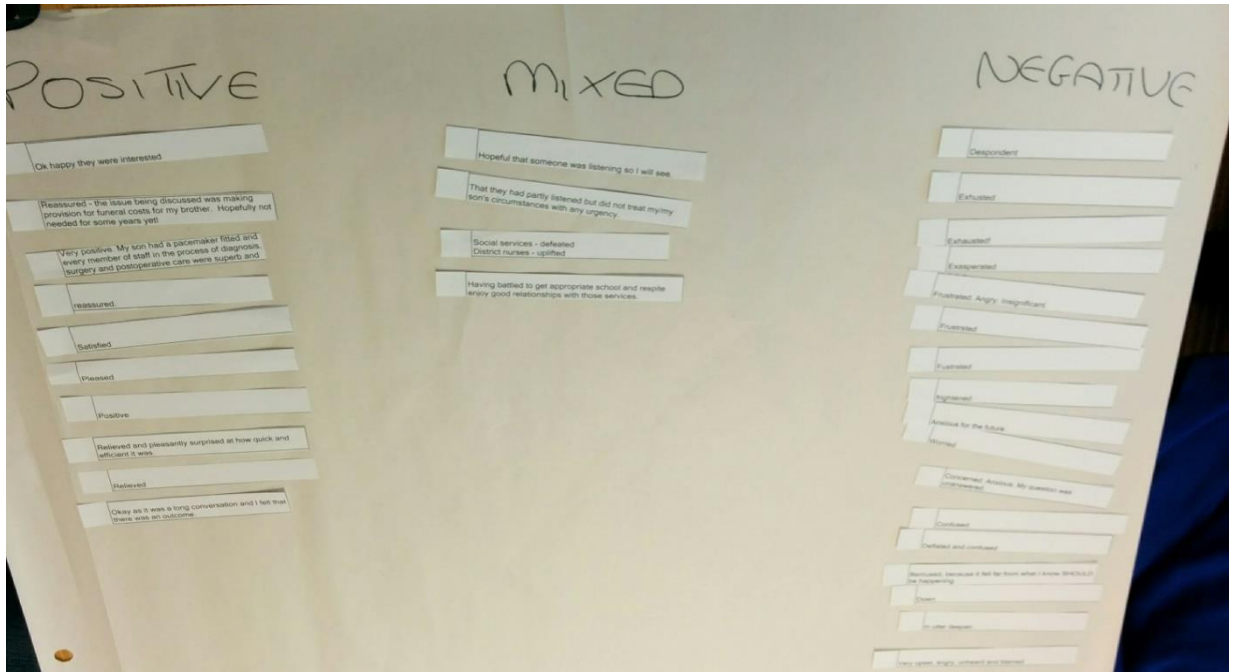
Figure 3 Thematic analysis of survey data September 2016
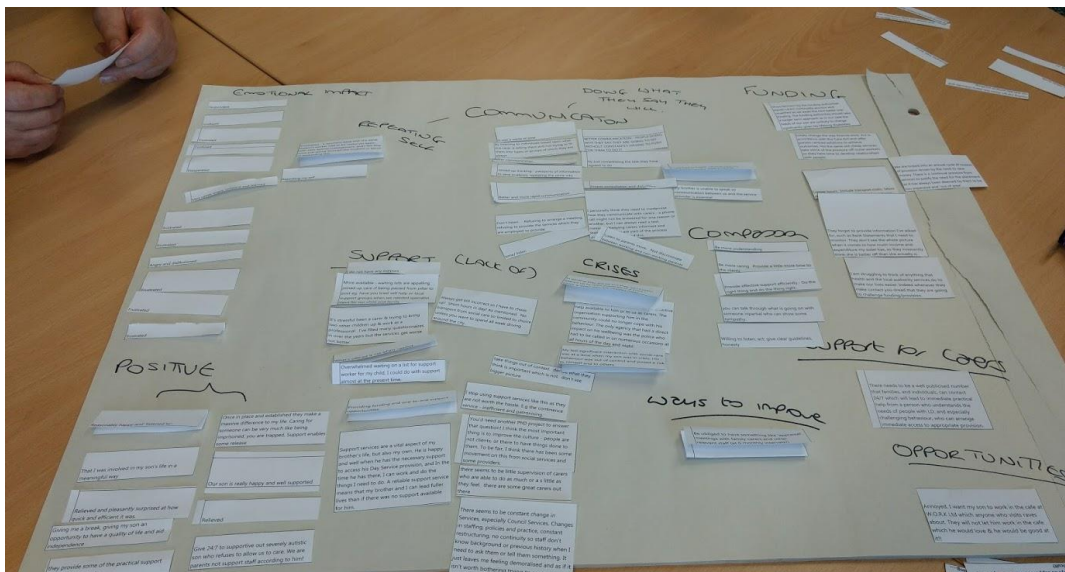
Figure 4 Thematic analysis of survey data March 2017

We then went on to look at the responses in more detail and discuss why some responses were negative and why some were positive. We also decided that the responses from the different questions fit into similar themes and could be analysed as an entire data set.

Some initial codes were not included in the final themes as only individual participants raised them. For example, one participant referred to a behaviour approach (Positive Behaviour Support) they wanted to support their son to use. Other participants however did describe how services were not person centrered, so this example was grouped under that theme. Another participant felt that media portrayals of people of benefits meant that people with disabilities

were negatively perceived. However, portrayal in the media was not referred to by anyone else. By our final analysis session, we found that the majority of the responses could be grouped under themes we had identified at previous meetings. This showed we had reached data saturation when further coding is no longer possible (Fusch & Ness, 2015). After the six meetings, I drafted three key themes and took them back to the group. The group discussed these and changed some of the wording.

Braun and Clarkes' six stages of thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2013) worked particularly well in group sessions over a series of meetings. Having several meetings enabled the group to review and check the themes while the group members became more familiar with the task. By reassigning the themes over several meetings we could ensure that we were analysing the data rather than simply describing it. Our analysis was methodical and considered all of the data rather than just those anecdotes that chimed with the experiences of the group (Braun & Clarke, 2006). This was a risk as some of the responses from carers described very positive relationships with service providers. Although this did not match the experiences of the group these responses still had to be coded and included. By working through each response in turn it ensured that we did not just select the responses that matched the groups' experiences but considered other viewpoints as well. Co-analysing the qualitative data together resulted in interesting group discussions. It also highlighted the similarity between the discussion we had in Phase 1 and the survey responses. Several times members of the group joked that they could have completed the survey with the same responses.

By taking it in turns to read out the responses it encouraged everyone to join in with the discussion and be engaged in the analysis. However, the group members did respond to the comments in different ways. Dave tended to respond to each comment in relation to his own experiences rather than view the responses as part of a wider data set. The group members continued to use the meetings to share their own personal experiences and I considered that this was because they viewed the research group as a supportive environment to share these experiences. Sharing information in this way was more familiar to them than conducting analysis. I was mindful of the need to complete the analysis but did not want to make the members of the group feel that they were not being listened to or that their own experiences had become unimportant:

> Maybe he (*Dave*) just wants to tell the story; maybe he still thinks that that is what I'm looking for I'm not sure. Its fine I just hope he still feels like acknowledged (field notes dated 16th January 2017).

This shift from unstructured group discussions to having tasks to complete is something I considered several times in my field notes. Particularly in relation to Dave; Sharon and Jenny found it easier to move away from discussions about their own experiences to considering and analysing the responses. I worried that this shift may result in Dave becoming disengaged:

> This felt like quite a practical meeting. It did not include as much of the discussion is previous meetings. I wonder if the parents miss this slightly …We did take the time to have these discussions as they are still important for the bonding of the group but it does make me think about what will happen when the group no longer meets to have the space to talk (field notes dated 17th May 2016).

The group did not have the same reservations about conducting this analysis as they did the quantitative analysis. The qualitative analysis was conducted via group discussion which was similar to our Phase 1 meetings. However, the quantitative analysis was less familiar to them. On reflection I could have done more to encourage their participation in this. The desire to complete the analysis in a timely manner and agree the next stages of the study influenced my decision not to put as much effort into encouraging the co-researchers to participate in the quantitative analysis.

7.6 Co-Researchers Views on Designing a Research Study

The meetings in Phase 2 were more practical than the first phase. For example, working on a presentation or developing survey questions. For me this felt easier as they had a clearer remit but I was concerned the group members would feel they were missing the type of discussions we had in earlier meetings:

> This felt like quite a practical meeting. It did not include as much of the discussion is previous meetings. I wonder if the parents miss this slightly as Dave was very keen to discuss the issues that he was having at home. We did take the time to have these discussions as they are still important for the bonding of the group but it does make me think about what will happen when the group no longer meets (field notes 17th May 2016).

However, co-researchers' articulated their enjoyment at being involved in developing a research study. Jenny expressed how much she enjoyed developing the survey, having completed so many herself, and Sharon messaged me via SMS to state how much she had enjoyed a meeting where we began to co-analyse the survey data "I really enjoyed it as it felt so productive" (SMS from Sharon received 19th September 2016). Although I was concerned, the group may miss the discussions they did seem to be enjoying the opportunity to develop skills in research methods and analysis.

7.7 Summary

The process of developing and analysing the survey as a group had many benefits. The co-researchers' own experience of completing surveys meant that they were able to suggest ways in which they could be made more accessible to other carers, for example making it clear they could complete the survey more than once, defining terms like "services" and using a frequency likert scale. My own experience of analysis meant that I could suggest ways in which the data could be analysed which influenced the questions we asked for example asking the participant to share their postcode so we could compare the responses from those based in the local area and those based elsewhere. Using the co-researchers' own contacts, for example services they or the people they cared used, meant that we could direct our emails to individuals and therefore we were more likely to get a response. When we approached organisations using their 'general enquiries' email address we got less responses. In some instances, the co-researchers followed up with organisations, such as the City Council and got a response where my original email had not. Therefore, I feel that designing and sharing surveys collaboratively increased the response rate, if the co-researchers had not been involved in the study there may have been less responses.

My field notes show the research process had to be more guided by me than I originally thought. I had deliberately held back from being too directive but over time it because clear that the group needed me to take on this role. As the study progressed, I became more comfortable with the fact that we all brought different experiences and expertise to the study and my experience of delivering research meant that I could help shape the study.

Chapter 8
Phase 2 Results: A Collaborative Research Study

8.1 Introduction

In this chapter I will explore the results from the two surveys developed in the second phase research study. First the family carer survey, followed by the service provider survey. I will compare the two sets of results to highlight the differences between them.

8.2 Family Carer Survey

8.2.1 Participants

We received survey responses from 151 participants. However, 24 of the 151 participants only completed the first page of the survey. This could have been because they did not have time to complete the survey passed this point. The survey was shared with organisations that supported carers, not just carers of people with learning disabilities, and so potential participants may have started the survey and realised at this point that the survey was specifically for carers of people with learning disabilities and therefore not completed it any further. Eleven surveys were completed by people who were not carers of people with learning disabilities, so their responses were not included in the analysis. A total of 116 responses are included in the analysis. The final four questions in the survey asked participants for demographic information about themselves. Reponses to each question are presented in Tables six to nine.

Participants' Age

Eighty-three participants answered this question; this could be because this question was on the final page and not all participants completed all pages. None of the participants were under 18 years old; one (1.2%) was aged 19 to 24 years old. Three participants (3.6%) were aged between 25 and 34 years. Eleven participants (13.3%) were 35 to 44 years and 26 (31.3%) were 45 to 54 years old. 35% of the participants (n=29) were aged 55 to 64 years, 10 (12%) were 65 to 74 years and another three (3.6%) were aged 75 to 85 years old. No one aged over 85 completed the survey. Over half (66%) were in the 45 to 64 age range.

Table 6 Family Carer Survey Participant Age

Question 18: How old are you? (n=83)		
Under 18	0	0%
19-24 years	1	1.2%
25-34 years	3	3.6%
35-44 years	11	13.3%
45-54 years	26	31.3%
55-64 years	29	34.9%
65-74 years	10	12%
75-85 years	3	3.6%
Over 85	0	0%
Total	**83**	**100%**

Question 19: What is your gender?

Only 81 participants answered this question (again this may be because it was on the final page of the survey). The majority of the participants (n=69) were female. Eleven (13.6%) were male and one preferred not to state their gender (1.2%)

Table 7 Family Carer Survey Participant Gender

Question 19: What is your gender? (n=81)		
Female	69	85.2%
Male	11	13.6%
Rather not say	1	1.2%
Total	**81**	**100%**

Question 20: Please describe your ethnicity

Eighty-three participants completed this question and the majority, 69 (83.1%), described their ethnicity as White English/Scottish/Welsh/Northern Irish/UK. Three (3.6%) described their ethnicity as Asian/Asian British-Pakistani and three (3.6%) as White Irish. Two (2.4%) described their ethnicity as Black/Black British-Caribbean, two (2.4%) as Mixed/multiple ethnic groups-White and Black Caribbean and two (2.4%) preferred to not disclose their ethnicity. One (1.2%) participant described their ethnicity as 'any other Asian background' and one (1.2%) as White Gypsy traveller.

Table 8 Family Carer Survey Participant Ethnicity

Question 20: Please describe your ethnicity (n=83)		
White-English/Scottish/Welsh/Northern Irish/UK	69	83.1%
Asian/Asian British-Pakistani	3	3.6%
Any other Asian background	1	1.2%
White gypsy traveller	1	1.2%
White Irish	3	3.3%
Black/Black British-Caribbean	2	2.4%
Mixed/multiple ethnic groups-White and Black Caribbean	2	2.4%
Rather not say	2	2.4%
Total	**83**	**100%**

Question 21: Please enter the first part of your postcode

Participants were asked to state the first part of their postcode. Eighty-three participants completed this question, of those 28 (33.7%) lived in the city where the research was conducted and 55 (66.3%) lived elsewhere in the country. Nobody who completed the survey lived outside of the United Kingdom.

Table 9 Family Carer Survey Participant Postcode

Question 21: Please enter the first part of your postcode (n=83)		
City where the research was conducted	28	33.7%
Other	55	66.3%
Total	**83**	**100%**

8.2.2   Responses relating to the person being cared for

Question 3: How old is the person you care for?

One hundred and sixteen participants answered this question. Forty-six (38.8%) cared for a person aged under 18 years old. In the analyses, we have classed this group as caring for a child and everyone else (61.2%) as caring for an adult. The largest group cared for an adult aged 25-49 years (n=39; 33.6%). Twenty-four (21%) participants cared for a person aged 18 to 24 years old and 7 (6%) cared for someone aged 50 and over.

Table 10 How old is the person you care for?

Question 3: How old is the person you care for? (n=116)		
Under 18	46	39.7%
18-24 years	24	20.7%
25-49 years	39	33.6%
50 and over	7	6%
Total	**116**	**100%**
Number caring for a child (under 18)	46	38.8%
Number caring for an adult (over 18)	70	61.2%
Total	**166**	**100%**

Question 4: What kind of support does the person you care for need? Please tick all that apply

One hundred and sixteen participants selected at least one option for this question. The majority (n=76; 65.5%) selected more than seven options. Almost everyone who answered this question stated the person they cared for needed support to go out (n=110; 95%), support to keep safe (n=109; 94%) and emotional support (n=108; 93%). One hundred and six participants said the person needed support around the home (91%), 100 participants (86%) stated the person they cared for needed support to coordinate services, 99 (85%) reported the person needed medical support and 91 (78%) said the person needed personal care support. Seventy seven percent of participants (n=89) selected the option that the person needed financial support and 67% (n=78) selected the option "support with eating and drinking".

Only one quarter (n=29) said the person they cared for needed support to move around such as using a wheelchair or hoist. Most of the people who selected this option also selected at least eight of the other options (n=26) suggesting they cared for people with complex needs and possibly PMLD.

Table 11 What kind of support does the person you care for need?

Question 4: What kind of support does the person you care for need? Please tick all that apply (n=116)		
Personal care support	91	78%
Support around the home	106	91%
Medical support	99	85%
Support to go out	110	95%
Support to keep safe	109	94%
Emotional support	108	93%
Support to coordinate services	100	86%
Financial support	89	77%
Support with eating and drinking	78	67%
Support to move around	29	25%
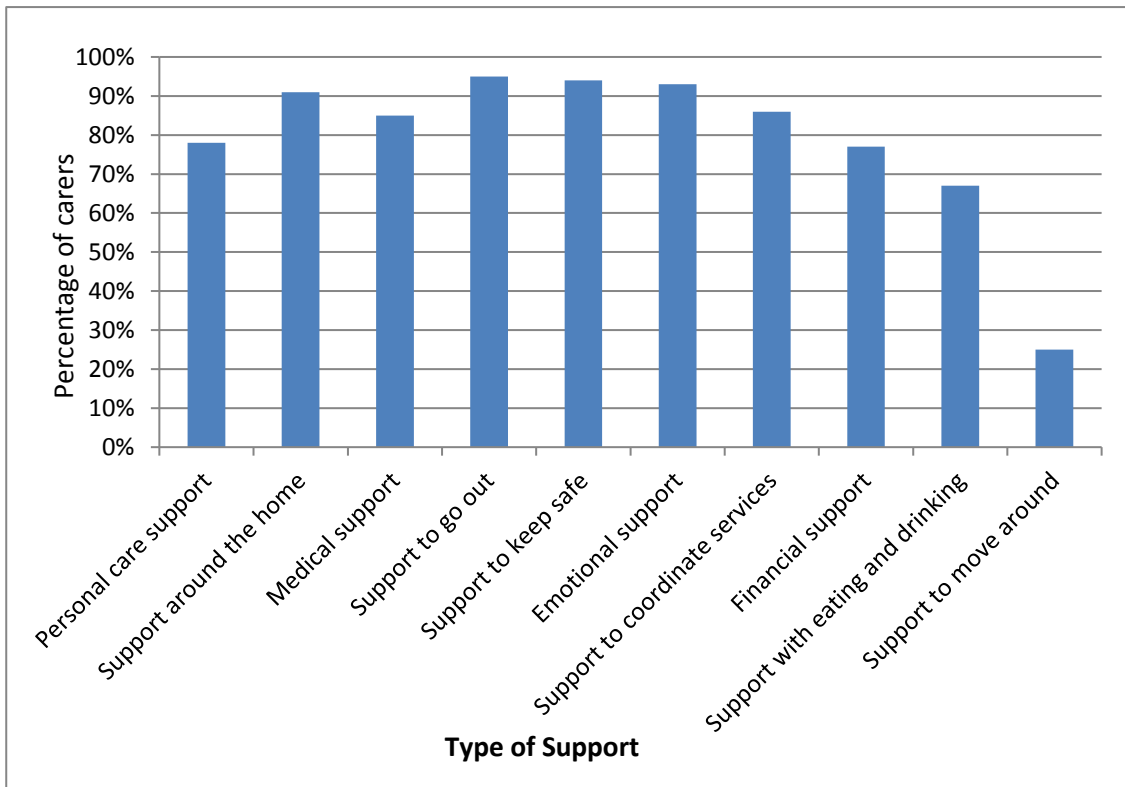
Figure 5 Showing percentage of carers who selected different types of support

Question 5: Does the person you care for live with you?

One hundred and fifteen participants answered this question, most of them (65%; n=75) lived with the person they cared for and 35% (n=40) did not.

Table 12 Does the person you care for live with you?

Question 5: Does the person you care for live with you? (n=115)		
Yes	75	65%
No	40	35%
Total	**115**	**100%**

Question 6: What is your relationship with the person you care for?

The majority of the 116 participants who responded to this question (n =101; 87%) were parents of the person they cared for. The next largest group (n=8; 6%) were siblings, three (3%) were grandparents and two (2%) were friends. Two (2%) selected "other" but did not state their relationship.

124

Table 13 What is your relationship with the person you care for?

Question 6: What is your relationship with the person you care for? (n=116)		
Parent	101	87%
Sibling	8	6%
Grandparent	3	3%
Friend	2	2%
Other	2	2%
Total	**116**	**100%**

Question 7: Does the person you care for use services to support their needs?

Three quarters of the 113 participants who responded to this question (N=85) said that the person they cared for used services whereas 28 (25%) said they did not.

Table 14 Does the person you care for use services to support their needs?

Question 7: Does the person you care for use services to support their needs? (n=113)		
Yes	85	75%
No	28	25%
Total	**113**	**100%**

Question 9: What funding does the person you care for receive? Please tick all that apply

One hundred and fourteen participants selected at least one option for this question. They were able to select all of the options that applied to them. Most of the group (n=69; 60.5%) said the person they cared for was in receipt of local authority funding, 28 (25%) selected health funding, and 19 (17%) selected education funding. Sixteen participants (14%) said the person they cared for received no funding at all and two (2%) would rather not say. Some of the participants who selected no funding were carers for children, so their child will be funded to attend education but because this money does not come to them directly they may not have factored this in their response. Twelve selected "other" and half of these (n=6) specified that the person they cared for received Disability Living Allowance (DLA) which is a non-means tested and non-contributory benefit. This benefit is being phased out and replaced with the Personal Independence Payment (PIP).

Table 15 What funding does the person you care for receive?

Question 9: What funding does the person you care for receive? Please tick all that apply (n=114)		
Local Authority	69	60.5%
Health	28	25%
Education	19	17%
No funding received	16	14%
Rather not say	2	2%
Other	12	10.5%
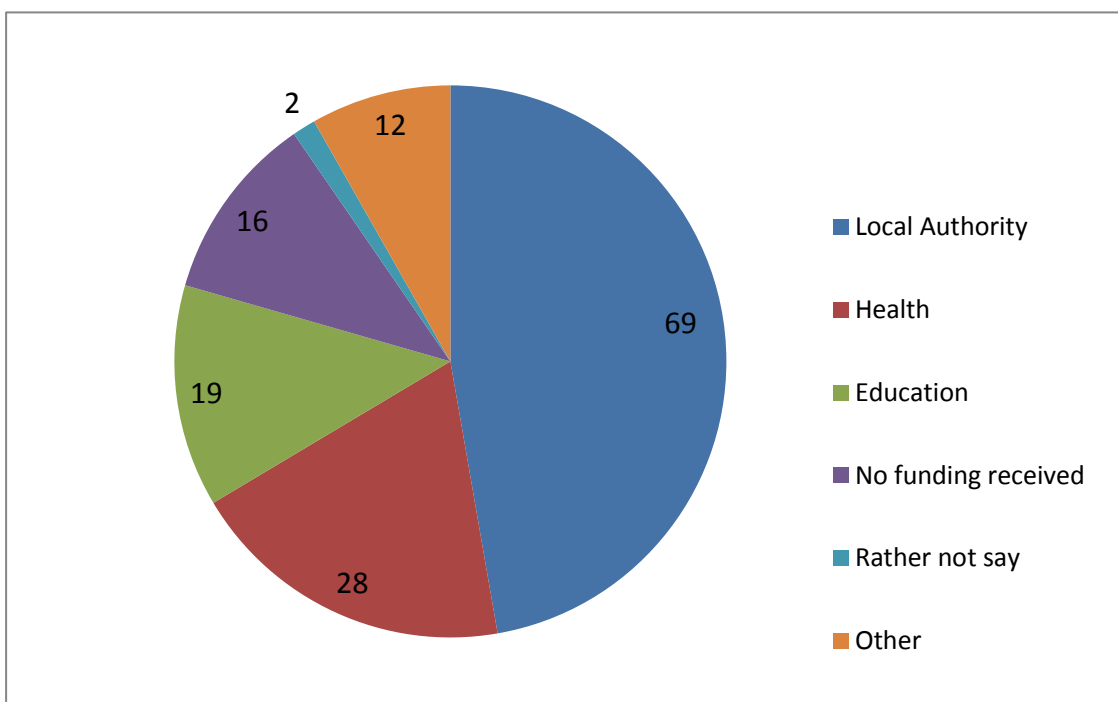
Figure 6 Type of funding the person receives

Question 22: Would you like to hear more about the study?

Participants were asked if they would like to hear more about the study so they were asked to complete their contact details. Eighty-three participants responded to this question, the majority (N = 60, 72%) indicated they would like to hear more about the study and these people completed their contact details. The participants who selected yes to this question were sent a summary of the research findings. Twenty-three selected (28%) no in response to this question.

Table 16 Would you like to hear more about the study?

Would you like to hear more about the study? (n=83)		
Yes	60	72%
No	23	28%
Total	83	100%

8.2.3 Family Carer: Likert Scale results

Family carers were asked to reflect on three different types of services and rate their experience of these services on a scale of 1 (Never) to 5 (Always). If they or the person they cared for did not use the type of service the participant was asked to leave the question out. There was also an option for "not applicable". The three types of service defined in the survey were:

1) Local Authority for example social services, housing and finance
2) Health Service for example General Practitioners (GPs), respite services and physiotherapists
3) Other service provider; these are any services not provided by the local authority or health for example support agencies, supported living, employment support and respite.

The number of participants who selected each option of the likert scale questions is presented in Tables 17, 18 and 19.

Question 10: Thinking about your interactions with local authority services (for example social services, housing, finance etc.). Please rate the following statements on a scale from 1 (never) to 5 (always). If you do not use these services, please move on to the next question.

Ninety participants responded to this question (see Table 17). Participants were instructed to miss the question if the person they cared for did not use local authority services. This may explain why this number is lower than for previous questions. It could also be because not everyone completed the whole survey.

Participants rated their knowledge as a carer was respected more often (average rating 2.7) than their needs as a carer (mean=2.5), suggesting they feel listened to but that there is not much action following the discussions. Carers felt that serious issues would be responded to (mean=3.3) more often than more minor issues (mean=2.8). In fact, the questions about raising serious issues received the highest average rating suggesting the local authority can respond in

a crisis situation. The lowest rating (1.9) was for the statement "I receive the information I need without asking".

Question 11: Thinking about your interactions with health services (for example GP's, respite, physios). Please rate the following statements on a scale from 1 (never) to 5 (always). If you do not use these services, please move on to the next question.

Eighty-nine participants (see Table 18) responded to this question (participants were instructed to miss out the question if the person they cared for did not use health services). The health services achieved the lowest average score for the statement, 'I receive the information I need without asking' (1.9 and 2.4 respectively). This statement was included following a group discussion in which Sharon expressed frustration with the fact she never receives a timetable of who will be supporting her son despite regularly asking and the fact the organisation will have to produce a timetable for their staff. She was clear that her family should be included in receiving the information that is being sent out without having to continually request it. The health services received the highest rating (mean 3.8) for the statement about raising a serious issue. The statement regarding more minor issues was rated lower (mean 3.5). Carers rated their knowledge was respected more often (mean 3.4) than their needs (mean 3.1). The rating is the second lowest rating health services receive.

Question 12: Thinking about your interactions with other service providers (these are any services not provided by the local authority or health, for example support agencies, supported living, employment support, respite etc.). Please rate the following statements on a scale from 1 (never) to 5 (always). If you do not use these services, please move on to the next question.

Seventy-six participants responded to this question (see Table 19). Participants were instructed to miss out the question if the person they cared for did not use other service provider's services so this may explain why this number is lower. The other services covered are statutory or health services whereas this category included charities or more specialist services. Therefore, we would not expect as many participants to be using these as the other types of services. 'I receive the information I need without asking' received the lowest rating (mean 3.0). The highest rating this group of services received was 3.7 for two statements; 1) when I email someone gets back to me and; 2) if I raise an important issue I know it will be taken seriously. The response regarding more minor issues was lower (mean 3.5). Respect for the needs of the carer was rated lower (mean 3.4) than respect for their knowledge (mean 3.5) but the difference was smaller than for health and local authority services.

128

Table 17 Question 10 Frequency Table

Question 10: Family carers responses to the question (n=90) Thinking about your interactions with local authority services (for example social services, housing, finance etc.). Please rate the following statements on a scale from 1 (never) to 5 (always).								
	5 Always	4 Often	3 Sometimes	2 Rarely	1 Never	Not Applicable	Total	Mean
When I call someone gets back to me	10	13	34	16	10	6	89	3
When I email someone gets back to me	10	17	37	14	4	6	88	3.2
If I raise an important issue it will be taken seriously	20	6	37	19	2	6	90	3.3
If I raise a minor issue it will be taken seriously	11	10	27	27	11	5	91	2.8
I am listened to	8	11	27	30	8	5	89	2.8
I receive the information I need when I ask	7	10	33	31	5	4	90	2.8
I receive the information I need without asking	0	4	18	31	34	3	90	1.9
My needs as a carer are respected	5	6	31	26	17	5	90	2.5
My knowledge as a carer is respected	7	16	22	29	12	3	89	2.7
I trust what the services are saying	5	8	28	30	15	4	90	2.5
I feel included in decisions made	15	20	28	17	6	4	90	3.2
If they say something will be done it will be done	5	17	20	33	11	4	90	2.7

Table 18 Question 11 Frequency Table

	5 Always	4 Often	3 Sometimes	2 Rarely	1 Never	Not Applicable	Total	Mean
Question 11: Family carers responses to the question (n=89) **Thinking about your interactions with health services (for example GP's, respite, physios). Please rate the following statements on a scale from 1 (never) to 5 (always).**								
When I call someone gets back to me	18	17	38	9	2	4	88	3.5
When I email someone gets back to me	6	12	29	8	3	30	88	3.2
If I raise an important issue it will be taken seriously	23	26	29	4	2	4	88	3.8
If I raise a minor issue it will be taken seriously	14	29	21	14	3	7	88	3.5
I am listened to	16	22	31	13	2	3	87	3.4
I receive the information I need when I ask	14	23	32	15	1	3	88	3.4
I receive the information I need without asking	4	8	24	26	22	3	87	2.4
My needs as a carer are respected	11	16	29	21	4	5	86	3.1
My knowledge as a carer is respected	16	24	26	15	5	3	89	3.4
I trust what the services are saying	13	23	33	12	4	3	88	3.3
I feel included in decisions made	22	22	30	8	4	3	89	3.6
If they say something will be done it will be done	12	21	35	14	3	4	88	3.3

Table 19 Question 12 Frequency Table

Question 12: Family carers responses to the question (n=76) Thinking about your interactions with other service providers (these are any services not provided by the local authority or health for example support agencies, supported living, employment support, respite etc.). Please rate the following statements on a scale from 1 (never) to 5 (always).								
	5 Always	4 Often	3 Sometimes	2 Rarely	1 Never	Not Applicable	Total	Mean
When I call someone gets back to me	16	19	15	6	4	16	76	3.6
When I email someone gets back to me	16	17	11	7	3	22	76	3.7
If I raise an important issue it will be taken seriously	20	16	15	6	3	16	76	3.7
If I raise a minor issue it will be taken seriously	14	19	13	8	6	16	76	3.5
I am listened to	18	17	14	6	5	15	75	3.6
I receive the information I need when I ask	16	14	17	8	4	15	74	3.5
I receive the information I need without asking	7	13	20	13	7	15	75	3.0
My needs as a carer are respected	13	13	16	9	5	18	74	3.4
My knowledge as a carer is respected	16	16	15	7	5	15	74	3.5
I trust what the services are saying	11	18	20	9	3	14	75	3.4
I feel included in decisions made	16	16	15	10	3	14	74	3.5
If they say something will be done it will be done	14	18	17	9	3	14	75	3.5

Overall the local authority ratings were lower than that of the other types of service provider. The health and other services were rated similarly. All types of services received the lowest rating for the statements 'I receive the information I need without asking', suggesting services are not proactively passing information to carers. In the cases of all three types of service carers felt their knowledge was respected more often than their needs. This could be that services are respectful to carers and acknowledge their expertise but do not provide the support carers require to meet their needs. Services were reported to respond more proactively when a major situation was reported rather than a more minor one. This could be because services are more designed to respond in a crisis, more minor issues may be missed or not given due attention.

8.2.4 Statistical Analysis

Statistical analysis was used to compare the ratings given to the different types of service provider. For each participant a total was calculated from the responses they gave to a particular type of service provider. A response of 'always' was given 5 points and 'never' given 1. For example if a participant rated the local authority as 'sometimes' for every response their total would be three points times twelve questions which would equal a total of thirty six. The means of these totals were then compared to see if there were any statistically significant differences between each type of service. Before comparing the means I checked for internal consistency between the ratings. A Cronbach's Alpha test was conducted on the responses for each type of provider, the nearer to 1 the score the higher the consistency between responses.

Table 20 Cronbach's Alpha Scores

Type of Provider	Cronbach's Alpha Score
Local Authority Services	0.948
Health Services	0.955
Other Service Providers	0.985

As the responses were consistent across each of the types of service it was possible to compare the total scores. To determine which test, parametric or non-parametric, to use checks for normality were conducted. Histograms (see Appendix M) and the Kolmogorov-Smirnov tests indicated the data was normally distributed and parametric tests could be conducted on the data (Davis, 2013). Kolmogorov-Smirnov is the appropriate test for normally for data sets of 50 or more cases and as the scores are not significant it suggests the data is normally distributed (Davis, 2013)

Table 21 Kolmogorov-Smirnov Test for Normalcy

Type of Provider	Kolmogorov-Smirnov
Local Authority Services	0.200
Health Services	0.200
Other Service Providers	0.200

As I was comparing more than two groups an ANOVA was the appropriate parametric test to conduct (Davis, 2013)The responses in the survey were not from independent groups of participants but the same group rating their experiences across different types of provider. Therefore, a repeated measures, or within-subjects, ANOVA with Bonferoni corrections was conducted. Prior to this the data was tested for sphericity which is another assumption the data must meet before conducting a repeated measures ANOVA (Davis, 2013). Mauchley's test for sphericity was not significant (0.113) and therefore the test was conducted. The test showed that the ratings for Local Authority services were significantly lower than health or other types of service provider. There was no significant difference in the ratings given for health and other service providers.

Table 22 Results from Repeated Measures ANOVA

Type of Provider	P Value
Local Authority total score compared to Health total score	0.000
Local Authority total score compared to Other Service Provider total score	0.000
Other Service Provider total score compared to Health total score	1.000
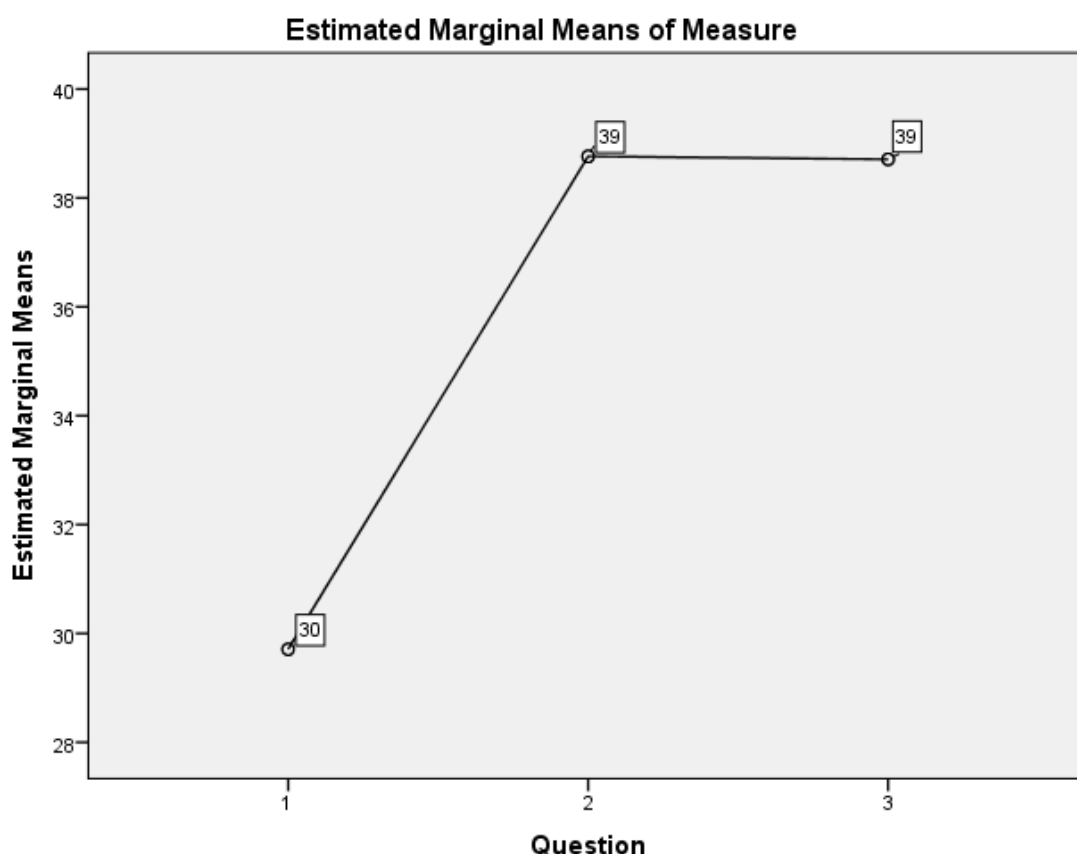
Figure 7 Graph to show results of the Repeated Measures ANOVA where 1 relates to responses regarding local authority providers, 2 is responses in relation to health services and 3 to other service providers

8.3 Understanding Responses from Different Groups of Participants

8.3.1 Comparing responses from carers of adults and carers of children

As a group, we were interested in comparing the responses from carers of adults (people aged eighteen and over) and carers with children (aged eighteen years and under). During our own group discussions, the carers described their caring responsibilities increasing as their children reached adulthood. Their children were no longer occupied during the daytime by school and

there was no one to coordinate the services. We anticipated that carers of adults would rate services lower than carers of children because they had been involved with services for longer and might be more frustrated with them. Previous studies show that caring for an adult with learning disabilities can be more physically challenging for carers than caring for a child (Hubert, 2010). The effects of caring can be more keenly felt by the carer the longer they have cared for (Carers UK, 2015b). Carers of adults may rely on services more and therefore feel more frustrated if they are not of good enough quality.

8.3.2 Method

We received 70 responses from carers of adults (61.2%) and 46 from carers of children (38.8%). The difference between the total scores given for the likert scale questions was compared for these two groups. The differences were tested for normal distribution using histograms and the Shapiro Wilks test. The p value using this test was above 0.05 which suggests the data is normally distributed.

Table 23 Shapiro Wilks test for data organised by age of person being cared for

Type of Provider	Shapiro Wilks Test: Age of person cared for
Local Authority Services over 18 years	0.196
Local Authority Services under 18 years	0.272
Health Services over 18 years	0.432
Health Services under 18 years	0.689
Other Service Providers over 18 years	0.350
Other Service Providers under 18 years	0.488

8.3.3 Analysis

Independent T Tests were used to analyse the responses between carers of adults (aged 18 years and over) and carers of children (aged under 18 years). These T Tests showed no significant difference between the two groups.

Table 24 Independent Sample T Tests: Comparing responses between carers of children and carers of adults

Type of Provider	P Value
Local Authority Services	0.969
Health Services	0.134
Other Service Providers	0.698

8.3.4 Results

The carers of adults and the carers of children both rated local authority services lower than the health services or other service providers. The ratings of health and other service providers were similar to each other across both groups. As a group we expected that carers of children would be more satisfied with services than carers of adults, but this was not the case and their responses were similar regardless of the age of the person they cared for. This could be because the participants who chose to complete the survey did so because they were dissatisfied with the services offered and therefore wanted to express their frustration. Carers of adults or children who were satisfied with services may have been less likely to complete the survey.

8.3.5 Comparing responses of carers from the city where the research was conducted and carers from other locations

We were interested in comparing the responses from carers who lived in the city where the research was conducted with carers who lived in other locations. This was of interest to the research group for two reasons; 1) to find out if the frustrations they experienced were specific to the local area and; 2) as we would be disseminating findings to service providers based in the local area we thought that information specifically related to this area would be of more interest to them.

8.3.6 Method

83 participants completed the question asking for the first part of their postcode. Of those 28 were from the local city and 55 were from other locations.

Table 25 Where participants live

Number of responses from carers living in the city where the research was conducted	Number of responses from carers living elsewhere
28 (33.7%)	55 (66.3%)

These responses were analysed for normality and the data was normally distributed.

Table 26 Shapiro Wilks test for data organised by location of participant

Type of Provider	Shapiro Wilks Test: Location of participant
Local Authority Services in the city	0.147
Local Authority Services outside the city	0.339
Health Services in the city	0.272
Health Services outside the city	0.424
Other Service Providers in the city	0.372
Other Service Providers outside the city	0.126

8.3.7 Analysis

Independent T Tests were conducted to compare the mean scores of those carers living in Sheffield and those living elsewhere.

8.3.8 Results

On average carers living in the city where the research was conducted rated the local authority services lower than those who lived elsewhere. However, independent T Tests showed that these differences were not significant. The average responses from carers living in the city and carers living elsewhere in the country were also not particularly different for health services and other service providers. For both groups the responses related to the local authority services were lower than those related to health services and other service providers.

Table 27 Independent Sample T Tests Comparing responses between carers living in the city where the research was conducted and carers living elsewhere

Type of Service	P Value
Local Authority Services	0.132
Health Services	0.411
Other Service Providers	0.943

8.3.9 Qualitative Analysis

Using Braun and Clarkes' (2006) model of Thematic Analysis as a group we familiarised ourselves with the data by reading and re-reading the written survey responses. We then created a long

list of codes and grouped these into themes. The themes were agreed after discussion with the group.

The three themes agreed from the data were:

1) The emotional impact on carers of interacting with service providers
2) Services being viewed by carers as not fit for purpose
3) Communication from service providers being poor

To enhance the rigour of these themes they, along with 20% (n=66) of the comments, were shared with a post-graduate researcher conducting qualitative research. She agreed that the themes were appropriate but that they did not cover those responses that were positive. She also suggested that allocation of resources was covered in one of the themes. Therefore, the themes were slightly altered. The final themes were:

1) The emotional burden on carers of interacting with service providers
2) Inadequate services and resources
3) Communication from service providers

8.3.10 Qualitative Results

The emotional burden on carers of interacting with service providers

Carers used a range of terms to describe how they felt after their last interaction with service providers. A term frequently used was "frustrated" (n=17) but participants also used strongly emotive terms to describe the impact these interactions had on the way they felt including "unheard and blamed", "exhausted, "in utter despair", and "deflated and confused".

One carer stated that service providers in their home left them feeling "un believed and un important. Get a nervous feeling before seeing them. Invasive being in my home". However, it was not only responses to the question "my last interaction with service providers left me feeling…" that showed this emotional impact. It also came out of the other questions. For example, 19 carers said that they could not identify any ways in which services made their life easier. One parent said "they make my life harder. My emotional wellbeing is suffering".

Carers identified ways in which interactions with service providers' increased their anxiety by making them feel patronised, demoralised, left out and undermined. For some carers' this attitude, and the emotional burden it placed upon them, made them less likely to use services or they had decided to stop using services completely. One carer described social care services as:

Intimidating, frightening, stressful and unhelpful. A service to be navigated, to be ready to fight to achieve my daughter's wellbeing and rights.

When asked how services could improve some carers described the need for an attitude shift by services which would result in carers being included, listened to and their concerns taken seriously. The ways in which services are organised and delivered also have an emotional impact on carers; "short-termism by the funding authorities leaves carers continually anxious and unsettled as we await the next battle over funding". Carers are constantly awaiting the next break down in support or need to fight for the rights of the person they care for. The majority of the carers in this study described service providers as an opponent rather than an ally. Their attitude and the lack of trust made interactions stressful experiences for carers.

Inadequate services and resources

Family carers often felt let down by services and that services were not fulfilling their function, which was to provide support for people with learning disabilities and their families. Carers identified some practical support services provided, which enabled the carer to do something other than caring such as going to work or enjoying their retirement. However, this was not always enough:

> **Question: In what ways do support services make your life easier?**
> Response: Can't think of anything! Apart from they are there! Otherwise my son would just be at home all day. Start 9:30am or 10am to 3pm! This is not a proper working day?

Seventy-seven carers identified ways in which services were not fit for purpose and made their life more difficult. We asked carers to identify how services could be improved and 79 carers made suggested improvements. Many of these suggestions focussed on making services more fit for purpose. Carers felt this would happen if there were increased resources including more support staff and social workers:

> More staff!!!!! All are over worked and are therefore off sick leaving very few to deal with too many.

> 11 month wait between referral to social services after my brother kicked off and hurt me and when I was finally seen.

Many carers expressed anxiety about funding cuts and a fear that this would mean a cut in the support available. Support was not viewed as being long term but liable to change and be reduced. One solution suggested was a single contact who could pull together various services as this often fell to carers:

There needs to be a well-publicised number that families, and individuals, can contact 24/7 which will lead to immediate practical help from a person who understands the needs of people with LD (learning disabilities) … who can arrange immediate access to appropriate provision.

Services were seen by carers as being unresponsive, only available in a crisis and not aware of current legislation and up to date information.

Communication from service providers

Much of the carer frustration was as a result of poor communication from service providers. This included not getting information needed; messages going un-returned and not being listened to. Service providers did not consider the impact on carers in their actions:

Not being alerted to things like last minute changes, or failures and oversights on the part of support services can have a knock-on effect that I believe is not often considered.

Carers stated they needed to constantly repeat themselves and describe the support the person they cared for needed. As a result of this poor communication carers were left feeling anxious. The carer did not receive the information they needed and the service provider did not collect or retain the correct information. This resulted in mistakes:

They forget to provide information I've asked for, such as Bank Statements that I need to monitor. They don't see the whole picture when it comes to how much income and expenditure my sister has, so they innocently think she is better off than she actually is.

The poor communication meant carers felt excluded from the discussions, they described having to fight for meetings, feeling like decisions had already been made and not receiving any meeting minutes:

Decisions would be made by the 'professionals' and had probably been made already, the meeting being an attempt to make it appear I was involved and consulted. There have been a few of such meetings but there have never been any minutes submitted so no-one is accountable for the decisions that result from them.

Other carers described meetings and reviews as "tick box exercises"; they did not consider themselves to be equal partners in the discussion but consulted so that services could demonstrate that they involved carers. However, some carers did describe examples of good communication, this included feeling listened to, receiving the information they needed and being kept informed by support staff. The poor communication described by carers left them feeling distrustful of service providers and not listened to. A significant minority of carers could not identify any ways in which services made their life easier.

8.4 Service Provider Survey

8.4.1 Participants

We received survey responses from 61 participants. However, ten (16%) did not complete further than the first page of the survey so their responses were not included in the analysis. One participant identified them self as a parent or carer so their responses have not been included in this analysis. Fifty responses are included in the analysis. Demographic information about the participants is presented in the tables below

Question 12: What is your gender?

Thirty-nine participants answered this question. The majority (n=32; 82%) were female, four participants (10%) were male and three (8%) preferred not to state their gender.

Table 28 Service Provider Survey Participant Gender

Question 12: What is your gender? (n=39)		
Female	32	82%
Male	4	10%
Rather not say	3	8%
Total	**39**	**100%**

Question 31: How old are you?

Thirty-nine participants responded to this question. The majority of participants (n=28; 72%) were aged 45 to 60 years old. Only one (3%) was 18-29 years old, 21% (n=8) were aged 30 to 44 years and 5% (n=2) were over 61 years.

Table 29 Service Provider Survey Participant Age

Question 13: How old are you? (n=39)		
18-29 years	1	3%
30-44 years	8	21%
45-60 years	28	72%
61 and over	2	4%
Total	**39**	**100%**

Question 14: Please describe your ethnicity

Thirty-nine participants responded to this question. The majority (N = 35; 90%) describe their ethnicity as white English/Scottish/Welsh/Northern Irish/UK, 1 (3%) as White-other and three (8%) preferred not to say.

Table 30 Service Provider Survey Participant Ethnicity

Please describe your ethnicity (n=39)		
White-English/Scottish/Welsh/Northern Irish/UK	35	90%
White other	1	3%
Rather not say	3	7%
Total	**39**	**100%**

Question 15: Please enter the first part of your postcode.

Thirty-five participants completed this question by entering the first part of their postcode. Using this we could work out which area of the country the participant lived. Most of the participants (n=25; 71%) lived in city where the research was being conducted and the rest (n=10; 29%) lived elsewhere in the county including London, Manchester, Merseyside and Guilford. None of the participants came from outside of the United Kingdom.

Table 31 Service Provider Survey Participant Postcode

Question 15: Please enter the first part of your postcode (n=35)		
City where the research was conducted	25	71%
Other	10	29%
Total	**35**	**100%**

8.4.2 Quantitative Results

Descriptive analysis was conducted on the responses from the Service Provider Survey. Table 32 shows an overview of who completed the survey. An incomplete survey response is classed as one where the participant has not completed further than the first page of survey. Percentages for each question are based on the number of participants who answered that question. The analysis was carried out on the responses from the 50 participants who completed the survey. One parent carer completed this survey. Their responses have not been included in the analysis.

Table 32 Service Provider Survey Number of Responses

Number of responses	
All	61
Complete responses	50

Question 3: What kind of service do you work for?

Fifty participants responded to this question. Fifteen (30%) participants worked for a charity/not-for-profit organisation. The rest of the responses are presented in Table 33. Thirteen (26%) worked for a local authority, 11 (22%) for a health service and 7 for another service provider (14%). Four (8%) participants selected the option 'other', these participants were asked to specify the kind of organisation they worked for the responses they gave were:

- Private
- Private residential
- Home care,
- LA trading company

Table 33 What kind of service do you work for?

Question 3: What kind of service do you work for? (n=50)		
Local authority	13	26%
Charity/not for profit	15	30%
Health	11	22%
Other service provider	7	14%
One to one worker	0	0
Other	4	8%
Total	**50**	**100%**

Question 4: How long have you worked with people with learning difficulties?

Fifty participants responded to this question, the largest group (N = 23; 46%) had worked with people with learning disabilities for over 20 years. Four participants (8%) had worked with people with learning disabilities for less than 1 year, seven (14%) for between 1 and 5 years and another seven (14%) selected 6 to 10 years. Nine participants (18%) had worked with people with learning disabilities for between 11 and 20 years.

Table 34 How long have you worked with people with learning difficulties?

Question 4: How long have you worked with people with learning disabilities? (n=50)		
Less than 1 year	4	8%
1 to 5 years	7	14%
6 to 10 years	7	14%
11 to 20 years	9	18%
Over 20 years	23	46%
Total	**50**	**100%**
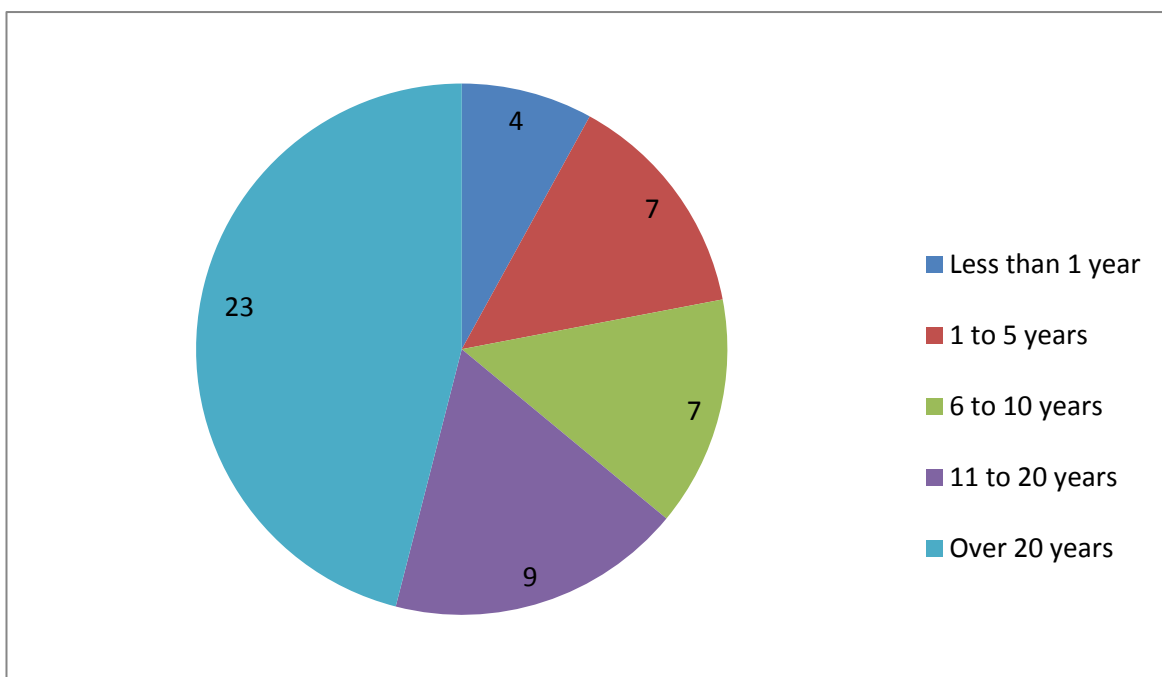
Figure 8 How long have you worked with people with learning disabilities?

Question 16: Would you like to hear more about the study?

We asked participants if they would like to hear more about the study and receive a summary of the findings. Thirty-five participants answered the question; 24 (69%) responded that they would like to hear more about the study and 11 (31%) that they would not.

Table 35 Would you like to hear more about the study?

Question 16: Would you like to hear more about the study? (n=35)		
Yes	24	69%
No	11	31%
Total	**35**	**100%**

8.4.3   Service Providers Survey: Likert Scale Results

Question 6: Please rate how much you agree with the following statements on a scale of 1 (strongly agree) to 5 (strongly disagree).

The number of participants who selected each option of the likert scale questions is presented in Table 36. Forty participants responded to this question. The majority of them agreed or strongly agreed with the statements (rating them a 4 or 5). All of the participants agreed with the statement 'the concerns of family carers should always be taken seriously' (mean=4.9) and 97% agreed with the statement 'family carers should always be included in meetings about the person they care for' (mean 4.7). Four participants disagreed with the statement 'family carers are not always the expert' and a further eight neither agreed nor disagreed. This statement received the lowest average rating (mean 3.5) along with the statement 'family carers are not always the best people to make decisions'. This is to be expected as these statements are deliberately more negatively worded to try and discourage participants from selecting the highest rating for all the statements. Apart from these statements, which we expected to receive lower ratings, the two questions that received the lowest scores (both with a rating of 4.2) were 'I have a good relationship with family carers' and 'my employer makes it clear how to work with family carers'. Service providers may work with a range of carers which is why participants may have rated this slightly lower. The differing needs and demands of the carers will mean the participant has a better relationship with some than others. Also some senior staff responded to this survey, they may not interact with carers in their day to day work. Participants did not agree as strongly that their organisation made it clear how to support carers. Some clarity about this may make relationships between carers and service providers more successful.

Table 36 Question 6 Frequency Table

Question 6: Please rate how much you agree with the following statements on a scale of 1 (strongly agree) to 5 (strongly disagree) (n=40)	1 Strongly Agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly Disagree	Not Applicable	Total	Mean
Family carers should be considered to have expert knowledge in the person	21	15	2	1	0	0	39	4.4
Family carers should always be included in meetings about the person	30	8	1	0	0	0	39	4.7
The concerns of family carers should always be taken seriously	33	5	0	0	0	0	38	4.9
My employer makes it clear how we should work with family carers	18	12	6	3	0	0	39	4.2
If a family carer leaves a message my priority to get back to them	23	13	1	0	0	2	39	4.4
I have a good relationship with the family carers I work with	18	18	1	0	0	2	39	4.2
Family carers are not always the experts	2	20	11	5	0	0	38	3.5
I make it a priority to ensure family carers receive the information they need	26	10	1	0	1	1	39	4.5
The organisation I work for values the knowledge of family carers	27	9	2	0	0	1	39	4.5
Family carers are not always the best people to make decisions	3	20	11	4	1	0	39	3.5
The organisation I work for respects family carers	29	8	1	1	0	1	40	4.6

8.4.4   Qualitative Results

The group co-analysed data from this survey using Braun and Clarkes' (2006) model of Thematic Analysis. The themes we identified were discussed with the group and it was agreed that these were an accurate reflection.

The three themes agreed from the data were

1) Carers needing to be more open and engaged with services
2) Carers understanding the limitations of services
3) Services need to improve their communication with carers

Carers being more open and engaged with services

Service providers were asked to identify ways in which carers could work more effectively with their organisation. Twenty-nine responded to this question although five answered that there was nothing family carers could do. Many of those that answered this question identified ways in which carers could be more engaged with services for example, attending meetings, making complaints to services and giving feedback. They felt that family carers should be willing to share information with services about the support they and the person they care for needs. Some participants described carers as "jaded" and "cynical" and that this was the reason they did not engage with services. They suggested that carers could help to train staff and make contact with services before meetings to inform them how best to communicate with the person they care for.

Understanding the limitations of services

Some of the service providers who completed the survey described carers as not being "realistic" about what services could offer. Carers expected them to have "magic wands" and they needed to understand that they did not. They described carers who wanted change to happen but did not understand the constraints and timescales of service providers:

> An understanding of the legal constraints and regulations by which providers must abide might help. Particularly where there may be barriers in terms of the support that can be provided or in the way something may have to be done.

Services need to improve their communication with carers

Participants were asked to identify ways in which their organization could work more effectively with family carers. Thirty-three responded to the question but eight participants felt there was nothing more their organisation could be doing. Twenty-five identified ways in which their

services could work more effectively and the majority (n= 18) of these related to better communication. This included keeping carers better informed, information sharing event, thinking of different ways of communicating (for example via Skype) and setting up peer support groups. One service provider identified that issues can go unresolved and that there should be a designated person to work with the family to resolve any issues. Another felt that there should be more opportunities for communication outside of office hours and that services should be more accessible to carers.

8.5   Comparing the survey results

The results from the family carer survey and the service provider survey often contradicted. For example, 36 (93%) service providers agreed with the statement "I make it a priority to ensure family carers receive the information they need" whereas many (n=132 across Questions 10, 11 and 12 of the family carer survey) carers said that they rarely or never got the information they needed without having to ask for it. Thirty-six (93%) service providers said that they would make it a priority to response to family carers if they left a message whereas 47 (19%) carers reported that they rarely or never received a response if they left a telephone message. The questions we asked service providers and family carers were slightly different, so it is difficult to compare them exactly however Figure 9 shows the average score of service providers and family carers to questions that were similar or related to the same topics (for example returning messages and sharing information). The service providers tended to agree or agree strongly with the statements whereas the family carers, on average, reported they only happened sometimes, or rarely.
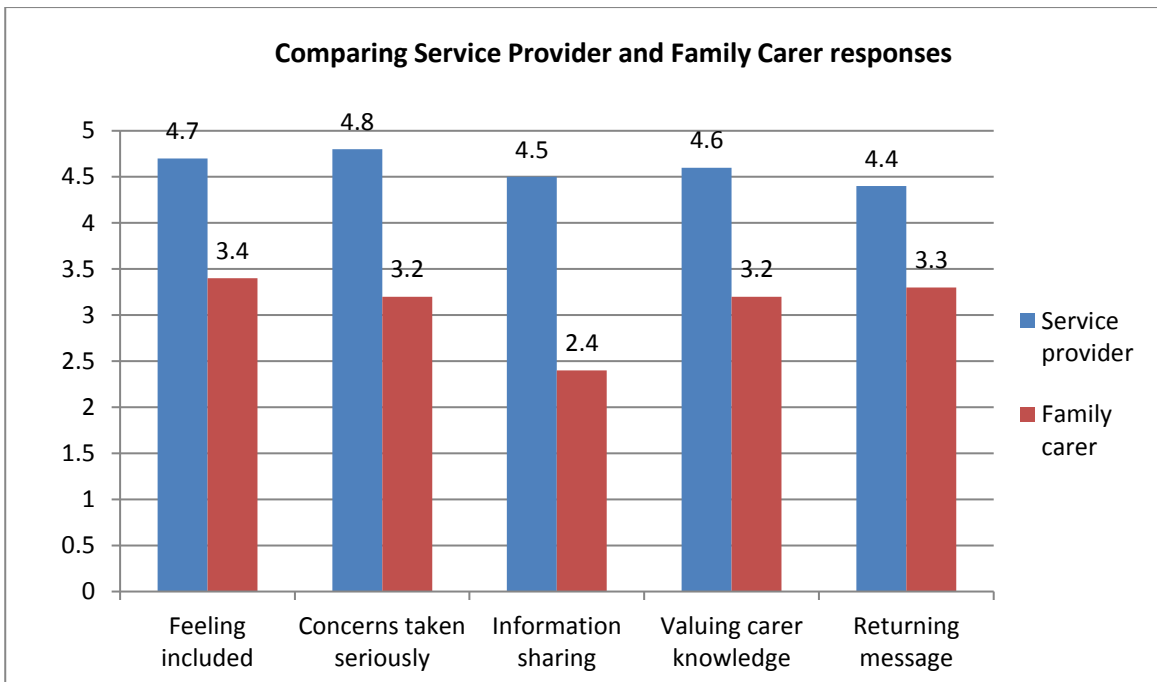
Figure 9 Comparing the responses of service providers and family carers

The results of the family carer survey show that carers rate local authority services lower than they rate health services or other service providers. However, we had very few responses from local authority services (n=13) which made it difficult to compare both sets of responses. For the carers in the research group they described the lack of response from the local City Council as a sign of their disengagement. It was only once one of the carers had made contact with senior management in the learning disability services that we received some responses from local City Council employees.

8.6 Summary of Findings

The aims of this phase of the study were twofold. Firstly, to use some of the themes identified from the first phase of the study to determine if the experiences of the research group were shared by carers more widely and secondly to test the feasibility of working with the group of family carers as co researchers to design and conduct a research study.

The findings from the family carer survey showed that the experiences of the group as discussed in Phase 1 were shared by other family carers. For example, carers reported that serious issues were responded to more often than minor ones and interactions with service providers could be negative and frustrating. Although some family carers in the survey expressed that they were happy with the services that they received, many expressed frustration, anger and despair about the quality of services they experienced. They described having to repeat themselves on

multiple occasions, feeling patronised or dismissed by services and not being able to access the services they needed at the time they required them. The responses to the likert scale questions showed the local authority services were rated significantly worse than other services by carers of adults, carers of children, carers living in the city where the research was conducted and carers living elsewhere in the country.

The responses from service providers showed a different picture. Service providers rated their relationships with family carers as good and their interactions as positive. Where they agreed that they prioritised communication with family carers the family carers did not report that this was the case.

The survey responses demonstrated a wide range of carer experience with some being satisfied with the services the person they care for used but many more being frustrated and dissatisfied. This can be seen in the literature about carers in which some studies demonstrate carers are happy with the amount of communication they receive from service providers (De Geeter et al, 2002) whereas others feel ignored by services (Mencap, 2001) and find formal service providers add to their stress (White and Hastings, 2004). Over half (66%) the carers who completed our survey were aged 45 years to 66 years, previous studies show that issues relating the caring such as mental and physical ill health can increase the longer the care cares for (Carers UK, 2012). This could explain why responses to our survey were mainly negative as the participants had been caring for many years and felt disillusioned about the quality of the support the person they cared for received. Beresford (1994) reported that carers find formal services stressful, as they were inflexible and associated with times of crisis. Our participants reported the same and those services did not work in a preventative way.

8.7 Co-researchers responses to the Survey Findings

Co-analysing the survey responses took several months. As the group only met monthly we would take time first to re-familiarise ourselves the analysis we already done. However, by taking our time to analyse the data it ensured that we all contributed to the analysis. The co-analysis of the data provided further interesting insights from the group. These insights were based on their own experiences and reflections. However, as in keeping with participatory action research (Reason and Bradbury, 2006), the co-researchers were not expected to set aside their own experiences for the analysis as their experiences added a deeper insight in to the findings.

The findings from the family carer survey showed that the experiences of the group as discussed in Phase 1 were shared by other family carers. For example, carers reported that serious issues

were responded to more often than minor ones. This reflected our group discussions when Jenny described how she felt confident that her sons would be supported in situations such as health appointments but less urgent, yet still important issues, such as needing a new phone or new shoes was overlooked and fell to her to sort out. Some of the written responses to the questions were very similar to statements the carers have made during Phase 1. Several times during our analysis the carers made jokes about whether they had actually completed the survey and forgotten about it because the responses they were reading were so similar to their own experiences.

As a group we discussed the differences between the carer and service provider responses. The group reflected that often they may not express the full extent of their frustration whilst they are interacting with service providers in an attempt to remain polite. We discussed that this could be underpinning the trend in our data. Family carers may not reveal the extent of their dissatisfaction to the service provider because they may be worried about making the situation worse for the person they care for or losing the support they receive. Whilst designing the Service Provider Survey we decided to include the question 'how could family carers work better with your organisation'. One of the reasons we included this was to ensure that the tone of the survey was not too negative towards service providers. However, the responses to this question caused mixed reactions from the group. Dave thought that it was positive that service providers were saying they wanted the family carers to be more proactive in making contact with them however; Jenny was annoyed by the responses that implied the family carers should be doing more, for example attending training or learning more about services.

Working with the carers during this phase added new insights to the data for example the reflection that service providers may not appreciate the depth of the carers dissatisfaction because the carers do not express it. These reflections were based on their own experiences which they drew on during the analysis process.

During the analysis phase of the study the group planned a dissemination event to share the findings and to explore, with both carers and service providers, how their experiences can be improved. Planning the event is outside the scope of this thesis so it is not discussed here but further information about the event is included in Appendix N. However, I will reflect upon some learning from the event in Chapters 9 and 10 as it was the culmination of our group work.

8.8 Limitations

The survey and Information Sheets are in English; therefore, they may not be accessible to people who are not English speaking. I approached organisations that support carers from Black and Minority Ethnic (BME) communalities and offered to translate the survey but only had a response from one of these organisations. Therefore, there was little diversity amongst the participants. The majority of the family carers who responded were female (n=69) and white British (n=69). This means that the results may not be applicable to male carers or those from BME communities. There were no participants aged 85 and over. Dave wondered if this was because we did not share any paper copies of the survey. He felt they may have been more likely to complete a paper based survey rather than an online one. The service provider survey was also mainly completed by females (n= 24) and people who described themselves as white British (n=25). We also did not get as many responses to the service provider survey as we got from the family carer survey this makes it difficult to make generalisations about service providers due to the low number of responses. The responses could be skewed by participants who have a particularly set of experiences. The service providers who completed the survey might be those who see the value of working closely with family carers and therefore do take the time to provide them with information or response to messages. Equally the family carers who have taken time to complete the survey may have had negative experiences of service providers and wanted to use the survey as an opportunity to share these experiences. The survey was not piloted on carers of children so it may not have felt as relevant or appropriate to this group of carers.

The data is also limited by the choice of questions and the focus on more adult services, for example there are no questions relating to education or children's services. Therefore participants may have skipped questions in an attempt to find ones that related more closely to their experience. In addition, the 'types of service' we defined were very broad. They did not differentiate size of service or location. We asked the participants to define where they lived but not where the services they referred to were based. They may have been referring to services in different location in the country to where they lived. These limit some of the interpretations we can make about the data.

We had a number of participants for both surveys who only completed the first page. This could be because it was not explicit that there were further pages to complete or that they were not clear, when starting the survey, who it was for. This is a learning point when designing surveys that the cover information needs to make it clear how long the survey is and who the intended audience is. I split the survey over several pages to try and make it look less crowded on the

screen, but this may not have been the best way of formatting the survey. I should perhaps have had all the questions on one page so that participants could clearly see how many more questions there were to complete. Nulty (2008) synthesised the literature around response rates for online surveys and found a range from 20% to 47% and often achieving a lower response rate than paper based surveys. Although I am not able to calculate an exact response rate as I relied on others to distribute the survey the responses exceeded the number identified in the Ethics application as being a sufficient response.

8.9   Benefits of Working with Co-researchers

Working with family cares as co-researchers had considerable benefits. The carers brought their own experience of completing surveys to the discussions so this enabled us to ensure the questions were easy to understand and did not use jargon or overly complex terms. They also made sure the questions we included were respectful and sensitive, for example not asking carers to label the severity of need of the person they care for. The co-researchers' experiences, for example caring for more than one person, also influenced how we structured the survey and the type of information we asked carers to provide. As well as their input in designing the survey the carers' own contacts and knowledge of service providers meant we could reach more potential participants. They suggested services we might approach, named contacts and followed up if we had no response from a particular provider. Being known to the services meant that we were more likely to have our survey shared. We utilised my co-researchers' knowledge of caring and completing surveys and my experience of survey design and analysis, which resulted in an accessible survey that provided the information we needed.

8.10 Summary

The results of the survey showed that interacting with service providers often had a significant emotional impact on carers with them describing relationships as frustrating and invasive. They could identify the many ways in which services were not fit for purpose and in some cases had stopped using them completely. Much of the frustration stemmed from poor communication such as not being listened to or receiving the information they need. Service providers responses differed from carers in that they felt they had good relationships with carers and did communicate well with them. Service providers reported that it was sometimes hard to engage with carers.

Chapter 9
Reflecting on the Research Together

9.1   Introduction

In this chapter I explore the reflections of my co-researchers on the process of conducting research together. These reflections were collected during group discussions and via an end of study survey. I will then reflect on the project from my perspective, drawing on audio recordings of my own reflections following each group meeting and from my research journal.

9.2   Co-Researchers' Reflections

The group reflected on the research process and their role in it throughout the study, in addition to three specific times when their reflections about the research process were discussed and recorded. These are; 1) prior to co-presenting at a conference *Challenges and Best Practice in Co-Production* in May 2016; 2) during a reflection session held at the university in August 2016 and; 3) in a survey sent to the group members after the final meeting in April 2018.

Phase 1: Understanding Carers Experiences

1) Recruit a research group consisting of family carers

2) Use group discussions to explore carers experiences and identify themes

Phase 2: Working Together: A Collaborative Study

1) Collaboratively conduct a research study using the themes from Phase 1. Design, share and analyse responses

2) Disseminate the findings and produce a set of resources

- May 2016: Reflections for Co-Production Conference presentation
- August 2016 : Reflection Session at the University of Sheffield

- April 2018: End of Study Survey

Figure 10 Group reflection sessions

9.2.1 Challenges and Best Practice in Co-Production Conference

In May 2016, Dave, Jenny and I presented at the *Challenges and Best Practice in Co-Production* conference held at The Workstation. I asked the group during the meeting in March 2016 if they would be interested in presenting at the conference with me and they said that they would be. I submitted an abstract which was successful and we were allotted 15 minutes to present. I suggested that the easiest way for us to develop a presentation would be for me to email the group three questions, they could send me their responses and I could pull these together in to a PowerPoint presentation. As it could be quite challenging to find dates we were all available to meet face to face this seemed to be the most efficient way of developing a presentation using email. The questions I sent to the group were:

1) What interested you in the research project?

2) How have you found the experience? (Please feel free to be honest here and list challenges as well as positives!)

3) What outcome would you like from the project (email sent by me 14th April 2016)

I also highlighted in this email that they were welcome to suggest their own questions for the presentation and this list was merely a suggestion "if you would like to adapt the questions or you would like to cover something else that is absolutely fine. This is your presentation as well; I just thought this would get us started" (email sent by me 14th April 2016).

The group members did not add any of their own questions and sent their responses to ones I asked via email. See Appendix O for the co-researchers' full responses. Once I had developed the presentation I shared it with the group for their feedback. None of the group suggested any changes however; in her response to the email about the presentation Sharon sent her apologies that she would not be able to attend the conference:

> This looks really good but I'm sorry to have to tell you I won't now be able to join you as well still be in London cat sitting. Please feel free to quote me, use my bullet points or any way it helps the presentation as I feel it is well worth celebrating (email received from Sharon 28th April 2016).

Jenny, Dave and I met on Tuesday 17th May 2016 to practise the presentation. I had copied their responses on to cards. Jenny asked if she would be able to add to her question responses and say how much she had enjoyed creating the survey. I reflected on this in my field notes:

I think that would be great it would be lovely if they do something other than just read off the card and also great that she spontaneously came up with that (field notes 17th May 2016).

We presented at the conference on Wednesday 18th May 2016, I introduced the study but most of the presentation was delivered by Dave and Jenny. We were the only group at this conference about co-production who co-presented. The rest of the presentations were delivered by academic staff and students. As Jenny highlighted in her email following the conference "I think we showed them co-production while the others just talked about it" (email received from Jenny 19th May 2016).

The conference presentation was a positive experience. Jenny and Dave felt confident to expand on the responses they had given me originally and the inclusion of their personal experiences really elevated the presentation. Several people approached them afterwards to thank them for their insight. During questions after the presentation both Jenny and Dave expressed that they felt fully involved in all aspects of the study. This was very reassuring to me as I had often reflected in my field notes about my role and ensuring the group felt like it was their study and not just mine.

> From a personal point of view it felt really heartening to hear both Dave and Jenny say that they felt truly involved in the project and that it truly was our project. It has been something that I have worried about and grappled with so for them to say that in public really made me feel good (field notes audio 18th May 2016).

Presenting at the conference felt like a turning point for the group. Dave and Jenny seemed more confident as a result of it and it reassured me that the group did find this a participative experience. When we started planning the co-production event to share our findings Jenny and Dave often referred back to this presentation. I think delivering this presentation gave them the confidence they could deliver another presentation at our event.

9.2.2 Feedback Session August 2016

In August 2016, the surveys for Phase 2 had been designed but the group were awaiting ethical approval before sharing the surveys. I suggested we use the meeting time in August 2016 to reflect on the process up to this point. We discussed the following questions:

1) What had worked well?
2) What had not worked well?
3) What do we want to achieve?

Our discussions were recorded on flip chart paper and this was photographed (see Appendix P).

What had worked well?

The main success of our study was it represented a good example of co-production in which the carers had been involved from the outset and no decisions had been made without their input. They appreciated having someone in the group who dealt with the practicalities such as room bookings and refreshments. Having someone take on this role ensured the group had a place to meet and also that meetings were booked in advance and kept happening on a regular basis. The co-researchers recognised that we all had different roles and summed this up as "equal but not the same" (taken from Image 1 shown in Appendix P). As a group we valued our differences in knowledge and experiences but were all included in the process. Sharon described this as a "microcosm" (taken from Image 1 see Appendix P) of how she would like interactions with services to run. In which everyone has their role and expertise but come together as equals. We discussed the size of the group and the co-researchers all expressed a preference for the small group size. They were concerned it could have been difficult to take everyone's views and interests into account in a larger group describing it as potentially "unmanageable" (taken from Image 1 see Appendix P). Dave highlighted that key to the success of any participatory action research group was communication. We discussed at this stage whether or not the group was satisfied with the way we communicated, via group meeting with email and between, and they expressed that they were.

What had not worked so well?

The group was mainly positive about the process. They expressed concern about the lack of diversity within the group and how we could ensure our surveys were accessible. We discussed having the surveys translated and contacting service providers who work specifically with carers from black and minority ethnic (BME) communities. We also discussed different ways to enable participation, such as social media and Skype, but the group agreed that they preferred the face to face meetings.

What do we want to achieve?

Ultimately the group members wanted the study to be a catalyst to making improvements to services. We discussed how we could share our study and its findings to make the most impact including in meetings with service providers or using presentations. The group was keen that we should think creatively about how we could do this, for example using role play. Sharon described this as doing something "a bit different" (Image 3 in Appendix P). Although we had

not yet shared our survey and collected the responses the group were sure the surveys would demonstrate a divide between carers and service providers that we should identify.

Like the feedback collected in May 2016 for the conference, the session in August 2016 showed the group considered their participation in the study as a positive experience in which they felt fully included. They still saw the process as a good example of working with family carers and acknowledging their experiences. They hoped this study would lead to improvements in how services and carers worked together.

9.2.3   End of Study Survey

In April 2018, the group met for the last time. However, we did continue to keep in touch via SMS and email and we went out for a celebratory meal. After this meeting I shared a Survey Monkey survey (see Appendix Q for survey questions) which I asked the group to complete. All three members of the group completed the survey; I did not ask them to include their names with their responses. This was an attempt to enable the co-researchers to be honest. Our previous reflection sessions had been face to face and therefore they may have felt unable to raise negative points. The group all rated the study as highly co-productive, with two co-researchers rating it 10 out of 10 and one 9 out of 10. None of the group could think of any ways in which it could have been more inclusive. One co-researcher said:

> Nothing springs to mind. It is one of the most equal, inclusive groups I have ever worked in (co-researcher 1 response).

The group was asked which aspects of the study they most enjoyed. They were invited to tick as many options as they wished. All the options were selected at least once. All three co-researchers selected our group meetings at the university.
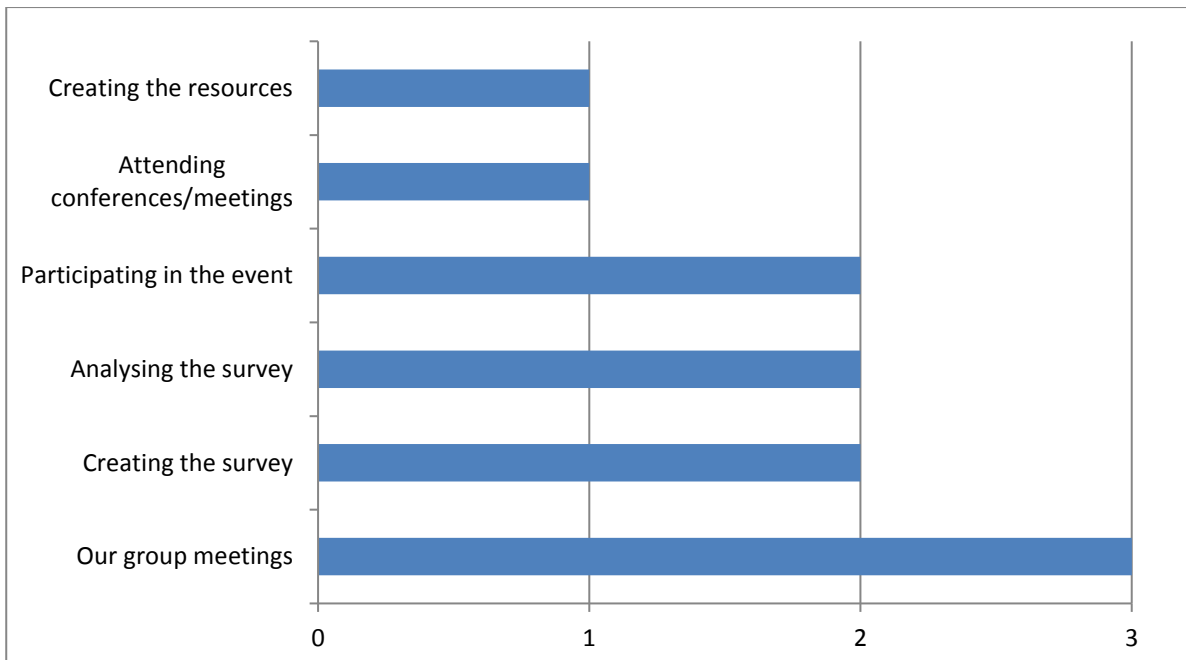
Figure 11 Co-researchers responses: which part of the project did you most enjoy?

One co-researcher also used the comments box to write:

> The ongoing sense that the project might contribute to an ongoing change in policy production (co-researcher 2 response).

This matches the aims expressed at the feedback session in August 2016. The group were asked to identify aspects of the study they had least enjoyed. Two participants did not answer the question and one selected 'creating the resources'. They went onto clarify that:

> I was less involved in actually creating resources but was happy to leave this task to the project co-ordinator (co-researcher 3 response).

The co-researchers were asked if there was anything they would have liked to have done more of as part of the study. Only co-researcher 2 answered this with:

> I would have liked to have had a greater reach to organisations, but we did what we could with the resources that we had. My own resources have now been considerably increased … so when I release my next …blog it will have an extensive reach (co-researcher 3 response).

True participatory action research needs to enact a change in the co-researchers (McTaggart, 1991). The group members were asked to identify if anything had changed for them as a result of the project. Their responses were:

> Yes, definitely. As well as my understanding of co-production also the confidence and skills to try it out in practice (co-researcher 1).

> Certainly more understanding re research and it has encouraged me to promote myself more (co-researcher 2).

> I think I now have a good understanding of how co-production should work. Creating the survey was interesting and harder than I thought it would be to get it right. I found it very interesting analysing the survey. If I was starting with a new provider I feel much clearer about what I would be asking of them when communicating with me (co-researcher 3).

All three co-researchers could identify ways in which their knowledge had increased both about research and co-production. For co-researcher 3, s/he repeated that this would impact on how s/he interacted with new service providers and the expectations they had of them. Co-researchers 1 and 2 both described an increase in confidence; one in using co-productive approaches and the other in promoting themselves more. The group reported that we had achieved our aims; with one co-researcher rating it a 10 out of 10 and two rating it a 9 out of 10. When the group members were asked to identify what more the group could, one wrote there was nothing more. One wanted to have had more attendees at the co-production event and the other to be able to have a larger print run of the resources in an attempt to reach more services.

Overall the group was positive about the research process describing it as "great" (co-researcher 2) and "enjoyable and interesting" (co-researcher 3). Co-researcher 1 highlighted the large time commitment and that he/she not always been able to attend meetings but appreciated the one to one meetings I had organised to keep him/her up to date with the project. The final question asked the co-researchers if they had any further comments; two answered this question:

> Thank you to the project leader and all other participants for their co-productive time and sharing some very personal experiences. Our integrity and compassion has, I believed been central to the project (co-researcher 1).

I know you will have to depart to ensure your thesis is completed but would like to know when your graduation is. I would wish to keep in touch to advise how I am proceeding with trying to continue. Would it be possible to have access to the creations on the Carer Voice website as I wish to recreate it on Wordpress, so it will be still there when your Carer Voice subscription finishes (co-researcher 2) (I followed up with co-researcher 2 about taking this forward).

The group and I had met with each other from June 2015 to April 2018. They had invested a large amount of time into the study. It was heartening to see that they had found the process positive. They felt that they had changed as a result of the study and that they had achieved their aims. Although there were aspects where they would have liked to have done more this did not detract from what the group had achieved. Deciding how and when to end the group meetings was quite challenging for myself and the co-researchers. While one member of the

group was very keen to continue to promote the work of the group others were ready to finish. Sharon emailed me with concerns:

> I understand there is a lot of enthusiasm, and applaud that, but maybe we should discuss its future in a bit more detail when we next meet. I would like to retire when your research project finishes, as that seems like a natural endpoint (email from Sharon 14th April 2018).

This needed addressing in the meeting in April 2018 with an honest discussion; before this I had not realised there was anxiety within the group. During this meeting I explained my own position in that I would be unable to start new work with the group as I needed complete my thesis. I encouraged the group to honestly express what they wanted to happen next to support Sharon to express the anxieties she had mentioned in her email. She did this and explained she was ready to conclude our work. Jenny agreed with her but expressed an interest in staying in touch and potentially presenting other conferences. Dave was keen to continue to promote the work we had been doing with his own contacts but agreed that he could do that independently, with some support from me, and that the group no longer needed to meet. We ended the meeting by agreeing that this would be our last but arranging a date for a meal. By meeting again but in a different venue I hoped this would signal the end of the group work in a way that celebrated the work we had done. I was concerned Dave was disappointed that the group was concluding so hoped this would be a positive event. After this meeting I sent an email to thank the group for all of their insights, time and commitment to the study.

9.3   Initiating Research Reflections

The initiating researcher in PAR must be continually reflecting and become co-subject as well as co-researcher (Heron, 1981). They do not stand apart from the group but are fully immersed. Marshall (2006) identifies self-reflective practice as a "necessary core" (2006: 35) for all inquiry. To ensure I was continually reflecting I would audio record field notes immediately after every meeting with the group. I also kept a written diary of my reflections throughout the study. During these field notes I would reflect on the content of the meeting but often on my own role within the group. My own reflections were analysed using thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2013). Using the field notes I came to have a better understanding about my place in the group and my own motivations. For example, I had offered to meet the research group on a one to one basis. In my field notes, I reflected that I found one to one meetings easier than group meetings but that this should not be my motive for offering them. They should be used to enable participation, for example to keep a group member updated if they had missed

meetings, not because I found them more comfortable. In the field notes, I highlighted my own nerves and anxieties.

> I felt incredibly nervous to start with. I feel like I am 'winging it' and using up other people's time in the process (field notes after the first meeting in June 2015).

Even after the meeting in April 2016, which was well into Phase 2, I noted that although the meetings got easier they were not something I felt particularly relaxed in:

> I find a slight element of relief at the end of meetings not because I do not like the people involved but I do find them stressful (field notes April 2016).

The stress of the meetings came from arranging the room booking, parking spaces and refreshments but also feeling the pressure to ensure they had a purpose and did not waste the co-researchers' time. Where I recorded feeling more positive was at times when I had discussed with the group how we could adapt our group discussions into a research study.

> I feel good ... as I have done something that has actually made me a bit scared which was to say to people "right what needs to happen next?" I think I have been shying away for fear of dominating the conversation or fear of scaring people off (field notes December 2015).

Much of my anxiety stemmed from my own uncertainty about my role in the group. The group would defer to me about the next stages of the study or they would refer to it as "my" study. I was unsure how to support the group to think of it as their own study. Originally, I was waiting for this change to come from the group but I had to reflect in January 2016 that the group needed support to do this:

> I do think that the group may need more support than I originally thought they did. Their comfort with talking about their experiences does not translate to knowledge of research which is fine and that is fair enough but maybe I overestimated what they would already know. Maybe that is why in those weeks where I have left the ball in their court things have not moved on as much (field notes January 2016).

However, I was mindful that the more I directed the study the more the risk of moving away from a collaborative piece of work. Even at the end of the study in April 2018 co-researcher 1 referred to me as the "project leader" (co researcher 1 end of study survey). This role of leader may have been because I invited the co-researchers to participate in the study originally, took a lead in organising meetings and they were aware that I would then be going on to write a thesis and so would continue to be working on the study. It still shows that, to the group, I occupied a different role to them. I was not a co-researcher but the leader of the group. As I am not a family carer to someone with learning disabilities I would sometimes draw on my experience as a

parent to relate to what the group was describing. I was unsure about using my experiences as a parent as it was not the same as the experiences they described as carers of adults:

> I relate some of these situations back to being a parent generally but I worry about whether or not I should be comparing here...experiences of being a carer of an adult with disabilities to a parent of a typically developing toddler. I do not know whether that comparison helps or whether it seems patronising, (field notes 22nd October 2015).

However, by not discussing my family at all, I would have distanced myself further from the group as they discussed their families, not just their family member with disabilities. It helped the group feel more bonded as we learned more about each other including our families, hobbies and holidays. I noted that the group became more relaxed with each other as the study progressed:

> And it was really good it was a much more relaxed meeting, lots of laughing and joking. I do not know if that is because it is Christmas or if we're used to each other but it felt lighter and we laughed at things. Although they were serious things it was still stuff that was making us laugh and there was a bit more banter between the groups (field notes 14th December 2015).

Another occasion which highlighted the difference between myself and the rest of the group was in our reactions to some of the survey responses. For example, the response from a service provider which suggested family carers needed educating was insulting to the family carers in the group. I reflected that I was surprised we had received responses like that and therefore had not considered warning the group that some of the responses may be upsetting:

> I don't think this was very easy for the group, particularly Jenny, to hear so I'm wondering if I should've made the point that some of this feedback might not be very complementary and might not be particularly easy to hear. I didn't really think that... I assumed everyone would just tow the party line and put what they think we wanted to hear rather than be as honest as some of these people had been (field notes 20th June 2016).

In such an evolving and changing study as this, self-reflection became a vital way to explore any new issues that arose and how I could address them. Although I had considered co-researchers' distress in Phase 1, when discussing their own experiences, I had not considered that the survey responses could potentially be upsetting.

Opportunities to share our study, and the feedback that brought, were positive experiences for the group. *The Challenges and Best Practice in Co-Production* Conference in May 2016 and the co-production event in October 2017 (see Appendix N) felt like successful occasions to celebrate our work. Prior to the co-production event I was anxious about it for many reasons including

that disgruntled carers may use the opportunity to raise grievances with specific service providers. I recorded in my research journal:

> There is so much that can go wrong. What if no-one comes? What if the discussion gets heated and I can't cope? What if people find it a waste of time? It's all v. v. Stressful (Research journal May 2017).

However, the main criticisms of the event did not come from carers on the whole but the smaller service providers. They felt that we should have asked the carers in the survey which service providers they were referring to when they made negative comments as they believed they related to statutory services rather than small service providers such as their own. I was conscious of the attendees from the local authority as in our results the local authority had the lowest ratings and then both carer and other service providers criticised the local authority (though not those staff members specifically). I did not want the local authority staff members to feel targeted by the group. At the end of the session most attendees stayed behind to talk to each other so this made me feel that the experience cannot have been too negative as they did not choose to leave immediately.

After the co-production event, the group continued to meet to develop the resources. It also became clear that I would need to define the end point. While one member of the group was making contacts and arranging meetings another was keen to finish their work in the study. I struggled with how to balance these two viewpoints. I did not want the person who was enthusiastic to feel unsupported but equally I did not want anyone to be anxious about the study and the workload. I realised that this needed to be explicitly addressed and the group members needed to be given permission to say that they no longer wanted to be part of the group. I made it clear that my own availability would be changing and although I would complete the work we had committed to and would be in contact we would not be starting anything new at this point. This gave the co-researchers opportunity to express their own commitments going forward. Concluding the group needed to be more explicit than I had realised.

9.4 Summary

Self-reflection is key to PAR, by reflecting internally it enables the initiating researcher to understand their external actions and responses (Marshall, 2006) within the group. My field notes and research journal allowed me to express my anxieties, question my actions, acknowledge what worked well and be aware of where changes might be necessary. My field notes show a shift in how I understood my role, moving from anxiety about the fact I am not a family carer to accepting that we do not all need the same experience as long as everyone's

experience is valued, and all the co-researchers feel heard. Making space during the study for the group to reflect provided opportunity to revisit our aims, give everyone an opportunity to speak and ensure that the group all felt included in the process.

Chapter 10
Discussion

10.1 Introduction

The aims of this study were to understand the experiences of family carers of people with learning disabilities by collaborating with them as co-researchers in conducting a research study. In this chapter I will explore a number of important contributions that this study makes both to existing academic literature, participatory action research (PAR) methodology, and to ongoing discussions about practice in support services. I will go on to demonstrate that the collaborative research study conducted by the co-researcher group adds to the existing literature about how services increase carers' stress. It adds new information as to how carers feel perceived by services and the strength of feeling they have before, during and after interactions with service providers. It also adds new insights into conducting PAR studies, demonstrating not only that carers understand research methods but that these methods can be used to inform and enact change. This chapter discusses the methodological limitations of this study, and considers the challenges of PAR, implications for the practice of PAR and implications for practice in support services.

10.2 Method and Study

This study used PAR to explore the experiences of family carers by working with carers to identify and conduct a research study and disseminate the findings. PAR is research with, rather than on groups (Kindon, Pain, & Kesby, 2007). The aims of any PAR study should not only be to increase knowledge but to also enact change and uncover practical solutions (Reason & Bradbury, 2006). At the root of the study needs to be a commitment to supporting communities and individuals to "flourish" (Reason & Bradbury, 2006: 2). This method in particular can increase our existing understanding of family carers and the support they need by involving carers in the research process and focussing on the issues that are relevant to them. By including carers in all stages of the research process, this method ensures the study remains grounded in the experiences and priorities of family carers and not those of the initiating researcher.

This was a two phase PAR study involving family carers of people with learning disabilities. In Phase 1 of the study (see chapter 5), carers were recruited to join the group and asked to share their experiences in unstructured group discussions. These discussions were audio recorded, transcribed and thematically analysed by the initiating researcher. These themes were discussed in the group and formed the basis of our Phase 2 collaborative research study, (see Chapter 8).

Here, we explored the interactions between carers and service providers using two surveys. The responses were co-analysed and shared at a co-production workshop attended by representatives from the third and statutory sectors in October 2017. Based on the feedback from the workshop, we developed a set of resources for service providers to improve their interactions with carers. These have been shared with all of the service providers who attended the event, all of the service providers who provided their contact details on completion of the survey and five more providers who saw a write up of the event on the Choice Forum website or in the National Family Carer Network Newsletter. They were also shared with all carers who attended the event, provided their contact details on completion of the survey and three carers who contacted me after reading about the event. After our final meeting the group reflected on the process of the study using a survey. Figure 11 summarises the two phases of the study and outlines the variety of data collected over the course of the study.

The aims of this study were to:

1   Gain a rich understanding of the experiences of carers of people with learning disabilities using methods that are participative and solution focussed.
2   Identify the research agenda of family carers of people with learning disabilities around understanding the needs of people with learning disabilities and their carers
3   Use the identified research agenda to conduct a research study and disseminate findings in line with participative research methodology.

In the following three sections, which speak to each aim in turn, I critically reflect how this study has addressed each of these aims in relation both to the study's findings, and to the existing literature.

Phase 1: Understanding Carers' Experiences

1) Recruit a research group consisting of family carers

2) Collect audio recorded qualitative discussion data from unstructured group discussions to explore carers' experiences and identify themes. Along with this, collected researcher reflections using fieldnotes and a research journal

Phase 2: Working Together: A Collaborative Study

1) Collaboratively conduct a research study using the themes from Phase 1. Design, share and analyse responses. Two surveys developed and shared which generated qualitative and quantitative data.

2) Disseminate the findings and produce a set of resources for service providers to utilise in their interactions with families.

3) Reflect on the process using a survey which included rating scales and open questions.

Figure 12 Flow chart showing the two phases of the study

10.3 Findings

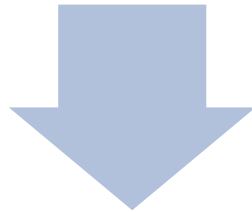**Aim 1: Gain a rich understanding of the experiences of carers of people with learning disabilities using methods that are participative and solution focussed.**

The role of Phase 1 was to address aim 1 and really understand the experiences carers have in a way that was not restricted by interview questions or any particular agenda. This element of the research brought into relief a number of key issues, which both build upon and suggest gaps in the existing literature. The main themes identified from the Phase 1 discussions, which I explored more fully in chapter 6, were:

1) Lack of carer power
2) Caring for an adult with learning disabilities
3) What's not being said
4) Impact on siblings

These themes highlight the difficulty carers experience when attempting to navigate the wide range of services involved in their family's life. Discussions revealed, for example, that interactions with local authority, health and some third sector services were disempowering. Services as the cause of carers' stress and anxiety build on the findings from previous research (Beresford, 1994; White & Hastings, 2004). White and Hastings (2004) identified formal services, as opposed to informal support provided by families and friends, could increase carer stress rather than alleviate it. Beresford (1994) identified the root of this stress was the inflexibility of services, the difficulty in attempting to access support and stressful interactions with professionals. However, Kyzar (2012) highlighted that more research is needed to fully understand the role of formal support for carers. The current study identifies a range of strategies carers adopt to get the most out of these interactions to try and access the support the person they cared for needed. The variety of strategies and work done by carers, explored in Chapter 6, such as attempting to use certain language and highlight the most negative traits of the person they care for is an important and underexplored issue.

In this study, carers reported the stress caused by interacting with services impacted on their trust in services. Carers worried who would advocate for their children after they died. This has been previously identified as an issue for carers and a great cause of anxiety (Bibby, 2013; Bowey & McGlaughlin, 2005; Jokinen & Brown, 2005). Research shows that parents often identified their other children to replace them as primary carer for their sibling with disabilities

(Dillenburger & McKerr, 2010; Jokinen & Brown, 2005). The current study contradicts this as my co-researchers did not expect their other children to become primary carers; they were hopeful their other children would play a role in their sibling's lives but not to provide their care. They identified that this as a burden they did not expect their other children to take on which is supported by previous research (Dillenburger & McKerr, 2010). While we had a sibling carer in the group, she expressed uncertainty about her role in her brother's life, she was not permitted to sign consent forms on his behalf and often felt ignored by providers. Tozer and Atkin (2015) reported that siblings can feel side lined and judged by service providers making them reluctant to engage with them. This study highlights an important issue which is the role of sibling carers and the expectations placed on them after their parents die. In this group, the co-researchers did not want their children without disabilities to become primary carers but did want them to have a role in their sibling's lives. This role may go above and beyond simply being a sibling, such as overseeing care and acting as an advocate. However, the role of the sibling carer is already a complex and uncertain one. This study highlights the need for siblings and services to understand the role of the sibling carers and also to identify what the expectations may be of them once their parents are no longer able to care. This should be part of future planning with family carers in a family centred way.

Chapter 8 presented the results from the Phase 2 surveys and demonstrated the overlap with the Phase 1 results presented in Chapter 6. In their responses, family carers described the frustration and anxiety interacting with service providers caused them, to the extent that some had stopped using services completely. The difficulties described are mirrored in the published accounts of Mark Neary (2011; 2013) in which he considered caring for a disabled child easier than navigating services with their inaccessible documents and judgemental attitudes. This study adds further evidence to Neary's (2011; 2013) personal reflections as they demonstrate his difficulties are widely felt by family carers. By using PAR, we were able to deepen our understanding of carers' experiences by identifying the carers' own priorities and basing a collaborative study on these priorities. The research study participants described services as not fit for purpose where they were not treated as equal partners. Where English policy defines carers as "expert care partners" (Department of Health, 2010: 5) our survey findings (see chapter 8) demonstrated that carers did not consider themselves treated in this way. They described feeling nervous before meeting with service providers. Interactions left them feeling "unheard and blamed" and in "utter despair". This confirms the mismatch between policy and the reality for carers and the people they care for (Graungaard & Skov, 2007; Mencap, 2001a; Michael Oliver, 1990). It also adds an important new finding which is the huge emotional burden that

interacting with service providers places on family carers. The language carers use to describe this is highly emotive and demonstrates the depth of their feelings. This has not been previously explored and merits much wider consideration as it impacts on future interactions or, as this study showed, whether or not families chose to engage with service providers at all.

The survey results identified that carers felt more regularly included and respected by specialist or third sector services and less so by local authority services. Statistical analysis demonstrated that this was the case regardless of whether the carer cared for a child or an adult or where in the country they lived. The disconnect between how service providers reported working with carers and how carers actually felt was highlighted in the findings. Service providers reported a good relationship with carers and agreed strongly that communication with carers was a priority. That is not to say that the participants employed by services were not transparent in their responses, but it does suggest that their policies about working with families are not reaching the carers they support. This will be explored further in the Implications for Practice section of this chapter.

In their response to the survey, some providers indicated that carers needed training to understand how services work. However, my experience from Phase 1 is that carers do understand how services work and the ways in which they are limited by funding and high staff turnover. Carers are not unsympathetic to constraints on services but are frustrated when they perceive they are not included in discussions about how these limitations are impacting on the support their loved ones receive. Carers perceive decisions are made to save money but these decisions are presented as being in the best interests of the person they care for. This increases carers' perceptions that they are not worthy of receiving a transparent response to a situation or they are viewed as not being capable of understanding this. Service providers' assumptions that carers need education or training supports the carers' views that they are not considered expert partners – something which is also reported in previous studies (Bigby, 1998; Graungaard & Skov, 2007; Mencap, 2001a). This current study goes further by asking each group to reflect on their interactions with each other. Recognising these misaligned assumptions between family carers and service providers has potential for impact on practice. They highlight the need for honest discussion and service providers to recognise the assumptions they hold about carers. This is not without challenges as it requires a shift not just in practice but in attitude. Oliver, Sapey and Thomas (2012) explore the ways in which the attitudes of service providers, namely social workers, impact on the support received by people with disabilities. They also highlight that this attitude can affect family carers, they caution against using only "professional

judgement" (Oliver, Sapey, & Thomas, 2012: 58) and call instead for "sensitivity and open mindedness" (Oliver et al., 2012: 58).

Aim 2: Identify the research agenda of family carers of people with learning disabilities around understanding the needs of people with learning disabilities and their carers

This section explores the second aim of the study in which I sought to understand the co-researchers' own research agenda. By conducting a PAR study, I sought to centralise carers' voices. However, translating their experiences into research was not always easy. Originally this aim was to work with carers to identify the issues they felt merited research and what their research priorities were. However, the carers did not come to the study with a research agenda identified so instead we used the phase 1 discussions to recognise which issues were most pertinent to carers and formulate a research study from there. I used the themes from the analysed phase 1 data to generate discussions that enabled the carers to express the issues related to caring that mattered to them and explore ways in which to articulate these issues as research questions. Once we had done this the group members were able to identify methods they may use to answer these questions, the two surveys, and some of the questions that could be included in the surveys. Therefore, rather than identifying the research agenda of family carers we worked as a group to identify the issues family carers experienced and developed a research study that aimed to address some of these.

My co-researchers did not spontaneously begin this process by generating suggestions for research questions or potential studies. The Phase 1 discussions enabled the group to highlight the issues that were most pertinent to them and to help me to understand my role within the group. While the group shared their experiences of caring I brought my experience of both research and having previously worked for service providers. However, as Reason (1998) cautions, just bringing together a group does not necessarily result in genuine collaboration or successful research. The processes within a research group need to be constantly reflected on and adapted (Reason, 1988) and many of the skills required can only be acquired through "doing" (Reason, 1988:19). This was certainly the case in this study. My co-researchers attended many meetings and support groups and were skilled in discussing their experiences but had little or no experience in translating these to research questions. It was my conclusion that the group needed someone whose role it was to explore how their experiences might form the basis of a research study and what methods could be used. Appreciating that everyone could inhabit different roles was key to feeling more comfortable in my place within the group. Reason (1998)

states that "just because we are setting up a co-operative inquiry group does not mean that all those involved participate in identical ways" (1998:27).

A reoccurring theme from the Phase 1 discussions was carers felt service providers perceived them negatively. Service providers considered them over-protective, too risk averse and getting in the way. They identified service providers' focus on independent living, main stream services and employment as being at odds with their priorities and as being not person centred. They saw themselves as offering an alternative viewpoint to the philosophies of service providers. These differing opinions coupled with their mistrust of service providers made interactions with them stressful. They adopted strategies to cope with these interactions. As identified by Kyzar (2012) more research is needed to fully understand the role of formal support in the lives of family carers. However, Phase 1 demonstrated that for this group of carers formal support, provided by service providers, was not working for them or the family member they cared for. Moreover, attempting to rectify the issues, for example by leaving telephone messages or requesting information, was a stressful, and often fruitless, experience. The interactions between family carers and service providers was the issue we decided to focus Phase 2 of our research study on, as not only is there little literature around this but it was a topic of high relevance to the group. By using PAR, we were able to explore deeply what mattered most to the carers thus highlighting an issue that is not widely addressed in literature. Without using PAR we may not have uncovered this everyday issue that has a large impact on carers. This study gave greater insight into how the emotional labour placed on carers during these interactions compounds their experiences and influences future interactions. By exploring what makes these interactions so stressful we could attempt to find practical solutions (Reason & Bradbury, 2006).

Oliver et al (2012) expressed reservations about carers' rights being enshrined in law. They argue that this perpetuates the image of people with disabilities being dependents and burdensome rather than an independent agents (Oliver et al., 2012). I was mindful in this study that we should not be speaking on behalf of people with learning disabilities or taking the views of carers as a proxy for those with learning disabilities. We needed to explore the experiences of carers and the ways in which changes in service delivery, for example personalisation, impacted on them (Brooks, Mitchell, & Glendinning, 2017) but remain conscious that it was the carers' experience we were focussing on. We did not have people with learning disabilities in our co-researcher group and therefore could not fall in to the trap of speaking for people with disabilities without having their interests represented in the research group. However, this study demonstrated that the carers in this group did not view the person they cared for as the burden, as Oliver et al (2012) suggest, but the burden was the need to support them within services that were not fit

for purpose. The burden on carers was as a result of the many agencies they had to interact with, the emotional impact of these interactions, phone calls not being returned, and poor communication, amongst many other frustrations.

This study showed carers were often conflicted between ensuring the safety of the person they cared for and respecting their status as an adult. They discussed sending emails using the BCC function so their adult child did not know who else was included in the email. They described situations where the service provider's focus on independence did not seem appropriate or applicable for the person they cared for. This is an important finding; carers and services need to be able to explore the ways in which the person with disabilities can be supported to reach their full potential within the context of their abilities, preferences and needs. This may require supporting families to recognise where their priorities and preferences are not the same as the person the care for. However, without trusting and open relationships between carers and service providers these discussions would be very difficult and potentially viewed with suspicion by both parties.

Aim 3: Use the identified research agenda to conduct a research study and disseminate findings in line with participative research methodology.

This section explores the third aim of the study, conducting the research study, in reference both to what I did, what the group did and to existing literature. The final aim of the study was to conduct a collaborative research study using PAR methods. By using PAR it should bridge the gap between the experience of the participants and the way the researchers construct this experience (Heron, 1996). Therefore, it should more accurately represent the experiences of the group being researched and be more ethical and beneficial to them (Brydon-Miller, 2008). The limited, previous evidence of carers as researchers (Santerelli et al, 1998; Walmsley and Mannan, 2009) indicates that it can be empowering and increase the voice of carers (Walmsley and Mannan, 2009). However, there needs to be a balance between talking and action as the process could be frustrating to carers if they considered there was too much talking and insufficient action (Walmsley and Mannan, 2009).

However, it is up to the group to find that balance (Heron & Reason, 2006). In this study the balance between reflection and action was split across the phases with the first being mainly reflection and the second mainly action. That said, Phase 2 allowed time for reflection. Without this we would not have been able to ensure the co-researchers were having their aims met, that the research was answering our questions and that any potential for distress was being addressed and acknowledged.

The collaborative study we designed sought to explore the emotional impact on carers during their interactions with service providers. The proposal of creating two surveys to explore how carers and service providers perceived their interactions with each other was generated by my co-researchers. As a group we had discussed various research methods and what was feasible but the proposals came from the group members. Using the themes from Phase 1 the group identified the issues discussed, which mattered to them but wanted some confirmation this was also the experience of other carers. As a group we discussed whether the survey should be open to all carers or just those of people with learning disabilities. The group decided on the latter as they felt caring for a person with learning disabilities was unique and unlike other caring roles. The unique position of carers of people with learning disabilities are reflected in the literature (Kyzar et al., 2012; Twigg & Atkin, 1994), partly because the services for people with learning disabilities are much more grounded in social care philosophies, such as independent living and normalisation, rather than health care (Twigg & Atkin, 1994). Carers who cared for people with more severe needs, as the members of this group did, also faced issues such as being able to afford good quality care, finding qualified staff and getting sufficient rest (Kyzar et al., 2012). By basing the content of the survey on the discussions from Phase 1 it ensured that the research study was rooted in the lived experience of the carers. Without working in this way I would not have appreciated the depth of feeling carers have about interactions with service providers and how their experience in one interaction can feed into how they perceive the next. I was also unaware of how much carers' felt judged by services and how this also colours their interactions with them.

Chapter 8 shows throughout the study the carers would continue to relate what we were doing or finding out with their own lives and experiences. They would relate potential survey questions and survey responses back to their own personal experience of a particular service or process, for example attending a health appointment. This is understandable as being a carer is something they are very knowledgeable of. Caring is also ongoing for them; it did not stop simply because we had moved onto Phase 2 of the study. This constant moving between action and reflection is a central component to PAR, constantly reflecting enables the group to make sense of the work they are doing and come to understand issues in different ways (Heron & Reason, 2006). The co-researchers seemed to value having the space in the group to discuss what was happening in their home life and previous meetings and events they attended. I reflected that I must ensure there was room for these discussions and not just a focus on completing the research tasks.

This continual relating the study back to their own experiences was positive for the study as it kept us focussed on ensuring what we did was relevant to carers. The group was not expected to set their experiences aside for the study but to utilise them in the study design. In particular, this knowledge was very useful for designing and sharing the survey as demonstrated in Chapter 8. The survey had a high response rate and this suggests it was easy to complete and accessible. We used the groups' own contacts to share the survey link, and in some cases a member of the group would follow up on my original email and ask service providers to distribute the survey link. I was unknown to these providers but the carers were known to them and more likely to get a response. The carers were instrumental in designing the survey so this may have increased their willingness to share it; they knew what the survey involved and how the data would be used. They would also give me named contacts to approach rather than using generic email address that often went unanswered. By having a named contact and being able to refer to one of the co-researchers I was working with increased the possibility of the survey being shared. The group occasionally shared the survey themselves but generally were happy to leave this to me.

As a method, PAR encourages discussion to reach a consensus amongst the group however this means there are occasions for disagreement. In the current study, the group members would occasionally disagree about the survey design. If this happened via email discussion, I recommended discussing it face to face at our next meeting as having several people responding to emails could make it confusing. Pain et al (2012) recommend taking time to thoroughly discuss disagreements in an attempt to reach a solution. However, where that cannot happen the different opinions all need to be covered in reporting so that all viewpoints are acknowledged (Pain et al., 2012). Traylen (1994) described the disagreements in her study as adding validity to the research in which health visitors attempted to be more direct with the families they visited. Without being able to be more direct with each other how could they be more direct with the families they worked with (Traylen, 1994)?

Discussing the survey design in meetings meant that it took longer to finish as we only met once every four to six weeks but it was less confusing than in email and ensured everyone had an opportunity to express their opinions. By discussing each question, we could look back on why we had included it and worded it in a certain way, this helped us to decide if it needed to be altered or not. The slight disagreements in questions were easily resolved when we were in meetings together, however Reason and Heron (2006) caution against reaching a consensus at the expense of everyone in the group feeling heard. They recommend a member of the group taking on a devils' advocate role to challenge agreed ways of thinking (Heron & Reason, 2006).

We did not do that but as facilitator I would ensure that everyone had taken a turn to speak and express their views. As we also communicated by email and SMS I also had some co-researchers contact me after a meeting if they wanted to address something that was not covered in the meeting, such as Sharon's text about concluding the group work. In her study with mothers on welfare Whitmore (1994) found that the activities she had planned to address the conflict in the group did not work whereas having an informal chat over a cigarette break was much more effective. As a group, we would sometimes defer to each other's' expertise, for example in the case of the question asking carers to rate the severity of the disability of the person I accepted Sharon's view point that this was not a comfortable question for carers to answer. However, sometimes the group would defer to me about the layout of the question and what type of analysis we could complete. These minor disagreements and discussions were positive for the study; they enabled us to remain accountable to each other and the aims of the study. They also provided opportunities for further discussions about the carers' experiences and increased my knowledge about the types of information carers are expected to provide.

Of particular importance to me, as initiating researcher, was that the study felt truly collaborative and not like some of the carers' previous experiences of projects. In these projects the carers had not felt like true co-researchers but that they were being included merely as a tick box exercise so the service could say they had consulted with carers. True collaboration included working with the co-researchers through each step of the research process including analysis and dissemination. The group was very engaged in the analysis of the qualitative data and this yielded interesting group discussions. It also highlighted the similarity between the discussions we had in Phase 1 and the survey responses. There were occasions when it was challenging for the group. As part of the piloting phase, the group looked at the responses from two day service workers who had completed the survey. One of these had responded to the question "Do you think there is anything that family carers could do to work more effectively with your organisation?" with the response "be more open minded, educated in same principals as the authority". The group was shocked by this comment and the implication that parent carers need to be educated. It highlighted that the survey responses could be upsetting or distressing and I needed to be sensitive to this. I had not considered that the analysis could cause distress and it showed me that some of these responses would feel personal to the group in a way they did not to me. Managing distress is identified as a validity procedure when conducting participatory research such as cooperative inquiry (Heron & Reason, 2006). Repressed distress can be projected and thus distort the research therefore it must be surfaced and examined so that it can be recognised and acknowledged (Heron & Reason, 2006). In their collaborative

research study De Venney-Tiernan et al (1994) appointed distress managers to support their fellow co-researchers. In this study, we did not rush the meetings. Even when there was a specific task to complete, such as practising a presentation, we still left time for discussions that were off-task. This is something I reflected on in my field notes as the importance of allowing for these discussions became clearer as the process went on. Embarking on a process which may cause distress raises ethical considerations (Rowan, 2006). Rowan refers to "interpersonal ethics" (2006: 115) in which all members of the group have a duty of care to each other. However, this relies on a well bonded group that feel able to be open and honest with each other and speak up in defence of each other. In this study Phase 1 was instrumental in creating that group bond. Despite occasional upsetting or annoying responses, on the whole, the group enjoyed the analysis of the survey.

By bringing together the carers' knowledge and experience and my research background we designed a survey that was not only accessible to carers but that also answered our original research questions. Carers overwhelmingly reported their experiences of services were not positive and they did not feel part of an equal relationship. Where carers did report positive interactions these were with individual staff members rather than an organisation as a whole. Service providers considered their relationships with carers to work well and the majority reported their organisation made it clear how they were expected to work with carers. We identified a gap in how service providers and carers rate communication between the two groups. This could be because the carers who completed the survey did so because they were disgruntled whereas more satisfied carers were not motivated to complete a survey. Equally the service providers who completed the survey may have been those who already worked well with carers. We did not ask carers to name the service providers they were referring to so could not match their responses to the services providers that completed a survey.

When disseminating findings from a participatory action research study, written reports should not be the only output the findings should also be talked about (Reason, 1988). Our co-production event was planned in full consultation with the group. Whereas I had envisaged something that was an information sharing session; Sharon suggested a workshop in which service providers and carers worked together. Again, this demonstrates that working collaboratively led to approaching issues, such as disseminating research findings, in more interesting ways. In PAR consideration must be given to who has the authority to speak on behalf of communities and who the audiences are (Cahill & Torre, 2007). Therefore, it was essential that decisions about how we shared the findings and with who, were agreed as a group.

Often the group would need to be reminded that our results were valid and of a high standard as they would become concerned that they did not have the authority to criticise service providers or suggest there were more positive ways in which they could work. This was an important issue as it showed the carers lack of confidence in their interactions with service providers. This is an understandable reaction from the group, in their previous interactions with service providers they had not been perceived as "experts partners in care" (Department of Health, 2010) so being experts in research, a much newer role for them, was challenging. However, PAR seeks to challenge these power imbalances. This requires challenging accepted expertise and opening the research process to "include new voices" (Cahill & Torre, 2007: 72). The carers came to inhabit the role of researcher more confidently; this is particularly apparent in Sharon. In Phase 1, she expressed that although she would attend an event she would not present at it. She would only feel comfortable attending as a guest and did not want to be referred to as a member of the research group. She was concerned that by standing up and potentially being negative about service providers, she would find it more difficult to access the support her son needed. At the co-production event she joined the group at the front to deliver the presentation and then facilitated discussion at one of the tables. This shows how she gained in confidence through her role in the study, by giving worth to her expertise, owning the results and being active in the study design and delivery she was able to present the findings in front of an audience of professionals.

As an initiating researcher it can be difficult to appreciate the depth of feeling experienced by the co-researchers and therefore particular attention needs to be paid to their distress levels but also to self-care and reflection. It is an area largely ignored in the literature (Adams & Moore, 2007). Working so closely with groups can place an emotional burden on the initiating researcher particularly if the co-researchers hold some pre-conceived ideas about the academic researcher or the organisation the initiating researcher is employed by. During the co-production workshop, one carer in attendance pressed me for a guarantee that attending the event would result in changes to practice. She had attended many meetings where nothing happened and wanted assurances this would be different. It was difficult as, because I am not employed or commissioned by a service, I cannot guarantee they will make changes following the event. I assured her that we would be producing resources and keeping in contact with service providers, but we could not demand changes to practice. She contacted me again by email after the event to say that she was disappointed with the event and that I had been interested in my own academic gain and had used the carers to facilitate this. As the initiating researcher this was very difficult to receive and quite upsetting though I understood the carer's

frustration. Entering a space in which so much resentment has built up over the years is risky and requires "conflict management" (Adams & Moore, 2007: 41) and sensitivity (Adams & Moore, 2007). However, in PAR the initiating researcher is not a bystander facilitating two groups of people so it requires more than this. The initiating researcher may be part of the organisations being criticised, or represent other powerful institutions such as universities. Therefore, as in my case, they may find themselves the target for frustration and resentment. The initiating researcher may be supporting two groups to manage their conflict but they may also be part of those groups and therefore need ways to manage abuse or frustration that is directed at them. I made use of supervisions and talking to peers to express these issues and find support. Support systems need to be in place for not only the co-researchers but also the initiating researcher.

In this role, I also felt a pressure to deliver results not only for the co-researcher group but for the carers we had invited to the workshop. Detractors of PAR question its ability to really enact change and suggest instead it is still only academic researchers who benefit from its outputs (Oliver, 1997). Oliver cautions that good intentions are not enough to challenge the power imbalances in research production (Oliver, 1997). One way to ensure our study challenged such structures was our commitment to action and follow up communications after the event to keep attendees informed of our plans. I also offered support to other organisations such as the Clinical Commissioning Group (CCG) to implement and evaluate the resources so they could embed them in their practice. Oliver (1997) proposes a method he calls emancipatory research in which oppressed groups come together to conduct research without links to academic institutions. Although, as Oliver (1997) himself highlights, this rarely happens as groups may not know about research methods or be aware that research could empower them. Although I acknowledge the power imbalances and that the initiating researcher can be a main beneficiary of participatory approaches, I do not accept that this means that participatory research is not a valid method. By working collaboratively we all, initiating researcher and co-researchers, benefitted from this study. The carers reported that the group was supportive, they were listened to and that it introduced them to new research methods and to co-production. They reported that their own expectations of service providers had increased as a result of taking part in the study.

Following the final meeting in April 2018 Dave contacted me as he was interested in designing a survey himself. Therefore, the group now had increased knowledge of research methods which could enable them to pursue their own research interests. Without the study we conducted this would not have been possible.

As my own reflections and the group discussions demonstrate, the group needed Phase 1 and my support to apply their own experiences to a research study. They then needed support to design a survey and analyse the results. My position at an academic institution meant that we had access to funding for the co-production event and printing and access to a room and equipment for our meetings. As a postgraduate student, I had supervisions throughout the study and we had to adhere to the university ethical requirements. This ensured our study was ethical, rigorous and robust. Without access to an academic institution the quality of the study may not have been as high. I acknowledge that, as Oliver (1997) states, there will be benefits to me as the initiating researcher but my own reflections throughout the process were also to ensure that the study was beneficial and meaningful for everyone involved. This meant I did not rush the group through their discussions and ensured there was time to discuss their experiences including in the more practical meetings, such as when planning a presentation or designing a survey. We also revisited the group's own expectations of the study regularly to ensure we were working to these. In our August 2016 reflection session the group highlighted the value of having someone to facilitate the group, both in terms of the discussions but also taking care of the practical issues such as refreshments, room bookings and parking. For the group this ensured the meetings continued to take place on a regular basis. Although one co-researcher reported that the study was a large time commitment it was not too onerous for them to complete. This may have been because I took the lead in facilitation and the practical issues of running the group. Oliver's (1997) criticism of participatory research highlights the power imbalances between oppressed groups and the institutions that fund and conduct research. However, this study demonstrated that while these power imbalances should not be ignored, links to an academic institution is beneficial to research studies and that participatory methods can benefit the whole group, not only the initiating researcher.

10.4 Reflections: Managing Initiating and Co-researcher Expectations

This section seeks to explore the challenges of working within a co-researcher group. It covers the role of the initiating researcher, balancing the priorities of the all the group members and ending the group.

Reason and Bradbury (2006) define two types of research study 1) where the group spontaneously come together and; 2) one that is researcher led. For those that are researcher led, the initiating researcher must demonstrate "high quality awareness"(Heron, 1988: 58). I often reflected in my field notes that I found understanding my place in the group difficult. In part because I was not in the same position as the group, in that I was not a family carer and

therefore could not bring my experiences of caring. I grappled with this throughout the study. I reflected on whether I should attempt to find common ground by referring to my son, who was one at the start of the study, but was concerned this could be patronising. I would make reference to my previous work experience but again experience of employment is very different to experience of living with a person. Thinking about my previous work experience could sometimes feel uncomfortable as I reflected on my own behaviour whilst at work. I could remember having referred to a carer as "over protective" without understanding where this behaviour may have come from and how my attitude could have coloured my interactions with this carer. I would also have failed to appreciate how many services the carers were in contact with and how many meetings they attended. I can also remember being puzzled by what I perceived to be carer's cynicism without considering the amount of time they had spent interacting with services. My one-sided experiences meant that I needed to take time to listen and reflect with the group before we moved on to designing the study. I could not have understood what mattered to carers without Phase 1. Equally, they needed time to ask questions and come to understand the research process. The fact they explicitly asked me to give them ideas about research questions suggests they needed support to develop a study. We needed the time in Phase one to get to know each other so we all felt comfortable sharing both what we did and what we did not yet understand.

In her cooperative inquiry study about health visitors, Traylen (1994) also struggled with what her role was. She was aware of the need to facilitate the early group meetings but did not want to get trapped in this role and not become fully integrated into the group. She was also viewed as the cooperative inquiry "expert" (Traylen, 1994: 65). Again, a role she was reluctant to accept as it made her feel separate from the rest of the group. In my own reflections I came to accept this role as necessary. I was able to offer a different viewpoint but was still a member of the group. My role supported us to take the carers' experiences and ideas about research and formulate it into a study. I also used my connections with the university department to secure funding for the co-production event and printing. Reason (1988) highlights that not everyone involved in a participatory action research group has to participate in the same way, the different roles need to be recognised and negotiated.

There are ethical issues to consider when a researcher from an academic institution initiates a participatory research study including the purpose of the study, who benefits from it and who has ownership of the research product (Minkler, 2004; Oliver, 1997). The group members were aware that I would benefit from the study with academic recognition and therefore it seemed only fair that I took the lead in the more administrative tasks such as room booking,

refreshments, meeting minutes and reminders. I had designated time to do these tasks whereas the other members of the group did not. The group members were not paid for their time so I was conscious of the process not being too arduous or time consuming for them and this meant I took on tasks that potentially could have been shared, such as using Survey Monkey to create and amend the surveys. I negotiated trying to balance working together with not making the study too arduous for the rest of the group. This may have appeared like I was leading the group but I was wary of losing members of the group because the study required too much of them. Minkler (2004) recommends continual dialogue between the initiating and co-researchers about the ethical issues including ownership, what constitutes valid research and what is important to all stakeholders. I learned to do this during the process. At first I attempted to answer these questions myself as I was fearful of seeming incompetent to the group but these conversations actually served to bring the group closer and ensure we all felt like equal partners.

Being equal partners meant all ideas were valid and explored. When Dave suggested using a survey to collect data this was a valid and pragmatic suggestion. However, I felt conflicted by this as this is not a participative method. Questionnaires have been used in other participatory research studies such as Whitmore's (1994) work with four single mothers as co-evaluators evaluating the Single Parent Centre in America. In an attempt to make the surveys slightly more inclusive, participants were asked to include their email address if they wanted updates on the study. Those that did were contacted three times after completing the survey; 1) with an update about the study and an invite to the workshop; 2) with a summary of the workshop and copy of the presentation slides and; 3) with a link to the resources and an offer to post hard copies. Eight survey participants out of 166 (4.8%) contacted me to request hard copies of the resources (five carers and three service providers). Maintaining contact with the participants ensured they were kept informed about how their responses had been used and what they had contributed to. Reason (1994) argues that knowledge and action are not separate and should not be treated as such. By contacting the survey participants I was demonstrating to them, their responses had been used in action. I appreciate that this is still a positivist method of collecting data but by working with my co-researchers to understand their experiences and develop the survey it was at least grounded in carer experience and guided by that experience rather than by what a researcher deemed to be important and worthy of investigation. The survey was a direct suggestion from a member of the group. Up until this point, the group had struggled to articulate how to design a research study so if I had dismissed this suggestion I could have made the group feel as though their contributions were not valid or equal to mine. In her study with Health Visitors, Traylen (1994) recounted that her co-researchers did not feel discussing their

experiences was really research. This could be the same for my group; we often understand research to be surveys and interviews. On reflection, without training or information about other methodologies it is understandable that they chose a data collection method that was familiar to them.

As Reason (1988) also identified, ending the group was difficult due to the differing needs of the group members. Where Sharon was keen to end the group work, Dave wanted to build on it via his contacts. This was difficult to balance and required open and honest discussion. My own circumstances meant I was able to support Dave to attend some meetings after April 2018 and support him to develop presentations but this would not be the case for all initiating researchers. Ending the study needs to be planned into the timeline and explicitly agreed with the whole group. Having a group member continue to promote the resources and the study after the group had concluded their meetings raised issues of ownership. Who owned the materials we had produced and was there a certain manner in which these should be shared? Minkler (2004) highlighted ownership as one of the ethical issues that should be considered in a PAR study. The resources we produced were freely available and could be accessed from the website I had developed during the study so there was not an ownership issue. I did have some anxiety about loosening my control over the materials we had produced as I was no longer sure how and where they were being shared. However, they belonged to the entire group not just to me therefore had no right to assume control of them or deny others using them. Especially those members of the group who would continue to have contact with service providers in a way I would not. I had to reflect on my own responses here, did I think that I was more able to share the resources or attend meetings than the rest of the group? The end of study survey showed that co-researchers could all identify ways in which participating in the study had changed them; either in terms of their own confidence or their interactions with service providers. Making changes that co-researchers carry with them into other areas of their life is the sign of a successful PAR study (Reason, 1988).

10.5 Overall Critical Reflection

This chapter demonstrates that the study addressed all the aims, but it was not without methodological challenges. The Phase 1 discussions provided great insight into the experiences of family carers. They reported that interactions with service providers were disempowering. They did not feel equal to the service providers or kept fully informed. They suspected information was withheld from them and that service providers had hidden agendas. They did not trust the providers and this lack of trust impacted on their interactions with them as they

did not believe the information they were receiving. This was a period of reflection in the participatory action research process in which the group explored their experiences and grounded the subsequent collaborative study in their experiential knowing (Heron & Reason, 2006). The amount of data and information collected in the first phase meant it had the potential to be a study in its own right and therefore I explored the limitations and implications of this phase including the lack of diversity in the group and the fact they were not carers of people with PMLD which had been an original aim of the study.

The group was able to reflect on their experiences but needed support to incorporate these into a research study. The second aim of this study, to identify the career's research agenda, was not fully realised as the carers did not have a predefined research agenda. Therefore we used the first phase unstructured discussions to identify their priorities. Once these priorities were identified the group could decide together which methods were most appropriate to explore them in more detail, such as surveys. My experience of conducting research studies helped to facilitate these discussions. Participatory action research is a responsive and reactive process so it was possible to utilise methods to support the group to explore what issues they would like to research. By conducting the thematic analysis and sharing the findings with the group they were able to see which issues they discussed regular and consider what felt most important to them to explore further.

Working with the co-researchers enhanced the quality of the research. Firstly it ensured the topics we researched mattered to carers and was meaningful to them but also it provided practical benefits such as using their experiences of design an accessible survey and contacts to share the survey.

10.6 Challenges and limitations of Study

Originally, the aim of this study was to explore the experiences of family carers of adults with profound and multiple learning disabilities (PMLD). A group of people defined as "the most disabled in our society" (Mansell, 2010). During the pilot, three of the carers in the group had sons with PMLD but none continued with the main study. In two cases this was due to their child's health needs and in one case the carer's son passed away. During the main study only one carer out of the original five cared for someone with PMLD. This carer had to stop participating due to her own health. Engaging with carers of people with PMLD was difficult for a number of reasons. Often people with PMLD have complex health needs that can fluctuate over time (Bellamy et al, 2010). This was the case for the carers in my pilot study who left the study when they had to spend more time attending hospital appointments. Caring for a person

with PMLD can take up an enormous amount of time (Mencap, 2001) and again this could restrict the number of carers able to commit to the study. The nature of this study meant that neither the time frame nor the outcomes were defined in the information sheets as they were both to be defined by the group. One service provider offered to share my information sheet but felt this lack of detail could be off putting for the carers they work with as they may not want to commit to such a long scale study.

Of the three carers who completed one had a daughter with mobility issues as well as learning disabilities and autism and the others had adult children with learning disabilities and autism. However, the issues we explored during our meetings highlighted all of the carers had difficulties and issues in their engagement with service providers. For the carer whose daughter had mobility issues her needs meant he had to interact with even more providers, for mobility aides and adaptations, but expressed similar frustrations to the rest of the group. Mencap found 60% of carers of people with PMLD spent 10 hours or more a day caring (Mencap, 2001). Dave, whose daughter has complex needs and mobility issues, now had 24-hour support staff working in his home. Until this time, he and his wife had shared night care for their daughter. The amount of time spent caring differed between the members of the group but Chapters 6 and 8 shows they all reported having to co-ordinate numerous different support providers, feeling undermined by services and fearing who would care for their child when they no longer could. These experiences were also shared by the participants who completed the survey. This is a small sample size so it is not possible to say whether carers of people with more complex needs have a different experience of interacting with services than carers of people with less severe disabilities. To explore this using participatory approaches it would be necessary to explore other means of participation as there may be times, as my own study showed, that carers are not able to attend meetings. Social media, audio or video diaries could be utilised to enable participation without necessarily attending group meetings.

Another issue with engaging with carers is the time they have available. If they have young children or are in employment it could be very difficult to attend regular meetings. The three carers who remained in my study were all retired. Committing to a long-term study could be impossible for carers who have to attend work or look after school aged, or preschool children. A participatory study seeking to engage with carers in employment or carers with younger children would again need to consider different methods for participation or offer facilities such as childcare or a crèche.

The research group, excluding me, were all married, retired carers of adults. The group did not attract single carers, carers of school aged children or working carers. The study proved to be too time consuming for the participants who cared for someone with PMLD. This raises the question of how could a study like this be more accessible to a more diverse group? We maintained a similar structure throughout which were regular meetings at the university with emails in between. If a group member had missed a meeting I would offer to meet him/her at home, so they were kept informed about what the group had discussed and any activity, we had agreed. Although I offered different locations or ways of keeping in touch, the group I worked with were happy to meet at the university. However, attending regular meetings could be difficult for carers, who work, have school aged children or care for someone with PMLD who does not have any other carers.

The information sheets and the surveys were written in English and therefore not accessible to those who did not speak English. Although they were written in plain English they may also have been too complex for potential participants who struggled with reading. I contacted service providers who supported carers from Black and Ethnic Minority communities and asked them to distribute my survey and information sheet but only one service responded. This support group for British Muslim carers shared my survey but said that it would not need to be translated as they were all English speakers. Surveys can be biased towards participants who have something to say, either good or bad. This can result in the responses being more negative; people who were happy about the services they received may not have been motivated to complete the survey.

The group and I conducted thematic analysis of the survey data together. We gave participants the option of including their name on the survey. As a result, the group was familiar with some of the participants. Although we discussed confidentiality and not sharing the responses outside of the group the co-researchers may have responded to certain answers differently if they knew the person completing the survey. If a group member had a poor experience with a certain service provider, they may have viewed their survey responses more cynically than if the provider was unknown to them. To reduce the risk of this I separated the responses from the names of the participants, but the group still knew that some of the responses came from service providers they were familiar with.

Although I have experience of research studies I was not experienced in using PAR methods. My reflections were vital for exploring my role and how I supported the group. However, as I was familiarising myself with the method there may be ways that I would approach the study

differently were I to conduct another PAR study. For example, being more aware of the support a group needs to plan a research study. I would also explore different ways to support participation to enable other carers to participate in the study. I would be more open with the group from the outset about some of my own concerns and questions to encourage the co-researchers to have more ownership of the study and to view it as our study rather than my study.

10.7 Rigour of the Study

Action research faces criticism for not being sufficiently rigorous and only producing "good stories" (Levin, 2012: 135). Therefore action researchers have sought to identify practices to guarantee rigour. Levin (2012) describes a process for maximising integrity and rigour in action research. To ensure this rigour Levin identifies five key components that action researchers must not only be aware of but address in the presentation of the work. I will address each in turn in relation to the rigour within my own study.

- **Research partners**

  Working with research partners encourages alternative opinions and assumptions to be considered. As a group we discussed a range of experiences and the group were willing to disagree with each other. Therefore, it was never a single persons experience or opinions being considered but a range of viewpoints. However, that said the group were all retired carers of adult children from white British backgrounds. Therefore, we lacked insights from research partners who may have had alternative experiences such as caring for children, being from different ethnicities or caring and whilst working. The collaborative nature of the dissemination event, and the follow up working group, was an attempt to engage with other carers and service providers as we recognised they were not represented in our research group. I would also use the structures within the university such as supervisions and research cluster meetings to discuss my study and seek advice. This enabled viewpoints from researchers not involved in the study and using alternative methods.

- **Awareness of own biases**

  I reflected throughout the process on my own biases and assumptions via my field notes and my research journal. Refection is a vital process of participatory action research (Heron, 1981). In my field notes I would explore my own responses to the group meetings and my role within them. As someone who had previously worked as a service

provider I had to reflect on the ways in which I may have made judgments or assumptions about carers. As a group we also had to reflect on our own biases. The groups negative experiences with service provides meant that we needed to be mindful of how we perceived some of their responses. For example, when planning the event we were conscious of the providers in the room not feeling targeted. We tried to include balance in the surveys, for example asking participants to consider the ways in which carers and participants could work together more positively rather than all of the changes needed to come from providers. Reason and Heron (2006) suggest inviting 'outsiders', such as service providers, into the group meetings to incorporate alternative viewpoints. However, we did not do this. This decision may have limited the range of viewpoints in the meetings but also ensured a safe space for the carers to reflect and be open and honest.

- **Standardized methods**

  In this study we used quantitative and qualitative research methods. To ensure the rigour of the survey it was piloted with carers and people who use services and amended accordingly. As a group we had many discussions about it over several months to make sure the questions were easy to understand and addressed the issues we wanted to explore. I also sought advice from my academic supervisors. One limitation of this process is that we did not pilot the survey with carers of children but we did go on to share the survey with carers of children. Therefore, the survey may not have been as accessible to this group of carers.

  The first phase of the study yielded qualitative data as did the open ended questions in the survey. These were both analysed using the stages of thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2013). This method was selected as it is appropriate for large data sets, group analysis and producing findings that can contribute to policy change. The stages of the analysis process identified by Braun and Clarke (2006; 2013) ensured the analysis was grounded in the data rather than assumptions made based on existing biases. The themes identified with this process were shared with the co-researchers and, in the case of the survey data, shared with a fellow postgraduate researcher. This was to sense check the themes against a sample of the responses and make sure they fully represented the responses collected. Levin (2012) also encourages action researchers to explore the limitations of the methods selected. This has been done in sections 6.6, 8.6 and 10.6 of this thesis.

- **Alternative explanations**

   As a group we did not explicitly consider alternative explanations to the results we identified. However, by using a clearly structured method of analysis we did ensure the results we shared were grounded in the data. We also discussed them in depth as a group. By sharing our findings at the co-production event we also invited others to give their opinions on what we had found. At this event they offered experiences which differed from the carers in the groups. For example small service providers explaining that they too were often the victim of poor communication from local authority services. They would feel stuck in the middle between carers needing information and local authorities not providing it.

- **Trustworthiness**

   I attempted to be trustworthy and transparent in all of my interactions throughout this process. This included sharing findings and interpretations with the carers group as well as my concerns. The group reported feeling well support and included in the process. I was always mindful that the co-researchers were sharing their time and experiences with me and I had to treat these cautiously and with utmost respect.

10.8 Research Implications

This study has clear implications for research; it demonstrates the ways in which working collaboratively with co-researchers who have lived experience of the issue being research can add insight to the research process and the findings. The descriptions of their experiences during Phase 1 ensured that the collaborative research study of Phase 2 was grounded in experiential knowing (Reason & Heron, 2008). This type of knowing should form the base of a participatory action research study (Reason & Heron, 2008). Their experience also practically supported the Phase 2 study. Their knowledge of caring meant they contributed to ensuring the research questions were accessible and meaningful. They provided contacts to approach to share the survey and chased up their own contacts where we had received no response. Walmley and Mannan (2009) described the potential for PAR to empower carers and increase their voice. The study has shown this to be the case and that, with support, carers can engage with designing research studies and understanding how research methods can be employed to answer questions. In this study, the group met regularly for three years. This is not possible in all studies and previous researchers have explored the issues of using these methods to a tight

timescale (Traylen, 1994). However, involving carers in the research design could still be possible in other ways such as consulting them in the survey design or how and where to disseminate the findings. That said, if carers are only being involved in part of the study then it should be made clear to them what their role will be. The group I worked with was very aware when something was referred to as "co-production" but actually the main decisions had been made without them. If they are being asked to consult or advise, then these are the terms that should be used. To enable a wide range of carers to participate in a PAR study, such as carers of people with PMLD who may be engaged in caring activities for many hours of the day (Mencap, 2001), participation needs to be looked at in a flexible way. This may not necessarily be face to face meetings but utilise technology such as Skype, video blogging and social media to collect data. Services such as support for the person or child care may need to be offered.

During this study the co-researchers continued to include their experiences in the analysis stage. For example when the service providers described their interactions with carers as positive the group members reflected that they would try and remain polite whilst in contact with providers even if they were not that satisfied with the outcome of the discussion. As a result service providers may assume they were satisfied with the outcome and therefore describe it as positive. This has an implication for both research and practice. For research it demonstrates that having the carers involved in the process adds an extra layer of insight and increases the depth of how the responses can be understood.

As with previous research this study demonstrated that there can be an emotional burden for initiating researcher-they may experience conflict in the group (Adams & Moore, 2007), be the target of co-researcher and other stakeholders' frustration or feel under pressure to deliver results. Therefore, safeguards need to be in place to ensure they are supported (Adams & Moore, 2007). For example, an opportunity to speak to other PAR researchers to share experiences, meetings with supervisors or managers and a space to reflect on difficult meetings and interactions. The initiating researcher does not need to be a fully formed expert before the process begins (Reason, 1994); therefore, they need to be able to share concerns or issues with the group. This research study showed how this enables the group to feel more included and bonded and to share the burden on the initiating researcher.

This study has shown that engaging with groups of people with experience of the issue being researched can increase the relevance of the study and the materials being used. There are many levels of engagement from consulting through to full participation and the method being utilised should be described honestly and clearly. The carers in this study could identify examples

where their involvement had not been truly collaborative. This study was also limited in terms of participation and showed that studies that rely on face to face meetings can exclude particular groups from the experience and therefore flexible means of participation should be explored.

10.9 Implications for Practice

In this study, carers of people with learning disabilities expressed frustration and anxiety about interacting with service providers. The depth of these feelings meant that, in some cases, carers had stopped using services entirely. It also showed that service providers did not always recognise how difficult these interactions could be and viewed this instead as a lack of understanding or engagement on the carers' part. The rights of carers are now enshrined in law (Department of Health, 2014) and engagement with carers forms part of the Care Quality Commission (CQC) Inspection framework (Care Quality Commission, 2017) therefore services need to clearly demonstrate how they work with carers. This could be done in the following ways:

Equal and Included

The carers I worked with demonstrated that they were aware of how services operated and could identify times they were excluded or only included as a tokenistic gesture. Carers need to be brought fully into the discussions around the support of the person they care for. They should be included in deciding the time, date and location of meetings and sent copies of meeting minutes and actions. Without these they do not feel true participants. The carers I worked with valued honesty. If something was not possible then a clear and honest explanation of why was much better received. Another small gesture to help build relationships with carers is returning phone calls, even if there is no new news to impart. Carers valued being kept informed. Carers reporting feeling anxious when they received a letter stating a meeting had been arranged but with no explanation as to what the meeting was for. Clear, open information is essential to allay carers' anxieties and build the foundations of a more positive meeting.

Carers recognise the power imbalance between carers and service providers, particularly the large organisation such as the local authority. In our survey, the majority of service providers felt carers had been satisfied in their last interaction with them whereas the carers were dissatisfied. This could be because carers are concerned of the consequences of being overly critical about services, which could result in changes to support for their loved one. Service providers also need to recognise this power imbalance and the impact on relationships with carers. Services need to recognise and address the power imbalances that exist. They also need

to reflect honestly and critically about the attitudes they hold about family carers. This could be in supportive peer meetings or through supervision or appraisal. The service needs to be open enough that employees can challenge negative attitudes regarding family carers.

That is not to say that the person with disabilities should be left out of these discussions or that family carers are always best placed to make decisions. The research group all agreed there were times when family carers were not acting in the person with disabilities' best interests. However, dismissing carer concerns or making decisions without them leads to mistrust and poor interactions. More honest and open discussions could make it possible to gently raise issues with family carers and find the best solution for the person they care for.

Understand what had gone before

Carers of people with learning disabilities often provide lifelong care for that person (Walker & Walker, 1998). Our study showed that carers felt cynical about what they deemed to be a cycle of structure and restructure that dominated social care services. Therefore, they often received new initiatives, that did not feel new to them, without enthusiasm. This did not mean that the carers needed training but they did need understanding. The lifelong nature of the care they provide, and thus the lifelong nature of their interactions with services has an impact on how they view services. They have also had to attend meetings where they describe their loved one in the most negative terms possible in an attempt to access the support they need. This is an experience that creates feeling of guilt in carers and can affect the way they approach future meetings.

Accountability

Carers in our survey could identify individuals who worked with them well but rarely praised an entire service. Services need to clearly express to their staff how they should be engaging with carers; it should be a service-wide approach not just the good practice of individuals. There needs to be clear accountability. If good quality, family centred support is not being delivered carers need to be made aware of the complaints procedure and how they can express their dissatisfaction if they are not being adequately included in support decisions. If a complaint is received this needs to be acted on by the service provider and the outcomes of the complaint clearly explain to the carer. Without this carers will not engage again in the future.

Be Clear

The carers in this study expressed they sometimes felt deliberately misled by service providers with information being deliberately complex or not there at all. Information about how services

194

interact with carers needs to be clear, accessible and shared with carers. Carers should not have to continually request information that should be forthcoming, particularly information that is being produced anyway such as timetables and meeting minutes. Carers are often required by service providers to engage with them, for example completing surveys. However, if the carers do not get the information they need they are not motivated to complete the information the service provider requests. They are doubly reluctant to complete surveys when they do not see any change as a result of their feedback. If services are asking carers to provide information they must make it clear what responses they received and what action they will take as a result.

Concluding Comments

This study worked with co-researchers to highlight and examine an issue of great importance to the carers: how service providers perceive them and how this impacts on their interactions. The results highlighted the strategies that the carers were forced to adopt when dealing with services, the negative perceptions of interactions with services, and the impact of mistrust and negativity. This is despite increasing legislation that defines carers as expert (Department of Health, 2010). The survey results described an emotional burden of interacting with service providers: A burden that service providers did not fully recognise and interpreted instead as a lack of carer understanding or engagement.

This study has important implications for both practice and for research. Service providers need to fully involve carers in the support of people with learning disabilities. Tokenistic attempts at collaboration with carers is recognised as 'paying lip service' and increases carers' feelings of exclusion. Service providers need to acknowledge the power imbalances that operate and the fear that carers hold - that the person they care for may lose services and not be well supported if they complain. A lack of complaint does not mean carers are satisfied with the support being offered.

The PAR experience was empowering for these carers. They could recognise ways in which the process had changed them and increased their confidence and willingness to challenge the status quo. It was also empowering for me, with my own confidence increasing throughout the process. By reflecting and coming to better understand my role and what I could bring to the group I felt more able to raise concerns, hand over responsibility and take risks, such as running a co-production workshop with local service providers and family carers. This study has demonstrated that participatory approaches can increase the relevance and impact of the research question and methods. PAR enabled a deeper understanding and exploration of the issues being raised and has had a lasting impact on the perceptions and actions of all members

of the group. This project has worked with a typically marginalised group, not only to allow their voices to be heard and respected, but to enable them to conduct research aligned with their priorities and then to use findings to facilitate meaningful change at a service level

Appendices

Appendix A **Pilot Information Sheet**

Research Project

Who I am?

Hi, my name is **Rachael Black**

I am a **student** at the University of [CITY]. Before that I worked as a support worker for many years with adults and children with learning disabilities.

What is this research project about?

I would love to work with **family members of people with disabilities** to find out your **experiences.** I would do this using a research method called Co-operative Inquiry. This means that you would be acting as a **researcher** in the project. The reason for this is to make sure that the topics and the questions that we research are **interesting and important** to you as a family member.

In your role as researcher you will be asked to attend **group sessions** every 6-8 weeks to join in with group discussions. You may also be asked to write down, or record your thoughts while

you are at home which you may (or may not) wish to share with the rest of the group.

At first I will organise the groups and contact you to let you know where they will be. I may also bring a list of topics with me to help the discussions. However this is just to get us started. In time, hopefully you would feel able to suggest some things to talk about but this will be up to you and when you are ready.

The aim of this project is to carry out some research which you feel **fully involved** in and where you can decide the topics we research. This is to try and make sure that it looks at the questions you find important and is something you can **use in your day to day life**. We will also work together to produce something from the project such as some guidelines for people working with families, a film of our experiences or a presentation.

There will be many things to talk about and decide along the way, such as how we will share our research, who we will share it with, how often we will meet and where. But these can be decided as we make our way through the project.

For now the first step is to form our group and have our first meeting. You can attend this meeting to find out a bit more about the project. By coming along you are not agreeing to take part in the project and can leave at any time.

If you do decide to take part in the project but then change your mind at a later date that is absolutely fine. You can leave the project without having to give any reasons why.

What next?

If you think you would be interested in this project and would like to know more about it then please contact me on [CONTACT DETAILS] for an informal chat. I would also be happy to come and meet you at your home (or somewhere else that is convenient for you) so that we could have a chat about it.

Thank you for your time!

My Contact Details [INCLUDED IN ORGINAL]

Appendix B Detailed Participant Information Sheets

17th February 2014

Using participative research methods to explore the experiences of family members of people with PMLD

You are being invited to take part in a research project led by the Department of Human Communication Sciences at the University of [NAMES CITY]

. The project will be supervised by Dr Judy Clegg, Senior Lecturer and Dr Sarah Spencer, Lecturer.

Please take the time to read this information sheet so that you know what the project is for and how the research will be carried out. If you have any questions about the project please contact Rachael Black (PhD student). Her contact details are at the end of this information sheet.

What is the Project for?

The project is to look at your experiences as a family carer of someone with learning disabilities.

This research uses a method called Participatory Action Research. This means that you would be involved as a researcher in the project. The reason for this is to make sure that the topics that are researched are important to you as a family member.

In your role as researcher you will be asked to attend group sessions every few weeks. Once you are there you will be invited to join in with group discussions with other family members. You may also be asked to record your thoughts while you are at home which you may (or may not) wish to share with the rest of the group.

At first Rachael will organise the groups and contact you to let you know where they will be. She may also bring a list of topics with her to help the discussions. However this is just to get us started. In time, hopefully you will feel able to suggest some things to talk about but this will be up to you and when you are ready.

The aim of this project is to carry out some research which you feel fully involved in and where you can decide the topics we research. This is to make sure that we look at the questions are important to you.

There will be many things to talk about and decide along the way, such as how we will share our research, who we will share it with, how often we will meet and where. But these can be decided as we make our way through the project.

For now the first step is to form our group and have our first meeting. You can attend this meeting to find out a bit more about the project. By coming along you are not agreeing to take part in the project and can leave at any time.

If you do decide to take part in the project but change your mind at a later date that is absolutely fine. You can leave the project without having to give any reasons why.

You may feel uncertain about what it means to be a researcher on a project. If so, ask as many questions as you want before you decide to take part. You will not be expected to take part in anything that you feel uncomfortable with and hopefully you will have the chance to share your views and experiences and possibly learn some new skills.

Why have I been chosen for this project?

You have been chosen because you are a family carer of a person with learning disabilities.

What will happen if I decide to take part in the project?

You will be contacted by Rachael and invited to come to the first meeting. Rachael will have a list of topics to discuss. You can take part in as many of the discussions as you want. We will not share anything you say outside of the group.

You will be asked if Rachael can take notes of the conversation so that she can write some meeting minutes, you do not have to give permission for this if you don't want to.

Do I have to take part in the project?

No. It is entirely up to you, you can choose not to take part.

If you choose not to take part then that is fine. There will be no negative consequences for you or your family if you decide you do not want to take part.

You are free to pull out from the research at any time. You can do this by contacting Rachael Black on [CONTACT DETAILS], you do not have to give any reasons why or explain yourself in any way.

If you do choose to pull out of the research any recordings that have been taken of the sessions so far will be kept until the end of the project. However none of your information or contributions to the discussions will be used in any way.

When do the sessions take place and how long do they last?

The first meeting will last for about 2 hours, this will give us time to discuss the project, introduce ourselves and ask any questions. Refreshments will be provided.

The group will meet every 4 to 8 weeks for one year. The sessions will last for 2 hours and will take place at the Mencap [ADDRESS]

What will happen to this information?

When we meet you will be asked to give your permission for Rachael to audio record the conversations we have. You do not have to agree to this.

If you do agree to have the session recorded then the audio recorded information will be typed up word for word by Rachael. When Rachael types up your information she will not include your name, where you live or the names of your family. The information will be saved on the computer with a password to protect it. Any written information about you will be stored in the Department of Human Communication Sciences, University of [CITY] in a locked filing cabinet in a locked office.

We will decide as a group how your answers will be used (for example it may be in a report or presentation). We will not include your names or those of your family members to keep the information anonymous.

All the written and recorded information will be brought back to the group at the end of the project. At this time you can decide what you want to do with it. You may want to take it home or you may want to destroy it.

Do I need to give my consent?

Yes. You will be asked to complete a consent form. This is a form to say you have understood the project and are happy to take part in it.

Will my information be kept confidential?

Yes. It will be locked away to keep it safe and it will not be shared with anyone else.

Who has ethically approved this?

This project has been ethically approved by the Department of Human Communication Sciences Research Ethics Review Committee within the University of [CITY].

This means that a panel has agreed that this project is fair and that every effort has been made to protect you and your personal information.

Contact Details

If you would like to talk about this some more please contact Rachael Black (PhD Student) or the project supervisor, Dr Judy Clegg, on the details below

PhD Student: Rachael Black

[CONTACT DETAILS PROVIDED IN ORIGINAL FORM]

Supervisor: Dr Judy Clegg

[CONTACT DETAILS PROVIDED IN ORIGINAL FORM]

What if I would like to make a complaint?

If you would like to make any complaints about this project, for example about the way you have been approached or treated, the University of [CITY] complaints systems are available to you. First please contact Dr Judy Clegg [CONTACT DETAILS PROVIDED IN ORIGINAL FORM]

If you do not feel that your complaint has been handled properly then please contact the Head of Department, Shelagh Brumfitt on [CONTACT DETAILS PROVIDED IN ORIGINAL FORM] If you are still not satisfied then please contact the University Registrar and Secretary on [CONTACT DETAILS PROVIDED IN ORIGINAL FORM].

Finally, thank you for reading!

Appendix C Ethics Application Phase 1

Briefly summarise: The project's aims and objectives: (this must be in language comprehensible to a lay person)

People with Profound and Multiple Learning Disabilities (PMLD) are described as "the most disabled" in our society (Mansell 2010). They have complex support needs resulting from extremely delayed intellectual and social functioning and associated medical conditions (Bellamy et al, 2010). The majority of people with PMLD live with their parents (Emerson, 2008).

A study of parents of people with PMLD found that:

60% of parents spent more than ten hours per day on basic physical care.

48% received no support from outside the family to help with their care tasks (Mencap, 2001).

Current social policy states that "carers will be respected as expert care partners" (DoH, 2010) however there is very little research about the needs of family carers of people with PMLD (Jansen et al, 2013).

This study aims to address this gap in the research using a Co-operative Inquiry (CI) methodology. CI works on a cycle of action and reflection in which groups of co-researchers work together to address issues that are of mutual interest to them. CI is an Action Research methodology which prioritises action and collaboration; however it also has a set of validity procedures to ensure the findings from the inquiry are accurate and robust.

CI practices include:

1) Defining the research question and research design as a group of co-researchers
2) Deciding who will carry out which tasks
3) Coming together as a group to reflect and share experiences
4) Working as a group to co-analyse data.
5) Deciding how and where the results will be shared.

Using these research methods with family carers of people with PMLD will ensure that the research question is relevant to them and addresses the issues that they find pertinent.

The researcher will act as initiating researcher who initially brings the group together and acts as a facilitator in the early sessions (however the co-researchers may wish to take on this role as the project progresses).

204

Project Aims

Involve family carers of people with PMLD into the research agenda around understanding the needs of people with PMLD and their carers

Identify the research agenda of family carers of people with PMLD around understanding the needs of people with PMLD and their carers

Integrate the identified research agenda in to a new research project.

Conduct the research project, evaluate it and disseminate findings.

Research Questions

1) Can participative research methods enable family carers of people with PMLD to collaborate in research?

2) Does the current research and policy agenda reflect the needs of family carers?

3) How do family carers want to see research about people with PMLD and their families prioritised?

The project's methodology (this must be in language comprehensible to a lay person)

This is a co-operative inquiry action research study which seeks to engage family carers of people with PMLD as co-researchers involved in all stages of the research process including 1) devising a question; 2) collecting data; 3) analysing data and; 4) disseminating findings.

This application is to approach, recruit and support family carers to take part in a research project in which they work as co-researchers.

At the start of the project the group members will have a consent form to complete to show they have understood the project and how their information will be used (see Appendix 1). Discussions with the project partner (Mencap) have highlighted that the information sheet and consent form need to be written in simple, jargon free language. It will be made clear to the co-researchers at this time that they are free to withdraw from the project at any time without giving a reason.

There will also be an information sheet (Appendix 2) which will explain to the participants that they are under no obligation to take part in the project and that any information they provide will not be shared with anyone outside of the research team (of which they themselves will be a part of). All written information will be stored in a locked filing cabinet in a locked office in the

Department of Humans Communication Sciences. Identifiable information will be disposed of via confidential waste as soon as the project is ended.

The project will consist of several cycles of action and reflection. The action cycles will be when the co-researchers are in their day to day lives (for example in the early stages the 'action' may be to be aware of their responses to certain experiences and write these responses down). The reflection cycles will be when the group comes together to discuss their experiences. These sessions will either be audio recorded (if the researchers give their permission) or written notes will be taken. The group will meet approximately once every 4 to 8 weeks for one year. This will give the group time to carry out their action but not leave a long gap between meetings. There will be a maximum of 13 sessions plus an introduction session and an evaluation session. The sessions will be 2 hours in length. The project group meetings will take place at the Mencap premises. This location has been selected as it is familiar to the potential co-researchers.

All recorded data will be transcribed by the initiating researcher. This data will be stored in the Department of Human Communication Sciences in a locked filing cabinet in a locked office.

In the early stages of the project the initiating researcher will arrange the meetings and create an agenda to facilitate discussion and ensure that everyone has an opportunity to speak, should they wish to. The initiating researcher will also carry out the administrative tasks such as producing meeting minutes and arranging room bookings. However this may change as the project progresses and other members of the research team may take on these tasks.

CI is an emergent methodology where research questions and research aims are defined once the group is convened. Therefore it is not always possible to write a detailed research plan at this stage. However a Risk Assessment has been completed (Appendix 3) to identify potential risks and how they may be addressed.

What is the potential for physical and/or psychological harm / distress to participants?

As this is a project where co-researchers may be reflecting on their own lives and actions there is some risk that this may be distressing or produce anxiety. To try and minimise this risk

Co-researchers do not have be involved in any discussions where they do not feel comfortable

Co-researchers can take time away from the group and spend some time alone or talking one to one to another member of the group.

The co-researchers can decide at any time if there is something they do not wish to have included in the project

206

The research team will have the initiating researcher's contact details and can contact them if they need reassurance.

The initiating researcher wills discuss the project with her supervisors and seek extra support if she needs extra guidance or feels in any way concerned.

Ground rules will be agreed by the group at the start of the project and referred to throughout.

Co-researchers may be concerned about anonymity and confidentiality. This will be addressed by the Information Sheet will explain how the data will be stored, shared and analysed and how anonymity and confidentiality will be ensured.

Co-researchers may be concerned that information shared in the group may be repeated outside of the confines of the focus group. The risk of this will be minimised by agreeing a set of ground rules and agreeing to respect each other's opinions and treat the information shared in the group as confidential. This will be addressed and the start of the project and re-iterated throughout.

Co-researchers will be reassured that they do not have to answer or contribute to all of the questions and discussions.

They will also be assured that the data will be kept anonymous and stored securely.

Does your research raise any issues of personal safety for you or other researchers involved in the project? (Especially if taking place outside working hours or off University premises

The researcher will attend support groups; private organisations and potentially people's homes to carry out discussions and take part in meetings. This will be approved by her supervisors. The researcher will attempt to arrange data collection such as interviews within working hours but may need to conduct some outside of these hours. Again this will be discussed with and approved by her supervisors. The project group meetings will take place at the Mencap premises. These will be during working hours.

If yes, explain how these issues will be managed.

Judy Clegg (first supervisor), Sarah Spencer (second supervisor) and/or other relevant departmental staff will be kept informed of where the researcher is and what time she expects to return to the University premises. The researcher will keep a written record of where she is which will be regularly updated and stored in a shared folder that can be accessed by her supervisors. If the researcher is working outside of office house she will contact her supervisor by text to say when she has arrived and departed.

The researcher will keep a fully charged mobile phone with her at all times so that she can contact/be contacted.

How will the potential participants in the project be:

Identified?

Potential participants will be identified via groups and services specifically for adults with PMLD and/or their carers, for example the organisations IBK Initiatives, It's My Life and Mencap's Sharing Caring project.

The researcher will attend carers meetings to discuss the project and distribute information sheets. The carers present will have time to ask questions about the project and then decide if they would wish to participate in the project. The carers will be given the research teams' contact details so they can discuss the project further. It will be made very clear to participants that they are under no obligation to participate and that there will be no negative consequences to them or their son or daughter if they do not wish to take part.

Approached?

The carers will be approached by employees of Mencap. They will distribute the Information Sheets and the researchers contact details. This is to minimise possible coercion. The carers will be given the research teams' contact details so they can discuss the project further. During this project the research team will need to ensure that the information they produce and share is easily understood by potential participants. This will be managed by ensuring that all written information is easy to read and free from jargon. The written information can be translated in to other languages or in to large print. Information about the project will also be shared verbally with potential participants.

Recruited?

Recruitment to this project will be entirely voluntary. Potential co-researchers will be given an information sheet explaining the project and inviting them to attend an introductory meeting. The potential researchers will be asked to give their contact details if they are interested in attending this meeting and also there will be opportunities to discuss potential times and venues to best meet potential participant's needs. The researcher will then contact them to check that they would still like to attend and confirm the venue and time of the introductory meeting. If they are unable to make the meeting they will be offered an individual discussion at a time and

a place that is convenient. No data will be collected at this first meeting but discussions will be had about how data can be collected at subsequent meetings.

Will informed consent be obtained from the participants?

Yes

This question is only applicable if you are planning to obtain informed consent:

How do you plan to obtain informed consent? (i.e. the proposed process?):

In the introductory meeting the initiating researcher will explain the project and the agenda of the session. The researcher will then open discussions about how the data can be collected, analysed, stored and used. At this point the participants will be given a consent form (please see Appendix 1). The potential co-researchers will then take away the consent form to read through in their own time. They will be invited to contact the researcher if they have any questions. They will be asked to return the consent form either by stamped addressed envelope or to staff members at Mencap. The researcher will also make it clear that participants can withdraw at any time and neither they nor their family will face any consequences for this.

If some of the group do not wish to be recorded then we will discuss their reservations and try and provide reassurance about how the data will be stored. If they still do not wish to be recorded then we will not record the sessions and will take hand written notes. The group will be asked at the start of each session if they give permission to be audio recorded.

If one participant withdraws from the group it will be explained that although none of their data will be used in the project reports the recordings of the groups will be retained until the end of the project. This is so that the group recordings can still be analysed and used in the findings. There may be discussions involving other group members that can still be used. This will be explained on the information sheet and verbally by the initiating researcher.

What measures will be put in place to ensure confidentiality of personal data, where appropriate

The signed consent forms will be stored in a locked filing cabinet in a locked office in the Department of Human Communication Sciences.

Electronic audio data will be stored on the university network drive. This is based on advice received by CICs (Corporate Information and Computing Service) on Thursday 9th January 2014 about best practice when securely storing data (please see Appendix 4, an email confirming this

advice). Storing data on the network drive is recommended as it is regularly backed up so prevents the risk of information being lost and it requires a password to access.

The transcribed data will not include any names and will be password protected and stored electronically on the university network drive (U Drive). The initiating researcher and her supervisors will have access to the passwords.

At the end of the project there will be a discussion with the participants about how they want to use their data. If they want to keep what they have collected it will be returned to them, if not it will be destroyed via confidential waste.

Will financial / in kind payments (other than reasonable expenses and compensation for time) be offered to participants? (Indicate how much and on what basis this has been decided)

No

Will the research involve the production of recorded media such as audio and/or video recordings?

Yes

This question is only applicable if you are planning to produce recorded media:

How will you ensure that there is a clear agreement with participants as to how these recorded media may be stored, used and (if appropriate) destroyed?

It will be explained to the participants (verbally and on a written information sheet) that electronic audio data will be stored on the university network drive, based on advice received by CICs (Corporate Information and Computing Service).

It will also be explained that the transcribed data will not include any names and will be password protected and stored electronically on the university network drive (U Drive). The co-researchers will be informed that the initiating researcher and her supervisors will have access to the passwords At the end of the project there will be a discussion with the participants about how they want to use their data. If they want to keep what they have collected it will be returned to them, if not it will be destroyed via confidential waste.

 It will also be explained that this data will be destroyed at the end of the project (in September 2020).

Appendix D Participant Consent Form Phase 1

Title of Research Project: Using participative research methods to explore the experiences

of family members of people with PMLD

Name of Researcher: Rachael Black

I have read and I understand the information sheet dated 17ᵗʰ February 2014 which explains this research project.	☐
I have had the chance to ask questions about the project.	
I understand I am consenting to becoming a co-researcher in this project.	☐
I am free to leave this project at any time without giving any reason and without there being any bad consequences. I do this by calling Rachael Black on 0114 2222412.	☐
	☐
I do not have to answer any questions or take part in any discussions if I do not want to.	
	☐
I understand that my responses will be kept strictly confidential; this means they will be kept locked away and not be shared with anyone else.	
	☐
I give permission for members of the research team to have access to what I have said. People will not be able to tell that it is me in any reports that are written.	☐
I give my consent/do not give my consent (*please circle as appropriate*) to be audio recorded.	☐

_____   _____   _____

Name of Co-Researcher   Date   Signature

(or legal representative)

_____   _____   _____

Initiating Researcher   Date   Signature

To be signed and dated in presence of the participant

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Appendix E   Detailed Descriptions of Phase 1 Meetings

These summaries are created from notes taken during the meeting, listening back to the audio recordings and my field notes. They explore in more detail the main subjects the group discussed as well as how we started to move our discussions from experiential to research focussed and how I came to understand my role as initiating researcher.

Meeting 1: 18th June 2015

Four carers attended the first group meeting at the Department of Human Communication Sciences. Two had been part of the pilot phase and two recruited since I had returned from maternity leave (Joanna and Sharon). This meeting was not audio recorded as the group had not completed consent forms nor did I want to cause any anxiety for the group. I wanted the meeting to be relaxed and for members to feel able to ask questions; the presence of an audio recorder may make people nervous or uncomfortable. As this was the first time the group had been to the department, I met each of them at the door and walked them to the room. This meant the group was left alone, particularly as I then made hot drinks for everyone. However, as I went back into the room I could hear people introducing themselves and making conversation. I was aware of the fact that Jenny, Dave and Sharon knew each other but Joanna did not know the rest of the group. She was the only carer that had approached me via the Parent Carers Forum rather than through Mencap and the only carer of a school aged person. I had not specified that the carers should only care for an adult but was aware that she may have different experiences from the rest of the group who cared for adults.

I began the meeting with a brief introduction and asked the group to introduce themselves. This was the last question I asked of the group as the conversation flowed with the main topic being the various ways service providers caused frustration or anxiety for the carers. Joanna described the huge difficulty she faced accessing respite services for her son as he has behaviour that challenges and community transport refused to collect him from there, as the address did not match their paperwork. She contacted her local member of parliament to try and find a solution. She also expressed frustration that her son's specialist college did not provide one to one speech therapy, despite there being a therapist onsite. She was reluctant to move him from college as there are no other specialist services available and she wanted him to access education for as long as possible; she was not sure what support he could access were he not in education. The other carers shared the huge difficulties they had trying to access support once their children left education. Dave described the guilt that came with using a service that was not of a high standard that he knew his daughter did not like attending but having no other options. Joanna

and Jenny had both been told their sons' package of care was expensive; they queried how to react to this as this was funding their children were entitled to. It was less expensive than crisis care, such as having to call the emergency services.

As Joanna's son is in full time education she had to leave to ensure she was home when he was returned home by community transport. As she was leaving she asked me what I wanted to do next. I made some suggestions, for example the carers keeping a diary so that if they could not attend a meeting they could still record their experiences, however as I was aware of the time my explanation felt rushed and not particularly clear. I reflected in my field notes if I should ensure the research methods are discussed earlier in future meetings. Sharon expressed that a diary would be too much on top of her other commitment and the group agreed. She suggested that I could have access to her calendars and diaries to see the volume of people she interacts with on a regular basis. I reflected later in my field notes that the fact the group felt able to say if something would not work for them and make other suggestions was quite heartening as it meant they felt able to speak out if something would not work for them:

> Their reluctance to complete a diary didn't bother me too much. It showed they were willing to say "no" and also came up with an alternative (field notes written July 2015).

Some of discussions we had matched those from the pilot, the use of labels and diagnosis and what happens to the person after the carers can no longer care. This could be because there were some of the same people in attendance or because these are common themes. This time some of the reactions to certain topics were different; Sharon and Joanna both described how useful diagnosis and labels could be rather than always being negative. For Joanna reactions to her son's behaviour in public were more sympatric once she explained he has autism. To Sharon the diagnosis of autism added gravitas when she requested certain types of support for her son before this she felt dismissed by services as being over protective.

The part time nature of my PhD meant I had not had chance to write the field notes up until nearly a month after the first meeting therefore I decided to audio record them. The meeting felt positive, despite my initial nerves, particularly when they got their diaries to arrange a date for the next meeting. In my field notes I expressed concern that Joanna had dominated the meeting and I wanted to be aware of this and ensure everyone got their turn to speak.

Meeting 2: 16th July 2015

This meeting was attended by Dave, Sharon and Jenny; Sharon joined the meeting late. To begin with we discussed what we meant by communication. Firstly, Dave described the way his

daughter communicated. I reflected in my field notes some concern about this. The group are used to speaking on behalf of their adult children at meetings and reviews but I am reluctant to do the same in this study.

> I don't want this project is to be a "he said she said" where people tell me what their son or daughter has said. Not that I don't think the conversation matters but I don't think we do a research project on that because why would I not speak to the son or daughter (my field notes audio recorded 16th July 2015)

Previous learning disability research has been criticised for using parents as a proxy for people with learning disabilities (Kiernan, 1999). This study aims to explore the experiences of family carers rather than using carers as spokespeople for their children. However, the conversation did move on to exploring other types of communication particularly how service providers communicate with carers and how carers communicate with service providers. Dave expressed frustration that carers were not willing to make complaints to services. We considered why this may be and concluded carers are frightened of losing what support they do have and compromising the quality of care the person they care for receives. To Dave part of this anxiety stems from how intimidating the City Council can be even the fact that many of the meetings are held at the Town Hall can be off-putting for carers trying to engage.

Dave and Jenny had recently had positive experiences of interacting with a social worker; they joked it must be the same one. It was two different social workers and the carers identified good practice as someone who listens without discounting their ideas and suggestions. They appreciated not everything they asked for was deliverable but appreciated being listened to. They both the social workers were the first people they had spoken to recently who had not mentioned cost and money to them. These social workers demonstrated good understanding of their sons and daughters. In Dave's case by spending time with his daughter but did not insisting she stayed in the meeting which would cause her distress and for Sharon that they spoke to and acknowledge her son.

A reoccurring theme in my field notes is the considering how the discussions such as this about good practice could be turned in to research questions and how explicit I should make these considerations to the rest of the group. Throughout the field notes I express anxieties about drawing the conversations back to the research study but equally not wanting to dominate the group discussions. In these field notes I concluded that I should bring research questions and issues to the group, for example issues around ensuring the meetings were accessible, as otherwise it would be difficult to move the study on from being my study to a collaborative, group study:

One of the things I did suggest that the meeting is whether or not I should arrange follow meetings for people who couldn't attend and Sharon felt that that would be too....I think asking them things like that is better I think I should bring more things there to the group rather than thinking that I need to all of this smoothed out ready for the meetings because otherwise I really don't know how it's going to become their meeting rather than mine so I think I will keep dropping in research questions and research dilemmas because they are my co-researchers (my field notes audio recorded 16th July 2015).

In field notes I use the term "blanket policies" (my field notes audio recorded 16th July 2015) to describe policies in adult learning disability services that prioritise the person's status as an adult rather than reflecting their need. This is described by Twigg and Atkins as the "philosophy of learning disability services" (Twigg & Atkin, 1994) and results in carers being side-lined. One example of such a policy is people having to be present at their reviews even though for some people, such as Dave's daughter, this can be distressing. Sharon's example of this was that letters are always addressed to her son and he will take those letters and hide them without fully understanding the contents. This has led to issues where he has not paid money or provided information he needed to. The carers could understand these policies to an extent; non-disabled adults receive their own post, but struggled with the one-size-fits-all approach. At the end of the meeting, the group arranged a date for the next meeting appearing to me that they were happy to continue to be involved.

Meeting 3: 12th October 2015

I cancelled the meeting in September; I did not feel that the group were well enough established to meet without me there at this stage.

It proved very difficult to find an alternative date and I was concerned that we would lose momentum with members losing interest in the study. To reduce this risk, I arranged one to one meetings to ensure the co-researchers were still aware of the study.

This meeting was with Dave at the Department of Human Communication Sciences. I felt more confident meeting individually than I do with a group. In group meetings I struggled with my role in terms of how much to direct the conversation whereas meeting on a one to one felt more natural. This was the first meeting I audio recorded so I was aware that this may influence the flow of the conversation; I decided not to use the recorder for some parts of the meeting where Dave was describing his mental health problems:

> None of this was in the recorded section of the conversation we had because this conversation started with Dave telling me about some health problems he had and then getting upset it didn't feel that appropriate to turn the recorder on and interrupt the conversation. Also the conversation did feel like it changed when the recorder came on. Less of a flow and a bit more me asking him questions. So I think this conversation probably flowed a bit more by leaving the recorder out of it (My field notes audio recorded 12th October 2015).

Dave was a lot more open in this meeting describing not only his experiences as a carer but also his own mental health problems. He became quite tearful as he described the pressure he felt he was under. That said caring for his daughter, and her reliance on him, gave him purpose. He described a need to be out of the house, which I reflected later may be one of the reasons he decided to participate in the study. Dave expressed anxiety during the meeting as he had forgotten to submit a time sheet for one of the support workers he employed who then had not been paid. Dave is not in good health and now embarking upon becoming an employer. Another important event happening to Dave and his family was his daughter would be receiving 24-hour care. Previously support had been delivered 9:00 until 15:00, which came with issues:

> And they've got to respect that it's our house as well. They can't just say, "I want things to be done this way." Because we find that if they've picked something up they'll put it where they want to put it. And then we spend about two hours looking for where it is (Dave one to one meeting 12th October 2015)

However now someone would be present 24 hours a day, I asked during the meeting if he felt this support would be better for him and he replied "It is better for [DAUGHTERS NAME] (Dave one to one meeting 12th October 2015)".

218

This suggests that he does not want someone in house all of the time but knows it is better for his daughter.

Dave stated that he could quickly assess if a support worker offered a good level of care mainly by his daughter's reaction them. If they did not interact well with her she would express that she wanted them to leave. Dave described in great detail his experiences of services being insufficient for example not being able to get specialist equipment, such as the hoist, repaired over the weekend. He is very distrusting of the local authority describing them as a vindictive, powerful organisation that pulls rank against people with disabilities and their carers. He reemphasised his frustration that others carers were not as outspoken as he is, however he did acknowledge that this was something he had developed confidence in

> And like a lot of people, I didn't want to say something that would make things worse. And then I found out you can't make it worse (Dave one to one meeting 12th October 2015).

We discussed what happens when Dave and his wife can no longer care for their daughter, a topic that has been raised previously, not only do they not know what will happen but also they do not how to start to prepare. He mused that if their daughter tried to live away from home and the placement was unsuccessful they would have to start again to access the level of support they do now and he felt their daughter would no longer trust them. In my own reflections I noted that this had been an opportunity to get to know Dave better but was struck by how tired and stressed he was. That said he spoke very lovingly about his fun-loving daughter and her sense of humour. This meeting highlighted how this study relied on carers sharing personal information which could be upsetting for them.

Meeting 4: 22nd October 2015

I was unsure what to expect from this one to one meeting with Ayesha at her home as; 1) she had not been to any of the other meetings and; 2) this was the first meeting I had conducted away from the department.

As a sibling carer Ayesha has a different perspective to the rest of the group. She recounted an example of, despite being her brother's main carer; she was not allowed to sign a consent form when he was in hospital. The doctor selected the same option on the form that would be selected if her brother had arrived at accident and emergency inebriated. She was there with him but the paperwork would suggest he had arrived alone with no one to care for him. Being ignored or pushed out by professionals was raised regularly; Ayesha described it as "being ignored twice" (Ayesha one to one meeting 22nd October 2015), once as a carer and once as the

spokesperson for her brother. Ayesha raised the same issue the group had in which the opinions of the carer are viewed by service providers as being at odds with her brother's autonomy as an adult. As a result Ayesha being accused of mollycoddling him something she disagreed with strongly instead feeling she is acting in his best interest. It highlighted that carers and service providers can have very different ideas about what is in a person with learning disabilities best interests.

Ayesha was keen to explore different methods of participation as she was conscious of having not attended any meetings. We discussed how online forums, video or Skype might enable greater participation. The fluctuating health needs of her brother meant it could be difficult for her to commit to being out of the house on a regular basis.

I reflected later on the number of times Ayesha had referred to the study as being "my project", I considered options for encouraging others to accept some ownership of the study for example asking someone to take notes, or suggest meeting at a different location. As we discussed hospital admissions during this meeting I recounted my own experience of my son staying in hospital. I considered afterwards whether or not I should be comparing their experiences of carers of adults with my experience of being a parent to a young child. I worried that it could be seen as patronising or not a helpful comparison. This again highlighted the insider/outsider issue (Milligan, 2016) in which it is difficult for an initiating researcher to know their role within participative research group.

Meeting 5: 9th November 2015

The first group meeting since July 2015 meeting was held at the Department of Human Communication Sciences and audio recorded. As this was Ayesha's first group meeting I suggested we all introduce ourselves again. During her introduction Ayesha raised the issue of being a sibling carer meaning she did not have any rights this led to a discussion about carer rights over the adults they cared for. For carers to have legal rights to act on behalf of the person they care for they would need to apply for a court of protection, this is a legal process which involves the daunting prospect of attending court and presenting evidence. Dave highlighted that sometimes the professionals making decisions are not always familiar with the legal requirements and can give inaccurate information:

> It is very complicated and people who are making these decisions may not always make the right decisions because they don't understand the capacity legislation (Dave group meeting 9th November 2015).

220

At this meeting Jenny expressed her opinion that we would go on explore in many meetings; that caring for a person with learning disabilities is a unique caring role:

> It's very different though I think almost every other sort of carer is different from us because if you're looking after a partner it's you know you had a life with them probably before they got sick or...if you're looking after a parent you can probably see the end of it at some point whereas we have it from when our children were born we know that's it for the rest of our lives we've got that (Jenny group meeting 9th November 2015).

It is a lifelong commitment that can actually become more difficult as the person reaches adulthood as there is no one to coordinate services and act as a key contact whereas there was while that person was in education.

> My role is completely changing now or growing now instead of getting smaller as they get older it goes the other way (Sharon group meeting 9th November 2015).

However, as the role increases the carers authority and position in that relationship weakens. There is a difficult balance between treating the person as an adult whilst ensuring their safety and well-being. For Sharon this balance was exacerbated by the fact her son did not want her to know about his day-to-day activities. She understood his position and described disabled people as "public property" (Sharon group meeting 9th November 2015). She worked hard to balance his right to privacy with attempting to minimise risks.

Two issues about both support staff and the agencies that employed them were explored 1) the quality of care given by the individual and the group members agreed that they could recognise quickly how well that person was supporting their children or sibling and; 2) the quality of the agency itself. For example, how well the carers were kept updated about who will be coming to support, whether or not they returned telephone calls and whether they provided the information they said they would such as weekly timetables. To the group both the staff and information from these organisations lacked quality with staff members being changed at short notice, not reading the information about the person they would be supporting or leaving the organisation and no one informing the family.

During this meeting I noticed a slight tension between two members of the group I was unsure the most appropriate way to deal with this. I did not want anyone to feel uncomfortable during the meetings but equally wanted there to be room for open discussion and some disagreement. Neither were unable to express their views and so I decided to be aware of it in case it needed to be addressed but do nothing at this stage.

> They both seem able to hold their own Sharon seemed able to say "no that would work" and Jenny to be able to suggest that it might. I tried to, sort of, smooth things over by

suggesting the person centred approach would mean that people should get, would get the information in a way that they could handle it and those that couldn't wouldn't (My field notes recorded 9th November 2015).

Following this meeting I contacted Joanna by telephone and offered to meet her individually as she had not replied to any of my emails or SMS. Joanna did not get back to me or return my calls.

Meeting 6: 14th December 2015

Before this meeting, held at the University and audio recorded, I sent the group an email explaining that I intended to start this meeting with a discussion about research methods. This was an attempt to develop the conversations that we were having into potential research study questions. As I started to discuss this with the group Sharon's first question to me was what my ideas for the study were. I listed some possible outcomes from study such as presenting to service providers and carers, speaking to other carers about their experiences or making a video. However, I explained that these were only ideas and the final decision should be collaborative:

> I don't want to come in and say, "Right, we're all doing a video next week," because that just comes from me (Rachael group meeting 14th of December 2015).

I highlighted that they had more interaction with service providers than I did and therefore may be better placed to make decisions about what would have the most impact. When considering the role of the sibling carer following Ayesha's presence at the last meeting, all of the carers agreed that they did not want their other children to take on the caring responsibilities when they died. Dave described his younger daughter's resentment at having to care for her older sibling when she was a child.

A recurring phrase during the meetings was "talk the talk", Sharon mentioned it during this meeting to describe what service providers say they will do and what they are actually doing. For example the strategies they develop around people with learning disabilities getting into employment or living in the community; the support and funding for this to happen was not available so the strategies were not being enacted.

Following this meeting I reflected that I had made assumptions about the knowledge of the co-researchers. I had been very conscious of not directing the study too much but possibly had not directed it enough:

> These parents will talk, these parents will share experiences, these parents have shared experiences they are not going to pull themselves into an action research group that

was my bit and therefore maybe there is a responsibility to keep things directed (My field notes audio recorded 14th December 2017).

That said this meeting felt more light-hearted with the group joking with each other more, this could be because we had got to know each of the better. It felt as though this meeting was a turning point; moving from discussions about the carers experiences onto discussions about how to apply those experiences to a research study.

Appendix F Codes and Themes from Phase 1 Data

Initial Codes	Axial Codes	Themes
Jargon/legal terms	Institutional communication	Power imbalance
Services not listening	Poor communication	Power imbalance
They don't communicate with each other	Lack of communication	Navigating services
Not getting the right information	Lack of communication	Power imbalance/hidden agendas
Message unreturned	Lack of communication	Power imbalance
Feel ignored	Poor communication	Power imbalance
Use of labels	Intuitional communication	Power imbalance
How carers feel perceived	Not equal relationship	Power imbalance
They know best	Power of service providers	Power of services
Talking the talk/playing the game	Strategies	Navigating services
Carers coordinating services	Navigating services	Caring for an adult
Carer strategies to access support	Navigating services	Navigating hidden agendas
Service philosophy-independent living	Navigating services	Caring for an adult
Hidden agendas	Saving money/austerity	What is not being said
Inconsistent/limited resources	Navigating services	Hidden agendas
High turnover/lots of changes	Services not consistent	Navigating services

They 'get it'	Good practice	Power balance
Honesty	Good Practice	No hidden agenda
They listen even if they can't deliver	Good practice	Power balance
Out of city	Range of services	Caring for an adult
Respite	Range of services	Caring for an adult
Care in the home	Range of services	Caring for an adult/impact on siblings
Supported living	Range of services	Caring for an adult
Lifelong care	Unique caring role	Caring for a person with learning disabilities
Guilt over other children	Impact on siblings	Impact on siblings
Pressure and stress	Navigating services	Caring for an adult/Impact on siblings
What happens when we're not here	Unique caring role	Impact on siblings
Situation feels like it's getting worse	Saving money/Austerity	Impact on siblings

Appendix G   Ethics Application Phase 2 and Information Sheet

Ethics Application Phase 2

Section A: Applicant details

First name: Rachael

Last name: Black

Programme name: Human Communication Sciences

Module name: Post graduate research

Applying as: Postgraduate research

Research project title: Using participative research methods to explore the experiences of family members of people with learning disabilities

Section B: Basic information

1. **Supervisor(s):** Judy Clegg

2: Proposed project duration

Proposed start date: Sun 18 September 2016

Proposed end date: Tue 21 September 2021 3:

3: Suitability

Takes place outside UK? No

Involves NHS? No Healthcare research? No

ESRC funded? No

Involves adults who lack the capacity to consent? No

Led by another UK institution? No

Involves human tissue? No

Clinical trial? No

Social care research? No

4: Vulnerabilities

Involves potentially vulnerable participants? No

Involves potentially highly sensitive topics? Yes

Section C: Summary of research

1. Aims & Objectives

People with Profound and Multiple Learning Disabilities (PMLD) are described as "the most disabled" in our society (Mansell 2010). They have complex support needs resulting from extremely delayed intellectual and social functioning and associated medical conditions (Bellamy et al, 2010). The majority of people with PMLD live with their parents (Emerson, 2008). A study of parents of people with PMLD found that: 60% of parents spent more than ten hours per day on basic physical care. 48% received no support from outside the family to help with their care tasks (Mencap, 2001). Current social policy states that "carers will be respected as expert care partners" (DoH, 2010) however there is very little research about the needs of family carers of people with PMLD (Jansen et al, 2013). This study aims to address this gap in the research using participative research methods (PAR). PAR work on a cycle of action and reflection in which groups of co-researchers work together to address issues that are of mutual interest to them. PAR is a methodology which prioritises action and collaboration; however it also has a set of validity procedures to ensure the findings from the inquiry are accurate and robust. PAR practices include: Defining the research question and research design as a group of co-researchers. Deciding who will carry out which tasks, coming together as a group to reflect and share experiences. Working as a group to co-analyse data and deciding how and where the results will be shared. Using these research methods with family carers of people with PMLD will ensure that the research question is relevant to them and addresses the issues that they find pertinent. The researcher will act as initiating researcher who initially brings the group together and acts as a facilitator in the early sessions (however the co-researchers may wish to take on this role as the project progresses). This project consists of 2 phases and ethical approval was granted for the first phase in February 2014. The overall project aims are1) Involve family carers of people with PMLD into the research agenda around understanding the needs of people with PMLD and their carers 2) Identify the research agenda of family carers of people with PMLD around understanding the needs of people with PMLD and their carers 3) Integrate the identified research agenda in to a new research project. 4) Conduct the research project, evaluate it and disseminate findings. The first phase of this project has consisted of recruiting a group of family

carers and meeting regularly. It has been very difficult to recruit a group of family carers of people with PMLD so the criteria have been extended to family carers of people with learning disabilities. As a group, carers of people with learning disabilities, face unique issues as it is a lifelong caring responsibility and they can often feel isolated or side-lined by learning disability services (Twigg and Atkin, 1994) therefore this is still an appropriate group to work with using participative research methods. The research group has been meeting approximately once a month since June 2015. The group meetings have consisted of unstructured conversations which have been recorded and listened to by the postgraduate researcher. The postgraduate researcher has conducted qualitative analysis to identify themes in these conversations which have then been fed back to the group. The group worked collaboratively to decide how they would use these themes to form the basis of a subsequent, Phase 2, research project. This application is to gain ethical approval for the second phase of the project. For the Phase 2 research project, the group has decided they would like to explore the experiences of a wide range of family carers and service providers and that a survey will be an appropriate way to capture this information. The aim of the Phase 2 project is to explore how family carers and service providers feel during their interactions with each other. We felt this was an important theme as it came up regularly in the group discussions. The survey aims to 1. Identify whether family carers feel they are respected as expert care partners in their interactions with service providers 2. Explore what makes interactions with service providers a positive or negative experience for family carers 3. Explore how well service providers feel they meet the needs of family carers. 4. Explore how service providers feel they could work more effectively with family carers.

2. Methodology

Two short questionnaires have been devised for a) Family carers and b) Service providers. The surveys have been developed using an online survey builder called Survey Monkey. A link to the survey will be distributed via email to services for people with learning disabilities and their families (for example Mencap and the Carers Centre) and via online communities such as the Choice Forum. Service Provider surveys will be cascaded via a contact in the City Council. Family carers and service providers will receive an information sheet as an email attachment about their participation in the project. The survey contains a mixture of rating scales and questions that require a written response. The rating scales will be analysed using SPSS while the written responses will thematically analysed using NVivo. The family carers in the research group will be involved in co-analysing the responses. They will be involved with reading through the responses and identifying themes in the data we get with support from the post graduate researcher.

Personal Safety

Raises personal safety issues? No

Section D: About the participants

Recruiting Potential Participants

Potential participants will either be sent an email with a web link to the survey and the information sheet or they will be able to see the link on an online forum. The information sheet explains the project and how their response will be used. This will also be reiterated in the first four questions of both surveys which are 1) I have had the opportunity to read the Information Sheet 2) I understand that I am under no obligation to complete this survey 3) I understand that I can contact Rachael Black at any time and withdraw from this project 4) I understand that by completing the survey I am consenting to having my answers analysed and possibly used (anonymously) in presentations or reports Participants will then be able to choose if they wish to complete the survey.

2.1 Advertising methods Will the study be advertised using the volunteer lists for staff or students maintained by CiCS?

No

3. Will informed consent be obtained from the participants? (i.e. the proposed process)

No Information will be provided at the start of the survey which explains that by submitting the survey they are consenting to having their responses analysed and the data potentially being used in future reports and presentations (though the participant will not be identifiable in any way). This is instead of a separate Consent Form. This way the person does not have to send back any personal information or details.

4. Payment Will financial/in kind payments be offered to participants?

No

5. What is the potential for physical and/or psychological harm/distress to the participants?
There is very low risk for physical and/or psychological harm / distress to participants. Interaction with services may be an emotive subject for some people if they feel they (or the person they care for) has been poorly treated. Participants may be concerned about anonymity and confidentiality How will this be managed to ensure appropriate protection and well-being of the participants? The sensitivity of the topic will be addressed by the following: a) Participants

are under no obligation to complete the survey if they feel the topic is too sensitive for them. b) None of the questions are compulsory so they do not need to answer all of the questions if some are upsetting for them. c) The contact details of the postgraduate researcher are provided if they wish to contact her to speak in more detail about their responses. She can then signpost local advice services for carers. Anonymity and confidentiality of data will be addressed by the following a) Participants do not need to include their name on the survey, however if they do this will not be stored with their responses b) The information sheet will explain how the data will be stored and how anonymity and confidentiality will be ensured. c) The contact details of the postgraduate research student will be on the survey and Information sheet in case anyone would like to discuss any of the above issues before and after completing the questionnaire.

Section E: About the data

1. Data Confidentiality Measures

Participants are not required to disclose any identifying details when completing the survey. They are asked if they would wish to provide contact details but this is entirely at their discretion. If anyone does provide their contact details this will be stored separately from their survey responses. The family carers research group will be co-analysing some of the data therefore if participants have given their names and contact details these will be removed before the research group see the responses. This will reduce the risk of the research group recognising anyone they know through their responses. The postgraduate researcher will regularly emphasise the importance of keeping information confidential to the group.

2. Data Storage

The data received will be electronic. All electronic data will be stored on the university network drive. This is based on advice received by CICs (Corporate Information and Computing Service) on Thursday 9th January 2014 about best practice when securely storing data (see email in supporting documents). Storing data on the network drive is recommended as it is regularly backed up so prevents the risk of information being lost and it requires a password to access. If the participant provides their name or contact details these will not be stored with their responses but separately in a password protected document. Any printed data will be stored in a locked filing cabinet in a locked office. It will be destroyed via confidential waste when it is no longer required.

Participant Information Sheet

Project Title: Researching the experiences of family carers of people with learning disabilities.

You are being invited to take part in a research project led by the Department of Human Communication Sciences.

Please take the time to read this information sheet so that you know what the project is for and how the research will be carried out. If you have any questions about the project please do not hesitate to contact Rachael Black (PhD student) using the contact details at the end of this information sheet.

Background

Over the last year Rachael and a group of family carers of people with learning disabilities have been meeting regularly to discuss the issues faced by family carers. These discussions have been very interesting however we are aware that we are only a small group. We would be really interested to hear about the experiences of other family carers. This will help us to understand carers experiences and ensure a range of experiences are considered. To do this we have created a survey that we would like to invite you to complete.

What will happen if I decide to take part in the project?

If you would like to take part in the project then please complete the online survey by clicking on the link below

https://www.surveymonkey.co.uk/r/QJXTFVZ

If you would prefer to complete a paper copy of the survey then please contact Rachael who will be able to send one to you, along with a stamped addressed envelope.

How long will the survey take?

We have tried to keep the survey quite short so that it does not take up too much of your time. The survey questions are a mixture of rating scales and ones that require a written response. The survey should take no more than 15 minutes.

Do I have to take part in the project?

No. It is entirely up to you, you can choose not to take part.

You are under no obligation to take part and if you choose not to it will not affect any of the services that you or your family members use.

What will happen to this information?

All of your information will be stored securely. Information received online will be saved on a password protected computer. Any written information will be stored in the Department of Human Communication Sciences in a locked filing cabinet in a locked office. Information may be used in reports and presentations. However your name and details will not be used and no-one will be able to identify you from the information used. All the written and recorded information that has been collected will be destroyed on completion of the project.

There is a space on the survey to include your name and contact details but it is entirely up to you if you choose to complete this. Your name and contact details will not be saved with your survey responses.

Who has ethically approved this?

This project has been ethically approved by the Department of Human Communication Sciences Research Ethics Review Committee within the University of [NAMES CITY].

Contact for Further Information

For more information about this project please do not hesitate to contact Rachael Black (Postgraduate research student) on the details below

Research student: Rachael Black

                          Address: Department of Human Communication Sciences

                          [CONTACT DETAILS PROVIDED ON ORIGINAL FORM].

This project is supervised by Dr Judy Clegg and Dr Sarah Spencer.

Supervisors: Dr Judy Clegg   Dr Sarah Spencer

What if I would like to make a complaint?

You can speak with Rachael or her supervisors under any circumstances.

If you would like to speak to someone unrelated to the research team, you can contact the Ethics Administrator of the Department of Human Communication Sciences:

Dr Traci Walker

[CONTACT DETAILS PROVIDED ON ORIGNAL FORM]

If you are not satisfied with the responses from these individuals, you can contact the Office of the Registrar and Secretary at the [CONTACT DETAILS PROVIDED ON ORIGNAL FORM]

Finally, we would like to take this opportunity to thank you for taking the time to read this information sheet and considering taking part in this project.

Appendix H   Summary of Survey Design Discussions and Emails

Month	Type of contact	Discussions	Changes made
January 2016	Meeting	Decided, as a group, to design two surveys; one for family carers and one for service providers	
March 2016	Meeting	Started to discuss what we would cover in the survey and the type of questions we could include. Rachael took note of the suggestions and created a first draft of the family carers survey	
March 2016	Email	First draft of family carer survey shared with co-researchers (14th March 2016). Feedback received from Jenny and Sharon via email	Removed questions asking carers to rank the level of need of the person they care for from mild to profound as Sharon felt this was unnecessary. She emailed to say that she would struggle to label her son using those terms and did not feel we should expect other carers to do this. Decided instead to ask carers to select from a list of options what type of support the person needed. We agreed to include this question so that we could see if carers of people with more complex needs had different to those who cared for someone with less complex needs. Sharon also felt there was too much repetition in the wording and that it should be cut down. Jenny suggested changing the likert scale headings from strongly agree to strongly disagree to a rating of frequency (never to always). She stated that as she interacted with so many service providers it would be very difficult for her to answer these questions as she had hugely variable experiences with them. She felt a scale of

			frequency would be more appropriate.
April 2016	Meeting	At the meeting on the 11th April we discussed the content of both surveys and Jenny's suggestion that we changed the likert scale heading. The group agreed that Jenny's suggestion was more appropriate. Jenny also highlighted that as she is a carer to two sons' she would either need to complete the survey twice or just complete it about one of her son's. She would not be able to give the same responses for both sons	We changed the settings on the survey so participants can complete it more than once. This will also be highlighted in the Information sheet.
April 2016	Email	A second draft of the family carer sent to the co-researchers (14th April 2016). Here I raised the issue that I was struggling to define the different types of services that carers may access and asked for help from the group. The suggestions I made were Local authority Health Other Service Providers Dave responded to say these headings were fine and that he was happy with all of the questions. The first draft of the Service provider survey was shared via email on 21st April 2016 The second draft was sent on 28th April 2016.	Jenny suggested we amend the wording next to comment boxes from "please use this space to give more information" to "Please use this space if you wish to provide more information" so it did not seem like participants were obliged to fill in the comments box. Dave suggested a change to wording from "family carers should be included in meetings about the person they care for" to "family carers should be included in meetings about the person they care for, with the person's permission". He also suggested an additional question for the likert scale " Family carers are respected"

May 2016	Email	Dave responded to say he felt the Service Provider Survey was fine	
May 2016	Conference	Jenny, Dave and I presented at the Challenges and Best Practice in Co-Production Conference. Following this we decided to make some amendments to the Service Provider survey so that it did not seem too negative towards service providers. We felt that by acknowledging there may be more that carers can do we would facilitate a more constructive relationship with the service providers. If they felt blamed they may not wish to engage with the group	
May 2016	Email to group	Shared the survey with the new questions via email (19th May 2016). Sharon responded to say This looks great and I think the extra questions are a very positive addition (email received 19th May 2016). Jenny and Dave agreed via email.	Included two new questions 1) Do you think there is anything more your organisation could do to support family carers? 2) Do you think there is anything that family carers could do to work more effectively with your organisation?
May 2016	Email to supervisors	Shared via email with my PhD supervisors. Sarah (2nd Supervisor) suggested adding some counter-items to the service provider email such as "family carers are not always the expert" to try and discourage participants selecting strongly agree and not reading the statements. For the family carer survey Sarah suggested describing "emotional support" in more detail. This is one of the types of support carers can select when saying what type of support the person they can for needs.	Two counter statements were added and shared with the group. These were: 1) Family carers are not always the expert 2) Family carers are not always the right people to make decisions about the person they support. Examples were added to demonstrate what was meant by "emotional support". These were: Check the person is OK, listen to the person, talk to them, reassure them, provide advice and encouragement.

		My first supervisor agreed with Sarah's feedback	
June 2016		The piloting of the survey started in June 2016. This is described in more detail in the section 'Piloting the Survey'.	As a result of piloting the survey we 1) Added comments/other boxes to the Service Provider Survey 2) Amended some of the wording such as describing what is meant by "services" and re wording the "type of support" question, as there was some overlap in the types listed.

Appendix I   Final Survey Questions

Family Carer Survey

Please read the following statements and tick if you agree

1. I have had the opportunity to read the Information Sheet
2. I understand that I am under no obligation to complete this survey
3. I understand that I can contact Rachael Black at any time and withdraw from this project
4. I understand that by completing the survey I am consenting to having my answers analysed and possibly used (anonymously) in presentations or reports

The person you care for:

Are you a carer for a person with learning disabilities?

- Yes
- No

How old is the person you care for?

- Under 18
- Aged 18 to 24
- Aged 25 to 49
- Aged 50 and over

What kind of support does the person you care for need? Please tick all that apply:

- Personal care support-bathing, toileting, getting dressed
- Support around the home-preparing meals, keeping it clean, laundry etc
- Medical support-support to take medication, order repeat prescriptions
- Support to go out-attend leisure groups, go shopping, attend doctor/dental appointments, go to the hairdressers etc
- Support to keep safe
- Emotional support-check the person is OK, listen to the person, talk to them, reassure them, provide advice and encouragement Support to coordinate services-phone calls, attending reviews
- Financial support-checking benefits, paying bills, paying support staff Support with eating and drinking
- Support to move around-pushing someone's wheelchairs, supporting them to use the hoist etc

Please use this space to provide more information about any of the above

Does the person you care for live with you?

- Yes
- No

What is your relationship with the person you care for?

- Parent
- Sibling
- Grandparent
- Aunt or uncle
- Other relative (please specify in the box below)
- Friend
- Other (please specify)

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Services you, and the person you care for, use

Does the person you care for use any services to support their needs (other than that provided by friends and family)?

- Yes
- No (please go to question 8)

If yes: which services do they get their support from? Please describe in the box below

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What funding does the person you care for receive? Please tick all that apply

- Local authority
- Health
- Education
- No funding received
- Rather not say
- Other (please specify)

Communication with services

Thinking about your interactions with **local authority services** (for example social services, housing, finance etc.). Please rate the following statements on a scale from 1 (never) to 5 (always). If you do not use these services, please move on to the next question.

	1 Never	2 Rarely	3 Sometimes	4 Often	5 Always	Not Applicable
When I call I know someone will get back to me in a day or two						
When I send an email I know someone will get back to me in a day or two						
I know that if I raise an important issue it will be taken seriously						
I know that if I raise a more minor issue it will be taken seriously						
I feel that I am listened to						
I feel that I receive the information I need when I ask for it						
I feel that I receive the information I need without having to ask for it						
I feel that my needs as a carer are respected						
I feel that my knowledge as a carer is respected						
I trust what the services are saying						
I feel included in decisions made about the person I care for						
If services say that something will be done I trust that it will be done						

Please use this space if you wish to provide more information

Thinking about your interactions with **health services** (for example GP's, respite, physios). Please rate the following statements on a scale from 1 (never) to 5 (always). If you do not use these services, please move on to the next question.

	1 Never	2 Rarely	3 Sometimes	4 Often	5 Always	Not Applicable
When I call I know someone will get back to me in a day or two						
When I send an email I know someone will get back to me in a day or two						
I know that if I raise an important issue it will be taken seriously						
I know that if I raise a more minor issue it will be taken seriously						
I feel that I am listened to						
I feel that I receive the information I need when I ask for it						
I feel that I receive the information I need without having to ask for it						
I feel that my needs as a carer are respected						
I feel that my knowledge as a carer is respected						
I trust what the services are saying						
I feel included in decisions made about the person I care for						
If services say that something will be done I trust that it will be done						

Please use this space if you wish to provide more information

Thinking about your interactions with **other service providers** (these are any services not provided by the local authority or health for example support agencies, supported living, employment support, respite etc.). Please rate the following statements on a scale from 1 (never) to 5 (always). If you do not use these services, please move on to the next question.

	1 Never	2 Rarely	3 Sometimes	4 Often	5 Always	Not Applicable
When I call I know someone will get back to me in a day or two						
When I send an email I know someone will get back to me in a day or two						
I know that if I raise an important issue it will be taken seriously						
I know that if I raise a more minor issue it will be taken seriously						
I feel that I am listened to						
I feel that I receive the information I need when I ask for it						
I feel that I receive the information I need without having to ask for it						
I feel that my needs as a carer are respected						
I feel that my knowledge as a carer is respected						
I trust what the services are saying						
I feel included in decisions made about the person I care for						
If services say that something will be done I trust that it will be done						

Please use this space if you wish to provide more information

Please think about the last interaction you had with services (this could be any of the services you or your family use). The interaction could be by email, telephone or face to face. Use the box below to complete the following sentence.

My last interaction with services left me feeling.....

In what ways do support services make your life easier?

In what ways do support services make your life more difficult?

Is there anything else you'd like to tell us?

About you

How old are you?

- 18 years and under 19-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85 years and over

What is your gender?

- Female
- Male
- Rather not say

Please describe your ethnicity

{Drop Down Menu on Survey Monkey}

Any other ethnic group (please specify)

Please enter the first part of your postcode (e.g. S35)

246

Would you like to be kept informed about this research project? This could include being invited to take part in future stages of the project and receiving a summary of our results. If you would then please provide your name and contact details. Please note that all information provided in this survey will be treated in the strictest confidence.

Name

Telephone number

Email address

Thank you so much for taking the time to complete this survey

Service Provider Survey

Please read the following statements and tick if you agree

	I agree	I disagree
I have had the opportunity to read the Information Sheet		
I understand that I am under no obligation to complete this survey		
I understand that I can contact Rachael Black at any time and withdraw from this project		
I understand that by completing the survey I am consenting to having my answers analysed and possibly used (anonymously) in presentations or reports		

About your work

Do you work for a service that supports people with learning disabilities and/or their carers?

- Yes

- No

What kind of service do you work for?

- Local authority

- Charity

- Health

- Other service provider

- One to one worker employed by family

- Other (please specify)

What is your job title?

[   ]

How long have you worked with people with learning disabilities?

- Less than 1 year
- 1 year to 5 years
- 6 years to 10 years
- 11 years to 20 years
- Over 20 years

Working with family carers

Please rate how much you agree with the following statements on a scale of 1 (strongly disagree) to 5 (strongly agree)

	1 Strongly disagree	2 Disagree	3 Neither agree or disagree	4 Agree	5 Strongly agree	Not Applicable
Family carers should be considered to have expert knowledge in the person they care for						
Family carers should always be included in meetings about the person they care for (if this is appropriate and with the permission of the person they care for)						
The concerns of family carers should always be taken seriously						
The organisation I work for makes it clear how we should work with family carers						
If a family carer leaves a message it is my priority to get back to them						
I feel that I have a good relationship with the family carers I work with						
Family carers are not always the experts						
I make it a priority to ensure family carers receive the information they need						
The organisation I work for values the knowledge that family carers have						
Family carers are not always the best people to make decisions about the person they care for						
The organisation I work for respects family carers						

Please use this space to make further comments

Think about the last interaction you had with a family carer (this could be by telephone, email or a face to face meeting). Please complete the following statement:

The last interaction I had with a family carer probably left them feeling.....

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Why do you think they felt like that?

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Do you think there is anything more your organisation could do to support family carers?

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Do you think there is anything that family carers could do to work more effectively with your organisation?

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Is there anything else you would like to say?

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About you

Are you...?

- Male

- Female

- Rather not say

How old are you?

- 18-29 years

- 30-44 years

- 45-60 years

- 61 years and over

Please describe your ethnicity

{*Drop Down Menu in Survey Monkey*}

Please enter the first part of your postcode (e.g. S35)

Would you like to be kept informed about this research project? This could include being invited to take part in future stages of the project and receiving a summary of our results.

If you would then please provide your name and contact details. Please note that all information provided in this survey will be treated in the strictest confidence.

Name

Telephone number

Email

Thank you very much for taking the time to complete this questionnaire.

Appendix J   Organisations contacted about sharing the Family Carer Survey

Organisation	Type of contact	Date first contact made	Will they share the survey? Yes/No/No response
Mencap	Email	22/09/2016	Yes
Challenging Behaviour Foundation	Email	08/09/2016	Yes
Parent Carer Forum	Email	08/09/2016	Yes
Sharing Caring Study	Email	08/09/2016	Yes
Choices Forum	Online Forum	12/09/2016	Yes
Hesley Woods (Home Farm Trust run village)	Email	12/09/2016	Yes
Carers Special Interest Forum	Email	15/09/2016	Yes
Paces	Email	12/09/2016	Yes
Promoting a More Inclusive Society (PAMIS)	Email	12/09/2016	No Response
British Institute of Learning Disabilities (BILD)	Email	12/09/2016	No Response
Carers UK	Email	12/09/2016	No, they emailed to explain that they were contacted a lot to share surveys so therefore would only share surveys that were part of their own funded research studies. They were conscious of not contacting the carers they support with too many requests for information.
Home Farm Trust	Email	12/09/2016	No Response
Friends Together	Email	15/09/2016	No Response
Autism Plus	Email	15/09/2016	No Response
National Autistic Society	Email	12/09/2016	No Response
Down Syndrome Association	Email	12/09/2016	No Response
Association for Real Change	Email	12/09/2016	No Response

MECOPP Carers Centre	Email	12/09/2016	No Response
Pakistani Muslim Centre	Email	12/09/2016	No Response
University Carers Group	Email	01/09/2016	Yes
Muslim Autism group	Phone/Email	20/10/2016	Yes
IBK Initiatives	Email	20/10/2016	Yes
Carers Centre	Email	Sep-16	Yes

Appendix K Organisations contacted about sharing the Service Provider Survey

Organisation	Type of contact	Date contact made	Will they share the survey? Yes/No/No Response
Affinity Trust	Email	22/09/2016	No response
United Response	Email	22/09/2016	Yes
Leonard Cheshire	Email	22/09/2016	No response
Sanctuary Housing	Email	22/09/2016	No response
Keyring	Email	22/09/2016	No response
Citizenship First	Email	15/09/2016	No response
Mears Group	Email	22/09/2016	No response
Dimensions	Email	22/09/2016	No response
Thera North	Email	22/09/2016	No response
Community Integrated Care (CIC)	Email	22/09/2016	No response
Disabled Go	Email	22/09/2016	No response
Mencap	Email	22/09/2016	Yes
Patient Liaison Team	Email	22/09/2016	Yes
Challenging Behaviour Foundation	Email	08/09/2016	Yes
City Council	Email	08/09/2016 12/2/17	Yes
Parent Carer Forum	Email	08/09/2016	Yes
Sharing Caring Study	Email	08/09/2016	Yes
Choices Forum	Online Forum	12/09/2016	Yes
Hesley (Home Farm Trust run village)	Email	12/09/2016	Yes
Lynx Services	Email	15/09/2016	Responded with results to their own carer's survey. I believe they had misunderstood my request and thought I was asking for details of their survey. I responded to clarify but received no further response.
Potens UK	Email	15/09/2016	No response

Carers Special Interest Forum	Email	15/09/2016	No response
Disability Link Nurses	Email	04/10/2016	Yes
Derbyshire County Council	Email	20/10/2016	No response

Appendix L Initial Coding of the Survey Data

1) **Support**

    a. Funding

    b. Paperwork

    c. Crisis

    d. No Support/Lack of support

    e. Culture of services

    f. (Not) Fit for purpose

    g. Carer Need

    h. Person being cared for need

    i. Carers liaising with lots of different services

    j. Staffing/training

    k. Positive Behaviour Support

2) **Emotional Impact on Carers**

3) **Carers feeling dismissed/pushed out**

4) **Funding**

5) **Crisis**

6) **Knowledge of service providers**

7) **Positive experiences**

8) **Support (or lack of) for carers**

9) **Media portrayal of people who use support services**

10) **Health services-e.g. changing appointments regularly**

11) **Ways services can improve**

    a. Option and choice for people

    b. Increase funding

    c. Stop cutting services/staffing

    d. Respect carers

    e. Teamwork-include carers and person

    f. Training for staff

    g. Accountability

    h. More flexible and responsive services

    i. Reliability and continuity of services

    j. Listen to carers

    k. More person centrered support

    l. Services working/communication together better

12) Services are inflexible

13) Heath services

14) Communication

    a. Reviews

    b. Not joined up

    c. Not doing what they say they will

    d. Listening

    e. (Lack of) trust

    f. Suggestions for improvement

    g. Carers let out

    h. Poor communication

    i. Repeating self

15) Benefits of services

a. Access to the community-for the person

b. They don't

c. Staffing

d. Included/involved/ listening

e. Employment for carer

f. Quality of life-retirement. Life outside caring

g. Providing good support

h. Contact-someone to call

i. Confidence the person is well cared for/trust

j. Services having knowledge/answers

Appendix M Histograms showing Distribution of Survey Data

Histogram 1: Family carer responses related to Local Authority (LA) Services

Histogram

Mean = 22.6
Std. Dev. = 15.217
N = 113
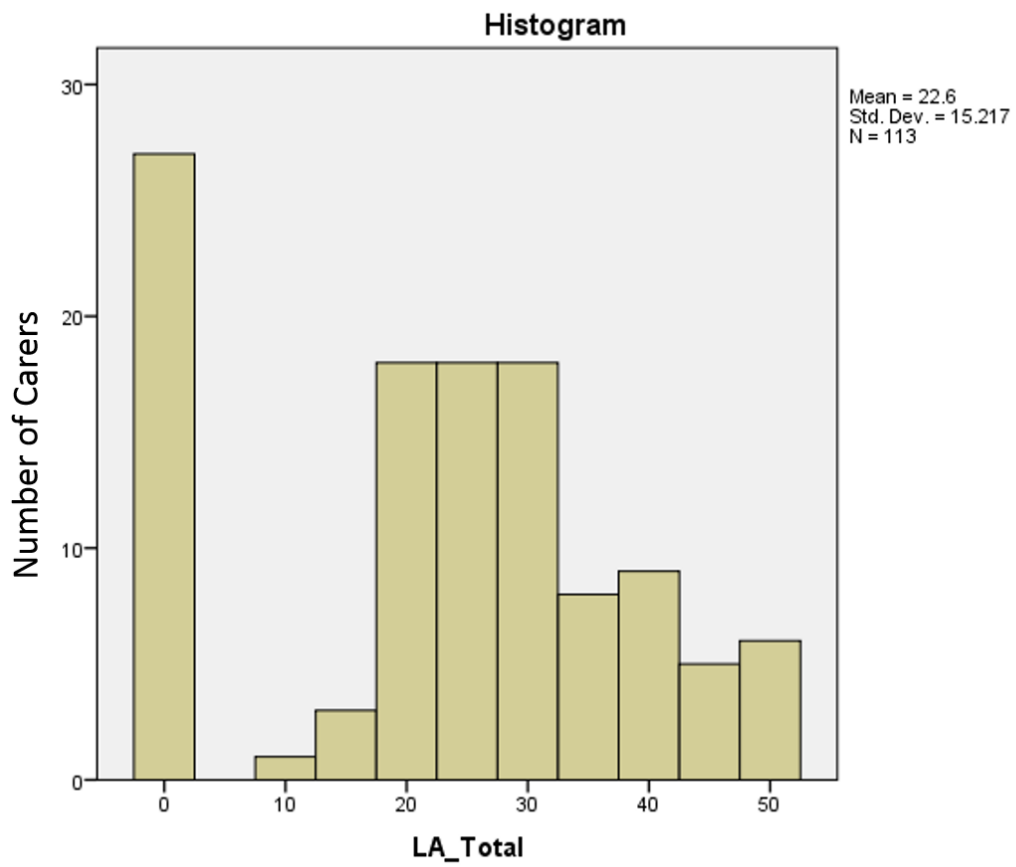
Histogram 2: Family Carers Responses relating to Health (H) Services.
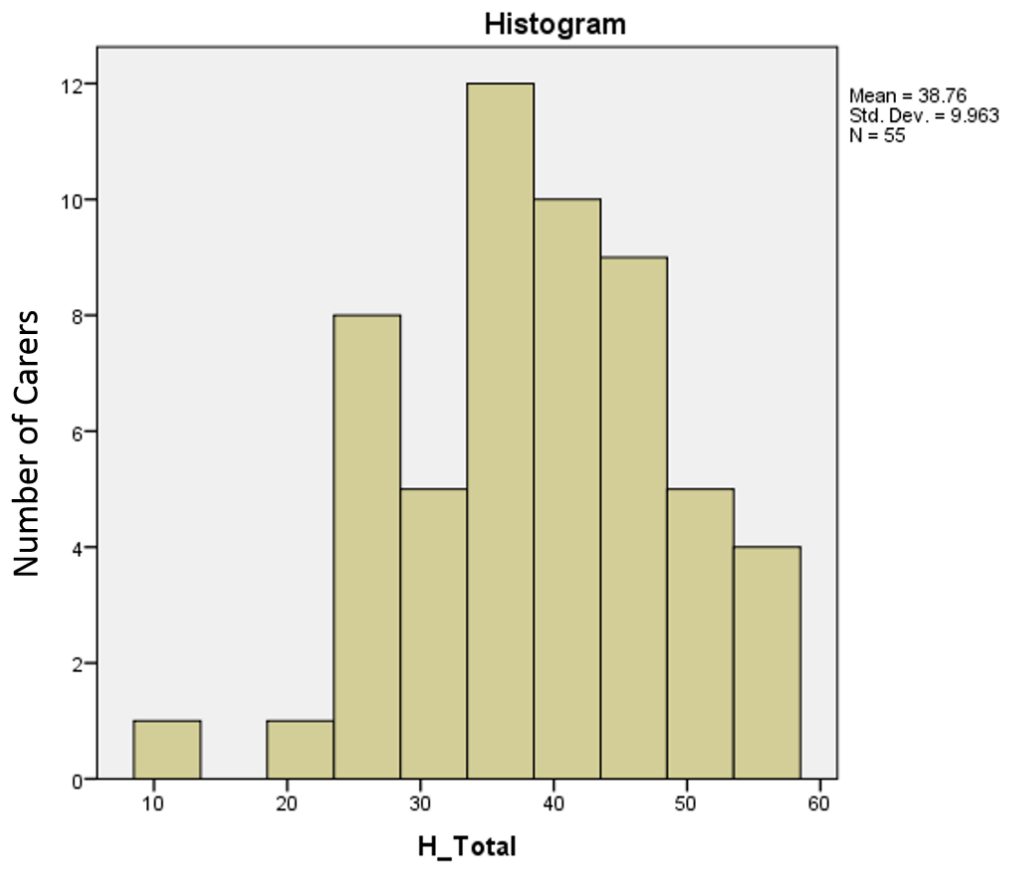
Histogram 3: Family carers **responses relating to Other (O) Services**

Histogram

Mean = 38.71
Std. Dev. = 12.541
N = 55

O_Total

Number of Carers
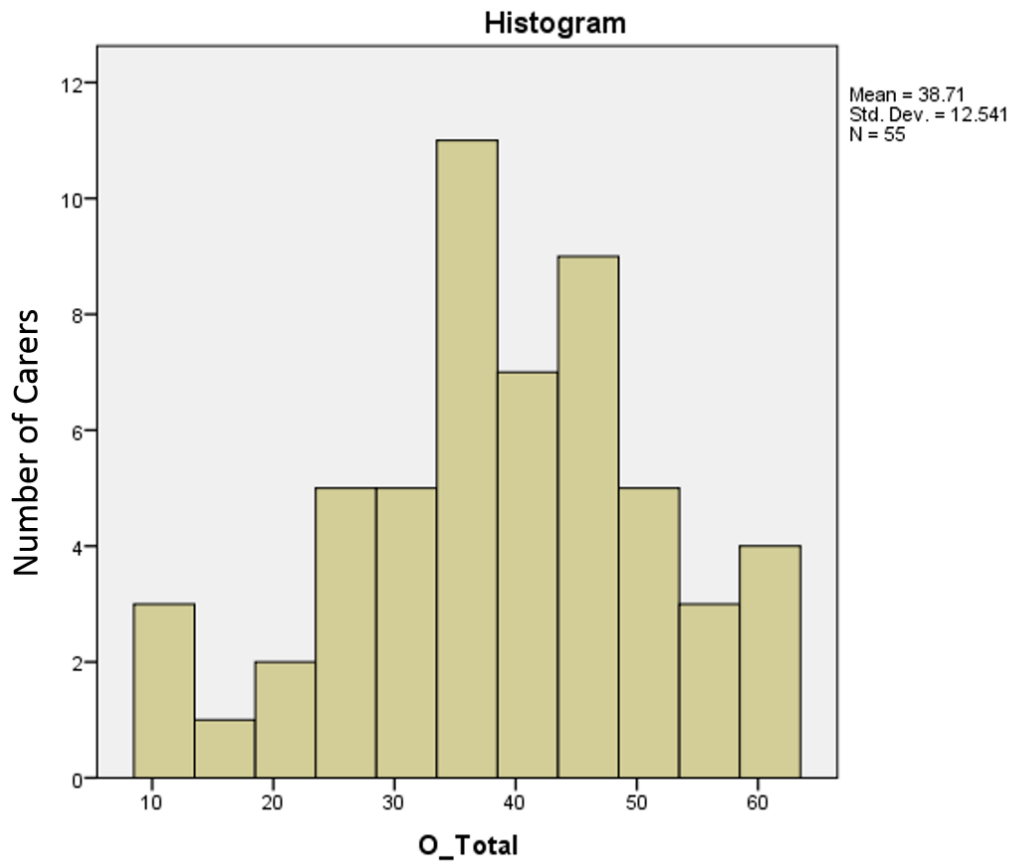
Appendix N Co-Produced Event to Share Findings

Disseminating Findings

Whilst analysing the survey data the research group would regularly discuss how we would share the findings and who with. We considered whether we should feedback to carers and service providers separately or if we should invite both groups to the same event. Dave is very active online, particularly on blogs and forums about social care and support for carers so would often receive invitations to participate in research that was happening at other universities; he also suggested that we may want to make contact with and feedback to other researchers. The conversations continued over several meetings until Sharon suggested, at the meeting in March 2017, that we organise a co-productive event. Rather than just feeding back what we have found out we then ask participants what they feel should happen next. As this is an action research method we were aware that we needed to produce an action and could use the event to test our suggestions and recommendations. We decided that it would be most effective to have both carers and service providers at the same even to hear each other's viewpoints. It would also be a neutral setting as neither group had arranged the meeting.

In June 2017 I made contact with the local City Council before the event to explain the project and request a meeting. I was put in contact with the Practice Development Officer and arranged to meet her. This meeting was to give her more information but also to investigate how to maximise the impact on service providers within the local authority. She suggested many internal mechanisms, such as the council intranet, where they could share anything that we produced as a result of the event. I suggested we might create some guidelines for working with family carers and she suggested calling them standards so that they did not feel optional but an expectation.

I applied for funding for the event so that we could hire a venue, provide refreshments and print flyers. My applications to the University's Festival of Social Science and the Wellcome Trust's Public Engagement Fund Award were both unsuccessful. However, I was able to secure some funding via my university department. As a group we were all involved in the planning but often I would produce something and then share it with the group for their feedback, for example I developed a website, designed a flyer and created the presentation. These were all done in collaboration with the group but due to only meeting every 4 to 6 weeks it would have taken several months if I had only waited for our meetings to create these materials.

As a group we decided that we would refer to ourselves as Carer Voice and to the event as Working Together. We described it as a workshop for service providers and carers of people with learning disabilities, to try and emphasise that we would be expecting the group to participate in discussions and contribute to the event. For the running of the event we decided to present our findings as a group and then break into tables to discuss a series of questions. We decided to have a facilitator for each table to try and ensure the group discussed the questions we had set and that if there were any specific grievances that someone wanted to discuss they were given a time to do this but did not dominate the entire discussion. As well as the three members of the researcher group my two supervisors and a Research Associate in the Department of Sociology also agreed to facilitate a table each. It was agreed that I would move amongst the tables and be on hand to deal with any other issues, for example people arriving late and putting out refreshments. I also took photographs of the event. We had discussions about where the event could be held; we wanted a neutral venue that was not connected to any particular service. Some of the fire stations in the local area offer free rooms for public events. I visited some of the rooms and fed back to the group. I booked the room in the city centre so that it could be easily reached by public transport and was near to public parking. The room held approximately 33 people.

The event was held in October 2017 from 10:30 until 1:00. We chose these times as often day opportunities for people with learning disabilities begin between 9:00 and 10:00 so family carers could come to the event while the person they cared for was at their day time opportunities. This is obviously not the case for everyone but we felt that a later start time increased the potential for carers to be able to attend. The event was advertised in the Carers Centre newsletter, at various meetings and via service providers known to the research group, for example Home Farm Trust. We allocated 40 tickets, as we assumed some people would not be able to attend on the day, half for service providers and half for family carers. We managed our bookings using the event manager website Eventbrite. All 40 tickets were booked prior to the event.

On the day of the event 32 of the family carers and service providers who had booked tickets attended and one family carer who had seen the event advertised in the Carers Centre Newsletter but not booked in advance. The table below shows the list of attendees from service providers and which services they were employed by.

Service Providers Attendees and Employers

Attendee	Organisation

1	Sharing Caring Project
2	Carers Centre
3	City Council
4	City Council
5	NHS Clinical Commissioning Group
6	Mencap
7	Mencap
8	Potens
9	Lifeways
10	Lifeways
11	Lynx Care
12	Friends Together
13	Friends Together
14	Home Farm Trust (HFT)

Everyone was given a name badge with a coloured sticker; this sticker denoted which of the tables they were sat at. Before the event I had allocated seating so that each table had a mixture of family carers and service providers. The event started with a joint presentation by the group which I had started but we had developed and practised during our meetings. We fed back our survey findings but also what we thought had worked well about working co-productively. We then introduced the group activities and the attendees worked on their own tables. There was one hour and 45 minutes for group discussions and then each table were invited to feedback. They were asked to identify one key point so that we could ensure all tables had a turn to feedback. However, we had enough time to take several points from the tables. Each facilitator had flip chart paper and a note pad to take notes. The feedback at the end was also recorded on flip chart paper. I took all of this away and typed it up. Lunch was served at 1:00 and all the attendees stayed to eat lunch and talk amongst themselves.

The Monday after the event, which was held on a Friday, I sent a feedback form to the group that I had developed via Survey Monkey with agreement from the research group. A further email was sent one week later reminding attendees to complete the form. I identified on the feedback forms which were from carers and which were from service providers to see if their responses differed. I also asked the facilitators to complete a feedback form.

Disseminating Findings: Feedback

Findings from the Event

From the event we gathered written notes, from the flip chart and facilitators notebooks. We also asked each person to complete a post it note with their response to the question 'what will you change as a result of attending today'. We took photographs; one carer made it clear they did not want to be photographed so any pictures they were on were deleted. The notes from the day were typed up and grouped them under the headings:

1) Recommendations
2) Communications
3) What Works
4) What does not
5) Long term changes

The themed notes are shown in the table below. A key piece of feedback from the event was that some of the service providers who attended did not feel that the negative survey findings applied to the service they delivered. They believed that this feedback related to statutory services rather than small service providers such as their own. They reported that they often had many of the same frustrations as carers when they tried to get information from and communication with statutory services.

There was a clear desire from carers for a named key worker and also for named care coordinator who could liaise with all the services the person they cared for used rather than this relying on family carers. One carer had been involved in the development of the City Council's Co-Production Charter. The majority of the group did not know this document existed so wrote on their post it notes that their action following the event would be to access a copy of it.

Themed feedback from the Working Together Event October 2017

Recommendations	Communication	What works	What does not	Long term changes
Have named person who co-ordinates services	Key person/point of contact	Autonomy for social workers-not always having to go back to a manager.	When someone becomes health funded social care has nothing more to do with them	Named social worker/key worker
Satisfaction Surveys-*USE* the information! Feedback how it is used	Services to do what they say they will	Learning Disability Partnership Board	Decision specific advocacy-need more general advocacy	Joining up of health and social carer at a systems level
Regular communication-not just at annual reviews	Communication *between* services	Good communication with carers and the person	Short-term thinking-carers are here for decades.	Autonomy for social workers
Working together-all support services come to reviews.	Clear definitions e.g. what is "wellbeing"	Care coordination-no longer seems to happen	Who provides the emotional support? Currently only carers.	The person doing the assessment liaising with the service provider in the long term
Be very clear *why* a decision has been made. Why something has/has not been done	Communication between statutory and private providers is poor-private providers do not get the info they need.	When carers are included in emails, meetings and receive notes and minutes.	High staff turnover, low pay. When it is "just a job"	High quality planning for what support is needed when the carer can no longer care for the person
Don't call it co-production unless it is.	Having to be "bleak", this impact on carers.		Carers feel "side-lined"	Social care remaining involved in someone's care even when they are health funded.
Don't just speak to carers when budgets are being changed or when you want information from them (e.g. a satisfaction survey)	Communication can feel combative, treated with contempt			Better definitions in the Care Act (e.g. well-being)

New service providers need to be informed who the important people are in the person's life.	Different terminology- confusing and unsettling			Better communication between statutory and private service providers.
Make it clear to the carer who is responsible for what. Keep them updated	Carers need to prove why they need money-as if they are trying to take what is not theirs.			
Carers to be included in outings (with the person's consent)	Need to build trust			
Use carer knowledge and input to agree good outcomes for the carer and the person they support. Not a one-size fits all.	Lots of info is recorded- e.g. daily log, but where does it go?			
Information sharing with carers- service providers should have knowledge of organisations that can help e.g. Carers Centre				
Use best practise from organisation where carer satisfaction is high.				
Senior staff to liaise with support workers who directly work with the person.				
Training for service providers about working with and including carers.				

268

Post Event Feedback

Seven carers (50% of those who attended) and eight service providers (38% of those who attended) completed forms. Four out of the six facilitators completed forms. This gives a total of 19 completed forms. We had decided not to hand out forms at the end of the event as we felt we had a lot to fit into the time and did not want the attendees to feel rushed. However, if we had we may have got a higher response rate. The forms did not ask for any personal or identifying information and the questions related only to the event.

Number of Feedback Forms returned

Group	Number of feedback forms
Carers	7
Service Providers	8
Facilitators	4
Total	19

Attendees were asked to rate the quality of the event. The majority (n=12) described it as excellent, five selected very good and two selected good. No-one selected fair or poor.

Responses to the Question Overall How did you Rate the event?

Group	Excellent	Very Good	Good	Fair	Poor
Carers	3	3	1	0	0
Service Providers	5	2	1		
Facilitators	4	0	0	0	0
Total	12	5	2	0	0

Attendees were asked about the length of the Working Together event. The majority (n=16) felt that the event was the right length of time. Two of the carers felt it should have been longer and one that it was too long. None of the service providers or facilitators felt it should have been a different length.

Responses to the Question Did you find the event...?

Group	Too Long	Just Right	Too Short
Carers	1	4	2
Service Providers	0	8	0
Facilitators	0	4	0
Total	1	16	2

Attendees were asked to rate the following five statements on a scale of 1 (strongly disagree) to 5 (strongly agree)

1) I received the information I needed before the workshop
2) The venue was comfortable
3) The refreshments were of good quality
4) I had chance to express my opinion
5) I feel like my opinions and experiences were listened to

One service provider selected "strongly disagree" for all of these but then expressed how much they had enjoyed the event and that there had been nothing that they disliked so they may have selected this option in error. Everyone agreed that the refreshments were of good quality and that the venue was comfortable. Though in the comments two people commented on the venue; one saying it was too warm and another too noisy. Although the majority of attendees agreed they had received the relevant information before the event one selected disagreed and three neither agreed nor disagreed. In some cases, attendees had been booked on the event by colleagues and I did not have access to their email addresses.

Responses to the statement: I received the information needed before the workshop

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Carers	0	1	1	3	2
Service Providers	1	0	2	3	2
Facilitators	0	0	0	0	3
Total	1	1	3	6	7

All attendees agreed that they had opportunities to express their opinion

Responses to the statement: I had chance to express my opinions

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Carers	0	0	0	4	3
Service Providers	1	0	0	1	6
Facilitators	0	0	0	0	3
Total	1	0	0	5	12

One carer did not feel they had their opinions were listened to but did not explain in their comments why they felt this was the case. One service provider neither agreed nor disagreed with the statement. The attendee went on to state that they would like to see:

> Clearer definitions about which type of organisation providing services is being criticised and/or praised. I feel without this clarification there will be nothing to ensure some service funders and service providers take responsibility for how their actions negatively impact on services provided and/or received; and rather blame other parties.

Responses to the statement: I feel like my opinions and experiences were listened to

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Carers	0	1	0	3	3
Service Providers	1	0	1	1	5
Facilitators	0	0	0	0	3
Total	1	1	1	4	11

Attendees were asked what Carer Voice should do following the event; they were given the following options:

1) Produce training slides for staff

2) Produce a Set of Standards

3) Produce a Guide for Service providers who work with Families

4) Create a template for an agreement between service providers and families

5) Something else (please say)

Most of the carers (n=6) selected the option "produce a set of standards" whereas most of the service providers (n=7) chose "produce a guide for service providers". However, all of the

options were selected by at least one member of each group suggesting that none of the options were considered unnecessary or completely unimportant.

Responses to the question: What do you think Carer Voice should do following Working Together?

	Produce training Slides for staff	Produce a Set of Standards	Produce a Guide for Service providers who work with Families	Create a template for an agreement between service providers and families	Something else (please say)
Carers	4	6	5	4	4
Service Providers	6	5	7	5	2
Facilitators	4	4	3	3	3
Total	14	15	15	12	9

There was a real interest in continuing to be involved in the work of Carer Voice. Most attendees wanted to be contacted via email (n=15) but a high proportion (n=14) also wanted to attend another workshop. This suggests that as a way of sharing information and ideas this approach is valued by both carers and service providers.

Responses to the question: Would you be interested in being involved with any future work that Carer Voice do? (Please tick all that apply)

	By Email	In person at meetings	Attending another workshop	Another Way
Carers	6	5	5	2
Service Providers	7	5	6	0
Facilitators	2	2	3	1
Total	15	12	14	3

Actions following Working Together

The feedback from the event and the feedback survey have been discussed with the research group. We agreed to devise a set of standards, some training slides for new staff and some further resources to support communication between service providers and family carers. A working group of service providers was arranged to ensure the resources the group devise appropriate and useable within the context of service provision. This work is ongoing and beyond the scope of this thesis.

Workshop Activities and Questions

Time	Activity/Discussion: Tables 1 and 4
10:45-11:15	Introduction/Icebreaker It is up to the facilitator how they do this. Either using an Ice Breaker task or just asking the group to say who they are Question: Thinking about your interactions with service providers/carers-how do they make you feel? What works well? What doesn't?
11:15-12:15	Family carers told us that interactions with service providers were difficult for them; it could make them feel anxious, frustrated or nervous. What could be done to make this situation easier? Think about what service providers could do and what family carers could do. Which of your suggestions could be put in place straight away and which would take longer? What are your Top 3 Recommendations as a table?
12:15-12:30	Choose one point that you would like to feedback Decide which member of the group will feedback **Facilitators**: Please remind each member of the group to complete a post it over lunch and stick it on the flip chart paper. The question we would like them to answer is "what will you change as a result of attending today".
12:30-13:00	Feedback
13:00-13:30	Lunch

Time	Activity/Discussion: Tables 2 and 5
10:45-11:15	Introduction/Icebreaker It is up to the facilitator how they do this. Either using an Ice Breaker task or just asking the group to say who they are **Question**: Thinking about your interactions with service providers/carers-how do they make you feel? What works well? What doesn't?
11:15-12:15	Family carers told us that they do not always get the information they need from service provider and can feel excluded. What could be done to make this situation easier? Think about what service providers could do and what family carers could do. Which of your suggestions could be put in place straight away and which would take longer? What are your Top 3 Recommendations as a table?
12:15-12:30	Choose one point that you would like to feedback Decide which member of the group will feedback **Facilitators** Please remind each member of the group to complete a post it over lunch and stick it on the flip chart paper. The question we would like them to answer is "what will you change as a result of attending today".
12:30-13:00	Feedback
13:00-13:30	Lunch

Time	Activity/Discussion: Tables 3 and 6
10:45-11:15	Introduction/Icebreaker It is up to the facilitator how they do this. Either using an Ice Breaker task or just asking the group to say who they are Question: Thinking about your interactions with service providers/carers-how do they make you feel? What works well? What doesn't?
11:15-12:15	Service providers told us that they struggle to engage with family carers. What could be done to make this situation easier? Think about what service providers could do and what family carers could do. Which of your suggestions could be put in place straight away and which would take longer? What are your Top 3 Recommendations as a table?
12:15-12:30	Choose one point that you would like to feedback Decide which member of the group will feedback **Facilitators**: Please remind each member of the group to complete a post it over lunch and stick it on the flip chart paper. The question we would like them to answer is "what will you change as a result of attending today".
12:30-13:00	Feedback
13:00-13:30	Lunch

The University Of Sheffield.

Carer Voice

Friday 20th October 2017

10:00	Arrival and Refreshments
10:30	Welcome and introduction
10:45	Presentation by Carer Voice
11:15	Workshop and activities
12:30	Lunch (provided)
13:15	Open discussion & Feedback
13:30	End of session

For more information and to register your interest please contact:
rachael@carervoicesheffield.org.uk

The event is free but places are limited so book early to avoid disappointment.

Friday 20th October 2017

10am till 1:30pm

Light Lunch Provided

Central Fire Station
197 Eyre Street
Sheffield
Satnav postcode: S1 3HU

email: rachael@carervoicesheffield.org.uk

carervoicesheffield.org.uk

The University Of Sheffield.

Carer **Voice**

Working Together: A workshop for service providers and carers for people with learning disabilities

Information for attendees

We are really looking forward to welcoming you to the *Working Together* workshop. Here is some more information about the event and how to get there.

On: Friday 20th October 2017
Time: 10:00 (for a 10:30 start)
Venue: Sheffield Central Fire Station
Eyre Street
Sheffield
S1 3FG (for sat nav postcode S1 3HU)

Agenda

10:00 Arrival and Refreshments

10:30 Welcome and presentation by Carer Voice

11:00 Workshop and activities

12:30 Feedback

13:15 Lunch (provided)

13:30 End of session

Expected Outcomes of the day

By the end of the event we hope we have all had chance to

1. Share ideas and experience

2. Start working towards a set of agreed, co-produced standards

3. Think about how we can keep the momentum of today going to make lasting changes

278

Public Transport

Train: Sheffield Train Station is 11 minutes walk away from Eyre Street or you can catch the X17 bus from Howard Street (Stop AG10)
Bus and tram: Eyre Street is right in the centre of Sheffield and accessible by bus and tram. The South Yorkshire Travel site can help you plan your route

http://tsy.yorkshiretravel.net/lts/#/travelInfo

Parking

Cars: Unfortunately there is no onsite parking at the Fire Station but many pay and display car parks nearby including

- Euro Car Parks on Matilda Street S1 3LA
- Bank Parking (a charity car park) on Arundel Street S1 4RE
- APCOA The Moor on Eyre Street S1 4QW
- Excel parking on Eyre Lane S1 4QW

This website gives information about nearby car parks and compares prices

https://en.parkopedia.co.uk/parking/carpark/eyre_lane

Bikes: There is a cycle rack at the back of the Fire Station if you are coming by bike.

Photographs

We are planning to take some photographs during the event. If you **would not** like to be included in photographs then please let Rachael know when you arrive.

Twitter

If you are a twitter user please tweet about the event using **#CarerVoiceSheffield**

Contact

If you need to speak to anyone before the event please contact Rachael on rachael@carervoicesheffield.org.uk.

We now have a waiting list for the event so please let me know if you are no longer able to attend.

We look forward to seeing you there!

Feedback Questions following Working Together

1. Overall, how would you rate *Working Together*?

- Excellent
- Very good
- Good
- Fair
- Poor

2. Did you find *Working Together...?*

- To Long
- Just right
- Too Short

3. Please rate the following aspects of the workshop on a scale of 1 (strongly disagree) to 5 (strongly agree)

- I received the information I needed before the workshop
- The venue was comfortable
- The refreshments were of good quality
- I had chance to express my opinion
- I feel like my opinions and experiences were listened to

4. What did you like about *Working Together*?

5. What did you dislike about *Working Together*?

6. What would you like to see change as a result of *Working Together*?

7. What do you think Carer Voice should do following *Working Together*?

- Produce training Slides for staff
- Produce a Set of Standards
- Produce a Guide for Service providers who work with Families
- Create a template for an agreement between service providers and families
- Something else (please say)

8. Would you be interested in being involved with any future work that *Carer Voice* do? (please tick all that apply)

- By Email
- In person at meetings
- Attending another workshop
- Another way (please say)

9. Chris facilitates a LD Carers Support Group, the 'LD Carers Butty Group', would you wish for your email to be added to his distribution list to receive articles of interest and notes from the support group meetings. There is a website if you would like more <u>information</u> about the group.

- Yes
- No

10. Is there anything else you would like to feedback?

Appendix O Co-Researchers' Responses to presentation questions in full

Response from Sharon; received 14th April 2106

Hi all

1. I have always been interested in and felt that one of the biggest barriers to progress for us as a family was communication, often lack of, but how, when, why, what and with whom. This seemed like a way of exploring these issues in a cooperative way

2. It has been a very interesting and supportive experience and totally accepting of all our views so therefore inclusive. Demands on my time, like most carers, are considerable and I was concerned this might be too much. However, we have been able to construct the research process so that it is not overwhelming. The recording idea is easier for me than keeping a diary for example. I like the way that we are taken seriously and our concerns, ideas listened to with respect. It is, actually, a good model of how good communication can help not hinder.

3. That we can share the information with all care providers and that they reflect honestly on their own practice then draw up firm plans with monitored outcomes to improve the quality of experience for parents and carers but especially people with 'learning difficulties'.

Not a lot to ask!

Response from Jenny; received 22nd April 2016

Hi Everyone,

Here are my replies to the questions.

1. I was interested because this research is targeted at families of people with profound, severe and complex disabilities who often feel left out. When autism and learning disability is mentioned the picture conjured up is usually not of our family members. For example we often hear "People with LD say this is what they want" Some people cannot communicate what they want yet their families, who know them best and are usually their only advocates, often feel ignored. They are not kept informed or consulted and can automatically be labelled over protective.

2. Hearing other parents' views and ideas and giving and receiving support and information. We have had plenty of time to chat and get to know each other and we can learn so much from each other. We all have different stories and ways of coping but have concerns in common which

have emerged over the months of meeting regularly The biggest of these I think is anxiety about the future and what will happen to our family members when we're no longer here and also the frustration we feel in communicating with those professionals involved in our family members care and support.

3. I would hope that the collaborative nature of the research would help us to focus on the things that matter most to carers. If there are areas of communication that cause problems for carers and service providers and these can be identified, then it would hopefully lead to improvements for all concerned.

Hope that's ok Rachael

Response from Dave; received 22nd April 2016

Hi Rachael

Thank you for the 3 questions my response is as follows:

1) What interested you in the research project?

Being a carer I am always interested to know all about any aspects relating to care to increase my own knowledge base, so the opportunity to be involved in a project in which being a carer and their living with caring was the primary focus sparked my initial interest. Then with this being part of a research project the thought that the outcomes could be of benefit to carers and caring strengthened my resolve to be involved. This was also coupled with the premise that I would be helping someone with their educational outlook to progress their own academical achievements.

The initial realisation that the project would use the principles of co-production also strengthened my interest to be involved.

2) How have you found the experience?

I am certainly enjoying the experience, especially the interactions between all the group members.

In the beginning I did wonder if my expressions, thoughts and input would be relevant, and this is a relic of my past when I was lacking in confidence to express myself.

However, the openness of the group members quickly provided myself with the ability to overcome these fears and worries.

It is however, while the group works well together, it is a concern that the diversity of the group is somewhat restricted and will this create a situation where some sections of the community have not had a voice and therefore will this have some impact on the statistical evidence in formulating the content of the outcomes. This will, however, be mitigated to some extent should the completed survey results be reflective to the diverse nature of the area to be covered by the survey distribution.

After a slow start, when we were creating the forum for expression we are now pulling together our collective ideas, thoughts and opinions to bring forth the next strand of the project, being the questionnaire. It is always great when the outcomes start to appear.

The issuing of the questionnaire and the collating of the results will be a good achievement. It is, however, a springboard to progress even further.

3) What outcome would you like from the project?

A good question, for the research to benefit the academic researcher (Rachael A Black) and persons and carers of persons with learning disabilities. In that the outcomes will be used improve situations within the learning disabilities area.

Thank you

Appendix P Photographs taken from feedback session August 2016
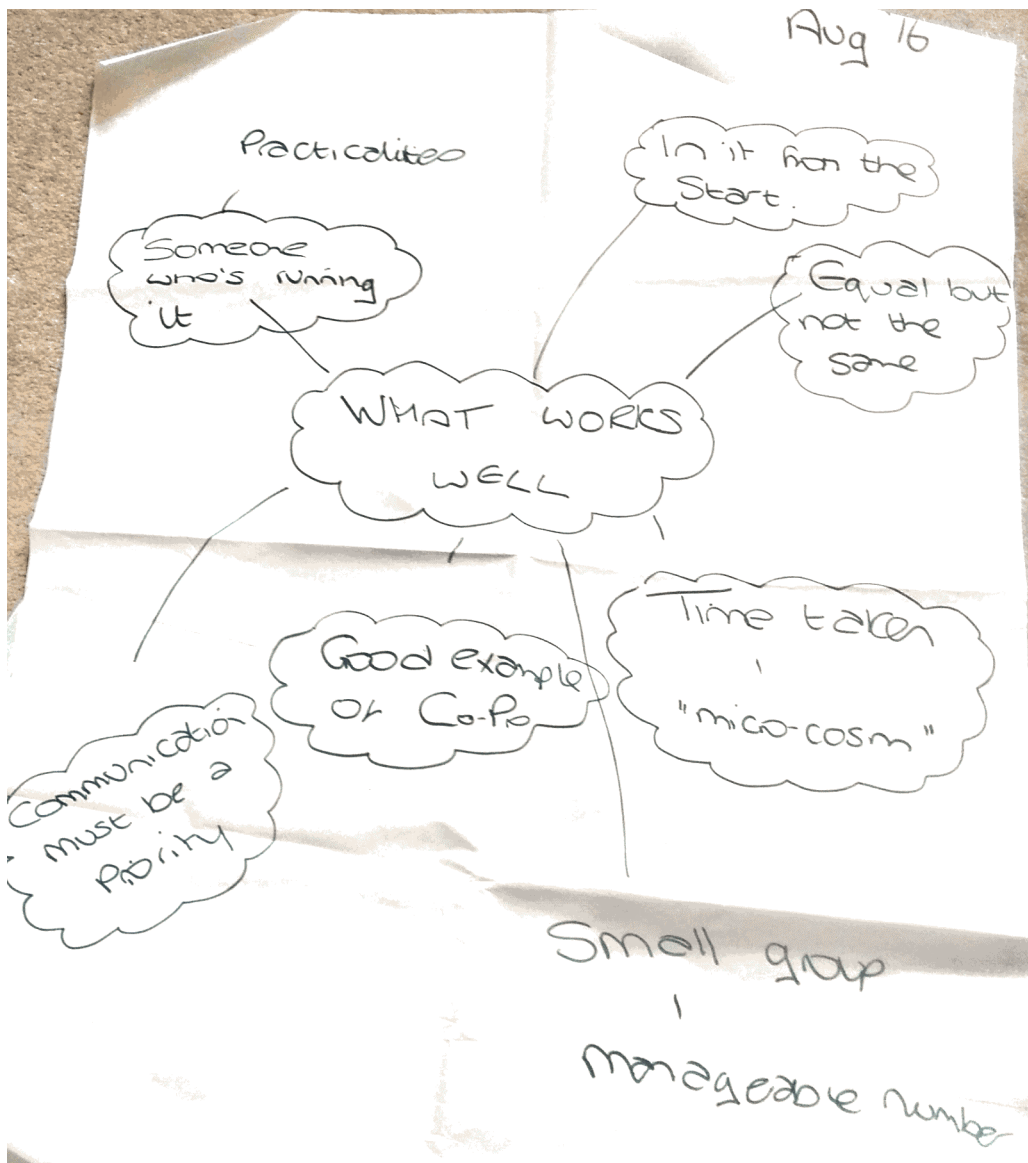
Image 1: What works well?
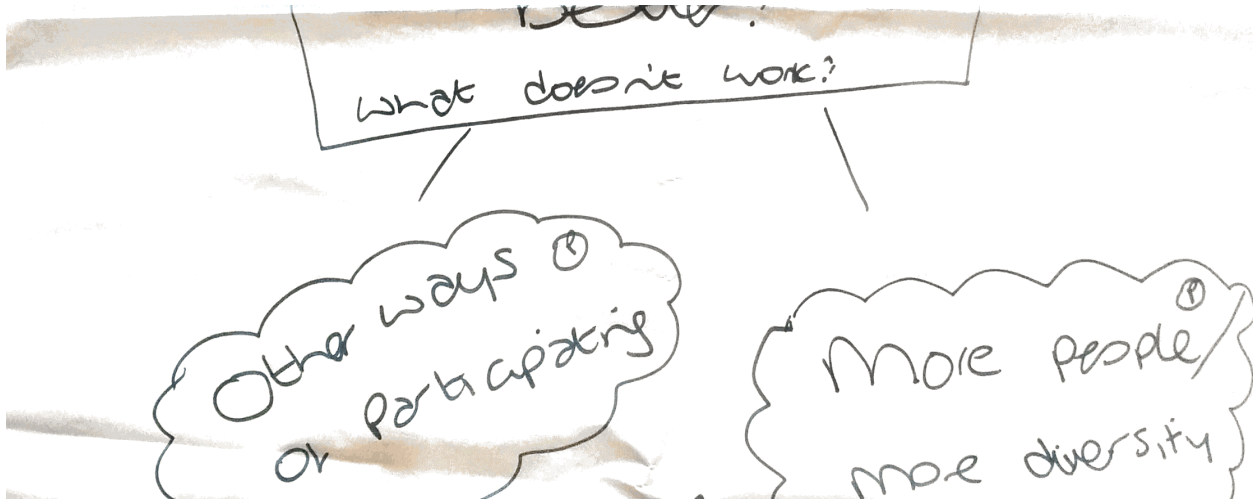
Image 2: What has not worked well?

What doesn't work?

Other ways of Participating

More people/ more diversity

Image 3: What do we want to achieve?

Translating??
Disability Sheffield
Cares
PmC
TNSC
Norfolk

"A Bit different"

Survey -urge people to add in comments

Meetings

Expose the gap between services + carers

What do we want to achieve?

Improvements

Making an impact on local services
- Presentation
- Conference
- Training

Role play

Creative ways

Appendix Q End of Study Survey Questions

1**.** On a scale of 1 to 10, where 1 is not at all and 10 is completely, how co-productive would you say this project has been?

2. Is there anything that could have been done to make it more co-productive? Other (please specify)

3. What parts of the project did you enjoy most (please tick all that apply)?

- Our group meetings at the university and sharing our experiences
- Creating the survey
- Analysing the survey
- Participating in the event
- Attending conferences/meetings to discuss our project
- Creating the resources
- Other (please specify)

4. What parts of the project did you enjoy least (please tick all that apply)?

- Our group meetings at the university and sharing our experiences
- Creating the survey
- Analysing the survey
- Participating in the event
- Attending conferences/meetings to discuss our project
- Creating the resources
- Other (please specify)

5. Is there anything you would have liked to have done more of during the project?

6. Do you think anything has changed for you as a result of co-producing this project? This can include anything at all-more understanding of co-production or research, changes to activity etc

7. On a scale of 1 to 10, where 1 is not at all and 10 is completely, do you think you achieved what you had hoped to from the project?

8. Is there anything more you would have liked the group to have done?

9. Overall, how have you felt about participating in this project?

10. Is there anything else you would like to say?

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