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**Bereavement Support for Adults with
Learning Disabilities:
An Inclusive Participatory Study**

Victoria Ann Mason-Angelow

A dissertation submitted to the University of Bristol in accordance with the requirements for award of the degree of PhD Disability Studies in the Faculty of Social Sciences and Law.

School for Policy Studies

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Abstract

Background: Bereavement support for people with learning disabilities in the UK has been described as 'at best inconsistent and at worst non-existent' (Read and Elliott, 2007, p.177). Much research in this area suggests that frontline support staff are responsible for this situation as they are unable to identify the impact bereavement has upon those they support (such as Arthur, 2003; Blackman, 2008; Gilrane-McGarry and Taggart, 2007). As a result, bereavement support training has been recommended for frontline staff in order to improve practice (such as Reynolds *et al*, 2008; Handley and Hutchinson, 2013). However, this recommendation is based on limited empirical evidence, which does not provide support workers with a voice in the literature. The research presented in this thesis aimed to rectify this situation by exploring this issue from the perspective of support workers and PAs themselves.

Method: An inclusive participatory approach was used to carry out this research. A group of people with support experience and a group of people with learning disabilities were members of the research community who conducted the research. This led to a concurrent approach to data collection being employed, with thirteen semi-structured face-to-face interviews carried out with support workers and PAs in the UK, followed by an online questionnaire completed by forty-four learning disability professionals in the same region.

Findings: Support workers and PAs are able to identify the impact bereavement has upon the people with learning disabilities they support. However, they are faced with a dilemma when it comes to providing support at these times due to the legal (HMSO, 2014; Skills for Care for Health, 2013) and organisational policies which govern their professional conduct. Support staff express an instinctive desire to provide bereavement support, but the services they work for widely dissuade this in preference for professional counselling and therapy services. Due to the lack of such services in the UK, many support staff express concern and frustration at the commodification of their emotions the services they work for expect of them at such a difficult time. This not only leaves support staff experiencing a crisis of professional identity but leaves many people without any support when someone they love dies.

Acknowledgements

I would firstly like to thank Ben Harrington, Rowena Travis Wilkinson, Julian Goodwin, Kerrie Ford, and Lisa Ponting for all their hard work, dedication and support throughout the lifespan of this research. Without your ideas, insights, and advice this thesis would not be the document it is today. I will forever be indebted to you¹.

I would also like to thank all those who participated in this study. Without your input this thesis would not provide the valuable insight into bereavement support for people with learning disabilities that it does².

Furthermore, I wish to extend my gratitude to; Professor Val Williams, Professor David Abbott and Anna Marriott who supported and advised me throughout my PhD journey; as well as my family, friends and colleagues at the Norah Fry Centre for Disability Studies, who have been there for me throughout; and to those individuals with learning disabilities who inspired the research from the outset³.

-
1. Please see page xviii and *Chapter Two* for more details of who these individuals were
 2. Throughout this thesis the names and identities of all participants have been altered to protect their identity.
 3. Throughout this thesis the names and identities of the individuals who motivated this study have been altered to protect their identity.

Authors Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University’s Regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is candidate’s own work. Work done in collaboration with, or with assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

SIGNED:..... **DATE**.....12/10/2017.....

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Note on Terminology

Learning Disability

Disability is a complex phenomenon. As a term, it is widely used to categorise a variety of individuals, yet there is no definitive definition of its meaning (ODI, 2009). The Equality Act (2010) goes some way to clarify the parameters of the term by stating that

“A person (P) has a disability if—

(a) P has a physical or mental impairment, and

(b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.”

(EA 2010, Section 6 (1)).

Yet this definition is all-encompassing and does little to further our understanding of the term, especially regarding those with a ‘mental impairment’ (EA 2010, Section 6 (1)). A range of terms are used interchangeably in the literature to refer to people with a ‘mental impairment’, including; ‘learning disability’, ‘intellectual disability’, ‘mental retardation’, and ‘learning difficulty’. Within this thesis the term ‘learning disability’ has been used and should be considered by readers to refer to those whom they may use one of the aforementioned terms to describe collectively. However, other terms do appear in quotations throughout the thesis.

The term ‘learning disability’ was chosen for use in this thesis for two reasons. Firstly, it has a ‘formal’ definition in England and Wales (DoH, 2009; DoH, 2001, DDA 1995), derived from the World Health Organization’s (WHO, 1992) definition (Northfield, 2004), which states that a learning disability is:

‘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’.

(DoH, 2001, p.14).

Secondly, after much discussion with the individuals with learning disabilities who worked on this research, the term ‘learning disability’ was chosen for use, as this is a

term they would happily use when talking about themselves, as well as their feeling that it is the term that would be most widely understood by readers in the UK.

Support Staff

Throughout this thesis the terms 'support worker' and 'personal assistant' or 'PA' are used to describe the individuals who provide direct support (such as personal care, household chores and accessing the community) on a daily basis to people with learning disabilities in the UK.

In this context, the term 'support worker' refers to someone who provides this support as an employee of a support service. They may work within a care home, supported living establishment or in someone's own home. In contrast, the term 'personal assistant' or 'PA' refers to someone who provides this support either as an employee of the person with learning disabilities they are supporting or an organisation working on their behalf, via Direct Payments or a Personal Budget (Skills for Care, 2014).

Note on those who Carried out the Research

Co-researchers with Support Experience

The co-researchers with support experience were:

Ben Harrington. Ben was in the first year of his Social Work Masters' Degree when he became a co-researcher with support experience in this research. He had experience of working with people with learning disabilities as a support worker both as an employee and whilst on placement for his Social Work Degree. Ben also had first-hand experience of working with those who were grieving or bereaved through his volunteering with the Samaritans.

Rowena Wilkinson. Rowena was also in the first year of her Social Work Master's Degree when she became a co-researcher with support experience in this research. Her experience predominantly lay with children and young people with learning disabilities where she had been a support worker prior to taking on her Masters' degree.

Advisory Group

The advisory group members were:

Julian Goodwin. Julian had worked at the Norah Fry Centre for Disability Studies (NFCDS) for over fifteen years when he joined this research's Advisory Group. He was an expert at turning research outputs into easy to understand information for people with learning disabilities, their families and supporters. Over the years Julian has done this using written, audio and video formats, as well as presenting the information he'd created at international conferences. Julian had also worked as a researcher on a number of projects at the Centre and taught Masters' Students and professionals about making information easy to understand for people with learning disabilities, both in the UK and abroad.

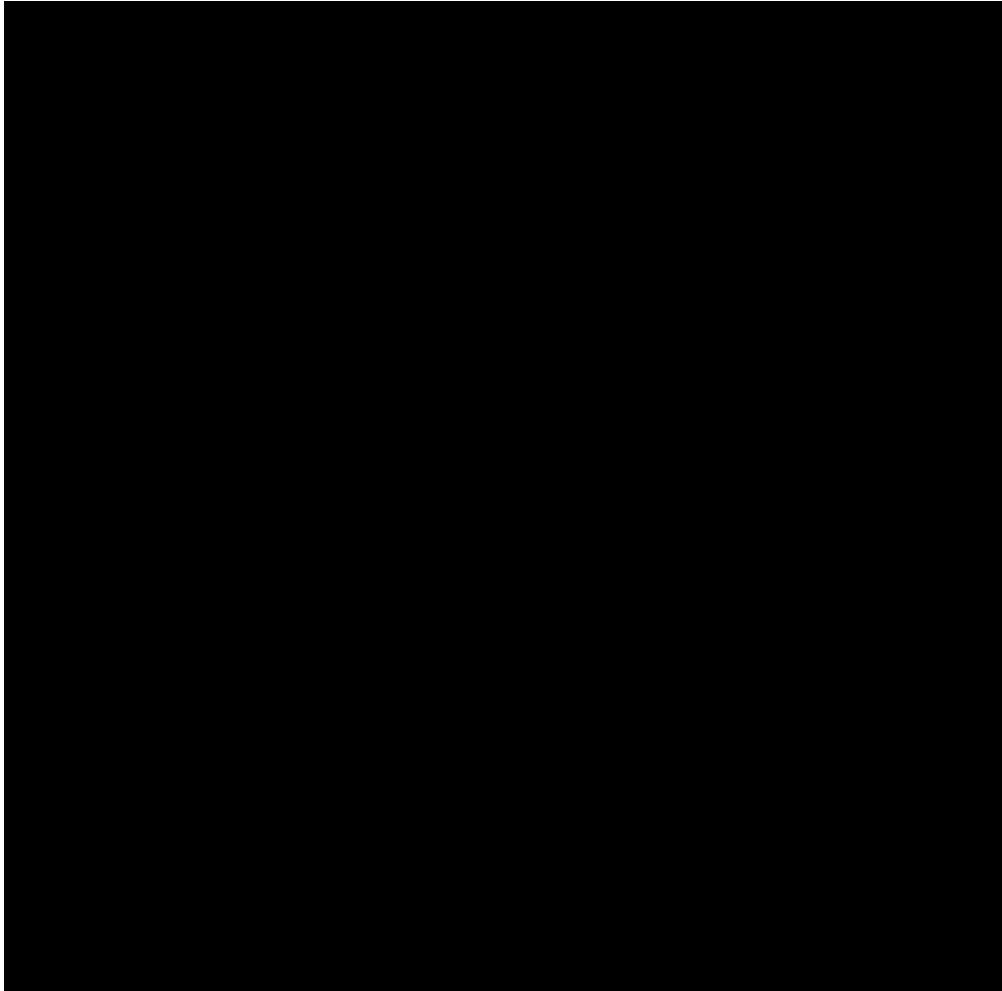
Kerrie Ford. Kerrie had worked at NFCDS since 2005 when she became a member of the research's Advisory Group. During her time at the Centre, she was involved in a

number of projects, working as a paid researcher on one project for a period of two years; presented at national conferences, and had regularly taught Masters Students undertaking degrees connected with the Centre.

Lisa Ponting. Lisa had also worked at NFCDS since 2005 when she joined the research's Advisory Group. Like Kerrie, Lisa had been involved in a number of projects, also working as a paid researcher on a project for a period of two years; presented at national conferences and regularly taught Masters' Students undertaking degrees connected with the Centre.

Co-researchers with Learning Disabilities

Julian Goodwin and Kerrie Ford's (details above) roles evolved during the lifespan of the research from members of the Advisory Group to that of co-researchers with learning disabilities. Their role as co-researchers was in addition to their role as advisory group members.



(Collins, 2008)

“Grief is not a disorder, a disease or a sign of weakness. It is an emotional, physical and spiritual necessity, the price you pay for love. The only cure for grief, is to grieve.”

Earl Grollman

Chapter 1

Introduction

“Grief is the price we pay for love.”

(Parkes, 1986)

Grief is a universal but unique phenomenon (Nagraj and Barclay, 2009). Everyone will experience periods of loss in their lives (bereavements), but who they are and the cultural, social, religious, and economic groups they associate with will affect the way they grieve (Mason and Dowling, 2016). There may be commonality in the human response to bereavement on an emotional level, but the manner in which individuals actively grieve is shaped by the ideals and norms of their social groupings and the prevailing social world (Mason and Dowling, 2016). For many people with learning disabilities, the ideals and norms of their social grouping are determined by wider social orthodoxies that are played out in their support relationships. As a result, research suggests that the emotional responses to loss that people with learning disabilities express, often go unacknowledged as those who support them do not afford them the wider cultural norms associated with grief and bereavement (Arthur, 2003).

The research set out in this thesis aimed to explore this issue from the view point of those employed as support workers and personal assistants (PAs) in the UK. In this thesis the term ‘support worker’ refers to someone who is employed by a service to support people with learning disabilities, whilst a ‘PA’ is someone who is either employed directly by someone with a learning disability or by an organisation on their behalf, via a Direct Payment or Personal Budget (Skills for Care, 2014).

This chapter introduces this research by setting out the rationale, theoretical underpinnings, and aims which have driven its completion. Discussion begins with an autobiographical note, which details the personal and professional motivations that led to this research being undertaken, before the rationale for its completion is explored. The theoretical underpinnings and aims of the study are then presented and the remainder of the thesis outlined.

1.1 Autobiographical Note

The focus of this study comes from an exceptionally personal place. It was born out of the culmination of my professional and academic experiences in the learning disabilities field, married with the bereavement and grief I have experienced in my personal life.

Since the age of 18 I have supported people with learning disabilities to live the lives they desire in the communities they choose, both in the UK and USA. Over the years, my role has evolved from support worker to PA and, along with it, the tasks I have undertaken, the rules I have been governed by, and the relationships I have developed.

From the earliest days of my career, I have felt it important to create a personal connection with those I have supported. Not to develop this connection would have made my working life problematic as I would not have gained the trust, and respect of those I was supporting. However, a number of services I have worked for challenged my viewpoint as being 'unprofessional' and tried to regulate my work relationships. These services afforded me no freedom to conduct myself in a manner which I used my professional judgement to deem both appropriate and safe for myself and those I was employed to support.

This is part of the reason why my career has evolved from working for services to working directly for individuals. I wanted my ability to connect with people to be the reason I was employed in a role I love, not a reason to be regulated. I have been blessed with a wonderful career, supporting people who have touched my life, even if only for a short time, and will stay with me forever. They have changed my perspective of the world, challenged my assumptions and allowed me to grow as an individual, both professionally and personally from their influence.

The connections I have had with those I have supported, is one of the driving influences behind the research presented in this thesis. Unpicking the complexities of human relationships situated within the professional context of providing intimate care; how these evolve; what they tell us about wider societal views of people with learning disabilities, and those who work in their charge are areas which I wanted to explore in my work, from my position as an 'insider' of this world. I feel privileged to be able to

bring this perspective to the fore, especially as this is something that is currently lacking in much academic and professional literature (Ahlstrom and Wadensten, 2010).

Working as both a support worker and PA, my voice has seldom been heard by those in authority or positions of power. I have always prided myself on being a 'shadow' to those I work for; my voice only being heard when appropriate to relationship and context, but when it is not heard, listened to, or is censored by those in authority, a work environment where I have felt undermined and disrespected has been created. Authors such as Ahlstrom and Wadensten (2010) suggest that this situation is common place within much of the adult social care workforce and state that until the voices of support workers and PAs, like myself, are heard and understood by service managers, social workers, academics and policy makers, the support people with learning disabilities receive in many areas of their lives is likely to remain questionable. Providing support workers and PAs with a voice in the research literature is one way of bringing about these changes, so I employed a group of individuals with support experience as co-researchers in this research (please see the *section 1.5* for more details).

A second, although connected motivator for this research, comes from the deaths I have experienced whilst working as a support worker and PA. Sadly, a number of the people with learning disabilities I have supported over the years have died; people whose lives I have been an integral part of, as well as their friends and family. However, in my earliest experience of death in this context, the support my superiors guided me to give to those left behind went against the relationships I had with them.

Three years into my career, in a small residential home for people with profound and multiple learning disabilities and challenging behaviour, a young man who lived there, James, passed away. As a small house, with a young and close-knit resident and staff community, the sudden loss of James moved us all. The manager of the home, who we all looked to for help, did little in way of providing us with the professional and personal guidance we needed to support ourselves and those he had lived with. Support from higher up in the organisation was also non-existent. As supporters we were left alone in our grief whilst having to support that of those we were there to care for.

Essentially, we were encouraged to carry on with life in the house as normal, not acknowledging that James was no longer with us. For Rebecca, a young woman who

lived in the house and who had known James for many years, this greatly affected her. She would regularly sign 'J', as Makaton was her main method of communication with us, and wanted us to talk about him, yet, if we did, she would become upset and harm herself or us. This continued for several weeks after James' death and led to our manager instructing us to ignore her when she signed 'J' and to do our best to distract her. Unsurprisingly, this only caused Rebecca to become more upset, and the harming of herself and us to escalate; a situation which peaked when someone new moved into James' empty room. In hindsight, I understand why the manager provided the limited guidance he did. He was having to manage a situation beyond his knowledge and was trying to save his staff from being assaulted at work every day for a significant period of time. Even with this in mind, I look back on this experience with regret. I know that I should have challenged my superiors about the way I was asked to support the people I was in service to. I did not stand up and challenge the things I knew were not right. On reflection I assign my inaction to my own grieving processes, as I had known James for 3 years; my lack of experience both professionally and personally around death; and little idea of how I could challenge the situation and do things differently.

Several years later, whilst studying for my Masters' degree at the University of Birmingham, I was working for a local authority day service when a similar situation arose. In my role at this service I worked with several people but developed a particularly close relationship with a middle-aged woman, Natalie, and her flat mate, Joanna. I worked closely with Natalie for just over a year, supporting her to live her life in the local community and go to work. She also assisted me with my Masters' dissertation, so we became close both personally and professionally. One night, Natalie died unexpectedly in her sleep. Joanna, her flat mate, found her first thing in the morning and raised the alarm. This was a distressing time for all involved, but mostly for Joanna. Her behaviour, as one might expect, became difficult to manage, assaults on staff who worked closely with her, including me, became a real concern and led to her being excluded from the day service. No support was put in place for Joanna, no 'joined up' discussions between her support team at home and us at the day service took place. The people whom she spent every day with, whom she knew well and trusted let her down and excluded her at the time she needed us all the most. Just as Rebecca's grief was not acknowledge when James died, I once again found myself witnessing a situation where Joanna's grief was not respected or supported.

I am proud to say that this time around, with a few more years' experience and, sadly, personal experiences of death, under my belt, I spoke to the managers of the day service about the importance of engaging with Joanna's grief. Unfortunately, this did little to change the decision, but I felt that I had raised my concerns and I informed Joanna that I had done something in the time I spent with her outside of work. I believe that she was grateful for this.

This experience, coupled with my interest in exploring interpersonal relationships in intimate support settings, raised a number of questions in my mind about why this was happening again in my workplace, several years after the situation with Rebecca. Why was the organisation I worked for responding to the grief of the individuals it worked with in this way? How were other organisations responding to grief when it occurred in their services? What have other support workers done when someone they support suffers a bereavement? Were they taught any skills to deal with this situation? Do they think being taught any skills would have been beneficial? What support did they personally receive from their employer to deal with this situation?

In a bid to help make sense of these questions that arose from my professional experiences, I utilised the access I had to both academic and professional literature via my Masters' studies. On my quest, I found an abundance of generic grief and bereavement work (such as; Kübler-Ross, 1969; Parkes, 1996), but only a limited body of work exploring the issue for people with learning disabilities (such as; Oswin, 1991; Kloepfel and Hollins, 1989; Hollins and Sireling, 1991; Hollins and Esterhuyzen, 1997; Summer and Witts, 2003; Dowling *et al*, 2006; Read and Elliott, 2007; Dodd *et al*, 2008) with a seemingly disproportionate number of these studies focusing upon therapeutic intervention for this population (such as; Summer and Witts, 2003; Dowling *et al*, 2006; Dodd *et al*, 2008).

This discovery did little to help answer any of my questions. On the one hand the literature seemed to suggest that there is little difference between people with learning disabilities and those without when they suffer a bereavement, as generic models of grief are applied unquestioningly to both populations. Whilst on the other hand, it seemed to suggest there are significant differences between them due to the need for therapeutic interventions to be put in place for people with learning disabilities to grieve and not for people without these disabilities. This dichotomy did little to provide useful

information about how to navigate bereavement support for front line practitioners like myself, especially as a number of authors appeared to criticise the work we were doing and introduced therapeutic interventions without exploring the issues from our perspectives (such as; Murray *et al*, 2000; Dowling *et al*, 2006; Blackman, 2008).

However, one consolation I took from the criticisms in this literature was the observation that the majority of studies were based upon limited empirical evidence of the work being done by support workers prior to an intervention being introduced and did little to provide them with a voice in the literature.

It therefore became my intention in this thesis to begin rectifying this oversight in previous research by unpicking some of the questions that arose from my professional experiences; to explore what is being done by support workers and PAs when faced with bereavement in their role before recommending what needs to be done to assist future practice.

1.2 Rationale

As has already been alluded to, people with learning disabilities are often not well supported when they suffer a bereavement (Read and Elliott, 2007; Blackman, 2008). The research presented in this thesis aimed to explore why this is the case through an investigation of how support workers and PAs perceive the support they have given someone with a learning disability during a period of bereavement. What they know about bereavement; what skills they utilised when supporting someone in practice; where they learnt these skills; and what impact providing this support had upon their emotional and psychological health, as well as their professional sense of self, are all explored. The experiences of support workers from different settings; residential care homes, supported living establishments and those who work as PAs under Direct Payments or Personal Budgets (CCDPA 1996), were sought, in a bid to open up the discussion around the nature of intimate support relationships in these settings.

The following four sub-sections of this chapter (1.2.1 to 1.2.4) introduce the key concepts that form the basis of the rationale for the research being carried out this way, with a full exploration of this literature presented in *Chapter 3: Literature Review*.

1.2.1 Bereavement and Grief

Bereavement has commonly been defined as the process of suffering after loss, whilst grief is the psychological, emotional and physical response to this loss (Kübler-Ross, 1969). Yet, how this loss is experienced, depends on the ideals and norms of the bereft's social groupings (Mason and Dowling, 2016), as does what they have lost and how it was lost (Tesik, 2013). For example, grieving for a loss that is not a shock, such as someone dying from a long-term illness, may not be as hard to come to terms with as the grief experienced when someone dies suddenly or unexpectedly (Doka, 1996).

A number of theories exist to explain the process of grieving. No one theory surpasses the others, with most suggesting that the bereaved need to engage with their loss and work through it, so that life can be reordered and made meaningful again (Dent, 2005). Traditional theories of grief, such as Kübler-Ross's 'Five Stages of Grief' model (1969), are underpinned by Bowlby's Theory of Attachment (1961) in which the bereft must work through the stages grief; denial, anger, bargaining, depression, and acceptance (Kübler-Ross, 1969). Modern grief theories have moved away from Bowlby's work and suggest that the bereft must work through grief as a process with specific tasks; accepting the reality of the loss, working through the pain of the loss, define new role and adjust to life without the deceased and to emotionally relocate the deceased and move on (Worden, 1991), whilst the Dual Process Model (Stroebe and Schut, 1995)

"...depicts grief as an oscillatory process in which a bereaved individual alternately experiences and avoids suffering during the same period of time rather than in a linear fashion with one stage ending and another beginning"

(Moyle Wright and Hogan, 2008, p.353).

This model focuses on grief as a dynamic process, in which the bereft alternates between focusing on the loss of the person who has died (loss orientation) and avoiding that focus (restoration orientation). 'Loss orientation' incorporates the grief work, whilst 'restoration orientation' involves dealing with secondary losses as a result of the death, such as the loss of a home. Both 'orientations' are necessary for future adjustment but the importance of each depends upon on the circumstances of the death, personality, gender and cultural background of each bereft person. This model has been used to

guide the research presented in this thesis, as it is able to incorporate the often complex life changes people with learning disabilities face when those closest to them die (Oswin, 1991; Read and Elliott, 2007; Blackman, 2008) and the impact this has upon the support they may require at this time (please see *section 1.3.1* for further discussion).

Although this model has guided the understanding of grief in this thesis, no matter which model is employed, empirical research suggests that the majority (90%) of people will cope with their loss within their own social circle (Worden, 1991). With the remaining ten percent never fully come to terms with their loss using these networks alone (Worden, 1991) instead requiring specialist support via bereavement counselling or therapy to move through the ‘complicated grief’ they have experienced (Schut, 2001).

1.2.2. Bereavement and Grief for People with Learning Disabilities

The number of people experiencing complicated grief in the learning-disabled population has not been quantified like it has for the non-learning-disabled population (Dowling *et al*, 2006), but is presumed to be a much higher number (Elliott, 1995) due to their marginalised status in British society and the subsequent challenges this creates (Read and Elliott, 2007).

Marginalised sectors of society often experience a disenfranchisement of grief as their ability to publicly mourn is not widely supported (Doka 1989). People with learning disabilities often experience such a disenfranchisement of grief, as society fails to acknowledge their emotional lives (Arthur, 2003) and does not believe they can emotionally comprehend the complexity of death (Conboy-Hill, 1992). This situation plays out in the intimate support relationships that so often surround people with learning disabilities in what Oswin (1991) terms this the ‘double taboo’ of death and disability, where any expression of grief is assigned to someone’s learning disability, rather than their grief. This is akin to ‘diagnostic overshadowing’ in the healthcare field whereby

‘symptoms of physical ill health are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person’s learning disabilities’

(Emerson and Baines, 2010).

Oswin's seminal work (1991) set out to challenge society's assumptions about people with learning disabilities and grief, but their legacy still resonates in society. Academic literature now widely accepts that people with learning disabilities grieve at the time of bereavement (Reynolds *et al*, 2008) and that their emotional responses to grief do not differ to those of other people (Stoddart *et al*, 2002), yet cases of 'diagnostic overshadowing' are still widely cited in the research literature (such as, Hollins & Esterhuyzen, 1997; Bonell-Pascual *et al*, 1999; Arthur, 2003; Gentile and Huber, 2005; Gilrane-McGarry and Taggart, 2007) as their

“...bereavement experiences are often unrecognized, denied or ignored by other people, including family members and care staff.”

(Dowling *et al*, 2006, p. 277).

Cases of people being denied the knowledge of a loved one's death and the associated mourning rituals (Forrester-Jones, 2013, Heslop *et al*, 2014; Mason and Dowling, 2016) and the resulting cases of complicated grief (Summers and Witts, 2003; Dodd *et al*, 2008) are also common place.

This situation is concerning for two main reasons; firstly, it highlights the stigmas and assumptions still held about people with learning disabilities in society; and secondly, as the learning disability population in the UK, along with the general population, is ageing (Ward, 2012) their experiences of grief are likely to be increasing and, in turn, their need for support.

The median age of death for people with learning disabilities is currently known to be 65 years for men and 63 years for women, in comparison to the general population median of 78 years for men and 83 years for women (Heslop *et al*, 2013). These figures are startling, especially as the data suggests that many of these deaths are avoidable or unnecessary (Mencap, 2007, 2012; Heslop *et al*, 2013), and have led to issues of death and dying becoming a key focus of many media and academic endeavours in the learning disability field. For example, the deaths of people with learning disabilities due to neglect or poor care frequently receive widespread media attention (such as, BBC, 2015) and much academic work has begun exploring what constitutes a 'good death' for people with learning disabilities and how services can facilitate this (Bekkema *et al*, 2013; Todd, 2013; Tuffrey-Wijne *et al*, 2013). These are both important endeavours

which should lead to improved end of life care for many people with learning disabilities in the future. However, Mencap (2007; 2012) and Heslop *et al's* (2013) findings have not stimulated the same level of interest into the issues of grief and bereavement that arise from the data we now have about the life expectancy of people with learning disabilities in the UK.

Whilst the median age of death for people with learning disabilities is significantly different to those without learning disabilities (Heslop *et al*, 2013), the data highlights that people with learning disabilities are living longer than ever before (Ward, 2012). If people are living longer, it can be assumed they are going to experience an increased number of bereavements as they begin to outlive their friends, family, housemates and/or colleagues (Blackman, 2008; PAMIS, 2014), so will require support to mourn these losses effectively. O'Driscoll suggests that if people with learning disabilities

'...receive the right (bereavement) support; they are more likely to get through the process; if they do not, their health can be affected'.

(2015).

As a result, research needs to be done to explore what constitutes 'the right support' (O'Driscoll, 2015) from the perspective of those at the front line of service; support workers and PAs, as well as those who receive this support. Something which is sadly missing from much of the research literature to date. The work of Handley and Hutchinson (2013) has begun to bring the views of paid support providers to the fore, but there are limited other studies in this area on which to base our understanding. The research in this thesis aimed to expand knowledge in this area.

1.2.3. Supporting People with Learning Disabilities Through a Period of Bereavement

As already alluded to, those employed to support people with learning disabilities are said to perpetuate the disenfranchisement of grief these individuals often experience (Read and Elliott, 2007) as they are 'often reluctant to reawaken memories of loss among the people they care[d] for' (Dowling *et al*, p. 280) and thus find it difficult to identify the emotional needs of those they support (Arthur, 2003; Gilrane- McGarry and Taggart, 2007; Handley and Hutchinson, 2013; O'Driscoll, 2015). Paradoxically however, the literature also suggests that support staff feel the need to protect those

they support from the reality of death due to the immense amount of sorrow it can cause them (Dowling *et al*, 2006; Handley and Hutchinson, 2013; Mason and Dowling, 2016). This suggestion is made explicitly clear in the findings of Williams (2011) which highlights the tensions support workers face in their role between the protection of the people they support and allowing them to make their own decisions.

This complex web of assumptions support workers are suggested to hold about people with learning disabilities and grief, are predominantly based upon research relating to therapeutic interventions (Murray *et al*, 2000; Summers and Witts, 2003; Dowling *et al*, 2006; Gilrane-McGarry and Taggart, 2007; Blackman, 2008). This body of work goes against the notion that individual social networks provide the best bereavement support (Worden, 1991), and is based upon limited empirical evidence of the knowledge support workers have and the tasks they carry out prior to the interventions being implemented. Furthermore, this work goes against the small body of empirical evidence which suggests that creative approaches, such as life story and reminiscence work, are highly beneficial to people with learning disabilities in times of grief when delivered by those who know them best (Read, 2005; Read and Spall 2006; Read and Bowler, 2007).

There is however, a burgeoning body of examples in this field which offer some insight into why support workers might hold this complex mix of assumptions about grief, such as; the fact that many residential support workers are young and inexperienced (McEnhill, 2004), their own experiences of loss make it difficult for them to support others when they are grieving (Dowling *et al*, 2006, p.285), they feel unsupported in their role (Handley and Hutchinson, 2013), and the emotionally taxing nature of the work they do leading to feelings of anxiety and institutional denial (O'Driscoll, 2015). Yet, once again, the majority of these findings stem from research that is problem focused and concludes with recommendations for implementing training interventions for support staff or professional counselling services for people with learning disabilities based upon limited empirical evidence (Read and Elliott, 2007; Blackman, 2008; Handley and Hutchinson, 2013; O'Driscoll, 2015). If this research does not explore what support staff do day to day, how can training be recommended? And furthermore, how effective will it be if it is not tailored to the individual work place? (Ahlstrom and Wadensten, 2012).

In contrast, research carried out by Mencap, (2007; 2012) and Heslop *et al* (2013), suggests that those employed in the learning disabilities field do acknowledge the

bereavement needs of those they support, but are let down by the guidance and resources available to them. These studies paint a more positive picture of the knowledge and skills support staff have, but it is important to note that their focus was not upon support staff, so they are unable to provide an in-depth exploration of what support staff know and do to support people when they are grieving. Without this insight into the inner workings of a support worker or PA's role, little can be done to help alter practice. If, of course, it needs to be altered. The research in this thesis aimed to begin providing this insight.

1.2.4. Support Work

Whilst there is a lack of consensus as to why bereavement support for people with learning disabilities has been suggested to be 'at best inconsistent and at worst non-existent' in the UK (Read and Elliott, 2007, p.177), it is known that supporting someone with learning disabilities through a period of bereavement is an emotionally taxing task (Bloom, 2005; Handley and Hutchinson, 2013; O'Driscoll, 2015). Research highlights the importance of support staff engaging with the emotional aspects of their role (Ellison and Ptacek, 2000), but also warns that undertaking taxing emotional labour can lead to increased stress levels (England, 2005; O'Driscoll, 2015). When this is combined with low control and autonomy, as is often the case in residential support work (Hatton *et al*, 1999), levels of staff burnout and turnover often increase (Skills for Care, 2017).

As has already been alluded to, working at the frontline of learning disabilities services is a role that is heavily criticised and widely scrutinised. This scrutiny not only comes from academic literature (such as those listed previously) but from inspection bodies, such as Care Quality Commission, the mass media (as previously mentioned), and, increasingly, social media. A key focus of the discussions held in these arenas relate to the professional conduct of those working in the field and their adherence to the regulations that govern their places of work (such as Skills for Care for Health, 2013). Whilst the enforcement of professional codes of conduct is commendable and indeed required in some areas, such as with regards to adult safeguarding, some elements of these codes do not appear to translate well to the increasingly individualistic framework of social care and what is known about effective bereavement support.

Since the 1980's the personalisation agenda has flourished in the learning disability field (Morris, 2011). Personalisation can be defined in a variety of ways, but it has often been guided by independent living principles, in which people with learning disabilities, their families and supporters have the choice, control and freedom to live the lives they want (DoH, 2012). Personal Budgets and Direct Payments (CCDPA, 1996) have been instrumental to this movement as they enable individuals to choose the support they receive and from whom, via the employment of PAs.

Personalisation has therefore changed the world of work for many people employed in the learning disabilities field; the jobs they do and the places in which they are doing them have changed. A wealth of research has focused on these changes from a policy perspective (such as, Spandler, 2004), a delivery perspective (such as, Barnes and Mercer, 2006) and an individual viewpoint (such as, Stainton and Boyce, 2004), but only a small subsection has brought the voices of those employed in the sector to the fore (Askheim, 2005; Leece and Pearce, 2010; Williams, 2011; Ahlstrom and Wandensten, 2013).

The voices that have been heard in this research express an awareness of the critical eye of the 'professionalism' agenda imposed upon their work. For example, one PA states that he sees his role, as being a 'professional shadow' to those he works for (Clayton, 2006, p.137). The use of the term 'shadow' fits within the personalisation agenda as it places the PA in service to the individual he works for. But the term 'professional' seems to detach him from those he works for, when he is likely to be a key member of their social network.

Statements such as these appear to imply a fear amongst support staff of acknowledging that in working for someone with a learning disability you become an inevitable part of their social network. Being a supporter is a social relationship, 'it can only be undertaken in the context of another person' (Payne, 2005, p.184); they are not independent of one another and the focus upon professional conduct within the support work arena detracts from what it is to be human (Kittay, 2001), and from what people learning disabilities say they want from their support relationships (Williams *et al*, 2010). To acknowledge the connections made between people in these relationships is beneficial to both those receiving support as well as those providing it (see *section 1.3.3*).

As has been discussed throughout this chapter, the majority of people cope with grief within their own social networks (Worden, 1991), yet for people with learning disabilities their social networks are, in part, made up of support staff who are conflicted about the role they are 'supposed' to play in these individuals lives, as a result of the codes of conduct that govern their places of work (Skills for Care for Health, 2013), media scrutiny and prevailing societal orthodoxies which influence them. Exploring how this combination of factors is experienced by support staff in practice may provide a new insight into the reasons behind the suggestion that support staff perpetuate the inconsistency of bereavement support in the UK (Arthur, 2003; Dowling *et al*, 2006; Gilrane-McGarry and Taggart, 2007; Read and Elliott, 2007; Blackman, 2008). Little work to date has explored this issue from the perspective of support staff themselves (Handley and Hutchinson, 2013) something this research aimed to change.

1.3 Theoretical Underpinnings

This research explored the phenomenon of bereavement support from a social constructionist position. It sought to understand the phenomenon from the perspective of its social actors; support workers and PAs, and its impact upon their professional sense of self.

Narrative accounts of providing bereavement support to someone with a learning disability were sought from participants and analysed as socially situated knowledge constructions in their own right (Polkinghorne 1995). Studying the phenomena in this way provides a deeper understanding of the lived experiences of participants by exposing taken for granted assumptions about ways of knowing, (Starks and Brown Trinidad, 2007) and is something which has seldom been done in the research conducted in this field before. At no stage in this research are grief and bereavement support assumed to be 'real' objects, but rather socially constructed phenomena, derived from experiences and perceptions of participants.

The study is further underpinned by three key theoretical concepts; the Dual Process Model of Grief (Stroebe and Schut, 1995), the Social Construction Model of Disability (Barnes, 2003) and the Commodification of Emotion Model of Care Work (England, 1995).

1.3.1. Dual Process Model of Grief

As already mentioned, the Dual Process Model of Grief (Stroebe and Schut, 1995) underpins this study. This model views grief as a dynamic process, in which the bereft alternates between focusing on the loss of the person who has died (loss orientation) and avoiding that focus (restoration orientation). 'Loss orientation' incorporates the grief work, whilst 'restoration orientation' involves dealing with secondary losses as a result of the death, such as the loss of a home. Stroebe and Schut (1995) state that both 'orientations' are necessary for future adjustment, but the importance of each depends on the circumstances of the death, personality, gender and cultural background of each bereft person.

This model has been chosen for two reasons. Firstly, due to the participatory methodology employed in the study, it was not possible to define the type of bereavements participants would have experienced before the work was undertaken. A model which allowed for different circumstances of death, personality, gender and cultural background was vital so as not to limit the study before it began. Secondly, as people with learning disabilities often suffer multiple losses when people in their lives die (Oswin, 1991; Machale and Carey, 2002; Dowling *et al*, 2006; Mason and Dowling 2016), a model which highlighted the importance of and personal nature of 'restoration' work in grief was paramount.

1.3.2. Disability Theory

This study was guided by the Social Construct Model of Disability (Barnes, 2003). This model views disability as a social construct, rather than an inevitable consequence of an individual's bodily limitations within society. This fits with the study, as it was interested in what bereavement support tells us about how people with learning disabilities are constructed by society. It did not locate the problem of bereavement within the individual, but saw the process as an interactional one, which involves the whole of society, played out through support relationships.

The 'medical' or individual models of disability (WHO, 1980; Oliver, 1996), which would situate bereavement within the individual, internalising the problems associated with it and recommending sustained medical (psychiatric) care (Shakespeare and Watson,

2002) have not been used as they would not have been beneficial to the study. It is these models of disability that have led to the 'double taboo' of death and disability (Oswin, 1991) and diagnostic overshadowing discussed in this chapter. As a result, discussion of these models and their resonance in modern society takes place throughout the thesis, but it is not the lens through which learning disability has been viewed in the research.

The Social Model of Disability (Oliver, 1996) has also not been used in its purest form, due to the difficulty with putting it into practice within the learning disability arena (Barnes, 2003). The text book definition of the social model proposes that whilst some people have physical, sensory, intellectual and/or psychological conditions, which may cause some functional impairment, it is the systematic barriers, negative attitudes and exclusion by society which define who is disabled (Oliver, 1996). The application and usefulness of this definition of the model to people with learning disabilities has been the cause of much debate within disability circles due to the effect such 'disabilities' have within many societal settings (Shakespeare and Watson, 2002; Goodley, 2010). These debates and the subsequent posturing for new models specific to people with learning disabilities reach far beyond the scope of usefulness in this thesis. Instead the Social Construct Model (Barnes, 2003), which adopts the social model notion of disability as something which is constructed relative to the society in which it is situated, has been used as the lens through which to view learning disability in this research as it is the model that has the 'best fit' with the research's aims and objectives (*section 1.4*).

1.3.3. Care Worker Theory

Theories of care work are in their infancy, however there are five emerging theoretical frameworks within the literature; the devaluation perspective, the public good, the prisoner of love, the commodification of emotion and the love and money framework (England, 2005). Each of these frameworks builds on a different perspective of care work. For instance, care work can be seen from a broad political perspective (the public good framework), the employer's perspective (the prisoner of love framework) or from an employee's perspective (the commodification of emotion framework).

As this study has focused on the individual and personal nature of relationships and emotional support within care work, the 'commodification of emotion' framework

(England, 2005) has guided the research. This framework explores what happens, psychologically and emotionally, to workers in emotionally laboured environments, such as supporting someone through a period of bereavement. At the time of writing, this framework has not been applied to the understanding of the impact bereavement support provision has upon support workers and PAs; something which the research in this thesis aimed to change.

1.4. Research Questions, Aims and Objectives

1.4.1. Research Questions

With a clearly identified gap in the literature, this study set out to answer the following five research questions:

1. How do support workers and PAs view the bereavement support they have provided someone with a learning disability?
2. What does providing bereavement support to someone with a learning disability involve?
3. Do support workers and PAs receive training to provide bereavement support to people with learning disabilities?
4. What impact does providing bereavement support to someone with a learning disability have upon support worker and PA emotional and mental health?
5. Do support workers and PAs have any thoughts about how bereavement support for people with learning disabilities should be done in the future?

1.4.2 Aims

As the questions above suggest, the research presented in this thesis aimed to explore the phenomenon of bereavement support for people with learning disabilities from the view point of the support workers and PAs who provide it in the UK. It further aimed to uncover what skills these support workers and PAs utilised when providing this support, where they learnt these skills, what impact this support had upon their own emotional and psychological health, as well as their sense of professional self.

The study also aimed to highlight how support work in the field of learning disabilities has changed via an exploration of how the personalisation agenda has affected

everyday support work in different support settings; residential care homes, supported living facilities and those employed under Personal Budgets or Direct Payments (CCDA, 1996).

Additionally, the study aimed to provide support workers and PAs with a voice in the literature through their 'employment' within an inclusive participatory research study. As

'staff on the frontlines of public services are recognised to have a distinctive voice and expertise as a result of regular interaction with service users'

(Needham, 2008, p.222/3)

yet they are often marginalised within the research literature.

In a similar vein, this research sought guidance from a group of people with learning disabilities who have received bereavement support from support staff in their lives (support workers and/or PAs) to ensure that they also began to have a voice in the research literature around this subject, whilst also ensuring the research was asking the 'right' questions of participants.

1.4.3. Objectives

In order to achieve these aims, the research had three objectives:

1. To explore the phenomenon of bereavement support from the perspective of support workers and PAs who provide it in the UK.
2. To involve and listen to support workers directly within an inclusive participatory research model.
3. To involve and be guided by the lived experiences of a group of people with learning disabilities within an inclusive participatory research model.

1.5. Approach

In a bid to achieve these aims and objectives, the research was carried out using an inclusive participatory approach. This approach was chosen as it was of paramount

importance that the knowledge created in the research was, at least in part, generated by those it was about and directly affects (Walmsley and Johnson, 2003; Bergold and Thomas, 2012). A group of people with support experience were therefore 'employed' as co-researchers in the study to guide the questions being asked, the analysis being carried out and the dissemination taking place. There were two main reasons for these individuals' 'employment' in the study; firstly, as I had worked as a PA for the 2 years prior to undertaking the research, I was acutely aware that the world of work within support services had changed dramatically since leaving. I therefore wanted the support and knowledge of those who had worked within services more recently to help guide the study. Secondly, as the literature relating to bereavement support for people with learning disabilities left a void where the voices of support workers and PAs should be (Ahlstrom and Wadensten, 2010; Leece and Peace, 2010), I wanted this research to begin filling this void with the voices of its researchers.

As well as a focus on including the voices of support workers and PAs in this research, it was equally important to include the voices of people with learning disabilities. There has been a shift within much learning disability research in recent years towards the inclusion of people with learning disabilities as the researchers not just the researched (see, for example Williams *et al*, 2009) and this is something this study aimed to continue. People with learning disabilities are the 'experts by experience' of what it is like to experience a bereavement as someone with a learning disability, and to receive support at this time from those who are paid to be there. Three individuals with a learning disability were therefore 'employed' to advise the study on aspects relating to their experience. Two of these group members also became co-researchers during the lifespan of the study as is discussed in Chapters *Two* and *Four*.

The voices of the co-researchers with support experience, advisory group members, co-researchers with learning disabilities and I are presented throughout the remainder of the thesis via boxed inserts, like the one below. These inserts have been taken from the research diaries members of the research community kept throughout the lifespan of their involvement in the research and from the research meetings they attended.

Some of the research community chose to keep their research diaries using traditional methods (handwritten or typed notes), whilst some chose to keep their diaries via a series of audio/video recordings. Individuals did not have to share their diary entries, but

each chose to share at least some of their entries, which have been incorporated into this thesis.

Boxed inserts

The authors words are written in Purple;

The co-researchers with support experience words are written in Orange;

The advisory group members and co-researchers with learning disabilities words are written in Green

All quotes are clearly labelled.

1.5.1. Data Collection

Data was collected from participants via two methods within a concurrent mixed methods approach (Ivankova, *et al*, 2006); semi-structured narrative interviews and an online questionnaire. The interviews were undertaken on a one-to-one basis with thirteen participant support workers and PAs; whilst the online questionnaire was completed by forty-four participant support workers and a variety of other professionals in the field of learning disability support (please see *Chapters Two and Four* for a full discussion).

1.5.2 Analysis

An interpretive narrative approach was used to analyse the data collected from both the interview and questionnaire participants. (Please see *Chapter's Four, Five and Six* for a full discussion). Descriptive statistical analysis was also carried out on the demographic data collected from both interview and questionnaire participants. This analysis has been carried out using the Statistical Package for the Social Sciences (SPSS).

1.6. Structure of Thesis

The remainder of this thesis is divided into eight chapters. *Chapter Two* introduces the concept of inclusive research and provides an overview of steps taken to carry out the research inclusively. *Chapter Three* presents a critical discussion of the existing research literature from the fields of 'thanatology', 'disability', 'grief', and 'learning

disability practice'. *Chapter Four* details the methodology used to carry out the study, building on the context provided in *Chapter Two* to present details of the research design, participant recruitment and data collection tools used. *Chapters Five* and *Six* present the findings of the research in relation to 'grief theory', 'care worker theory', 'disability studies' and 'learning disability practice'. *Chapter Seven* discusses these findings in greater detail and, *Chapter Eight*, explores how the inclusive research approach used in the research has worked; discussing the strengths and limitations of working in this way and exploring how it was experienced by those involved through detailed excerpts from group members' research journals and meeting transcripts. *Chapter Nine* provides conclusions and recommendations for future practice and research in this area, before the thesis draws to a close with a personal reflection on the impact this research has had upon the issues raised in the '*Autobiographical Note*' section of this chapter.

Chapter 2

Inclusive Participatory Research: Making it work

2.1 Introduction

As has been introduced in *Chapter One*, the research presented in this thesis was carried out using an inclusive participatory approach. But what does this mean? Who was included? And what did they participate in?

In this chapter, Inclusive Participatory Research is introduced, its history explored and the debates that exist around its use examined. From this starting point, the chapter moves on to explain how the research presented in this thesis utilised this approach, using a diagram to help illustrate the complexities (p.40). The chapter draws to a close looking forward to the ontological, epistemological and ethical issues raised by using an inclusive participatory approach, which are explored in *Chapters Four* and *Eight*.

2.2 What is Inclusive Participatory Research?

Inclusive Participatory Research is an approach, which merges together the principles of both Inclusive and Participatory Research. It borrows from participatory research the notion that research can be a vehicle for social change and personal liberation for marginalised groups of people, through high-level participation in studies which explore issues that directly affect their lives (Bergold and Thomas, 2012). Combining with this the inclusive research principle that for people with learning disabilities to achieve high level participation in research, accessible strategies may be required (Ollerton, 2012).

2.2.1. Participatory Research

Participatory research is not a singular approach, but one which encompasses a number of qualitative methods and techniques in social research (Bergold and Thomas, 2012). Each of these approaches aim to hand power from traditional researchers (scientists and academics) to those traditionally viewed as participants (marginalised groups and community-based organisations) by giving them control of the research agenda, data collection, analysis, and, most importantly, the actions taken as a result of

the work done (Pain and Francis, 2003). However, it is important to note that this does not make participatory approaches fit the criteria for what is termed 'emancipatory' research (Oliver, 1992). Participatory studies are usually instigated by traditional researchers who ask marginalised groups to become co-researchers or consultants to the research (such as Cook and Inglis, 2012), rather than the research evolving from these groups' concerns and carried out completely under their control (such as Barnes, 1991; Priestley, 1999; Williams and Simons, 2005). Yet, in Zarb's (1992) words', participatory approaches which involve

"...disabled people in a meaningful way is perhaps a prerequisite to emancipatory research in the sense that researchers can learn from disabled people and vice versa, and that it paves the way for researchers to make themselves 'available' to disabled people."

(p.128).

As an approach, participatory research can have its roots traced, in part, to the end of the Second World War (Walmsley and Johnson, 2003). This was a time of great social change within much of the Western world as the destruction, segregation and attempted extermination of entire populations, brought social justice into public consciousness (Russell, 1946; Freire 1970; Crothers and Platt, 2010). The rights of marginalised groups and how to protect them became part of social discourse at this time and, in turn, part of the discourse of social research (Freire, 1972). Discussions began to take place in the social sciences about the role research could play in protecting people's rights and changing structures in society (Oakley, 2000). These discussions challenged the principles of social science research with a positivist leaning, which had dominated, and failed to take into account the differences in class, ethnicity, gender and culture of participants, as they called for a shift in how research was seen and conducted (Oakley, 2000). This led to the creation of many qualitative approaches to research that saw the world as a complex and socially constructed place which is best understood by those who live within it, rather than something which can be reduced to a list of observable variables which can be predicted (Oakley, 2000).

Running in parallel to these shifts in social thinking, the breakdown of colonial empires at this time led to a rise in thinking which critiqued the simplistic, modernist, Eurocentric

views of progress that colonialism espoused and called for a new way of viewing cultures and society (Walmsley and Johnson, 2003):

“They [colonisers] talk to me about progress, about achievements, diseases cured, improved standards of living, I am talking about societies drained of their essence, cultures trampled underfoot, institutions undermined, lands confiscated, religions smashed, magnificent artistic creations destroyed, extraordinary possibilities wiped out.”

(Cesaire, 1972, p.23-24 Plummer 2002, p. 297).

These two socio-historic events combined, led to the birth of Participatory Research, and many other qualitative approaches, as they offered the ability to redistribute power to marginalised groups and create a more just society through research (Oakley, 2000).

Today, some of the techniques used in participatory research studies, include digital storytelling (see Manning, 2010), action research (see Swift and Mattingly, 2009), focus groups (see Williams 1999, and Swift *et al*, 2013,), Photovoice (see Wang, 1999; Booth and Booth, 2003), collecting oral testimonies (see, Manning, 2010), stakeholder meetings (see Williams and Simons, 2005, and Williams *et al*, 2010), and reflective accounts (see Carolan, 2003, and Ortlipp, 2008) to name just a few .The research in this thesis combined a number of these techniques to gather data including; stakeholder meetings, collecting oral testimonies and written accounts (please see *Chapter Four* for more information).

2.2.2. Inclusive Research

Inclusive Research, the second approach to social research that inclusive participatory research borrows from, has a distinct history within the Western learning disability field, which spans the past forty years (Walmsley and Johnson, 2003).

Just like participatory research, inclusive research is not a singular approach, but rather an umbrella term which covers a number of traditional techniques, such as; Emancipatory, User-Led, Participatory, Action and Community Research, that have been adapted to enable people with learning disabilities to be researchers (Walmsley and Johnson, 2003). As a result, the socio-historical context which gave rise to each of

these approaches (discussed in *section 2.2.1*) applies similarly to inclusive research approaches, but with the addition of the developments within the disability movement that were taking place at a similar time (Walmsley and Johnson, 2003).

2.2.2.1 De-institutionalisation, Normalisation and Social Role Valorisation

In the 1950's the majority of people with learning disabilities in the Western world were living in segregated settings with limited connections to outside communities and limited roles within the ones they did connect with (Goffman, 1961). These conditions were observed by social scientists, reformers, and advocates of people with learning disabilities and discussions began to take place about how they could be changed. These discussions led to the creation of the theory of Normalisation (Banks-Mikkelson, 1969), or the Normalisation Principle (Nirje, 1969), which implied that people with learning disabilities should live as close to normal life as those without learning disabilities (Bank-Mikkelson, 1969). This was a commendable development in academic and social thinking about people with learning disabilities at the time, but the theory was quickly criticised for not being more radical (Culham and Nind, 2003; Chappell, 2007). It was argued that the goal of Normalisation as set out by Bank-Mikkelson (1969) and Nirje (1969) could be obtained within segregated settings, so would therefore not challenge the living conditions or power imbalance in the lives of people with learning disabilities as it was intended (Emerson, 1992).

As a result, the theory was reworked in the USA by Wolfensberger (1972) to recognise that people with learning disabilities should live in such a way that is

“...as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible.”

(Wolfensberger, 1972, p.28).

This removed the doubt from the previous theory that people with learning disabilities should remain in segregated communities with little power over their own lives. However, this definition was still scrutinised by activists and academics, which led to a total reworking of the theory in 1980 to a new ideology; Social Role Valorisation (Wolfensberger, 1983). The premise of this new ideology was based upon the idea that

the good things in society are more easily accessible to people who occupy valued social roles within that society (Wolfensberger, 1983). Within this, Wolfensberger (1983) argued that people with learning disabilities needed to begin to be seen as people who can occupy valued social roles in order for them to have good lives in society.

Social Role Valorisation (Wolfensberger, 1983) was therefore seen by some as a great improvement on the theory of Normalisation (Bank-Mikkelsen, 1969; Nirje, 1969), but not by all, especially a number of disability activists and scholars (Emerson, 1992; Oliver, 1992). The full extent of their criticisms reach far beyond the scope of the discussion here, but there are two which are relevant to discuss as they relate directly to the ownership of the theories by disabled people themselves, and the notion of difference within these theories (Emerson, 1991).

Unlike other movements, such as feminism or anti-racism, Social Role Valorisation (Wolfensberger, 1983) was created by someone without a learning disability. It was not born out of the changes people with learning disabilities themselves wanted to see, but rather from the concerns of someone who, essentially, had power over them (Emerson, 1992). This imbalance of power was argued to be deeply imbedded within the ideology as it can easily side step asking people with learning disabilities for their opinions of how it is working (Kendrick, 1994); and places service providers and social workers as gatekeeper to the valued social roles available to people with learning disabilities (Oliver, 1992; Kendrick, 1994).

Furthermore, these theories suggest that people with learning disabilities are a homogenous group, who need to change their roles in order to fit the norms of the prevailing social world (Emerson, 1992). Rather than advocating for an inclusive society in which people with learning disabilities can be included on their terms (Oliver, 1992; Kendrick, 1994).

Although these criticisms are justified, this research wishes to argue, as it is by Walmsley and Johnson (2003), that without the theories of Normalisation (Bank-Mikkelsen, 1969; Nirje, 1969) and Social Role Valorisation (Wolfensberger, 1983), the scene would not have been set for inclusive research approaches to develop. That is, without the shifts in social and academic thinking created by the emergence of these theories, the developments in the political and legal frameworks in the UK, such as the

All Wales Strategy for the Development of Services for Mentally Handicapped People (1983), and the White Paper: Better Services for the Mentally Handicapped (1971), may have taken longer to occur, if at all (Walmsley and Johnson, 2003). A situation which would have delayed the shift in academic circles towards seeing people with learning disabilities as human beings who have valuable stories and insights to contribute to research (Walmsley and Johnson, 2003). Furthermore, without the theories of Normalisation (Bank-Mikkelsen, 1969; Nirje, 1969) and Social Role Valorisation (Wolfensberger, 1983) the People First movement and their theory 'Label Jars Not People' (People First, 1994) may not have developed in parallel to the developments in the wider academic and political arenas in the 1990s. This movement grew directly from people with learning disabilities themselves and in turn shaped their research interests.

2.2.2.2 The Disability Movement

Running in parallel to these changes in the learning disability field, similar, but unconnected, developments were occurring in the disability arena more widely. In the mid-nineteen-seventies the disability activism movement (UPIAS, 1976) began to take shape and with it the foundations for the Social Model of Disability (Oliver, 1983) were laid.

Although completely unconnected to the theories of Normalisation (Bank-Mikkelsen, 1969; Nirje, 1969) and Social Role Valorisation (Wolfensberger, 1983), the Social Model of Disability (Oliver, 1983) grew from a similar starting point; to gain equality and inclusion in everyday life for all disabled people. However, the model went much further than either of the learning disability theories did, as it called for disability to be viewed in a completely new way; as a societal issue rather than a personal one (Oliver, 1983, Finkelstein, 1980, 1990, 1991). It was also developed by disabled activists and academics so brought to the fore issues that were omitted in the learning disability theories (UPIAS, 1976; Oliver, 1983).

Within the social model, society's attitudes, practices and infrastructure are seen as the disabling force for individuals, rather than the individual themselves as it had been traditionally seen within the Medical Model of Disability (WHO, 1980). As a result, the social model called for social change to ensure that people were not disabled by society.

At this point, disabled activists and academics in the UK began to realise that they could use research to bring about this change in social thinking. By becoming researchers themselves, disabled people could not only help bring about the social and political change they wanted, but could also become valued members of society through their new roles as researchers, authors, and owners of knowledge that had not been available to them previously (Atkinson and Williams, 1990).

This led to the birth of Emancipatory Research (Oliver, 1992); an approach where disabled people themselves are the initiators and undertakers of research about matters which directly affected their lives (Barnes, 1991; Priestley, 1999). The development of this approach occurred as Social Role Valorisation (Wolfensberger 1983) was taking hold in the learning disability world and filtered into this arena. However, this relationship was not an easy one.

In its purist form, emancipatory research requires disabled people to be in complete control of the research process (Oliver, 1992), with the involvement and support of non-disabled people in this process being a highly contentious issue (Minkes *et al*, 1995; Atkinson, 1997; Oliver and Barnes, 1997; Ward and Simons, 1998; Williams, 1999). However, these strict rules do not translate well to people with learning disabilities as they often require support to create, develop and carry out research themselves (Atkinson, 1997; Walmsley and Johnson, 2003; Williams and Simons, 2005; Morgan *et al*, 2014). The need for this support has caused great debate in the emancipatory and disability research arenas (see Oliver and Barnes, 1997; Barnes and Sheldon, 2007) as the inclusion of non-disabled supporters is thought to detract from the disabled researcher's control (Oliver, 1992). However, within the learning disability arena, this support is not seen as a threat to control, but rather a tool required to make that control work (Chappell, 2000; Williams and Simons, 2005; Morgan *et al*, 2014). Walmsley and Johnson (2003) eloquently dispute the exclusionary and disabling arguments put forward from the emancipatory research arena, stating that just because

“[P]hysically impaired academics like Vic Finkelstein and Mike Oliver do not need plain text versions, Makaton symbols or illustrated reports to be able to understand research”

(p.53)

most people with learning disabilities do and they are entitled to the support they need to make this happen.

These debates led Walmsley to coin the term 'Inclusive Research' in 2001 to describe the approaches to social research which have been adapted to enable people with learning disabilities to carry out research on their terms. The application of this term sidesteps the debates about 'emancipatory' or 'participatory' research, by acknowledging the wide range of approaches which could count as inclusive (Walmsley, 2001).

2.2.2.3 Inclusive Research

As with emancipatory research approaches, there is no one definition of how inclusive research should be done, what methods should be employed or what philosophies and traditions should be followed (Facer and Enright, 2016). This has led to some confusion within traditional research circles where the encapsulating of many different approaches under one umbrella is seen in the same light as trying to converse 'about shoes and ships' (Walmsley and Johnson, 2003, p.24) Yet, for people with learning disabilities, their supporters and allies, placing all these approaches together under one umbrella term is more useful and less cumbersome than having to understand a plethora of research terms, and the nuances of academic debate (Walmsley and Johnson, 2003).

Although there is no definitive definition of 'inclusive research' available, there are a number of distinct principles which define what makes a piece of research inclusive. These are:

1. The research problem must be one that is owned (not necessarily initiated) by disabled people.
2. It should further the interests of disabled people; non-disabled researchers should be on the side of people with learning disabilities
3. It should be collaborative – people with learning disabilities should be involved in the process of doing the research
4. People with learning disabilities should be able to exert some control over process and outcomes

5. The research question, process and reports must be accessible to people with learning disabilities.

(Walmsley and Johnson, 2003, p. 64).

2.2.3 Merging Participatory and Inclusive Research

As suggested at the beginning of this chapter, Inclusive Participatory Research combines the notion that research can be a vehicle for social change and personal liberation for marginalised groups of people from participatory research (Bergold and Thomas, 2012); and the inclusive research principle that for people with learning disabilities to achieve these things in research, accessible strategies may be required. (Ollerton, 2012).

By combining these elements, a flexible approach is introduced into social research, which ensures that the most marginalised groups in society can be actively involved in research that directly affects their lives through collaboration with other groups, researchers and academics. This allows for a rich and diverse research community to develop, each containing a multitude of different skills and knowledge about the subject being explored. These differences are seen as assets within inclusive participatory approaches, and each project is able to move and adapt to utilise these skills at different times. This is able to happen, as power within inclusive participatory research is a fluid and relational concept, which shifts and alters as the group work and learn from each other (Woelders *et al*, 2015). This is known as relational empowerment (VanderPlaat, 1999) where all team members only exist in the research in relation to one another and as a result:

“...power is not given to one party by the other, or taken by one party from the other, because this would only confirm the existence of power imbalances. Therefore, empowerment is relational in that the interactions between people become more equal as they learn from each other and start to work together and divide power based on a mutual understanding of each other’s backgrounds, values and perspectives.”

(Baur and Abma, 2014, p.169).

Within the research in this thesis, two marginalised groups came together to undertake the research; people with learning disabilities and people who had experience of working as support workers and/or PAs. These groups worked as designers, advisors, data collectors, analysers, writers and disseminators of the research. The roles each group member took on and the work they undertook shifted throughout the lifespan of the research as they learnt from each other and the data; developing new skills throughout.

Of course, as Walmsley and Johnson (2003, p.146-163) note, working in this way is not plain sailing. There are a number of tensions, both tangible and theoretical, which affect the undertaking of all inclusive research studies and this research was no different. These tensions are discussed throughout the remainder of this chapter and in Chapters *Four* and *Eight*.

Team Work

“It’s about getting through the tough bits together. Working as a team to make it feel OK, doing the things we are good at to get through and finish the project.”

Lisa Ponting, Reflection Meeting 4th December 2015

2.3 Why was this Research done using an Inclusive Participatory Approach?

The professional experience that led to this research being undertaken (as discussed in *Chapter One*), also affected the choice of the methodology used. At the time of the research’s conception, the literature available on the subject was critical of the work being done by support workers and PAs without giving them, or the people they support, a voice (for example Arthur, 2003; Dowling *et al*, 2006; Gilrane-McGarry and Taggart, 2007). This raised the question; how can research criticise the work being done by support workers and PAs when they, and the people they support, have so little say in the research process?

By providing support workers, PAs and people with learning disabilities with the opportunity to direct the data collection, analysis and dissemination of a project that directly affected their lives, this research aimed to begin changing their status in the research literature. As a result, using an inclusive participatory approach seemed to be the logical approach to employ to achieve this aim.

Furthermore, the research needed an approach which would enable the two distinct groups involved in the project; support workers and PAs; and people with learning disabilities, to direct and guide the research as they saw fit, whilst also being honest about its non-emancipatory nature due to this being a piece of PhD research (please see *section 2.5* and *Chapters Four and Eight* for a full discussion).

2.3.1 Having a Voice

As has already been highlighted, one of the main principles of participatory approaches to research is to ensure that marginalised groups in society are able to guide research which directly affects their lives in order to bring about social change and, hopefully, create personal liberation (Bergold and Thomas, 2012). These elements of using a participatory method is what led to the approach being selected for use in this research as it would allow support workers, PAs, and people with learning disabilities to have a voice in the research literature; a voice that has valuable knowledge to share that has not yet been heard by the research community. By providing these groups with the opportunity to ask the questions, analyse the data and inform practice of what they found, would not only give them a voice in the literature, but also give them the space, at least in part, to attain the personal liberation that working in this way can create (Bergold and Thomas, 2012).

Furthermore, by employing this approach, the support workers and PAs involved in the research would have the time and space to reflect and develop as 'professionals'. However, it must be acknowledged that despite these aspirations, neither group would be completely in control of the research process; this is a PhD study not an emancipatory one (Oliver, 1992), and therefore personal liberation may not be achieved by those involved (please see *Chapters Four and Eight* for a full discussion of this point).

With the author's professional experience as a support worker and latterly a PA, her conducting the research alone would have given a voice to support workers and PAs in the research literature. However, her voice alone would not have provided the depth of insight necessary to unpick the issue of bereavement support as it was played out within services, due to her lack of experience within such services for some years (please see *Chapter One* for a full discussion of the author's support work and PA experience). It was therefore felt that a group of other support workers and PAs should be recruited as co-researchers who:

- had worked within support services,
- had recently supported someone with a learning disability through a period of bereavement, and
- had an interest in learning about research, to become co-researchers.

In addition to the voices of support workers and PAs, the voices of people with learning disabilities also had to be included in this research. This was important simply because the author does not have a learning disability. She is able to empathise with the bereavement issues people may face from her own bereavement experiences and the knowledge she has from being a support worker and PA, but this is only empathy. She is not in receipt of support; she does not have people involved in the most intimate and emotional parts of my life who are paid to be there. As a result, she does not know what receiving this support feels like when someone she loves dies and therefore, what questions to ask in the research. Because of this, it was paramount that people with learning disabilities who had lived experience of bereavement support being provided by a support worker or PA, helped guide the research. As a result, a group of individuals with this experience were recruited at the outset of the study.

The desire for people with learning disabilities to help guide the research, is what drew this research towards using an inclusive approach. The author knew from her experience as a support worker and PA that a number of adaptations to the research process would need to be made to enable the group to work in this way. Something an inclusive approach would allow for.

2.3.2. Filling the Gap

By providing support workers, PAs and people with learning disabilities with a voice in the research literature, this study aimed to begin filling the gap in the research landscape where their voices should be, as well providing useful empirical evidence for those working on the frontline of services. This research aspired to be there for the lost and confused support worker or PA to find when looking for support, advice and evidence of what might help them support the person with learning disabilities they work for through a period of bereavement, when they aren't getting this advice at work.

These are grand aspirations for this research. It is a small-scale PhD study. However, the author is optimistic that its presence in academic circles will demonstrate that work of this kind can be done and does generate valuable findings, which may lead to future studies being carried out in this way. It is also believed that the research's presence in professional circles will encourage learning disability organisations and people with learning disabilities themselves to pursue research which directly affects the services they provide and receive, as they know it will be listened to and taken seriously; thus, filling the gap further. Finally, it is hoped that there will be further work undertaken by those involved in this research, either in the form of further research or in direct action as a result of this research's findings.

2.4 How the Research was Done

As has been discussed throughout this Chapter, conducting research using an inclusive approach is often a complicated process to explain to those who were not involved in its undertaking. There is no formula for doing research in this way, and each study will address the research question afresh with new ideas, questions and resolutions (Walmsley and Johnson, 2003). Each project is unique and the research in this thesis was no exception. *Diagram 1* (p.40) was created by members of the research community to help explain how the research was conducted.

This diagram illustrates that this research was a process which evolved from a central point; the author. It was a research project which grew out of her professional experience and motivations for completing such a study. Without these ideas and the work done to develop the title, explore the literature and gain ethical approval, the

research would not have happened. As with other PhD theses conducted inclusively (Williams, 2002; Chapman and McNulty, 2004; Morgan *et al*, 2014) the positioning of the PhD researcher in relation advisors and/or co-researchers with learning disabilities is one which harbours potential tensions. It cannot be claimed that this process is ever emancipatory, since the PhD researcher stands to gain the most from the study.

However, this process did not give the author complete control over the research process. For example, when the ethics form at the start of the research was completed (Appendix 1), it was done in such a way as to leave the process of data collection, analysis and dissemination as open as possible. Once ethical approval was received, the research's advisory group of people with learning disabilities was recruited. These individuals; Julian, Kerrie and Lisa, were associated to the NFCDS as researchers, as well as individuals with lived experience of bereavement support in their own lives. Two members of this group had previous experience of working as paid researchers on a project within the NFCDS (Williams *et al*, 2009; Williams, 2011), whilst the third member had a successful career spanning fifteen years providing easy-read reports, audio and video outputs for research done in the Centre. All three group members also had experience of teaching University students in the UK and in Europe about Inclusive Research (please see p. xvii for more details about group members).

The advisory group spent four months working together with the author, sharing knowledge and developing research skills around the topic of bereavement support (see Appendix 2 and 3). After this time, the group helped to recruit the support workers and PAs who became co-researchers. A collective decision was made about who should be recruited, including what experience they should have had as support workers and/or PAs and the bereavement support experience they had within these roles. Recruiting this group of co-researchers was a challenging task. It took two attempts to get a small group of researchers together who had relevant experience. Local learning disability organisations and services were initially approached via email, social media (such as Facebook and Twitter) and online Forums (such as the Choice Forum) (please see Appendix 4 for a full list of the places used to advertise and Appendix 16 for the information sent out) but no one came forward. This led to the University of Bristol's School for Policy Studies student body being approached (please see Appendix 5 for a list of the student groups contacted and Appendix 17 for the information sent them),

which was successful and led to two individuals with experience of support work becoming co-researchers.

The advisory group and co-researchers with support experience met on one occasion to familiarise themselves with one another, but then worked independently from one another. The co-researchers met once a month, either in person or remotely for a period of thirteen months and the advisory group met once every three months in person for a period of two years (Table 1, p.41). Working in this way ensured that the purpose of each group was clear to each member; the co-researchers to collect the data, carry out the analysis and work out what it all means; and the advisory group to help advise each of these stages. Working in this way also ensured that the author was not put in a position where she had to actively 'take sides' with either group (Becker, 1967; Hammersley, 2010). However, working in this way raised the possibility of there being tensions between the different groups' views, and the need for clarity about how the researcher would position herself ethically should the situation arise (please see *Chapter Eight* for a thorough discussion of this issue).

This way of working led to the decision to gather data using one-to-one interviews carried out by the author but analysed collectively with the co-researchers and reviewed by the advisory group. This approach to data analysis, led to two members of the advisory group becoming co-researchers (Julian and Kerrie). They did not join the co-researchers with support experience, but formed a separate group (co-researchers with learning disabilities), based on their own interests and experiences. That is, from carrying out the review of the interview transcript analysis, both Julian and Kerrie were interested to know if the findings would be similar for support workers and PAs in other parts of the UK. There was time available in the research plan to incorporate exploring this, so Julian and Kerrie became co-researchers for this concurrent phase of data collection. To ensure the work Julian and Kerrie did in this phase is not confused with the work done by the co-researchers with support experience, they are referred to as co-researchers with learning disabilities throughout the remainder of the thesis (please see Diagram 1, p.40 and Table 1, p.41).

The co-researchers with learning disabilities met separately to the advisory group and co-researchers with support experience, on five occasions over a five-month period. In this group the Interview Schedule (Appendix 6) and pre-interview demographic

questionnaire (Appendix 20) were used to create an Online Questionnaire (Appendix 7), which was sent out to support workers and PAs across the UK using social media and online forums (Appendix 8).

This development within the research clearly demonstrates the points made earlier about the ability of inclusive participatory research projects to evolve and adapt throughout the lifespan of the work as the researchers learn from one another (Woelders *et al*, 2015) and the power shifts from one person to another (VanderPlaat, 1999). This will be discussed in greater detail in *Chapter Four*.

2.5 Summary

This chapter has introduced the origins of inclusive participatory approaches to social research, explored the debates within the literature, and discussed how they have been used in this research.

Inclusive participatory research sees research as a vehicle for social change and personal liberation for marginalised groups of people (Bergold and Thomas, 2012), achieved through accessible strategies (Ollerton, 2012). Yet, there is no one definition of how inclusive participatory research should be done, what methods should be employed or what philosophies and traditions should be followed (Facer and Enright, 2016), which causes confusion in many traditional research circles (Walmsley and Johnson, 2003, p.24). But, for people with learning disabilities, their supporters and allies, such an approach is useful as it removes the complexities and nuances that hamper academic research (Walmsley and Johnson, 2003).

The research presented in this thesis utilised this approach to provide support workers/PAs and people with learning disabilities with the chance to guide a project which directly affected their lives, providing them with a voice in the research literature and the opportunity to experience the personal liberation so often afforded to researchers in such studies.

As the discussion in this chapter has begun to highlight, these aims were reached to a greater or lesser extent throughout the lifespan of this study, but the journey to achieve them was not an easy one. *Chapters Four, Eight and Nine* explore each of these issues

in greater detail, along with others that occurred along the way. But before reaching these discussions, the following chapter provides a thorough review of the literature in the academic fields of disability, grief, thanatology, and organisational psychology, along with professional literature from learning disability practice.

Diagram 1: How we did our Research



Table 1. Data Collected

This Table lists the details of the data collected and discussed within this thesis. A full discussion of these are presented in Chapters *Five*, *Six* and *Eight*.

Name	Number of people	Who	Data
Victoria Mason-Angelow	1	PhD Student and PA	Diary entries
Advisory Group	3	People with learning disabilities	9 meetings Diary entries
Co-Researchers with support experience	2	People who have support work experience	3 meetings Emails Diary entries
Interview participants	13	Support workers, care workers, and PAs	13 interview transcripts
Co-Researchers with learning disabilities	2	Victoria Mason 2 members of the advisory group	5 meetings
Questionnaires	44	Support workers, care workers, PAs, learning disability nurses, Music Therapists,	44 questionnaire responses

Chapter 3

Literature Review

3.1 Introduction

This chapter draws on and develops the discussions presented in *Chapter One* through a thorough review of the literature in the academic fields of disability, grief, bereavement, thanatology, and organisational psychology, along with professional literature from learning disability practice.

The academic literature that has been reviewed in this chapter was sought from an initial Scopus search, followed by supplementary searches of Google Scholar and the Social Care Institute for Excellence databases. These sources were searched using the terms listed in Table 2, below, with the parameters set to return only UK based research carried out between 1980 and the present day. A further search of the 'grey material' in this area, such as learning disability professional publications, was also carried out via the Social Care for Excellence database and Google. The same search terms (Table 2, below) and parameters were used for this search.

Table 2: Literature Search Terms

Term searched
Grief
Models of grief
Bereavement
Learning disability
Learning disability bereavement support
Learning disability emotional lives
learning disability mental health
learning disability social networks
Learning disability support
Support Work
PAs
Support services for people with learning disabilities
Personalisation

This search revealed a variety of publications relating to the historical and modern day understanding of grief, bereavement and bereavement support for people with learning disabilities in the Western world. As well as several publications exploring the wider emotional and mental health needs of people with learning disabilities when they are grieving. The search also unearthed a body of literature that explores how and where support work in the learning disabilities field is done, the impact carrying out such work has upon those who do it and the role these individuals have within the social networks of the person they support.

The breadth of the literature gathered from this search has provided a number of pieces of the bereavement support 'puzzle'. Throughout this chapter the pieces of this puzzle are placed together to create a picture of bereavement support for people with learning disabilities as it is currently understood within the UK context and highlights where this research fits in the picture.

The first piece of the bereavement support puzzle to be laid relates to the historical positioning of death, grief and bereavement in Western society. This discussion explores several of the models of grief that have developed over time and across disciplines to conceptualise the notion of a 'normal' grieving process in the West. With these foundation pieces of the puzzle laid, the next few pieces relate directly to people with learning disabilities; the bereavements they suffer, the emotional support needs they have at this time and the impact the wider historical context has upon this support. Through the discussion of these issues, the pieces of the puzzle relating to the support networks of people with learning disabilities, specifically relating to their support workers and/or PAs, are brought to the fore. Exploring these networks leads to a discussion about who support workers and PAs are, what role they play in people's lives, the environments they work in, the expectations upon them in these roles, the notion of 'professionalism' within this context, and the impact emotional support work has upon them and their professional sense of self.

The chapter draws to a close by suggesting that whilst the picture of bereavement support created by these puzzle pieces is a rich and colourful one, it only goes some way to explaining why for many people with learning disabilities the support they receive is 'at best inconsistent and at worst non-existent' (Read and Elliott, 2007, p.177). Some vital pieces of the picture seem to be missing, which if explored may help aid our

understanding of why this support is inconsistent. It is felt that current research, which tells us about the support worker and PA workforce and the impact 'doing emotion work' has on them, is consistently done by those working outside these roles; the voices of those doing this work are not heard as researchers or experts by experience. By providing support workers and PAs with a voice in the research literature, both as co-researchers and participants in this study, will add this piece to the puzzle and help improve future bereavement support.

The literature presented in this chapter was shared with both the research advisory group and co-researchers at the beginning of their involvement in the research. How and why this was done is discussed in *Chapter Four*, and copies of the literature shared with the groups can be seen in Appendix 2 and 13

3.2. Bereavement and Grief

“Grief is a universal part of the human experience”

(Floyd, 2008).

Bereavement has been defined as the process of suffering after loss, whilst grief is the psychological, emotional and physical response to this loss (Kübler-Ross, 1969). Grief is said to be a universal, but unique phenomenon (Nagraj and Barclay, 2009) as everyone will experience periods of loss in their lives, but who they are and the cultural, social, religious, and economic groups they associate with will affect the way they grieve (Mason and Dowling, 2016). That is, there may be a commonality to the emotional responses to loss, but the manner in which individuals actively grieve is shaped by the ideals and norms of their social groupings and the prevailing social world (Mason and Dowling, 2016).

The relationship an individual has to the object that has been lost and how it was lost are also determining factors to the grieving process (Tesik, 2013). For example, the grief that is felt when a loss is not a shock, such as someone dying from a long-term illness, may not be as hard to come to terms with as the grief experienced when someone dies suddenly or unexpectedly (Doka, 1996; PAMIS, 2014; Moon 2016):

“When someone you love dies, and you're not expecting it, you don't lose her all at once; you lose her in pieces over a long time—the way the mail stops coming, and her scent fades from the pillows and even from the clothes in her closet and drawers. Gradually, you accumulate the parts of her that are gone. Just when the day comes—when there's a particular missing part that overwhelms you with the feeling that she's gone, forever—there comes another day, and another specifically missing part.”

(Irving, 1990).

The universal nature of the human grief experience (Nagraj and Barclay, 2009) has led philosophers, theologians, psychologists, anthropologists, and medics to study and contemplate its meaning for centuries. This has continued to the modern day, with issues of grief now commonplace within popular literature (Skelton, 2003) and omnipresent in the mass media (Meyer, 2005; Smith 2011). Yet, the individual experience of grief and its associated rituals are juxtaposed to its mass literary presence, as personal expression has become a taboo subject in much of the Western world (Clewel, 2004).

3.2.1 The Demonization of Death

Studies carried out in the field of social anthropology suggest that death and its associated grief rituals have gradually been demonised in Western society due to the rise of medical intervention (Gorer, 1977). The introduction of organised medicine in the latter part of the 19th Century removed death from the family home and placed it in the hands of medical professionals (Gorer, 1977). Modern medicine has continued this trend, with vast amounts of NHS resources spent each year on treatments to prolong death rather than preserving health (Kass, 1975; Amundson, 1978; Smith, 1995; Blackman, 2008; McDermid and Bagshaw, 2009; McHugh *et al*, 2015).

As a result, displays of mourning, which were public in Victorian society with women often dressed in 'full mourning, in black from top to toe' for months or even years after a loss (Gorer, 1977, p.1), have become private and an unacceptable topic for public discussion (Palgi and Abramavitch, 1984). Gorer notes' in his 1955 paper, death has

become comparable to the historic view of pornography in Western culture; an obscenity not to be discussed in polite company:

"The natural processes of corruption and decay have become as disgusting as the natural processes of birth and copulation were a century ago"

(Gorer, 1955, p. 196).

This quote still resonates in modern Britain, with issues of death, bereavement and grief remaining isolated and private matters for individuals to manage alone within an 'acceptable period of time' (Smith, 2011). For those unable to manage their feelings within this time, they are widely encouraged by those around them to seek specialist help to help them 'get over' their loss (Smith, 2011). However, attitudes are beginning to shift towards public discussions of death and expressions of grief being acceptable once again with the advent of movements such as 'Death Cafe' (Underwood, 2015). These cafés have been created as safe social spaces where people can talk openly about the issues of death, dying, grief and bereavement in a supportive environment. They are felt to be a positive step towards open conversations about death and bereavement taking place in British society once again (Underwood, 2015), but they are still in their infancy, so Gorer's (1955) observation of grief in modern society still rings true today (Walter, 1991 and 2002; Cox *et al*, 2012).

As this short discussion has highlighted, the UK, as with much of the Western world, has a polarised social history of death, which has led to modern society having a poor dialogue with the subject (Kübler-Ross, 1969). Modern Britain exposes its inhabitants to some of the most extreme scenes of death and suffering on a daily basis via rolling news networks and other media outlets (Smith, 2011) but when these individuals experience death within their own social circles they are still

"...without adequate guidance as to how to treat death and bereavement and without social help in living through and coming to terms with the grief and mourning which are inevitable responses in human beings to the death of someone whom they have loved."

(Gorer, 1977, p.110).

In a bid to help the lasting and damaging effects this situation can have upon individual members of society (Smith, 2011), a number of models of grief have developed over time and across disciplines to help conceptualise our understanding of what the 'normal' grieving process should look like and the support that it requires.

3.3 Models of Grief

Each of the models of grief that have been developed in the past Century highlight the uniqueness of grief and the range of potential responses (Parkes, 1986). No one model presides over the other, with most suggesting that the bereaved need to engage with their loss and work through it, so that life can be reordered and made meaningful again (Dent, 2005). These models are further based on the principle that if grief is denied an outlet, then the bereft will suffer either 'psychologically or physically or both.' (Gorer, 1977, p.111).

Freud pioneered the study of mourning in the early Twentieth Century, conducting a number of systematic studies on 'loss' (Clewell, 2004), which led to grief being defined

"...as an experience that usually follows a normal course but could lead to serious psychological consequences if the bereft failed to emotionally detach from the deceased."

(Dent, 2005, p. 22).

Freud's work resisted the cultural shift towards the repression of grief taking hold of society in the early Twentieth Century (previously discussed), instead theorising that whilst the psyche is the internal space where 'grief work' should take place, external expressions of grief are vital for a 'healthy' recovery (Clewell, 2004). Freud's pioneering work led to his psycho-analytic approach dominating the academic study of grief for over a Century, with only Bowlby's Theory of Attachment (1961) having equal prominence.

The Theory of Attachment explains the human tendency to develop strong emotional bonds to significant others and the predictable and universal response to the loss of this

bond (Bowlby, 1961). This Theory (Bowlby, 1961) underpins a number of more traditional theories of grief, such as Bowlby and Parkes' 'Phases of Grief' model (1970).

The 'Phases of Grief' model (Bowlby and Parkes, 1970) was developed from Bowlby's work with dying children and their parents and suggests that the bereft must work through four stages of grief; shock and numbness, yearning and searching, disorganisation and despair and reorganisation, in order to grieve successfully. This model has been criticised for its linear nature (Moyle-Wright and Hogan, 2008), which is often applied to the bereft as an inventory to be completed in an order which empirical research suggests are incorrect. For example, a longitudinal cohort study carried out by Maciejewski *et al* (2007), found that for the studies two hundred and thirty-three bereaved participants', 'shock and numbness' were not the first stage of their grieving process, but rather 'acceptance' was the most frequently endorsed first stage. These criticisms have however been defended by the argument that 'phase' theories of grief should only be viewed as descriptive; they do not propose that everyone will show signs of passing through all the phases and may not do so in the order listed (Morrell, 2013).

In 1969 Kübler-Ross adapted the Bowlby and Parkes' model (1970) from her clinical work with terminally ill patients, to create the 'Five Stages of Grief' model. This model proposed that the bereft must pass through a set of emotional responses to loss; denial and isolation, anger, bargaining and depression, in order to grieve successfully. This model is now widely accepted by the general public in much of the Western world as the way in which 'normal' grief is experienced (Maciejewski *et al*, 2007) and is the dominant model utilised within the medical profession (Downe-Wamboldt and Tamlyn, 1997). Yet, its validity is not consistently supported by the majority of empirical studies that have examined it (Kastenbaum, 2006; Moyle-Wright and Hogan 2008; Baxter, 2012). For example, the recent work of Bonanno (2010), suggests that there is no empirical evidence to imply that finite stages of grief exist, a finding also reported by Maciejewski *et al*'s (2007) longitudinal cohort study. However, just like Bowlby and Parkes' 'Phases of Grief' model (1970), these criticisms of Kübler-Ross's model have been defended as, like 'phase' models, 'stage' models should only be viewed as descriptive; they do not propose that everyone will show signs of passing through all the stages and may not do so in the order listed (Morell, 2013)

Although Kübler-Ross's 'Five Stages of Grief' model (1969) is the most widely known and accepted model of grief in the Western world (Downe-Wamboldt and Tamlyn, 1997; Maciejewski *et al*, 2007), a number of other theories exist which have been developed in more recent times (such as Wodern, 1991; Stroebe and Schut, 1995). These models have learnt from the criticisms of the 'phase' and 'stage' models of the past and are less influenced by Bowlby's Theory of Attachment (1961), instead looking to Freud's psychoanalytic approach (1917) for guidance. For example, in 1995 Stroebe and Schut developed the 'Dual Process Model of Grief', which

"...depicts grief as an oscillatory process in which a bereaved individual alternately experiences and avoids suffering during the same period of time"

(Moyle-Wright and Hogan, 2008, p.353).

As a result, this model focuses on grief as a dynamic process, in which the bereft alternate between focusing on the loss of the person who has died (loss orientation) and avoiding that focus (restoration orientation). 'Loss orientation' incorporates the 'grief work' introduced by Freud (1917), whilst 'restoration orientation' involves dealing with secondary losses as a result of the death, such as the loss of a home. Within this model, both 'orientations' are said to be necessary for future adjustment but the importance and prevalence of each, depends upon on the circumstances of the death, personality, gender and cultural background of each bereft person. The individual agency within the model is seen as its greatest strength and something which previous models have failed to acknowledge (Carr, 2010). However, it is criticised for not highlighting whether individuals are

"...actively and purposively choosing these strategies, or whether they are passively defaulting to strategies due to lack of options"

(Carr, 2010, p. 376).

and what should be done if the latter is the case (Carr, 2010). The model is also criticised for not discussing how much, how often and when the loss orientation and restoration orientation processes occur and interact with one another (Carr, 2010), something which empirical studies applying the model have also not addressed.

More recent developments in the study of grief have turned the tables on traditional models of understanding. For example, in 2010 Bonanno published the culmination of two decades clinical psychology research with bereaved participants from around the world. These participants had suffered losses from a variety of devastating life events such as bereavement from the death of a child, the premature death of a spouse and death caused by war; as well as trauma experienced from childhood sexual abuse (Bonanno, 2010). From his extensive research, Bonanno concluded that traditional theories of grief have failed to address the phenomenon of human resilience; a trait he believes is hardwired in humans to help them efficiently deal with their losses and understanding of themselves after traumatic life events, and are therefore not fit for purpose (Bonanno, 2010; Jennings *et al*, 2013). Bonanno's work shows, that many 'resilient' people do not show any of the responses to grief that traditional theories deem necessary for recovery (Freud, 1917; Kübler-Ross, 1969; Bowlby and Parkes, 1970; Worden, 1991; Stroebe and Schut, 1995), and that this is in fact a 'healthy' response for them, rather than a pathology to be feared (Bonanno, 2010). In light of this finding, Bonanno (2010) suggests that many universal grief counselling services can do more harm than good for any 'resilient' people who may frequent them, as they draw out emotions they are hard wired against (Bonanno, 2010).

After a Century of grief research built on the belief that humans must mourn their losses via a staged or phased process in order to avoid periods of complicated grief caused by the psychological damage of not mourning (Worden, 1991), Bonanno's (2010) findings are controversial. Those who work in the field find it hard to imagine that providing therapy to those who have suffered a loss could in fact be harmful. However, it has been known for the last two decades that the majority of people do not require specialist bereavement counselling when they suffer a bereavement, as ninety percent of people will utilise personal coping mechanisms and social support structures (Worden, 1991), so Bonanno's findings should not be too hard to comprehend.

Instead, the issue to be considered when criticising Bonanno's (2010) work is the lack of empirical support for his theory generated from non-resilient or 'vulnerable groups' of society; such as people with learning disabilities. For this population the literature suggests that the personal coping mechanisms and social support structures available to them differ to the non-learning-disabled population, so resilient personalities may not be developed (Morrison and Cosden, 1997). As a result, counselling and support

services may prove beneficial for people with learning disabilities if their social networks are unable to support them. As a result, Bonanno's findings (2010) should not heavily influence work in this area at this stage.

In light of the discussion here, the Dual Process Model of grief (Stroebe and Schut, 1995) has been used to underpin the understanding of grief within this research. This model has been chosen for two reasons. Firstly, research carried out by Machale and Carey (2002) into the impact of bereavement upon people with learning disability, found that people with learning disabilities often suffer multiple losses when people in their lives die. As a result, a model of grief that is able to incorporate these often complex life changes people with learning disabilities face and the impact this has upon the support they may require at this time was vital.

Secondly, the Dual Process Model does not restrict the study of grief to the loss of a particular relationship. Due to the Inclusive Participatory approach used in this research, this was an important factor in the model's selection. It was not possible prior to the recruitment of the advisory group or co-researchers with support experience to define the parameters of the bereavement support that would be explored in the research. As a result, a model, which views grief as a dynamic process that is loss specific, rather than relationship specific (Stroebe and Schut, 1995) was needed. (Please see *Chapter's One, Two and Four* for more details of the method employed in this research).

3.4 Bereavement and Grief for People with Learning Disabilities

Bereavement and grief for people with learning disabilities is a complex issue, with research suggesting that the support they receive at these times often leaves a lot to be desired (such as Read and Elliott, 2007; Blackman, 2008; Handley and Hutchinson, 2013). The remainder of this chapter explores why this is the case from the empirical evidence available. However, before unpicking this issue in greater detail, it is important to recognise the types of bereavements people with learning disabilities may suffer.

3.4.1 What Losses do People with Learning Disabilities Experience?

Just like the general population in the UK, the population of people with learning disabilities is aging (Ward, 2012). At the time of writing, the median age of death for people with learning disabilities in the UK is 65 years for men and 63 years for women, in comparison to the general population median of 78 years for men and 83 years for women (Heslop *et al*, 2013). These figures represent a significant difference in the age of death for people with learning disabilities and those without (Heslop *et al*, 2013), an issue which reaches far beyond the scope of this research, as well as highlighting that people with learning disabilities are living longer than ever before (Worden, 2012). One of the consequences of living longer is the increased likelihood of outliving family members, friends, colleagues and housemates (Blackman, 2008; Ryan *et al*, 2010, PAMIS, 2014), and the subsequent periods of grief this causes.

The deaths of family members, especially parents, have been suggested in the literature to be the bereavements that will affect aging people with learning disabilities the most due to the closeness of these relationships and the associated losses these deaths may bring (Machale and Carey, 2002; Blackman, 2008; Gibbs, 2014). That is, research suggests that sixty percent of people with learning disabilities live in the parental home and not in a professional care setting (DoH, 2001b; Gibbs, 2014). The accuracy of these statistics can be questioned, as it is only based on estimated figures for the number of people with learning disabilities in England and Wales (Holland, 2011), but it clearly highlights that the death of a parent is likely to have a significant emotional impact on a large number of people with learning disabilities in these regions.

Furthermore, the emotional impact of this loss is suggested by Machale and Carey (2002) to have a tangible effect on many people with learning disabilities, such as losing their home, daily routine and support network (see also Blackman, 2003; Hollins, 2016; Mason and Dowling, 2016)

The support networks of people with learning disabilities are known to differ greatly from people without learning disabilities (Blackman, 2003; Payne, 2005; Gibbs, 2014; Kamstra *et al*, 2014). They are often much smaller in nature, consisting mainly of parents and those who are paid to be there, such as support workers/PAs and social workers (Forrester-Jones *et al*, 2006; Williams *et al*, 2010; Williams 2011a). Friends are rarely included in this network as they are either not acknowledged by other members of

the group (Reinders, 2010), or there are no friends to include as the opportunity or skill to keep and maintain them has not been mastered by the individual being supported (Amado, 1993; O'Brien and O'Brien, 1993). As a result, people with learning disabilities often rely heavily upon family members, especially parents, for support and guidance throughout their lives, as well as their support workers or PAs (Williams, 2011a).

3.5 Support Workers and PAs

As the previous section has introduced, support workers and PAs form a vital part of many people with learning disabilities support networks (Payne, 2005; Forrester- Jones *et al*, 2006) and are therefore likely to play a pivotal role in providing support to these individuals when someone they love dies. However, before exploring this matter further it is felt important to explain who support workers and PAs are, where they work and the tasks they carry out.

3.5.1 *What is a Support Worker and What do they do?*

Defining the role of a 'support worker' in the learning disability field is a difficult task as so little is known about the work they do and the environments they work in (Manthorpe and Martineau, 2008). The majority of empirical research in the UK has focussed on the role within clinical settings such as hospitals and some nursing homes with little focus on learning disability services (Balwin *et al*, 2003). As a result, it is hard to define what a learning disability support worker does, but some of the tasks they might carry out include (but are not limited to); providing personal and health care related support, giving medication and injections, community participation, advocacy and assistance (Pickard *et al*, 2003; Department of Health, 2016). The places where these tasks are carried out is even harder to define as support services for people with learning disabilities in the UK are ever changing (Williams *et al*, 2010)

3.5.2 *Personalisation*

Since the 1980's the landscape in which support work for people with learning disabilities is done has altered due to the advent of the 'personalisation' movement

(Morris, 2011). This movement called for a shift in the provision of support from within a service-led model to one in which the individual's strengths, preferences and aspirations are placed at the centre of the support process (SCIE, 2010). For people with learning disabilities, this movement was also underpinned by a number of Independent Living Principles (DoH, 2012). These Principles do not advocate people with learning disabilities living 'independently', i.e. on their own, but rather that individuals take control of the support they require in an 'inter-dependent' relationship. They advocate for people with learning disabilities, their families and supporters having the choice, control and freedom to live the lives they want (DoH, 2012). The introduction of self-directed support systems has been instrumental to this movement as they have enabled individuals to choose the support they receive and from whom, via the employment of Personal Assistants (PAs). Within this system some people choose to have their Personal Budget or Direct Payment (CCDPA, 1996) paid directly to them so they can employ their own PA and have complete control over their support, whilst others choose to have their payment given to an organisation who then provides them with a PA.

The initial uptake of Direct Payments within the learning disability community in England was low due to the complexities of managing the finances and becoming an employer (Ungerson, 2004). But, a direct marketing campaign to explain the organisational route available for employing a PA saw these issues dissipate and the number of people with learning disabilities taking up Direct Payments increasing (Davey *et al*, 2007). The most recent data available suggests that in 2014/2015, 83,995 of the estimated 252,446 adults with learning disabilities in England (aged 18-64) were making use of self-directed support, with 21,580 of these adults using a Direct Payment (Public Health England, 2016). In comparison to the 42,625 adults using self-directed support in 2010/2011, with only 11,205 using a Direct Payment (Emerson *et al*, 2012).

As a result of these increases, the role of many people working in the learning disability field has changed from 'support worker' to 'PA'.

This shift towards the personalised provision of support is likely to have had an effect on the place support staff hold in people with learning disabilities social networks, but there is little empirical evidence to support this. That is, a wealth of research has focused on the changes personalisation has brought to the social care sector overall, such as the work of Spandler (2004) which explored the implications of Direct Payments from a policy perspective, and Barnes and Mercer's (2006) research which explored their

introduction from a service delivery point of view, but little research has focussed on the perspectives of those receiving and those providing support in this new arena. Some studies, such as those carried out by Stainton and Boyce (2004), Williams *et al* (2009), and Cunningham and Nickson (2010), have begun to highlight the perspective of individuals with learning disabilities who employ PAs. Yet, only a small subsection of the research literature has brought the voices of those employed as PAs to the fore (Askheim, 2005; Clayton, 2006; Williams, 2011a). The research presented in this thesis aimed to add more PA voices to this small body of literature via an exploration of the role they play in the support networks of the people with learning disabilities they support when someone they love dies.

3.5.3 Who are Support Workers and PAs?

Due to the lack of definition and multiple locations many support workers and PAs now work in in the UK, providing accurate demographic information about the workforce is challenging. The sources of information that are available fluctuate between providing data for all adult social care services in the UK or England and Wales separately, as well as excluding those working as PAs (Skills for Care, 2017).

However, from the data that is available, it is clear that there is a significant gender divide within the adult social care workforce with eighty-two percent of staff in the sector being female and eighteen percent male (Skills for Care, 2017); with thirty-three percent of senior management roles held by men (Skills for Care, 2017).

The workforce in England is also ethnically divided, as Table 3, below, highlights:

Table 3. Ethnic Makeup of the English Social Care Workforce

Ethnicity	Percentage of English Social Care workforce
White	80%
Mixed/multiple ethnic group	2%
Asian/Asian British	7%
Black/African/Caribbean/Black British	11%
Other	1%

(Skills for Care, 2017).

In addition, the majority of social care staff (seventy-seven percent) in England are aged between twenty-five and fifty-four, with the remaining twenty-three percent being aged over fifty-five (Skills for Care, 2017).

3.6 Bereavement, Learning Disabilities and Support

As introduced in *section 3.3*, research indicates that ninety percent of the non-learning-disabled population will cope with periods of bereavement within their own social circle (Worden, 1991), whilst ten percent will never fully come to terms with their loss without specialist support such as bereavement counselling or therapy (Schut, 2001). For the learning-disabled population, the number of people who will never fully come to terms with their bereavements in their own social circles, or will experience complicated grief, has never been quantified (Dowling *et al*, 2006). However, it is presumed that this population will experience much higher rates of complicated grief than the general population (Elliott, 1995; Blackman, 2003), due to their marginalised status in British society (Doka, 1989; Oswin, 1991; Blackman, 2003; Read and Elliott, 2007; Blackman, 2008) and the legacy the demonization of the death in Western society has upon societal orthodoxies, which may be played out in their support networks.

Doka argues that marginalised sectors of society often experience a disenfranchisement of grief as the prevailing social world does not support their ability to publicly mourn (Doka 1989). For people with learning disabilities this disenfranchisement is suggested to occur because society, and those who support them, fails to acknowledge their emotional lives (Arthur, 2003; Blackman, 2003) and does not believe they can emotionally comprehend the complexity of death (Conboy-Hill, 1992). Oswin (1991) terms this the 'double taboo' of death and disability which leads to any expression of grief being assigned to someone's learning disability, rather than their grief. This is akin to 'diagnostic overshadowing' in the healthcare field whereby

'symptoms of physical ill health are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities.'

(Emerson and Baines, 2010).

Until as recently as 1989 (Hollins and Kloeppel, 1989) these views dominated academic and societal thinking about grief and people with learning disabilities, with it widely accepted that they were unable to grieve at the time of bereavement (Dodd and Guerin, 2009). Oswin's seminal work (1991) set out to challenge society's assumptions about people with learning disabilities and grief, but their legacy has continued to resonate in wider society. Academic literature and support services now widely accept that people with learning disabilities grieve at the time of bereavement (Reynolds *et al*, 2008) and that their emotional responses to grief do not differ to those of other people (Stoddart *et al*, 2002; Blackman, 2003; PAMIS, 2014), yet cases of 'diagnostic overshadowing' are still widely cited in the research literature (such as, Hollins and Esterhuyzen, 1997; Bonell-Pascual *et al*, 1999; Arthur, 2003; Gentile and Huber, 2005; Gilrane-McGarry and Taggart, 2007), along with cases of people being denied the knowledge of a loved one's death and the associated mourning rituals (Forrester-Jones, 2013, Heslop *et al*, 2014; Mason and Dowling, 2016) and the resulting cases of complicated grief (Summers and Witts, 2003; Dodd *et al*, 2008). The following section will begin to explore why this is the case.

3.6.1. People with Learning Disabilities as Emotional Beings

A review of the research literature carried out by Arthur (2003), suggests that people with learning disabilities have significantly more emotional developmental problems than people without learning disabilities. It is important to note that Arthur's conclusion (2003) is based upon a review of studies carried out with people with learning disabilities and not in comparison with the non-learning disabled population, but it falls in line with previous research findings, which state that the prevalence of psychiatric disorder within the learning disability population falls between thirty and seventy-five percent, a figure much higher than that of the general population (Reiss, 1994).

Furthermore, an Inquiry carried out into the mental health needs of young people with learning disabilities in the UK, found that young people with learning disabilities were four times more likely to experience a mental health problem than those in the non-learning-disabled population (Carpenter, 2001). The co-morbidity of learning disability and psychiatric disorder noted in this Inquiry, is thought, in part, to be due to the assumption that people with learning disabilities are not emotional beings, so their emotional needs are not met (Carpenter, 2001; Blackman, 2003; Morgan, 2003).

The prevalence of psychiatric disorders within the learning disability population was acknowledged in *Valuing People* (DoH, 2001), and led to the recommendation that people with learning disabilities should be able to access general psychiatric services. The White Paper (DoH, 2001) went on to set out the requirement for all local mental health services to have clear learning disability protocols and to publish 'easy read' information. However, in 2009, *Valuing People Now* (DoH) highlighted that these requirements had not been met, with many people with learning disabilities still unable to access mainstream mental health services. The Royal College of Psychiatrists suggested this was due to mainstream mental health services lacking the resources, skills and expertise to manage people with learning disabilities (2006) and recommended that learning disability professionals began working in conjunction with mental health service providers in order for the mental health needs of the individuals they support to be met (2006). However, this need has been left widely under supported for many people with learning disabilities (Worden, 2012; Padraig *et al*, 2017).

Despite the evidence to suggest that people with learning disabilities are significantly more likely to have emotional developmental problems than people without learning disabilities (Reiss, 1994; Carpenter, 2001; Arthur, 2003; Williams and Heslop, 2006), in times of grief, research suggests that their emotional and mental health needs deteriorate similarly to those without a learning disabilities (Oswin 1991; Hollins and Esterhuyzen, 1997; PAMIS, 2014). In light of this evidence, the grief experienced by people with learning disabilities should not be 'pathologized' as a mental health issue or interpreted as 'problem behaviour' (Oswin, 1991), but rather acknowledged and supported within everyday support networks (Blackman, 2003; Williams and Heslop, 2006). Read's model of bereavement support for people with learning disabilities (2005; Read and Elliott, 2007) incorporates this learning by suggesting that for people with learning disabilities to be consistently supported they may need support from different people involved in their lives at different times during the grieving process (Read and Elliott, 2007). Read's (2005) model acknowledges the role an individual themselves play in their grief journey, alongside their families (Micro level); their support workers and/or carers (Meso level); local support organisations (Exo level); and national organisations (Macro level), suggesting that the input from each 'level' may fluctuate (or not be present at all) at different stages of a person's grieving. (This model will be explored in more detail in *Chapter Seven*).

Yet whilst it is known that people with learning disabilities should be supported to grieve within their everyday support networks (Blackman, 2003; Read, 2005; Williams and Heslop, 2006), the marginalised status they hold within much of Western society and the prevailing social orthodoxies of bereavement and grief which play out in their support networks, often still leads to cases of diagnostic overshadowing (such as Hollins and Esterhuyzen, 1997; Gentile and Huber, 2005; Gilrane-McGarry and Taggart, 2007) and periods of complicated grief being omnipresent in the research literature.

In a bid to help people with learning disabilities who reach crisis point as a result of this situation, a small number of specialist bereavement services for people with learning disabilities have developed in England (Blackman, 2008; DoH, 2009; Pitt, 2010; Respond, 2013). These services have been welcomed by some support workers who feel that they improve the quality of life of the individuals who receive their support (Blackman, 2008; Pitt, 2010), but the views of the individuals who have received their services are underreported. Furthermore, the development of 'specialist' services goes against the requirement for mainstream mental health services to ensure people with learning disabilities have access (DoH, 2001, 2009), and fails to address the issue of why support workers and PAs appear unable to engage with this element of their role.

3.7 Supporting People with Learning Disabilities through a Period of Bereavement

As the discussion in this chapter so far has made clear, the inconsistent and sometimes non-existent nature of the bereavement support people with learning disabilities in the UK receive (Read and Elliott, 2007) is a complex problem influenced by many factors. However, much of the empirical research carried out into this issue has been intervention focused (such as, Dowling *et al*, 2006; Ryan *et al*, 2010). These studies will be reviewed in this section.

For example, a randomised control study carried out by Dowling *et al* (2006) aimed to explore the effectiveness of two bereavement support interventions for people with learning disabilities; one delivered by professional grief counsellors and the other, an integrated intervention, delivered by two of the individual's usual carers (this could have included family members). The fifty-six participants involved in this study were recruited from a sample of individuals put forward by their carers as a result of them having recently experienced a significant bereavement, such as the death of a parent or sibling.

These participants did not have to demonstrate a particular level of distress to take part in the study as the author's assumed from their review of the literature that the referring carers would not be able to accurately identify such distress from an individual's behaviour. Despite this assumption, the study hypothesised that participants with learning disabilities would not benefit from the intervention delivered by professional counsellors but would rather reap significant benefits from the 'enhanced bereavement-specific support' delivered by their usual carers (p. 278). Participants were assigned to their intervention group using a cluster-randomisation approach; no control group was utilised, and each participant knew which group they were in based upon the intervention received. Twenty-five individuals were placed in the professional counselling intervention group and twenty-two in the integrated intervention; the remaining 9 were excluded from the study as they did not meet the criteria. The overall finding of this study provided demonstrable improvements for the individual with learning disabilities as a result of receiving the bereavement counsellor's intervention and none for those receiving the integrated intervention. However, the reasons behind these findings are in many ways more interesting and enlightening than the findings themselves. That is, no significant improvements were seen for individuals assigned to the integrated intervention group as eleven participants were withdrawn from the study on being assigned to this group, and a further eleven carers (four family members and seven paid carers) assigned to deliver this intervention withdrew themselves. In both of these groups, the reason for withdrawal was based upon concerns for the person with learning disabilities well-being (p. 285), with the author's surmising that the carers also withdrew themselves due to the task being too taxing, their own experiences of loss making it difficult for them to provide the support required, and the intervention not being practical to deliver. As a result, the authors suggest that carers (family carers and paid carers) are not best placed to deliver structured bereavement support to people with learning disabilities, this should be provided by professional counsellors, but they may be able to offer un-structured support if they

"...have come to terms with their own losses, and have the emotional maturity, confidence and time to commit to providing adequate support to a vulnerable adult."

(Dowling *et al*, 2006, p.286).

These are sensible recommendations based upon the outcomes of the study, but they do not address the interesting insight the research provides into the way bereavement support for people with learning disabilities may be seen by carers and support organisations. That is, these outcomes appear to suggest that carers and support organisations view bereavement support as something that ‘other’ people do for people with learning disabilities, not carers. This is an interesting finding which is unpicked in the remainder of this chapter and in the findings of this research.

In addition to the work carried out by Dowling *et al* (2006) and Ryan *et al*, (2010), the work of Blackman (2008), which proposed the implementation of a bereavement support assessment tool for people with learning disabilities, was also intervention focused. The premise for this proposal was based upon Blackman’s ten-year career within a specialist bereavement therapy service for people with learning disabilities, where she observed a variety of individuals with mild to moderate learning disabilities who were grieving. From these anecdotal observations, Blackman concluded that the majority of learning disability support services and staff teams did not acknowledge the broad range of factors that contributed to the grief people with learning disabilities suffer after a bereavement, including the practical losses associated to this loss and the previous bereavements they have suffered (Blackman, 2008). In a bid to rectify this situation, Blackman began developing a tool, based upon the models of Payne *et al* (1999) and Shuchter and Zisook (1993), to provide support staff with a way of continually assessing the individuals they work with to ensure the support they require is identified, along with the most appropriate person to provide it.

It is hard to argue against the practical efforts made by Blackman (2008) to improve the bereavement support for people with learning disabilities, especially as the tool she proposes compliments Read’s (2005) model of bereavement support for people with learning disabilities and its implementation is suggested to improve the confidence of support staff in talking about issues of death, grief and bereavement (Blackman, 2008). Yet the driver for its development was based upon ‘pathologizing’ the grief reactions of people with learning disabilities (Oswin, 1991) to ensure specialist services are employed when support staff do not identify the support that’s required of their own fruition. Furthermore, the development of the tool was based upon Blackman’s (2008), albeit extensive, anecdotal observations of how bereavement support was provided within local learning disability services, with limited engagement with the support staff in

these services with regards to how they viewed the issues of death, grief and bereavement, or how they provided such support in their working days.

This latter point is one which hampers a lot of empirical research into bereavement support for people with learning disabilities in the UK; the lack of support worker and/or PA voices. The work of Handley and Hutchinson (2013), is one of the few studies to incorporate the voices of these populations in the field through semi-structured interviews with seven family carers and four residential carers about their experiences of providing bereavement support to people with learning disabilities. The Interpretive Phenomenological Analysis of the data collected in this research provides valuable insight into what such support entails as understood by those providing it. For example, the research highlighted the emotional and practical challenges carers face when supporting someone through a period of bereavement, but also the reciprocity of the support relationship at this time which balanced out the challenges faced for some of those interviewed. This is a finding not reported elsewhere in the literature.

However, Handley and Hutchinson's (2013) research goes on to suggest, as has been suggested elsewhere in the literature (such as Read and Elliott, 2007; Ryan *et al*, 2010; Watters *et al*, 2012), that carers are not always able to identify the grief responses people with learning disabilities present and therefore require training to improve their understanding and the support they provide.

Although the intention behind this recommendation is commended as an attempt to improve service provision, it stems from limited empirical evidence of how bereavement support is done and understood by those providing it in their day-to-day roles. Of course, the work of Handley and Hutchinson (2013) begins to provide insight into this area, but this is only one study amongst many and only includes the voices of four paid carers (it is likely that familial carers have different experiences of providing bereavement support to those experienced by those paid to provide such support).

Without a clear understanding of the support, support staff already provide, the tasks they carry out and the challenges they face, the effectiveness of any training that is implemented is likely to be limited (Bloom, 2005; Ahlstrom and Wadensten, 2012).

Furthermore, a generic recommendation for staff training raises some interesting questions about how bereavement, grief and learning disability are viewed in society. For example, suggesting that support staff can be trained to undertake bereavement support, implies that there is an inherent belief system, which all of society assigns to and that this is the 'right' system to use to support someone with a learning disability. As the discussion in *section 3.3* highlighted, the literature suggests this is not the case as grief is a universal but unique phenomenon (Nagraj and Barclay, 2009) with no right or wrong way to experience it. Any training that is put in place would therefore have to explore all of these issues, which would be time consuming and costly, or be tailored to a particular support relationship in order to be useful. Likewise, any training that is implemented would need to incorporate the spiritual rituals that so often play a pivotal role in people's journeys through grief, including; formal religious rituals, visiting special places, encountering nature, music and art (PAMIS, 2014).

From the research that has been done into the effectiveness of bereavement support training carried out to date, it appears that, due to the omission of the issues discussed above, this training does not improve support staff knowledge or confidence in the long term. For example, a randomised control trial carried out by Watters *et al* (2012), found that whilst attending a one-day bereavement training course did improve the knowledge of support staff immediately after the course, the longer-term impact could not be measured. This thesis does not wish to belittle the importance of training for frontline staff within the learning disabilities field, but merely wishes to highlight that a generic recommendation for a 'one size fits all' approach to training about such a highly individualised matter like bereavement at present does not seem fit for purpose.

In contrast to the body of research which calls for the implementation of training for support staff, a number of other studies suggest that learning disabilities support staff do acknowledge the bereavement needs of those they support, but are unable to support these needs due to the lack of guidance and resources available to them (Mencap, 2007 and 2012; Heslop *et al*, 2013). Research carried out by Ryan *et al* (2010) eloquently highlights this point, as it found that residential support staff widely perceived the death of a peer service user to have an impact on those left behind:

“And it was a lady that had no communication, she was always in a chair. There was a death in that particular bungalow.... At some particular stage, either at the

removal or before the removal, I was standing between two chairs and she put her hand into mine. Now, that spoke volumes to me.”

(Ryan *et al*, 2010, p.261).

Additionally, the qualitative research carried out by Gilrane-McGarry and Taggart (2007), which explored the bereavement support structures available to people with learning disabilities from their perspective, suggests that front line support staff, are well equipped to provide practical bereavement support, such as involving individuals in funeral arrangements, but are let down by the resources available to them on both a professional and personal level to provide the emotional support needed.

This empirical evidence seems to suggest that the reason many people with learning disabilities do not have their emotional needs supported when someone they love dies is not due to the inability of support staff to acknowledge these needs, but rather that support staff are unable to meet these needs due to the resources they have available to them (Mencap, 2007 and 2012; Heslop *et al*, 2013). This situation leaves support staff with relatively little choice but to ‘pathologize’ the support needs of the individual they work with to get ‘professional’ support, or ignore the emotional needs until they get to such a point that ‘professional’ support has to be brought in. The research carried out by Dowling *et al* (2006) supports this suggestion as although support staff were keen to take part in the research at the outset, seven of them withdrew from the study when they were assigned to the integrated intervention partly due to the demanding nature of the intervention which they did not have the resources, such as time, to undertake.

The emotionally taxing nature of providing bereavement support to people with learning disabilities therefore needs to be explored further in order to provide support workers and PAs with the confidence and resources to provide this support. A shift towards training these staff to deal with bereavement issues is a positive step towards achieving this, but the literature suggests that more needs to be done to support staff in situ, especially within the ever changing the world of support work where the literature suggests that people are working increasingly closely with individuals in their own homes. Hearing more from those providing bereavement support in each of these locations may go some way to improving the current situation in the UK; something the research presented in this thesis aimed to achieve.

3.8 Providing Emotional Support

As has been discussed in *section 3.7* providing bereavement support is likely to be one of the most emotionally taxing tasks support workers and PAs have to carry out in their working lives (Bloom, 2005; Blackman, 2008; Handley and Hutchinson, 2013; O'Driscoll, 2015). Research carried out into the emotion work done by support staff more generally, highlights the importance of staff engaging with the emotional aspects of their role (Ptacek and Ellison, 2000), but also warns that undertaking taxing emotional labour can lead to increased stress levels (England, 2005; Tuffrey-Wijne *et al* 2009; Ryan *et al* 2011; Wiese *et al*, 2012; Todd, 2013; O'Driscoll, 2015). A limited amount of this research has focussed on the emotionally taxing elements of providing bereavement support, as the vast majority of this work focuses on 'end-of-life' care, but as the empirical evidence discussed in this chapter suggests, when faced with providing bereavement support, support workers need to have confidence in their abilities and the resources in place in order to provide such support.

3.8.1. *Being a Support Worker – Policies, Rules and 'Professionalism'*

The literature discussed throughout this chapter so far suggests that support workers and PAs work within a complex environment where their role is played out in the midst of a myriad of messages from professional, academic, media and societal sources. Each of these sources place different expectations on those working in these roles, which, when unpicked, may help explain why many people with learning disabilities are often left under-supported by their support staff when they suffer a bereavement (Read and Elliott, 2007; Blackman, 2008).

The message from much academic literature is clear; at present support workers are not best placed to provide the emotional support people with learning disabilities require when they are grieving as they often struggle to identify the impact bereavement has upon them (Hollins and Esterhuyzen, 1997; Bonell-Pascual *et al*, 1999; Arthur, 2003; Blackman, 2008; Handley and Hutchinson, 2013); are not confident in their abilities to provide such support (Dowling *et al*, 2006; Handley and Hutchinson, 2013); and, lack the resources to provide the support in situ (Mencap, 2007 and 2012; Heslop *et al*, 2013). As a result, 'professionals' such as specialist counsellors should deliver this support (Murray *et al*, 2000; Summers and Witts, 2003; Dowling *et al*, 2006; Blackman,

2008) and support staff should undertake training (Handley and Hutchinson, 2013). These messages divide the roles of those working in the learning disabilities field into those who are trained and capable of providing such support (e.g. specialist counsellors) and those who are not (support workers and PAs). The findings of Dowling *et al's* (2006) work, in which seven carers and eleven people with learning disabilities withdrew from the study when assigned to the integrated intervention group where bereavement support would be delivered by the carers, suggests that the division of labour expressed in the literature to date has been embodied in the learning disability workforce in the UK. But how has this happened? A review of the legislation (such as the Care Act, 2014) and the Code of Conduct (Skills for Care for Health, 2013), which govern the roles of those working in the adult social care workforce in England may provide a useful insight into this matter.

Both the Care Act (2014) and Code of Conduct (Skills for Care for Health, 2013) set out the legal duties and requirements for staff working in the adult social care field (and those working in the health sector). Both these documents frame these roles within the language of 'professionalism'. For example, support staff are seen as vital to the effective delivery of social care services in England and pivotal members of the people they support's networks, who must

"...providing [sic] high quality, compassionate healthcare, care and support."

(Skills for Care for Health, 2013, p.3).

whilst ensuring their

"...conduct does not fall below the standards detailed in the Code."

(Skills for Care for Health, 2013, p.3).

Of course, ensuring that all adult social care staff in England are '*working to standard*' (Skills for Care for Health, 2013, p. 3) is a commendable goal, especially where issues of safeguarding are concerned, but many of the guidance statements staff must follow sit juxtaposed to one another. For example, the Code of Conduct (Skills for Care for Health, 2013) states that all adult social care staff in England must

“[P]romote and uphold the privacy, dignity, rights, health and wellbeing of people who use health and care services and their carers at all times.”

(point 2, p.4).

Whilst also

“establish[ing] and maintain[ing] clear and appropriate professional boundaries in your relationships with people who use health and care services, carers and colleagues at all times.”

(point 6, p.4).

On the basis of these two examples alone, it can be seen that in order for support staff to be ‘*working to standard*’ (Skills for Care for Health, 2013, p.3) they must navigate a complex path whereby they are responsible for maintaining the health and wellbeing of those they support in a manner in which the Code, and those who use services, expect (p. 3), which includes remaining bounded and distant from those they support.

These juxtaposed messages go against the wealth of literature which states that being a supporter is a social relationship, ‘it can only be undertaken in the context of another person’ (Payne, 2005, p.184). These messages lean instead towards the literature which suggests that engaging in the interpersonal and therefore emotional work of being a supporter can be taxing for staff and may lead to increased staff turnover (England, 2005; Todd, 2013; O’Driscoll, 2015). In a sector where staff turnover is estimated to be 27.8% a year (350,000) (Skills for Care, 2017) this is perhaps an understandable stance to be taken at a policy level, but it fails to acknowledge the impact such regulations may have on staff when sat alongside the requirement to support someone’s wellbeing (England, 2005).

Additionally, these frameworks do not as yet govern the world of work for PAs in the adult social care workforce who work directly for individuals. This PA workforce in England goes about its work relatively unregulated and as such is a relatively understudied body (Carr and Robbins, 2009; Cunningham and Nickson, 2010; Shakespeare *et al*, 2017). However, the small section of research literature that has brought this workforce’s voice to the fore (Askheim, 2005; Leece and Pearce, 2010; Williams, 2011a; Ahlstrom and Wandensten, 2013) suggests that whilst the Care Act (2014) and Code of Conduction (Skills for Care for Health, 2013) do not directly apply to them, they are

aware of their presence and the critical eye they cast over the work they do. For example, one PA states that he sees his role, as being a '*professional shadow*' to those he works for (Clayton, 2006, p.137). The use of the term 'shadow' in this quote fits within the personalisation agenda that created his role, but the term 'professional' highlights his awareness of the scrutiny his role may be under from those receiving his support and detaches him from those he works for.

Exploring the frameworks which govern the role of support workers and their reach to those working as PAs, provides new insight into why bereavement support for people with learning disabilities in the UK has been described as 'at best inconsistent and at worst non-existent' (Read and Elliott, 2007, p.177). Providing bereavement support would fall into the 'wellbeing' arena that support staff must support, whilst also being one of the most emotionally taxing tasks they will ever have to undertake in their role (Bloom, 2005; Blackman, 2008; Handley and Hutchinson, 2013; O'Driscoll, 2015) and must therefore distance themselves from. It is likely that many learning disability support organisations translate these overarching messages into their policies and procedures, which become entrenched in their organisational practices. As a result, it is possible to suggest that support staff may also embody these contradictory messages in their everyday working lives, which results in findings such as Dowling *et al's* (2006) in the academic bereavement support literature.

The research in this thesis wanted to explore this issue further in order to understand what impact providing bereavement support in this context had upon the support workers and PAs providing it. As previously stated, being a supporter is a social relationship (Payne, 2005, p.184). and not acknowledging the personal and emotional connection those in these relationships have with one another detracts from what it is to be relational and may in fact cause *more* stress to support staff by denying it (Kittay, 2001).

3.8.2 Personal Resources

As the previous section has suggested, the embodiment of the 'professionalism' agenda within many learning disability support staff may be a contributing factor to their ability to provide bereavement support to people with learning disabilities. But are there other

factors at play? Support staff are not a homogenous group, so are there personal factors at play which affect their ability to provide bereavement support?

The work of McEnhill (2004) suggests that as many people employed in support worker and/or PA roles are young, they are likely to be inexperienced in matters of grief in their personal lives, which will translate into their ability to support someone else through a period of bereavement within the confines of the . However, as the discussion in *section 3.2* has highlighted, the ability of support staff to engage in issues of grief and bereavement is likely to have little to do with their age, but rather their cultural backgrounds (Mason and Dowling, 2016). Public expressions of grief and conversations about its presence remain taboo subjects in much of British culture (Arthur, 2003; Read and Elliott, 2007; Ryan *et al*, 2010), which will be played out in support relationship where the expectation is to provide care, protection and causing no harm (Williams, 2011a). Dowling *et al*'s (2006) work highlights this point by acknowledging that the support staff within their study were not engaged with their own grief issues due to the norms and values of the prevailing society.

If staff do not have the personal resources to engage with issues of bereavement and are not supported by their employers when faced with this situation at work, the emotionally taxing nature of this work is likely to lead to feelings of anxiety, institutional denial, stress and burnout (England, 2005; O'Driscoll, 2015).

3.9 Work Stress and Burnout

“Stress is the physical and psychological effects we experience as a result of the way we react to changes in the surrounding environment.”

(Stoyanov, 2012).

As the discussion in the previous section has alluded to, the internal conflict support workers and PAs are likely to experience due to the emotional resources and regulation they have to embody when faced with providing bereavement support to someone with a learning disability, is likely to increase their work-related stress levels (O'Driscoll, 2015).

Work stress is suggested to occur when the demands of an individual's job exceeds their internal and external resources to do that job (Folkman *et al*, 1987), whilst 'burnout' is a psychological syndrome that occurs in response to chronic, uncontrollable work stress (Maslach *et al*, 2001).

The concept of burnout was noted as a social problem long before it became the focus of Organisational Psychology studies, as it is a real social problem with 'derivations from social theory' (Maslach, 2003, p.189). It is said to manifest as exhaustion, distress, a tendency to depersonalize others and a reduced sense of personal accomplishment (Maslach *et al*, 2001).

Literature from the learning disabilities field suggests that a third of direct care workers experience work related stress levels indicative of the presence of a mental health problem (Hatton and Emerson, 1993), as such conditions are experienced "more readily by the type of person most valued as a human service provider' (Weinberg *et al*, 1983, p.251).

3.9.1 Personal Factors in Stress and Burnout

As the quote from Weiberg *et al* (1983) suggests, the personality traits of those working as support workers and PAs may play a role in predicting this workforces' experience of stress and burnout (Vollrath, 2006). For example, research carried out by Lazarus and Folkman (1984) suggests that an individual's personality affects how they perceive work tasks as well as their subsequent emotional and physiological reactions to them; in short, how stressful they find a situation (Suls and Martin, 2005; Vollrath, 2006). This research led to the creation of the theory of Cognitive Appraisal (Lazarus and Folkman, 1984).

This theory has now been broadened out to understand how personality traits influence work stress and individual perceptions of it and has led to the development of the Five Factor Model of Personality (Costa and McCrae, 1992). This model proposes that there are five personality traits; neuroticism, extraversion, openness to experience, agreeableness, and conscientiousness, which can be used to explain the characteristic differences between people's psychological well-being and thus, their perceptions of

stress and their responses to it (Tupes and Chrisstal, 1961). People with neurotic, extravert and conscientious personalities are thought to be more susceptible to stress and burnout than those with agreeable or open to experience personalities (Tupes and Chrisstal, 1961). Research suggests that those with neurotic, extravert and conscientious personalities are often drawn to work in supporting roles and therefore are more susceptible to higher rates of stress and burnout (Vlerick, 2001; Chung and Harding, 2009).

3.9.2 External Factors

Work from the field of organisational psychology suggests that a number of external factors can also be predictors of work stress and burnout for staff. From the discussion within this chapter, societal orthodoxies, professional regulation, media scrutiny, and interpersonal relationships in the workplace can all be considered external stressors experienced by support workers and PAs when providing bereavement support to someone with a learning disability (Hatton *et al*, 1999; Mencap, 2007 and 2012; Williams *et al*, 2009; Heslop *et al*, 2013).

As has already been discussed, a lack of support and available resources has been shown to reduce support workers' ability to cope with work-related stress (Lees and Ellis, 1990; Mencap, 2007 and 2012; Heslop *et al*, 2013), which in turn reduces their confidence, collegiality and understanding of their own and others emotional reactions (Frost *et al*, 1991; Tuffrey-Wijne *et al*, 2009; Ryan *et al*, 2011; Wiese *et al*, 2012; Todd, 2013).

Challenging behaviour is also cited in the literature to be a significant source of external stress for support workers in the learning disabilities field (Bersani and Heifetz, 1985; Corrigan, 1993), with research suggesting that the more support staff are exposed to challenging behaviour the more they are at risk of stress and/or burnout or attributed stress (Freeman, 1994; Hastings and Brown, 2002).

Challenging behaviour can be 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, 1995, p.4).

Due to the issues surrounding expressions of grief discussed throughout this chapter, instances of challenging behaviour can escalate in some people with learning disabilities when they are bereaved (Brickell, 2008). This situation presents support staff and PAs with a significant external stressor, which could lead to their burnout if experienced over a prolonged period of time. However, Hastings' (2002) review of the research literature suggests that there is only 'reasonable evidence' to suggest this implied causal relationship between 'challenging behaviour' and support staff burnout, as many studies purely rate 'challenging behaviour' as a stressor without measuring that challenging behaviour (Hastings, 2002, p.455). As a result, further work needs to be done to explore this issue; or better yet, improve bereavement support for people with learning disabilities so they do not reach the point where their behaviour could be experienced as 'challenging'.

Research carried out by Hatton *et al* (1999) suggests that depending upon what role someone holds within learning disability services the level to which personal and external factors affect their stress levels:

“...residential care staff and unqualified support team staff generally rated user challenging behaviour, poor user skills and having a low status job as highly stressful, and bureaucracy as relatively unstressful. In contrast, qualified support team staff (often in a managerial role), professional therapists, and managers generally rated bureaucracy and lack of resources as highly stressful, and rated having a low-status job as unstressful.”

(p.281).

These findings have been replicated in more recent studies, such as White *et al*'s (2006) study, which found that the interpersonal demands of helping relationships are the most stressful parts of direct learning disability work; and Devereux *et al*'s (2009) work which found that a lack of resources, such as organisational support, possibly caused burnout in senior learning disability staff.

In light of these findings, the data provided by Hatton and Emerson (1993) is of even more concern as it is likely that the reported levels of stress within the support worker population could lead to a deterioration in care provision (Courtney *et al*, 2010); a reduced quality of life for support workers (Courtenay *et al*, 2010); have a negative economic effect on services due to absenteeism and turnover (Jacobson *et al*, 1996; Raiger, 2005; Skills for Care, 2017); and reduce the interactions staff have with those they support (Rose *et al*, 1998).

However, no research to date has explored the levels of stress and burnout reported by those working as PAs, whether working directly for an individual or an organisation, from an organisational psychology point of view. There is a burgeoning body of work exploring the issues raised by working with an under regulated workforce, such as working conditions, safety, wages, training, pensions and reasonable working hours (Cunningham and Nicholson, 2010; Leece, 2010), all of which may be external factors to stress and burnout, but they are currently not explored in this context.

3.9.3 Care Worker Theory

The emerging field of Care Worker Theory (England, 2005) provides a framework in which to understand all the elements at play for support workers and PAs when faced with providing bereavement support to someone with a learning disability. The social and cultural expectations and norms that surround grief; the marginalised status people with learning disabilities have in society; the relationship they have the individual they are supporting; the expectations of the organisation they work for; the resources available to them in that organisation; and their own emotional responses to grief.

There are five emerging theoretical frameworks of care work within the literature which view the field from the broader political perspective (the Public Good Framework), the employer's perspective (the Prisoner of Love Framework) or from an employee's perspective (the Commodification of Emotion Framework):

1. The Devaluation Perspective, which seeks to understand the world of care work from a feminist perspective. This 'perspective' acknowledges the gender biases in the field which lead it to be undervalued and under paid as care organisations under estimate the role women play in the field

2. The Public Good Framework, which views care work as a practice that has a multitude of other indirect social benefits to all involved.
3. The Prisoner of Love Framework, which defines care work as work that provides services based on sustained personal interaction, and is motivated (at least in part) by concern about the recipient's welfare and not financial gain.
4. The Commodification of Emotion Framework, which focuses on the effects the market of care work has on care workers' personal experiences and individual well-being. And,
5. The Love and Money Framework, which attempts to reconcile the perceived divide between work done for intrinsic motivation and work done for pay

(England, 2005).

Each of these frameworks can offer a lot to the understanding of bereavement support provided by support workers and PAs. However, as the research presented in this thesis focused on the individual and personal nature of relationships and emotional support provided in care work, the 'Commodification of Emotion' framework (England, 2005) is the most suitable. This framework asserts that many jobs in the new service economy require workers to act emotions they do not really feel and that this process is harmful to workers. Such as support workers having to remain boundaried when providing bereavement support to people with learning disabilities (Skills for Care for Health, 2013), whilst feeling a need to engage on a human and emotional level with these individuals (Kittay, 2001). This framework has not been applied in this context before, but it is felt to provide a useful structure in which to explore the complexities involved in providing bereavement support to people with learning disabilities.

3.10 Summary

The discussion in this chapter has explored the literature from the academic fields of disability, grief, thanatology, and organisational psychology, along with professional literature from learning disability practice. This exploration has aimed to place the pieces of the bereavement support puzzle together to present a picture of what this support for

people with learning disabilities looks like in the modern UK context. However, the picture that has been created is a complex one.

The issue of how death, grief and bereavement are viewed in Western society has been viewed from an historical perspective began the chapter and is felt to unpin the empirical finding that bereavement support for people with learning disabilities in the UK is 'at best inconsistent and at worst non-existent' (Read and Elliott, 2007, p.177) due to its effect on support relationships. However, as the chapter progressed, and the wider body of bereavement support literature was explored, it became clear that a myriad of other reasons may be influencing this situation, including; the marginalised status people with learning disabilities hold within society, the disenfranchisement of grief this status creates, and the limited personal support and social networks they maintain. As well as the personal, professional and emotional resources support workers and PAs have available to them when having to provide support at this time.

In addition, it appears that the legal and professional frameworks (Skills for Care for Health, 2013; HMSO, 2014;) which govern support workers and PAs is affecting the bereavement support they can provide people with learning disabilities. That is, it seems that the 'professional' boundaries that support workers must adhere to, and PAs are aware of, sit in conflict to the intimate involvement they have in people's lives. This appears to cause many of the workforce to experience cognitive dissonance about the role they should play in people's lives when they are grieving, which they have to deal with alone as there are no resources available to draw on within the services they work for. However, at present, this can only be surmised from the literature as no research has explored this issue directly with support staff in the UK.

Exploring the literature in this way has highlighted how complex providing bereaving support to people with learning disabilities is, as well as shining a light on the gaps in the knowledge in this area. One of the most glaring holes in this knowledge is the lack of understanding about how each of these factors play out in the working lives of support workers and PAs as understood from their perspective. A plethora of research explores what support staff do wrong and what needs to be done to rectify this situation, but little explores the work they do, how they do it and what it feels like doing it. This is something which the research presented in this thesis aimed to begin rectifying.

Chapter 4

Research Methods

4.1 Introduction

This chapter builds on the discussion presented in *Chapter Two* to present details of the methodology used to conduct the research presented in this thesis. The chapter begins by reintroducing the research questions, aims and objectives, before detailing the methodology used to achieve them. The research design, participant recruitment and data collection tools are all discussed in line with the concurrent order in which they took place.

4.2 Research Questions, Aims and Objectives

4.2.1. Research Questions

As introduced in *Chapter One*, the research presented in this thesis was guided by the following five research questions:

1. How do support workers and PAs view the bereavement support they have provided someone with a learning disability?
2. What does providing bereavement support to someone with a learning disability involve?
3. Do support workers and PAs receive training to provide bereavement support to people with learning disabilities?
4. What impact does providing bereavement support to someone with a learning disability have upon support worker and PA emotional and mental health?
5. Do support workers and PAs have any thoughts about how bereavement support for people with learning disabilities should be done in the future?

4.2.2. Aims

As the questions in *Section 4.2.1* suggest, the research presented in this thesis aimed to explore the phenomenon of bereavement support for people with learning disabilities from the view point of the support workers and PAs who provide it in the UK. The research further aimed to uncover what skills these support workers and PAs utilised when providing this support, where they learnt these skills, what impact this support had upon their own emotional and psychological health, as well as their sense of self within this process.

The study also aimed to highlight how support work in the field of learning disabilities has changed via an exploration of how the personalisation agenda has affected everyday support work in different support settings; residential care homes, supported living facilities and those employed under Personal Budgets or Direct Payments (CCDA, 1996).

Additionally, the study aimed to provide support workers and PAs with a voice in the literature through their 'employment' within an inclusive participatory research study. As, as Needham (2008) notes

'staff on the frontlines of public services are recognised to have a distinctive voice and expertise as a result of regular interaction with service users'

(p.222/3).

yet they are often marginalised within the research literature.

In a similar vein, this research sought guidance from a group of people with learning disabilities who have received bereavement support from support staff in their lives (support workers and/or PAs) to ensure that they also began to have a voice in the research literature around this subject, but also to ensure that the research asked the 'right' questions.

4.2.3 Objectives

In order to achieve these aims, the research had three objectives:

1. To explore the phenomenon of bereavement support from the perspective of the support workers and PAs who provide it in the UK.
2. To involve and listen to support workers directly within an inclusive participatory research model.
3. To involve and be guided by the lived experiences of a group of people with learning disabilities within an inclusive participatory research model.

4.3 The Research Community

As has been discussed in *Chapters One* and *Two*, in order to meet *Objectives Two* and *Three* (above), a research community of people with learning disabilities (advisory group and, latterly, co-researchers), support workers and PAs (co-researchers) was set up at the start of the research process in order to achieve *Objective One* (above).

As introduced in *Chapter Two*, conducting research using an inclusive participatory approach is not plain sailing; there is no formula for doing research in this way, so every project is unique (Walmsley and Johnson, 2003). The research presented in this thesis is no different, and the remainder of this chapter will provide details of how the work was done. *Diagram 1* (p.40) provides a pictorial representation of how the community evolved and *Table 1* (p.40) provides details of the data collected.

4.3.1 The Author's Role

As *Diagram 1* (p.40) illustrates, this research evolved from a central point; the author. As a PhD study, which grew out of the authors own professional experience and motivations, the research would not have taken place without her involvement. That is, without her ideas and the work she did to develop the title, explore the literature and gain ethical approval for the work, the research would not have happened.

However, this did not give the author complete control over the research process. For example, as can be seen in Appendix 1, when the School for Policy Studies, University of Bristol, Ethics Form was completed it was done in such a way as to leave the process of data collection, analysis and dissemination as open as possible to allow for the advisory group and co-researchers to develop these once in position. Completing the ethical review process in this way, allowed the author to adhere to the PhD criteria set out by the University of Bristol, whilst also remaining closely aligned to the principles of inclusive participatory research. However, she was not able to relinquish complete control of the research process to the research community due to this being a PhD study; final decisions about data collection and analysis were her responsibility (please see *Section 2.5.1, of Chapter Two* for a full discussion of this issue).

4.3.2 Advisory Group

With ethical approval from the School for Policy Studies, University of Bristol received, recruitment for the people with learning disabilities who formed the research's Advisory Group was undertaken. These individuals were recruited from the pool of people with learning disabilities who were associated with the NFCDS as researchers and lecturers, using the information presented in Appendix 9.

Three individuals came forward as a result of circulating this information and, upon reading through the Information Sheet (Appendix 9), all three decided to become advisory group members. At this point all three group members signed a consent form (Appendix 11) and created a Research Agreement with the author, which set out their roles and responsibilities to the group and the research (Appendix 14), along with a set of ground rules (Appendix 15).

The group consisted of two individuals with previous experience of working as paid researchers on a project within the NFCDS (Williams *et al*, 2009; Williams, 2011), and one individual with a successful fifteen-year career providing easy-read reports, audio and video outputs for research done in the Centre. All three group members also had experience of teaching University students in the UK and in Europe about Inclusive Research (please see p. xviii for more information about who these group members were).

From this starting point, the advisory group spent four months working together with the author, sharing knowledge and developing research skills around the topic of bereavement support (see Appendix 2 and 3). Four two-hour meetings were held during these initial four months working together. When each group member felt they had a firm grasp of the research topic (two meetings), meetings moved on to thinking about recruiting the support workers and/or PAs who would become co-researchers in the study. Two meetings were held about this issue, which led to the following list of inclusion criteria being developed for recruitment:

- Located in the South West of England
- Worked in support services or directly for an individual in the last two years
- Has recently (in the past two years) supported an adult with a learning disability through a period of bereavement
- Have an interest in learning about research

With the inclusion criteria agreed, it was decided that potential co-researchers would be recruited via a series of informal meetings, held at different times of day at the University of Bristol, with refreshments and travel expenses paid. This approach was chosen based on the knowledge that support workers often work long, anti-social hours (Michie and Williams, 2009) for low wages (Giupponi *et al*, 2016) so providing different times and spaces to meet would allow interested individuals to meet us, ask questions about the research and potentially sign up to be co-researchers (Appendix 16). These meetings were advertised via a co-research recruitment information email/blog/forum/social media post (Appendix 16), which were distributed to the locations listed in Appendix 4.

Despite this advertising no one came to any of the recruitment meetings. There are several possible reasons for this, including the meetings being advertised in the wrong place, a lack of interest in the research within the support worker/PA population, and/or the meeting being held on the wrong day or at the wrong time to fit around the long, anti-social hours many support workers/PAs work (Michie and Williams, 2009).

4.3.3 Co-researchers with Support Experience

The reason why no one came to any of the initial recruitment meetings will never be known, but the experience was learnt from and the advisory group decided to utilise their contacts at the University of Bristol to recruit from the School for Policy Studies student body (Appendix 5 and 17). An email was sent to the course leaders of the different degree programmes within the School asking them to share the details of the research with their students. Due to the difficulties experienced in the first round of recruitment potential co-researchers were asked to email the author to express interest and arrange a face-to-face meeting (Appendix 17). This recruitment technique proved fruitful with two individuals on the MSc in Social Work course coming forward and agreeing to become co-researchers after reading and discussing the co-researcher information sheet (Appendix 10). Upon agreeing this, the co-researchers with support experience signed a consent form (Appendix 12) and then met together with the author to create a Research Agreement (Appendix 18) and set group rules (Appendix 19).

4.3.4 Working Together

Once the co-researchers with support experience were recruited, they and the advisory group met together, with the author, on one occasion. This meeting took place to allow both groups to familiarise themselves with each other, hear about the work they had been doing on the project so far and plan the work they would be doing in the future. After this initial meeting the two groups met with the author independently (in person or remotely) for the remainder of the project.

As can be seen in *Table 4* (below) the advisory group reduced the amount of involvement in the research from this point forward, meeting once every three months for the remainder of the research to advise on crucial elements of the data collection and analysis. The co-researchers with support experience were involved in the project once a month for a period of thirteen months. During this time, the co-researchers only met in person on three occasions, the rest of their involvement was done remotely, either via Skype or email (*Table 1*, p.41), the reasons for which are discussed in *Chapter Eight*. The co-researcher's involvement in the research included; developing the research questions and data collection tools, creating the research protocols and analysing the data. Towards the end of their involvement in the research, the co-

researchers took a step back from researching, as the group of co-researchers with learning disabilities took the lead on the research activities. The details of this development are discussed in *section 4.6* of this chapter.

Table 4: List of Advisory Group Meetings

Meeting	Date	Purpose
1	February 2015	Interview participant research information and consent form checking
2	April 2015	Interview schedule question checking
3	June 2015	Reviewing interview data
4	October 2015	Reviewing questionnaire data
5	December 2015	Reflection meeting

Table 5: List of Co-researchers with Support Experience Meetings

Meeting	Date	Purpose
1	November 2014	Literature sharing
2	December 2014	Literature sharing
3	January 2015	Creating interview participant protocols
4	February 2015	Creating interview schedule
5	March 2015	Piloting interview schedule
6	April 2015	Altering and re-piloting interview schedule as a result of the advisory group advice
7	June 2015	Interview data analysis
8	July 2015	Interview data analysis
9	October 2015	Reviewing online questionnaire data
10	December 2015	Reflecting on the research process

4.4 Data Collection

As introduced in *Chapter One*, the data collected in this research was done using a mixed-methods concurrent approach (Ivankova *et al*, 2006). That is, one-to-one interviews were chosen as the most appropriate approach to data collection by the

research community, the collective analysis of which led to the creation of an online questionnaire.

The remainder of this chapter presents details of how this data was collected, telling the story of the journey the research community went on at each stage.

4.5 Interviews

One-to-one semi-structured interviews were carried out with participant support workers and/or PAs as the primary source of data in this research. A semi-structured approach to the interviews was chosen to ensure consistency across all participants (May, 1991), whilst also ensuring participants had the freedom to tell their stories on their terms (DiCicco-Bloom and Crabtree, 2006). This second point is of particular importance in this research, due to the sensitive nature of the research topic (Dickson-Swift *et al.* 2009) That is, using a structured interview with a strict set of questions would not have been appropriate to explore the sensitive and emotive topic of bereavement support where participants' experiences were likely to have varied greatly (Melville and Hincks, 2016). Just as a narrative interview, with no prescribed interview questions or focus, may have proved too 'loose' an approach for some participants to have elicited any useful responses in this context (Muylaert *et al.*, 2014; Melville and Hincks, 2016).

A semi-structured interview schedule (Appendix 6) was created in collaboration with the co-researchers with support experience for this phase of data collection. This schedule was based upon the literature reviewed in *Chapter 3* and shared with the co-researchers (Appendix 13). The schedule went through several incarnations before being finalised, as advice was sought from the research advisory group and piloting took place between the researchers. The interview schedule was not piloted with any of the sampling frame due to the time available in the research, however as the co-researchers with support experience met the same criteria as potential participants, piloting the schedule with them was deemed appropriate and led to a comprehensive and coherent schedule being developed to guide the interviews. A short demographic questionnaire for interview participants to complete before undertaking the interview was also created, piloted and finalised at this time (Appendix 20). Again, this questionnaire was based upon the literature reviewed in *Chapter 3* and shared with the co-researchers (Appendix 13).

4.5.1 Ethics

Within the original Ethics Form completed at the beginning of the research process (Appendix 1) interviews were mentioned as a potential data collection method, so a new ethics form did not need to be completed. However, the interview schedule (Appendix 6), demographic questionnaire (Appendix 20), recruitment information (Appendix 21 and 22), information sheet (Appendix 23) consent form (Appendix 24) and end of interview information (Appendix 25) had to be approved by the School for Policy Studies, University of Bristol, Research Ethics Committee. These documents communicated with participants details of confidentiality, anonymity, data protection, and how their data would be used within the research and its dissemination (Appendix 23 and 24 specifically)

4.5.2 Participant Recruitment and Selection

Interview participants were sought from a purposive sample of individuals known to the research community and wider NFCDS. The criteria participants had to meet in order to be interviewed, was:

- Has experience of working as a support worker or PA with adults with learning disabilities
- Works for a service or individual with learning disabilities in a UK context
- Had provided bereavement support to an adult with learning disabilities within this context within the past two years.

As with the recruitment of the co-researchers with support experience, a recruitment email (Appendix 21) and forum/social media/blog post (Appendix 26) were circulated to contacts of the research community, NFCDS and a range of forum/social media/blog outlets (Appendix 27).

In this information potential participants were asked to contact the author, either via email or telephone to express their interest in taking part in the research. A total of sixteen individuals expressed an interest in being interviewed at this time (Appendix 21

and 26). After speaking with each of these individuals it became clear that only fifteen had relevant experience. In these initial conversations it also became clear that two of these individuals were in manager or assistant manager roles, which differed from the criteria of being a support worker or PA. However, both individuals had been actively involved in supporting people with learning disabilities on a day to day basis and had all provided someone with direct bereavement support within the past two years. As a result, the researchers decided these individuals met the inclusion criteria and could be interviewed. A further two individuals revealed at this initial stage that they no longer worked in the learning disability field, having left their jobs within the eighteen months prior to expressing an interest in taking part in the research. After some discussion with these individuals, it was discovered that their bereavement support experience fell within two years of their expressing an interest in the research, so again the researchers decided that they met the inclusion criteria and could be interviewed for the research.

The research information sheet (Appendix 23) was sent to these fifteen individuals to review, along with the request to contact the author again to arrange a convenient date, time and location for the interview if they were still interested in being involved after having read this information. Only thirteen of the fifteen individuals got in touch at this time all of whom were interviewed for the research. Three of these participants were known to members of the research community from their involvement in previous research projects undertaken at the NCFDS; there were no personal connections to these participants within the research community.

Selecting participants from a purposive sample meant that the data collected in this phase of the research was not representative of the wider learning disability support worker and PA workforce (Sharma, 2017). However, this research did not set out to be representative of this workforce. Instead, the research aimed to seek out individuals from the workforce who met a particular set of criteria (set out above) to explore the phenomenon of bereavement support from their experience of providing this support. Using this sampling method, allowed expert participants to be recruited quickly and with limited researcher bias as the criteria they had to meet was based upon in-depth understanding of the wider literature (Etikan *et al*, 2016).

4.5.3 Interview Process

Interviews took place in a variety of locations, convenient to the participants. Seven took place in a quiet space at the participant's place of work, four in participant's own homes, and two in quiet areas of coffee shops local to the participant.

Each interview began with a run through of the research information sheet (Appendix 23) and completing the consent form (Appendix 24). Participants then completed the short demographic questionnaire (Appendix 20) to help them focus their mind on the topic of the interview.

With the paperwork completed, permission was sought to turn on the Dictaphone (all agreed and were aware that it could be turned off at any time – Appendix 23 and 24) and the interview began with the author/interviewer sharing details of her career as a support worker and PA; how the research came about and her hopes for its outcomes. The information shared with each participant at this time, closely resembled the '*Autobiographical Note*' presented in *Chapter One* of this thesis (p.2), varying only slightly depending on the person being interviewed and the context in which it was taking place. This information was shared with participants as, as has been discussed throughout this thesis, the author's ontological position within this study was paramount. Who she is and the professional identity she has was the motivator for this research's' completion, but it was also an identity she shared with the participants that it was felt important to share with them, for two reasons. Firstly, by sharing her identity as 'one of them' and not 'just a researcher', it was predicted that participants would relax in the knowledge that she would understand their position and not judge their actions (Hayfield and Huxley, 2014). Secondly, as this research focused on a sensitive subject; death, dying and bereavement, the author/interviewer wanted to start the conversation with her experience to create an open and understanding interview setting (Melville and Hincks, 2016).

Whilst the author felt that sharing her identity and creating a safe and supportive interview setting in this way was of paramount importance, it is important to note that during each interview she kept the aims and objectives of the research at the forefront of her mind and made sure to refer to the interview schedule (Appendix 6), as:

‘Certainly, as a researcher, being a member of the same social group that one is researching may offer unique and empathetic insights. Equally it may skew data collection or produce biases during analysis.’

(Richardson and Laird, 2013. P. 69).

With these details shared with participants, the interviews began with each participant talking for between twenty and ninety minutes about their experiences of providing bereavement support. Each of these interviews were audio recorded using two encrypted Dictaphones.

When participants had finished sharing their experiences, the Dictaphones were turned off and space was provided for participants to relax and reflect on their experience. Participants were then provided with the details of local support organisations they could contact should they feel upset or distressed after the interview (Appendix 25). Participants were also reminded that they could withdraw from the research at any time before the 25th August 2015.

4.5.4 The Participants

The thirteen interview participants consisted of nine women and four men aged between 25 and 64. All participants were White British and none of the participants considered themselves to be disabled. Participants were from several different regions in England and Scotland:

Table 6: Interview Participants by Region

Region	Number of participants
London	0
East	1
South East	5
South West	1
West Midlands	1
East Midlands	0
Yorkshire and Humber	0
North West	0

North East	0
Wales	0
Scotland	5

Table 7 (below), presents a breakdown of the interview participants' job titles, places of work, and whether they work full-time or part-time as provided by them in their demographic questionnaire (Appendix 20). Please note the names used for participants are pseudonyms.

Table 7. Interview Participant Job Titles, Places of Work, and Hours Worked

Participant	Job Title	Place of Work	Hours Worked
Jane	Support Worker	Other	Part-time
Alan	Was a Supported Living Manager (now retired)	Was a supported living service	Other
Claire	Assistant Manager	Residential support service	Was full-time
John	Deputy Service Manager	Residential support service	Full-time
Steve	Care Worker with an IT specialism	Individual under Direct Payments	Self Employed
Chloe	Advocacy Worker	Advocacy organisation	Part-time
Beth	Support Worker	Residential support service	Full-time
Deborah	Care Worker	Residential support service	Full-time
Hannah	Senior Care Worker	Residential support service	Full-time
Kim	Relief Care Worker	Residential support service	Other
Thea	Care Worker	Residential support service	Part-time
Jessica	Care Worker	Residential support service	Full-time
Dom	Was a Support Worker (now a Gardener)	Was a residential support service	Was full-time

As can be seen in Table 7, interview participants had a variety of job titles, including; care worker, support worker, advocacy worker, and senior support worker, as well as assistant manager, and service manager. The difference between ‘care worker’ and ‘support worker’ in this context was a matter of semantics based upon the location of the participants’ employment. That is, ‘care worker’ was extensively used by participants in Scotland, and ‘support worker’ by those in the same role in England.

The places where participants worked ranged from residential services (ten participants), advocacy services (one participant), directly for individuals under direct payments (one participant) and in ‘other’ locations (one). The participant who stated they worked in an ‘other’ location, provided a qualitative description of their place of work in their demographic questionnaire (Appendix, 20), stating they were an ‘independent support worker’ who worked for an ‘independent support service’

Finally, Table 7 highlights that participants worked, for the most part on a full-time or part-time basis. Two participants worked on a ‘self-employed basis, stating in their demographic questionnaire response (Appendix 20), that because they worked for themselves they did not have a particular work pattern; they worked as and when the individuals they supported needed them to. In addition, the participant who answered ‘other’ to this question said that as they worked as a ‘relief care worker’ they worked when needed by the service or when it fitted around their family life.

4.5.5 Bereavement Support Training

Five of the interview participants had received some bereavement support training during their careers, whilst eight had not.

4.5.5.1 Received some Training

Those participants who had received some bereavement support training had done so in various forms. One participant had attended a one-day training course, several years ago, whilst another had attended ‘*some very basic training*’ (Dom), and another had had ‘*someone*’ visit their work place to come and talk about bereavement and grief

experience and their own mental health issues (Deborah). The two other participants did not provide a qualitative answer to this question.

Of these five participants, four said they had used their bereavement training in their everyday working lives. The fifth participant was not sure whether they had or not.

4.5.5.2 Received no Training

Of the eight participants who had not received any bereavement support training, seven of them said they would like to receive some in the future, whilst one said they weren't sure if they would or not. Of those who would like training, four participants provided reasons why they would like such training. One participant felt that training of this nature was needed, because *"...it's important"* (Chloe), whilst another

"...would like more guidance on how to do things. How to tell people someone they love has died"

(Alan).

Beth wanted some training to ensure she was able to *"provide the right support"* to those she was working with; a sentiment echoed by John who wanted the training to enable them *"to support clients that are going through a bereavement correctly"*

Claire, the participant who was *'not sure'* if she would like to receive any bereavement support training, did say that learning about *'Core skills would be useful'* but questioned how that could be trained; *"but how do you train that?"* (Claire)

These questionnaire responses provide further insight into the thoughts participants had about bereavement support prior to the interviews being undertaken. A number of these statements relate directly to the topics explored in the interviews, which are presented in the following section of this chapter.

4.5.6 Analysis

Each of the thirteen interviews were transcribed verbatim and an interpretive narrative approach was used to analyse the data in line with the aims and objects of the research (Section 4.2).

4.5.6.1 Interpretive Narrative Analysis

An interpretive narrative approach to data analysis is the merging of the two qualitative methods; narrative and phenomenology, to explore the lived experiences of participants in relation to the phenomenon of bereavement support.

As was introduced in *Chapter One*, the research presented in this thesis aimed to explore the phenomenon of bereavement support for people with learning disabilities from a social constructionist position, in which our understanding of the phenomenon is viewed through the lens of its social actors; support workers and PAs. At no stage in the research are grief, bereavement, and bereavement support assumed to be 'real' objects, but rather socially constructed phenomena, derived from experiences and perceptions of participants (Smith *et al*, 2009).

For reasons explored in *section 4.5*, a traditional narrative approach to interviewing where no specific questions are asked of participants (Andrews *et al*, 2013) was not used in the research, opting instead for a semi-structured approach. Yet despite this, the majority of participants (ten) provided fluid narratives of providing bereavement support to people with learning disabilities with little or no prompting after the initial introduction to the interview. That is, the participants shared their stories of providing this support in their own words and with their own focus (Etherington, 2012).

The gathering of this data lent itself to narrative analysis, as each story and its contents could be viewed as socially situated knowledge constructions in their own right (Polkinghorne 1995). However, due to the inclusive participatory approach employed in this research, an approach to data analysis which allowed for the interpretation of these stories by multiple individuals was needed.

As a result, elements of Interpretive Phenomenological Analysis (IPA), where data is analysed ideographically to expose how each participant makes sense of the phenomenon being explored (bereavement support), were combined with the narrative approach to data analysis. The most significant of the IPA elements to be combined with the narrative analysis in this research, was its interpretive element. IPA is an approach which is interested in both how the research participant makes sense of the experiences they describe in their narratives, and how we as researchers interpret these narratives and its meanings (Smith *et al*, 2009). This is referred to as the double hermeneutic

“...because the research is trying to make sense of the participant trying to make sense of what is happening to them.”

(Smith *et al*, 2009, p.3).

In this research, the double hermeneutic element of IPA was of paramount importance as it allowed the multiple ‘interpretations’ of participant narratives to take place during the analysis, something which could not be achieved using another approach. The following two sub-sections of this chapter provide step-by-step details of how this analysis was carried, with details of its outcomes presented in *Chapter Five*.

4.5.6.2 Questions Asked of the Data

A set of questions were developed to guide the analysis of interview data. These questions were developed to ensure that the analysis of participant narratives and the research team’s interpretation of them, went some way to answering the research’s overarching questions (p. 17).

1. What does bereavement and grief mean to participants?
2. What narrative are participants telling and why?
3. How do participants position themselves within their narrative?
4. How do participants position me in the interview/their narrative?
5. How do participants position people with learning disabilities in the narrative?

Analysis began within a Microsoft Word document before being analysed using NVivo software. Each step of the analysis took place on a participant by participant basis, as highlighted in Table 8 on the following page.

Table 8. Interpretive Narrative Analysis Procedure: Interviews

	Strategy	Description of work done
1	Listening, reading and re-reading	Listening to the recorded interviews, whilst reading the verbatim transcripts reminded me of the tone of the participant. Further reading of the transcripts allowed a deeper engagement with the narrative.
2	Initial noting	Initial noting during early readings was conducted and took the form of descriptions and comments regarding what was being said in a Microsoft Word document. Notes were made of the concepts being discussed within the experience being shared. Text which seemed to be important was underlined at this stage.
3	Developing emergent themes	The data was imported into NVivo and themes were identified from the relationships between notes made in step 2. These were clustered together as 'nodes' in NVivo
4	Searching for connections across emergent themes	Some themes/nodes were discarded at this stage on the basis that they did not relate to the research question Themes were re-clustered at this stage.
5	Moving to the next participant	Steps 1 to 4 were carried out for each transcript before moving on the next.
6	Sharing themes with co-researchers and advisory group.	With all 13 transcripts having gone through steps 1 – 4, the themes drawn from them were shared with the co-researchers and advisory group, respectively.
7	Looking for patterns across cases	Working initially with the co-researchers, identification of themes that emerged across all participants were drawn. These themes were then shared with the advisory group*
8	Finalising themes	With the whole research community's input, the superordinate and subordinate themes were decided upon.

*At this point, some of the advisory group members began to shift roles in the research community to co-researchers, due to their desire to explore the emerging themes in more depth with a wider population.

4.6 Online Questionnaires

As highlighted in Table 8 (on the previous page), the development of a concurrent approach to data collection came about during the collective analysis of interview data. During this analysis, two advisory group members (Julian and Kerrie) expressed an interest in gathering more data about bereavement support for people with learning disabilities in the UK. Julian and Kerrie also expressed a desire to develop their own research skills by being more actively involved in the data collection and analysis.

These initial conversations took place within an advisory group meeting, but it was agreed that a separate meeting was required to discuss the ideas further to ensure that they did not detract from the data analysis taking place, and to allow Lisa Ponting, who did not want to explore this issue, to opt out of this development in the research. As a result, a separate research meeting was held for Julian and Kerrie to discuss and plan this idea for data collection and research skill development with the author. This meeting led to Julian and Kerrie becoming co-researchers in the project; developing, guiding and conducting a concurrent strand of data collection in the form of an online questionnaire (Appendix 7).

This new group of co-researchers met a total of five times between June 2015 and October 2015. Table 9, below, lists the details of these meetings.

Table 9. Table of Co-Researchers with Learning Disabilities Meetings

Meeting	Date	Purpose
1	June 2015	Discussing idea of online questionnaire and developing the questions
2	June 2015	Creating the participant research protocols
3	June 2015	Completing ethics form amendments
4	July 2015	Setting the questionnaire 'live' online
5	Sept 2015	Analysing questionnaire responses
6	Oct 2015	Analysing questionnaire responses and sharing with co-researchers and advisory group.
7	Dec 2015	Reflection meeting

The online questionnaire that was developed in these meetings was guided by the same research questions, aims and objectives as the interview stage of data collection. The contents of the online questionnaire was also based upon the findings from this stage of data collection, specifically the responses received to the short demographic questionnaire that interview participants completed (Appendix 20). Within this short demographic questionnaire, it was found that the bereavement training available to support staff was an issue for all 13 participants, so it was decided that the online questionnaire should explore this issue further in order to provide greater context to the interview findings.

The online questionnaire utilised a mix of both quantitative and qualitative questions to elicit information from participants. This approach was chosen to ensure that the questionnaire struck the right balance between the needs of the research to gather rich and useable data from a larger number of participants, and the needs of the participants - to share their responses in a quick and convenient way. By providing participants with a number of questions that offered a selection of answers from a predetermined list the questionnaire was not too labour intensive or time consuming, whilst ensuring the research captured the data it needed (Wright, 2005). There was also the option of being able to add a different/additional answer as well, as well as open text box responses.

When the questions and format were agreed by the researchers, the questionnaire was created using the Bristol Online Survey (BOS) system (Appendix 7). Devising the content of the questionnaire was done collectively, however creating and hosting the questionnaire on the BOS system was not accessible to the whole group, as neither Julian nor Kerrie had an email address that was compatible with the system. As a result, the author's email address was used to access and post the questionnaire on the system (Appendix 7).

4.6.1 Ethics

As the online questionnaire was not a method of data collection discussed in the original Ethics Form submitted (Appendix 1), approval had to be sought from the School for Policy Studies, University of Bristol, Research Ethics Committee. This was done by making amendments to the original form (Appendix 1) and submitting it to the Research Ethics Committee (Appendix 28) along with copies of the participant recruitment email

(Appendix 29) social media/forum/blog recruitment posts (Appendix 30), research information and consent process as would be posted on the questionnaire 'landing page' when live online (Appendix 31), and Microsoft Word version of the questionnaire (Appendix 7).

Submitting these amendments to Research Ethics Committee was not an inclusive process as the ethics form is not available in a 'plain language' format. This is just one of the many challenges the research community faced during the lifespan of the research. These challenges and how they were addressed are in *Chapter Eight*.

4.6.2 Participant Recruitment and Selection

With ethical approval received from the Research Ethics Committee, the questionnaire went 'live' on the BOS system in July 2015. Links to the questionnaire were emailed to appropriate contacts and posts were placed on various social media (such as Facebook and Twitter), forum and blog sites related to learning disability support workers and PAs (please see Appendix 8 for the list of places where this information was circulated). These outlets were chosen as the criteria for participating in the questionnaire was the same as for interview participants:

- Has experience of working as a support worker or PA with adults with learning disabilities
- Works for a service or individual with learning disabilities in a UK context
- Had provided bereavement support to an adult with learning disabilities within this context within the past two years.

The questionnaire was 'live' online for six weeks during July and August 2015, which participants were made aware of in the recruitment emails, social media, forum and blog posts (Appendix 29 and 30).

Participants were a self-selecting purposive sample, choosing whether to follow the link in the email, social media, forum and/or blog posts (Appendix 29 and 30), and then whether to take part in the questionnaire after reading the research information on the

'landing page' from this link (Appendix 31). Participants expressed their consent to taking part in the research by clicking on a box at the bottom the questionnaire 'landing page' (Appendix 31). They were aware from the information provided that if they clicked this box and completed the questionnaire there would be no way of withdrawing from the research after this point as the process was completely anonymous.

It is important to note that recruiting participants using this method meant that the data collected was not representative of the wider learning disability workforce and may have been prone to 'self-selection bias' (Lavrakas, 2008). That is, participants may have been motivated to complete the questionnaire for reasons other than the advancement of knowledge, such as having a difficult experience at work that they wanted to off load (Lavrakas, 2008). However, this research did not set out to be representative of the learning disability workforce. Instead, the research aimed to seek out individuals from the workforce who met a particular set of criteria (set out above) to explore the phenomenon of bereavement support from their experience of providing this support. Their experiences of providing this support at work, difficult or otherwise, was exactly the information this research was seeking to gather. Using a self-selecting sample therefore allowed engaged and committed participants to be recruited quickly for this phase of the research (Sharma, 2017).

4.6.3 The Participants

Fifty-Four participants followed the link to the questionnaire from either the email, blog, forum, and/or social media posts that were circulated (Appendix 29 and 30) and read the 'landing page' information (Appendix 31). Upon reading this information, four participants did not complete the questionnaire. The remaining fifty people completed the questionnaire, but six individuals were excluded as they either did not know someone with a learning disability who had suffered a bereavement (three participants), had not provided direct bereavement support to someone with a learning disability (two participants), or was a family carer to someone learning disability (one participant).

Although support workers and PAs were targeted to complete the questionnaire (Appendix 29 and 30), a far broader mix of individuals completed the questionnaire, including nurses, psychologists, counsellors, therapists and a retired psychiatrist, as

Figure 1 (p.99) highlights. Participants were not asked for any more specific details of their places of work in the questionnaire, but on reviewing their responses they all had direct bereavement support experience which meant they met some of the inclusion criteria for the research, although they did not meet the criteria of having '*experience of working as a support worker or PA*' (Chapter 4).

After much consideration within the research community, it was decided that rather than lose the rich data these participants had provided, their responses would be included in the research as they added interesting contextual information to the data collected from interview participants. Choosing to include this data allowed for the research to remain support worker/PA focused, but with the added benefit of being able to explore the issue of bereavement support within the broader learning disability landscape.

Whilst the data online questionnaire participants provided this research has been invaluable, the researchers acknowledge that this was not the data intended to be collected in this phase of the research. The reason why so few support workers and no PAs engaged with this phase of data collection, will never be known, but may have been due to a flaw in the design of the questionnaire or the chosen distribution methods. It is recommended that future research takes heed of this situation, and if this research were to be done again the questionnaire would be piloted with a subsection of the sampling frame. These points are explored in greater detail in Chapter's *Six*, *Seven* and *Nine*.

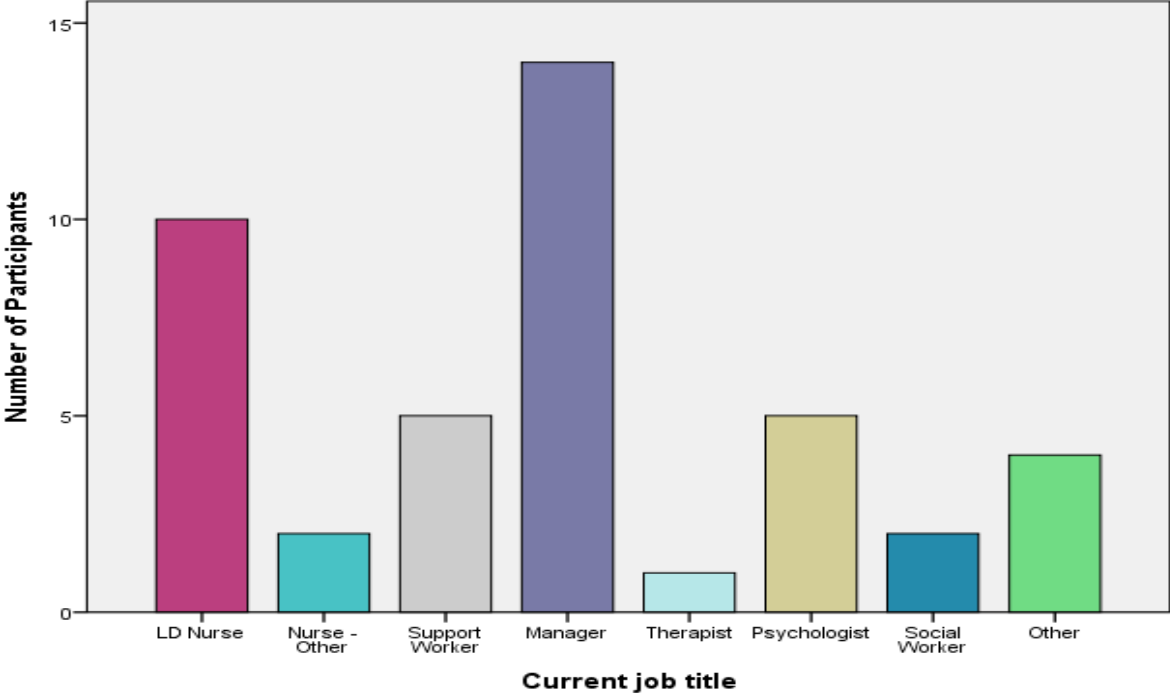
As a result of the decisions made by the research community, forty-four participant responses were analysed in this phase of data collection. The participant who had been excluded for being a family carer at the beginning of the data analysis process remained excluded after this change to the questions, as the research remained focussed on those employed to support people with learning disabilities and not family carers.

Details of where participants were geographically located was not collected, but they were all from the UK as the BOS online system logged the ISP addresses used by participants when completing the questionnaire.

Thirty-eight participants were women and six were men, all aged between twenty-five and eighty-one. They predominantly self-identified as being White British (thirty-two participants), but two participants identified as White Irish, six as Other White, two as

Mixed Ethnic, one as Caribbean, and one as Other Black. Three participants considered themselves to be disabled.

Figure 1. Questionnaire Participant Job Titles



As previously noted, it is not known why so few online questionnaire participants were support workers or PAs, as these populations were targeted in the advertising (Appendix 29 and 30) and pre-questionnaire information (Appendix 31), but possible reasons are discussed in *Chapter's Six, Seven and Eight*.

4.6.4 Analysis

Analysis of the online questionnaire data was carried out collectively with the co-researchers with learning disabilities. The data was analysed in line with the overarching research questions (p.75) utilising both descriptive statistics in SPSS for the quantifiable responses and elements of interpretive narrative analysis (please see *section 4.5.6.1* for details of why this approach was used) for the qualitative responses.

A set of questions were developed to guide the analysis of interview data. These questions were developed to ensure that the analysis of participant narratives and the

research team's interpretation of them, went some way to answering the research's overarching questions (p. 75):

1. What narrative are participants telling and why?
2. How do participants position themselves within their narrative?
3. How do participants position the research in their narrative?
4. How do participants position people with learning disabilities in the narrative?

Analysis of the qualitative responses began by exporting the data from the BOS system to Microsoft Word, and then into NVivo. Each step of the analysis took place on a participant by participant basis, as highlighted in Table 10, on the following page. The results of this analysis are presented in *Chapter Six*.

4.7 Summary

This chapter has presented details of how this research was completed using concurrent data collection methods; semi-structured qualitative interviews and an online questionnaire. The chapter began by explaining how and why a research community of people with learning disabilities, support workers and PAs came together to work on this research with me. Before moving on to provide in-depth details of the semi-structured interviews carried out as the primary data collection method in this research. The explanation of this methods' analysis in the chapter, led into a discussion of the online questionnaire, its creation, development and position within the research.

By presenting the details of the research methods in this way has provided greater insight into how the research was done and tells some more of the story about the journey that has been undertaken by the research community during the lifespan of this research (please see *Chapter Eight* for a full discussion of this journey).

Table 10. Interpretive Narrative Analysis Procedure: Questionnaires

	Strategy	Description of work done
1	Reading and re-reading	Reading the transcripts together allowed for understanding of the responses to be discussed and difficult words explored. Further reading of the transcripts allowed a deeper engagement with the narrative.
2	Initial noting	Initial noting during early readings was conducted and took the form of descriptions and comments regarding what was being said in a Microsoft Word document. Notes were made of the concepts being discussed within the experiences being shared. Text which seemed to be important was underlined at this stage.
3	Developing emergent themes	Transcripts were imported into NVivo and themes were identified from the relationships between notes. These were clustered together as 'nodes' in NVivo.
4	Searching for connections across emergent themes	Some themes were discarded at this stage on the basis that they did not relate to the research question Themes were re-clustered at this stage.
5	Moving to the next participant	Steps 1 to 4 were carried out for each transcript before moving on the next.
6	Sharing themes with co-researchers and advisory group.	With all 44 transcripts having gone through steps 1 – 4, the themes drawn from them were organised into superordinate and subordinate themes.

Chapter 5

The Meaning of Bereavement Support: Interview Data

5.1 Introduction

Due to the concurrent way in which the data was collected in this research, and the very different pieces of the bereavement support puzzle their findings provide, analysis of each approach's data is presented in two separate chapters. This chapter explores the findings from the interview data, and *Chapter Six* presents the data from the questionnaires.

This chapter begins with a series of pen-portraits detailing who participants were before moving on to discuss the themes drawn from the interpretive narrative analysis of the interview data. The chapter draws to a close looking forward to *Chapter Six*, which presents the online questionnaire data.

5.2 Participants

A total of thirteen participants were interviewed in this research. As discussed in *Chapter Four*, these individuals were drawn from a purposive sample of individuals who were recruited via contacts known to the NFCDS, learning disability forums, blogs and social media (please see Appendix 27 for a list of the locations used to advertise the research, and Appendix 21 and 26 for the material used to advertise the research).

5.3 Pen-portraits

At the start of each interview, participants were asked to complete a short demographic questionnaire (Appendix 20). The answers to these questions have been transformed into individual pen-portraits for each participant. These portraits set the scene for the rest of the data collected in the interviews by adding more contextual data to that already presented in Table 6 (p.88).

5.3.1 Jane

Jane was a part-time Support Worker who has worked in the learning disability field for ten years. She worked for a support service provider that is independent of social services at the time of her interview, but she has worked for a variety of organisations in her career. She was aged between twenty-five and thirty-four, considered herself to be White British and has a Bachelors' Degree. She has not received any grief and bereavement support training during her career but would like some.

5.3.2 Alan

Alan was a retired learning disability Service Manager at the time of being interviewed. He had worked in the field for over thirty years when he retired, ending his career managing a supported living service. As his retirement would suggest, Alan was aged between fifty-five and sixty-four years old, considered himself to be White British and holds a vocational management qualification. During his career Alan had received some grief and bereavement support training some years ago. However, the course he attended had only run for a day and he felt that most of what he learnt came from his own reading after the course. As a result, Alan felt that he would have liked to have had more training during his career to help guide him when issues of death, grief and bereavement arose, especially in relation to breaking this news to the people with learning disabilities he supported.

5.3.3 Claire

Claire was a full-time Assistant Manager of a day service for people with learning disabilities. This service was run by social services, but Claire has worked for a variety of different service providers in her twelve-year career in the sector. She was aged between twenty-five and thirty-four, considered herself to be White British, and held a vocational qualification related to her career. Claire had not received any grief and bereavement support training during her time in the sector but would have liked some. She says she would have liked this training to provide her and her staff team with the core skills required to give such support, although she is not sure how this could be taught.

5.3.4 John

John was a full-time Deputy Service Manager for a residential support service for people with learning disabilities. John had worked in the sector for five years, having only ever worked for this one service during this time. John was aged between thirty-five and forty-four, considered himself to be White British and the highest qualification he achieved was his GCSE's. During his career, John had not received any grief and bereavement support training but would have liked some to enable him to support those he worked with through bereavement effectively.

5.3.5 Steve

Steve was an independent Support Worker with an IT specialism who worked directly for individuals with learning disabilities who employ him through their Direct Payments or Personal Budgets. He worked as and when people needed him, or as suited his lifestyle. Steve had worked in the learning disability field for the past fifteen years, having worked for a social service's run support service prior to becoming an independent support worker. Steve was aged between forty-five and fifty-four, he considered himself to be White British and held a vocational qualification relevant to his role. He had not received any grief and bereavement support training during his career but would have liked some.

5.3.6 Chloe

Chloe was a part-time Advocacy Worker for a learning disability advocacy service. She had worked in the field for twenty-one years, having worked for a variety of different services in this time. Chloe was aged between thirty-five and forty-four years old, considered herself to be White British and held a Masters' Degree in an undisclosed subject. Chloe had not received any grief and bereavement support training during her career, although she would have liked some because she felt it was important to her role.

5.3.7 Beth

Beth was a full-time Support Worker within a residential support service for people with learning disabilities. She had worked in the field for thirty years, working for a number of support organisations in this time. Beth was aged between forty-five and fifty-four, considered herself to be White British and the highest qualification she held was her A-Levels. Beth had not received any grief and bereavement support training during her

thirty-year career, but she would have liked some to enable her to provide *'the right support'* to the people she worked with.

5.3.8 Deborah

Deborah was a full-time Care Worker who worked within a residential support service for people with learning disabilities. She had worked in the field for eleven years, having worked with children prior to her current role. Deborah has only worked for one support service during her career in the learning disabilities field. Deborah was aged between fifty-five and sixty-four, considered herself to be White British and the highest qualification she held was her A-Levels. Deborah has had some grief and bereavement support training during her career, describing it as *'someone coming to talk to us about our bereavement and grief experiences'*. Deborah felt that this training was useful, but questions whether the people she works with understand what happens when people die.

5.3.9 Hannah

Hannah was a full-time Senior Care Worker within a residential support service for people with learning disabilities. She had worked in the field for seventeen years, having worked in just one service throughout her career. Hannah was aged between fifty-five and sixty-four years old, considered herself to be White British and held a vocational qualification relevant to her role. Hannah has had some grief and bereavement support training during her career, but she is not sure whether this was useful to her work as she did not feel that it was particularly relevant to those she supports.

5.3.10 Kim

Kim was a Relief Care Worker within a residential service for people with learning disabilities. Kim had worked in this role for the past ten years, fitting it around her work within older peoples support services and her family life. Kim was aged between twenty-five and thirty-four years old, considered herself to be White British and held a Bachelors' Degree in an undisclosed subject. Kim has not received any grief and bereavement support training during her career, and she is not sure whether she would like some in the future.

5.3.11 Thea

Thea was a part-time Care Worker within a residential support service for people with learning disabilities. She had worked in this role for the past ten years and has only worked for one service during her career. Thea was aged between twenty-five and thirty-four years old, she considered herself to be White British and has a Bachelors' Degree in an undisclosed subject. Thea has not received any grief and bereavement support training during her career, and she is not sure whether she would like some in the future.

5.3.12 Jessica

Jessica was a full-time Care Worker within a residential support service for people with learning disabilities. She had worked in the field for twenty-two years, having worked in the clergy prior to joining the service she currently worked for. Jessica was aged between fifty-five and sixty-four years old, considered herself to be White British and held a Bachelors' Degree in an undisclosed subject. During her career, Jessica has received one session of bereavement and grief support training, which focused on these issues in relation to those she supports as well as her own mental health needs when providing such support. Jessica felt this training was useful as it allowed her to understand how she could allow people to grieve in their own way. However, Jessica did feel that it would have been useful to have more training around this issue, not just a one-off course.

5.3.13 Dom

Dom was a full-time self-employed Gardener at the time of his interview, having left his role as a full-time Support Worker within an independent support service for people with learning disabilities. Dom had worked as a support worker for twenty years prior to leaving the role. He had worked in a variety of settings during this time. Dom was aged between forty-five and fifty-four years old, considered himself to be White British and held a vocational qualification relevant to learning disability support work. During his support work career, Dom had received some grief and bereavement support training which he described as *'very basic'* but did allow him to *'identify the stages of grief people were moving through successfully.'*

5.4 Interpretive Narrative Analysis

5.4.1 Interview Process

As introduced in *Chapter Four*, once the demographic questionnaires were complete and each participant was comfortable, the interviews began. These interviews ran for between twenty and ninety minutes and were audio recorded. Each interview started with a short explanation of the reasons why the research was being undertaken, which involved the author/interviewer sharing details of her career as a support worker and PA (please see *Chapter One* and *Chapter Four*).

With this information shared, the interview began by asking participants to share details of their careers, which they did with little prompting. From this starting point, participants were asked questions about their bereavement support work experience. These questions were taken from the semi-structured interview schedule prepared earlier in the research process (Appendix 6). However, for a number of participants, only a minimal number of questions from this schedule were asked as they freely talked about their experiences without the need for much prompting, only acknowledgements and confirmations at important junctions in their narrative.

Once the interviews were complete the audio recordings were transcribed verbatim by a professional transcription service. The data was then analysed in line with the aims and objectives of the research (please see *Chapter One*) using an interpretive narrative approach to reveal the themes in the data (please see *Chapter Four*).

5.4.2 Themes

Eight superordinate themes were drawn from the analysis of the interview data:

1. Motivations for working as a support worker and/or PA
2. How people with learning disabilities are seen
3. Death, grief and bereavement
4. Challenges to providing bereavement support
5. Being professional
6. Training

7. Looking for confirmation and answers
8. Being involved in the research

Each of these superordinate themes are made up of a number of subordinate themes, which are discussed throughout the remainder of this chapter. As presented in Table 8 (p.95), the majority of these themes were created as a result of analysing the data through the lens of the research's questions, aims and objectives (*Chapter One*). However, analysis was not blinkered by this lens, it explored each interview for all details of how participants interpreted bereavement support, their role within it and how people with learning disabilities were seen; as well as the interviewer's interpretation of how this data was provided from her position within the interview. Viewing the data in this way gave rise to some of the themes; whilst taking this analysis to the research's co-researchers and advisory group led to themes being developed or added to using the approach described in Table 8 (p.95).

Before exploring each of the eight superordinate themes individually, it is important to note that throughout the interviews a number of participants referred to the identity they shared with the author/interviewer as a support worker/PA. This sharing of identities is not seen as a theme in its own right, as it does not relate to the research questions being asked, rather it is an observation of the methodology used to conduct the research which provides context to the analysis. A full discussion of this observation is presented in *Chapter Seven*.

Some of the interview participants were direct in their acknowledgement of the identity they shared with the author/interviewer:

"You know, well, you must do, you know what it's like working in the confines of a service. It's really difficult, you know, to manage their expectations, the clients and your own needs. I don't know how you managed it, but for me, well, it's been really draining at times."

(John).

Whilst others were more indirect in their acknowledgment of this issue:

“...it’s just how we deal with it, isn’t it? It’s how we have to adapt in the jobs we do”

(Steve).

These quotes highlight just how beneficial sharing an identity with the interviewer can be to a participant and the affect it has on the narratives they chose to tell in their interviews. For example, as Steve states (above), he believed that he was talking to someone who knew what he was talking about; someone who knew what it was like to face the same challenges at work as him so would not ‘judge’ him for what he was saying. When this is taken in conjunction with the observation (below) that participants notably shifted their body language from anxious to relaxed whilst the author/interviewer was sharing her story it can be assumed that the majority of participants shared Steve’s view.

Interview participant reflection

I’ve noticed them (the participants) change. Some of them seem so nervous and uncomfortable when I first meet them, but when I start telling them about working at (the house I began my career in) they change. A number of people’s shoulders have softened and they’ve notably shifted in their seats...it’s as if they have had a weight lifted off them as I talk.

Research journal entry, 24th June 2015

These physical and verbal acknowledgements of interviewer and interviewee shared identity are viewed as positive indicators of the impact this sharing had upon participants in the interview setting. It allowed the participants in this research to talk openly and frankly about a difficult subject, which may not have been the case had they felt less of connection with me as the interviewer and would not have led to the depth of responses that are discussed in the following sections of this chapter.

5.5 Motivations for Working as a Support Worker or PA

At the beginning of the interview, when participants were asked to provide some details about their career in the learning disability field, a number talked about their motivations for working in the field. These have been divided into three subordinate themes;

Familial motivations; The harmony of life and work, and; Getting away from the bureaucracy and rules.

5.5.1 Familial Motivations

Three participants spoke of their motivations for working in the social care sector as being related to their familial connections to disability and social care services.

For example:

“The disability field, I’ve lived with it all my life. My brother has muscular dystrophy, so from a very young age it were my responsibility to get him up in the morning, dress him, make sure he had breakfast, get him ready so he can go out to play, right? He needed help dressing. He could use his upper body, but his lower limbs, no.”

(Jessica).

As this excerpt highlights, the experiences Jessica had growing up, placed her in a supporting and caring role from a young age. Assisting others and including them in everyday life (albeit on her terms in her familial context) was part of her reality and led to an interest in the field at a very young age. This familial motivation led to Jessica running a church group where she:

“really got interested (in the field) – because of the different characters, the different disabilities they had, and how they coped with them and really enjoyed life...and that was it, I’ve worked in disability ever since.”

(Jessica).

Another participant, Alan, talked about his familial circumstance being a motivator for the work he does, as his brother-in-law has learning disabilities:

“it makes me think about my relative...he’s in a supported living service, that’s...He’s labelled as ‘severe learning disability’. Although – you know, he has to be labelled like that to get funding, but, you know, he can’t talk, he can’t communicate verbally, but if you tune into him he can certainly make his needs known on a – he can’t make big decisions, but he can certainly, in his own

environment, he can let you know what he wants. My wife and I do lots with and for him on a weekly basis, have done since we started courting (nearly 35 years ago) he's more part of my life than my own children sometimes!"

(Alan).

For Alan, someone with a learning disability, his brother-in-law, has been an integral part of his personal life. Alan did not make an overt link between his familial experiences and chosen career path in his interview, but he did make the connection that his view of 'good' and 'bad' support for people with learning disabilities is based upon how he wants his brother-in-law to be supported:

"...some of the people are great, but the way the service is changing...there's just not, it's not the same core team and that's really hard. It's disintegrated, and there's lots of people coming and going there. And that's...that's not his need. He needs consistency. Most people do. Good support happens when you know one another. I hate the thought that people Henry doesn't know are involved in so much of his life. I think about it a lot in the work I do, I've never got too involved in intimate parts of people's lives, or expected those who worked for me to get too involved until people got to know us a little first."

(Alan).

5.5.2 The Harmony of Life and Work

In addition to familial connections to the disability and social care sector as motivators for working in their current roles, four participants provided a number of other life circumstance motivators for the work they do in the learning disability field.

That is, one participant, Jessica, states that:

"...when I finished my degree, I needed a job, so I started working in a small home for adults with learning difficulties in Birmingham. And that was it. Here I am....twenty years later."

(Jessica).

Similarly, another participant, Thea, talked about the ability of her work to fit around her lifestyle and education being a key motivator for her choice to work in a supporting role:

“...through school and University...I’ve been relief (staff), and it’s worked really well, we get lots of hours...it’s really worked in with my life style, and it’s been flexible, it’s been fine.”

(Thea).

Adding to this, Thea went on to say that she is thinking about returning to University to study for a Masters’ Degree, and that if she does she’ll “*keep working relief as it just works well*”.

Another participant, Hannah, also mentioned her education as an important influencer on her choice to work in the field, as:

“When I left school it was office work, when I had my children I did school cleaning, worked in a bakery, and then decided I wasn’t going to work in a baker’s shop until I was 65, and a friend of mine suggested applying, you know – they were looking for staff here, so I thought, Right, OK, I’ll give it a go and see what happens. At the same time I’d also – I’d always wanted to be nursing, so I’d applied at the local technical college – to go and do some further education and apply to get in an access course...I was accepted to the access course, and I also got accepted here, at the House, The Lodge at the time. And I thought, Well, I’ll go for the Lodge, because I felt, going back to college at that time, children were still at school, I’d have had to self-fund myself, I suppose, I don’t think we would have gotten any help. And I thought, well, I could get some nursing kind of training here, even though we’re not nurses, but, I mean I would say that...and get paid for it at the same time.”

(Hannah).

In addition to Hannah’s education, her quote above also introduces the importance of her working life fitting around her family life, especially her children. This was also an important consideration for Kim:

“I've been here about seven years, on and off, between permanent positions and relief. I've done agency work with, sort of, in and out of a variety of services, so a sort of wider level of learning disabilities.... And I used to help run a local leisure group for adults with learning disabilities. So a few different settings at different times. I've got young children just now, so I'm not here...not here all that often, but pop in and out when needed, and when I can. It seems to work. It works for me and it seems to work for the House.”

(Kim).

These contextual responses that participants chose to share about their careers are interesting as they provide a deeper insight into why they do the jobs they do. It is interesting to note that the wider familial, lifestyle, and educational reasons given by participants all come from women, a finding that will be explored in greater detail in *Chapter Seven*.

5.5.3 Getting away from Bureaucracy and Rules

Two participants talked of leaving their posts within social service run settings due to the:

“...changes being made to the way support workers were being expected to work.”

(Steve).

For Steve the changes that were being made, meant that he:

“...could no longer work for them. I couldn't be part of what they were doing. It wasn't the way they didn't talk to us about what the new contracts would be, or the changes to pay, it was the way they wanted us to support people. It was so inhuman. I just couldn't do it. So I went out of my own— I'm a sole trader, I'm self-employed, my – folks I work for, so that could be the people directly, or it might be their parents or carers who employ me.”

(Steve).

Steve's choice to leave his job and go out on his own as a self-employed worker demonstrates a high level of self-confidence in his abilities to do his job. He would have had to believe that he had the knowledge and skills to do the work, as well as the contacts to get and maintain enough work to make a living in a way that sat more comfortably with his ethical and moral positioning than the role he was leaving within social services. As the interview continued, Steve talked more about his self-employed role and his ability to do what he does. For example, he talked about being aware that he didn't *'always get it right'*, but remedies this by paying:

"...for supervision, I go to a supervisor once every six weeks, and kind of check-up that I'm kind of – just for my own peace of mind – that I'm working... you know, what I'm doing is right, and what I'm telling people is right."

(Steve).

Engaging with his 'faults' in this way, further highlights Steve's high level of self-confidence as it shows that he is capable of dealing with constructive criticism of his practice. This is highly commendable as one of the hardest things to do is admit our faults and work on them (Anderson, 2013). However, it could be questioned why, if Steve has such a high level of self-confidence, he did not stay in his role within social services and try to make changes rather than leave. However, Steve explained this, unprompted, in the interview:

"...sometimes it is easier to change where you are rather than changing the system you are in. If it's not going how you want it to, then you can make it better rather having to fight. There is too much fighting in social care, I didn't want that to be my daily life."

(Steve).

The second participant who had previously worked directly for social services, but had left due to the ethical issues surrounding the changes being imposed on them talked about this in light of his new career:

"I loved the work I did, but I didn't love the service. It was breaking me down. I had to leave, to change what I did completely. So I started gardening. For friends and family at first, but then it became a business. I didn't think I'd work with

people with learning disabilities again, but actually we have someone training with us. So I get to use the skills and knowledge to help Dean learn and develop. It's great to be finally doing something I love in a place where I am in control of what the 'rules' are!"

(Dom).

For Dom, the changes in the learning disability field led to a complete change of career that was not intending to involve people with learning disabilities, but the circumstances and the skills he had meant that the two combined to create a career which he finds satisfying. A situation which would imply that Dom also has a high level of self-confidence similar to Steve.

From exploring each of the motivators presented in this section, valuable insight into how these participants viewed the work they do is provided. For example, the way these participants described their work in the context of their own lives, suggests they have each found harmonious ways of weaving their working and personal lives together in a way that suits them. At no point did these participants describe their working lives in tension to their personal lives, instead suggesting it is an important and worthwhile part of their life which is made even more worthwhile by its ability to fit around their familial, educational and personal commitments. This is an interesting finding as it appears, at least for these participants, to go against the body of literature that suggests that support workers and PAs work long anti-social hours that are not conducive to a good 'work-life balance' (see Michie and Williams, 2009).

5.6 How People with Learning Disabilities are seen by Participants

Throughout the interviews reference was made by participants to how they viewed people with learning disabilities. These references were quite often made in relation to how participants viewed the knowledge and abilities of people with learning disabilities to cope with issues of grief and bereavement in their lives. Unpicking these references at this stage in the chapter provides an insight into how participants construct the label 'learning disability' within their working lives, therefore setting the scene for the analysis of the bereavement support they provide in the remainder of the chapter.

There are two subordinate themes relating to this theme; Despite the learning disability, and; I don't know what they know or what they want to know.

5.6.1 *Despite the Learning Disability*

During the interviews a number of participants talked about the ability of the people with learning disabilities they support to understand the issues of bereavement and grief when they arise in their own lives:

“Pippa is just incredible, she might have the label of ‘learning disability’ but she is better at understanding and dealing with a lot of things that I find really hard. She is much more in tune with her emotions than I am, in fact, she is much more independent than me in lots of ways as well. We are very different in lots of ways and this seems to be what works so well between us.”

(Jane).

This quote, although appearing on the surface to be positive, implies an assumption that people with learning disabilities are not able to deal with the difficult emotions associated with grief and bereavement. For example, Jane's response suggests that she is astonished by Pippa's ability to deal with grief and bereavement in the way she does because she would not expect someone with a learning disability to be able to do this. Furthermore, Jane's comparison of her own abilities to deal with the difficult emotions of grief and bereavement to Pippa's abilities suggests an element of surprise at the ability of someone with a learning disability to deal with this *'better'* than someone without.

From this response, it seems that there is an expectation held by Jane that people with learning disabilities won't be *'in tune'* with their emotions, especially the difficult ones, so when they are *'in tune'* they are seen as remarkable as they are managing to do this despite their learning disability.

This way of viewing people with learning disabilities' abilities to deal with the issues of grief and bereavement can be seen as highly negative and harping back to the Medical Model view of disability (WHO, 1980; Oliver, 1996). However, in this instance, Jane's words are not felt to come from a place of malice. Instead, Jane seems to be somewhat

in awe of Pippa's abilities and sees their very different skills and abilities as part of the reason their support relationship works as well as it does.

5.6.2 I don't know what they know or what they want to know

Although some participants talked indirectly about the abilities of people with learning disabilities to understand issues of grief and bereavement, some talked more directly about this issue:

"I think it had more of an impact on the staff, probably due to the level of understanding of the service-users in here. I don't know that there was – they don't understand exactly happens."

(Kim).

"The thing is, it's really difficult, isn't it, because if someone dies and you're dealing with someone with a learning disability who's bereaved, you don't know what to say. Do you know what I mean? I don't know, really what they know, what they want to know, what they want me to say. I don't know what they understand."

(Chloe).

"And I couldn't get through to him. I don't think I...I did, anyway. There was a point – he never cries. I was trying to draw things, explain to him. I couldn't do it. I got upset, I just don't think he understood."

(Alan).

Quotes such as these, combined with those in *section 5.6.1*, are difficult to read as they seem to suggest that these participants hold, just under the surface, a belief that people with learning disabilities are unable to understand the complex issues which surround, death, grief and bereavement. In addition, these quotes also seem to suggest the equally concerning finding, that some participants doubt their ability to communicate with the people they support about issues of grief and bereavement or understand their responses. Chloe openly states that she doesn't '*know what to say*' because she doesn't '*really know what they know*' and seeks support from me in relation to the doubt she has in her own abilities.

The responses explored in this section appear to suggest that the way interview participants construct 'learning disabilities' is closely linked to the way they construct themselves as supporters. That is, whether participants see people with learning disabilities as dealing with difficult emotions despite their learning disability or as unable to understand these emotions; they view them in this way due to the self-doubt and low self-confidence they have in their own abilities to understand and provide appropriate support for these emotions. In fact, during Jane's interview she acknowledged this herself, stating:

"I think she surprised me, actually. And that's something I've been reflecting on whilst we are talking. You know, maybe I hadn't given her enough credit for her emotional – you know, her abilities to...not to feel, but just to understand – I think for me it was more about her understanding Hannah's feelings. I would not have thought that she could do that, because I expect her to find it difficult. Really it's me though, I find it difficult to see her doing that..."

(Jane).

5.7 Death, Grief and Bereavement

Building on *section 5.6*, interview participants talked extensively about their experiences of death, grief and bereavement in their work. As a result, there are three subordinate themes in this section: what bereavement means to participants; the bereavements people with learning disabilities experience; and, where bereavement support work is done.

5.7.1 What Bereavement means to Participants

Although this research focused upon bereavement support, no direct questions were asked in relation to what bereavement, or grief, meant to participants, although some participants did provide details of their own understandings of the terms and the processes:

"I think...I think we are pretty crap at dealing with death in this society. We don't talk about our losses and how we feel. We expect people to snap out of feeling

sad a couple of weeks after the funeral. I think I'm different to that. I think I'm very – because I'm a very open person, and quite ready to talk about how people might be feeling, it comes naturally to me to talk about a death. I don't skirt around it. You know, if someone's sad, then, 'Why are you sad? Let's...you know, talk to me about it'. It's so important to talk, to share...but our society's pretty rubbish at that..."

(Jane).

"I think one of the things that I'm quite passionate about is allowing people with LD to experience what we experience, so the good and the bad...I don't believe in wrapping people in cotton wool... I never sort of say, 'Oh, don't worry about that'...I do discuss it with people... I've got one gentleman who, he lost his grandfather a little while ago, and it's quite a regular thing that he will bring it up...we always talk about it, even though it was a long time ago. It's important he can talk to someone about what he is feeling when he is feeling it."

(Steve).

Whilst neither Jane nor Steve refer directly to theories of grief or how they interpret them in these responses, they both express a broad understanding of the theories, which suggest that utilising personal networks and talking about feelings is essential for passing through these periods healthily (see *Chapter Three* for a thorough discussion of these theories). These quotes suggest that both Jane and Steve are aware of theories of grief and how utilising these theories can help provide support to people with learning disabilities. However, in future research, participants might be asked directly about what grief and bereavement means to them in order to provide a greater insight into this issue.

5.7.2 The Bereavements People with Learning Disabilities Suffer

Throughout the interviews participants shared details of the bereavements the people they support had suffered. Parents (participants Steve, John, Chloe, Jessica, Jane, Claire), friends (participants Steve, Jane), the parents of friends (participants Jane, Claire), housemates (participants Jessica, Jane, Alan, Kim, Dom, Thea, Claire, Hannah, Deborah) and work colleagues (participant Chloe, Jane) were all discussed. This

finding is in line with the literature that suggests that as people with learning disabilities are living longer than ever before (Ward, 2012) within communities that reach beyond the familial home, the number and type of bereavements they suffer is also increasing (Read, 1998; Ryan *et al*, 2010).

5.7.3 Where Bereavement Support Work is Done

Throughout the interviews participants talked about where they do their job, not just in relation to the bereavement support they provide, but also wider support they provide on a daily basis. The places and tasks participants described were broad and varied, which highlights that people with learning disabilities' lives now reach far beyond their familial homes. For example:

"...we do a lot in the garden. It's one of the things he loves, really loves, so we spend a lot of time outside with the vegetables whatever the weather. I've been known to do weeding in snow flurries! It's worth it though when we harvest the crop and are able to sell them at the local market."

(Chloe).

"We spend a lot of time in the city library. There is a real community there so it's somewhere Samantha loves to spend time. There is always someone to talk to...there is a lot of support there for people, including me."

(John).

These two short examples not only provide an insight into the variety of locations support work can take place and the skills these support workers and PAs have, they also suggest that support workers and PAs are likely to be best placed to provide people with learning disabilities with bereavement support as they know the people and places who are integral to their lives, as well as the communities they might turn to in times of need. They are also well placed to know when someone in the person's life has died and that support is needed; a point made clear by Jane:

"Samantha had been into the library in the City, upset, talking to the staff there, just the library staff, about Diane, how Diane had died. So one evening, I was in

the library to run a group, like I say, it's all interlinked in this City, and Paul who Samantha had spoken to was doing the box office that night, and came to find me to tell me about Samantha having gone in and told him about Diane. So I took this information to the people who support her for more hours a week than I do, to help support her deal with these difficult emotions.”

(Jane).

As well providing this type of bereavement support, a number of participants talked about the direct support they had provided individuals in relation to attending funerals and memorials. For example, five participants talked about religious ceremonies such as funerals and burials as being a fundamental part of the bereavement support they provided people with learning disabilities:

“She died in the house, and we kept her in the house, and she had her funeral, she left from here. And she had a beautiful glass carriage for her funeral. She was of Romany stock, so her family appeared, and – lots of family appeared. And we had her funeral across the road, but we had her in a glass cage, and her horses, and everything – it was absolutely beautiful. And had purple plumes, because purple was her colour, and we walked down the high street, and then up another road to the church across the road, and we had our service there, and then she went back across the road to the funeral directors, and then she was taken down to her home town the next day, and then the minister went down there with her, and she was interred down there”.

(Hannah).

For the other eight participants, none of them had supported someone with a learning disability to go to a funeral or other formal religious ceremonies, but they had provided support to visit a grave:

“she goes to his grave almost every week, on a Monday, to the local church, and she stands there and talks to him...it's a humbling experience. She stands at the grave and talks to him, and I say, 'I'm just going to sit over on the bench quietly there, but give me a shout when you want to leave.”

(Jane).

Light a candle in a local church:

“...she wanted to go to a church to light a candle. And – you know, I'm her only support worker, I see her for two hours a week. And she...that's what she wanted to do, sort of mark her friend's mum's death. And I just thought that was such a lovely thing to do, so we did it together. And she cried, you know, real sobs. It was...you could – it was like I could feel that she was really feeling for her friend. And it was really moving. And I sort of put my – I put one arm around her shoulder and the other one on the other should, and just sort of held her while she cried. And then we sat down next to each other, and she cried until she'd finished.”

(Steve).

And visit a memorial garden:

“...she just took my hand and we walked, walked to the garden of remembrance, and she pulled me down opposite her, and made eye contact. I'd been working with this lady for five years at this point, she didn't really do eye contact. And she Just looked in my eyes, and I said, 'So you understand what's happened? Dad – it's not that he doesn't want to see you, but he's actually died'. And she just stroked my face, and then picked up my hand, and off we went.”

(Chloe).

These quotes suggest that participants in this research were willing and able to provide practical bereavement support to people with learning disabilities as has been found in previous research (such as, Read, 2005; Read and Spall 2006; Read and Bowler, 2007; Gilrane-McGarry and Taggart. 2007; Young and Garrard, 2015). But more than this, these responses highlight the personal and emotive nature of the bereavement support these participants have provided people with learning disabilities. Participants talked extensively about the numerous creative, personalised and empathetic support structures they have put in place with individuals, which suggests they are able to engage with the emotional aspects of bereavement support as well as the practical. For example:

“...we plant a tree for everyone who dies. We have a garden that people can reflect in and they can go there whenever they want, for as long as they want.”

(Claire).

“...memory boxes are a great thing. I've made them with someone recently. I learnt so much. We should do them before people die...I have thought about that.”

(Jessica).

“We made a CD, all his mum's favourite songs. They're great. Sometimes it makes him sad, but other times it makes him sing, well, make noises, and dance.”

(Hannah).

“...photographs, lots and lots of photos. We have them all over the house, and we talk – we look at the pictures and talk.”

(Alan).

Of course, just as with the previous quotes in this section, each of these quotes are somewhat practical in nature as they describe the creation of different memorials. However, creating these memorials will not have been done in isolation to the grief being felt by those involved. As Alan says, placing photographs around the house caused him to talk to those he works with about those who are no longer with them, which are likely to have been emotional conversations. Hannah also alludes to the emotional support she has given the man she works with in relation to the memorial they have created for his mum, as listening to the CD of her favourite songs ‘*makes him sad*’ but this is OK.

These findings are to be viewed positively and go against the tide of research literature which suggests that support staff are unable to provide this level of support (such as, Gilrane-McGarry and Taggart, 2007. See *Chapter Three* for a thorough exploration of this literature). They suggest that not only do participants have the skills, abilities and willingness to provide emotional support to people with learning disabilities when they are grieving, they provide this support effectively and allow those they are supporting to

express their grief openly even if the emotions which surface are difficult. Furthermore, these examples suggest that whilst participants might feel they lack confidence and have low self-esteem in relation to understanding the bereavement support needs of those they work with, they do know what support those they work with need and have the confidence to provide it. As a result, the question arises as to whether the lack of confidence support staff express when talking generally about the bereavement support they provide (rather than about specific acts like those presented in this section) is due to a lack of confidence in their abilities as supporters more generally. This question is explored throughout the remaining sections of this chapter.

5.8 Challenges to Providing Bereavement Support

Although participants talked openly about the bereavement support they have provided, they also talked about the challenges they face to providing this support. This theme has been divided into four subordinate themes; Families; The lack of support for everyone concerned; Drawing on our own resources, and; Box it up and keeping it closed!

5.8.1 Families

A number of participants talked about the challenges people's families posed to the bereavement support they were trying to provide:

“the dad, he didn't want him knowing about his mum. We, we all really wanted to tell him to explain that she wouldn't be coming no more, but he wouldn't, he didn't, he didn't visit no more so we weren't allowed to say anything. Ted is non-verbal and PMLD so I don't know what he thought, but suddenly no family were visiting and his dad wouldn't let us tell him why”

(Jessica).

“...they didn't think it was right for her to be travelling all that way, but I know it was the fact the family did not want her to be there. They didn't want to be having to think about her when they were grieving, even though I was willing and able to take her so they wouldn't have to deal with, with all of that emotion. But they

just wouldn't consent to it. So I took her to a service at the same time at a local church. It was all I could think of doing."

(Thea).

Reading these quotes was challenging to the members of the research advisory group, as they had all been unable to attend a funeral due to their family's wishes. It was also difficult for the co-researchers with support experience, as they had each faced similar challenges and struggled with the morale conflict Thea describes of wanting to do the best they could for the people they support whilst adhering to the family's wishes.

Thea described remedying this conflict by making the decision to do what she felt was right for the person she was supporting, but she did this alone without the support of the family. In situations like this, support from the organisations participants worked for was needed, but as the following section explores, this was sadly not the case for many participants in this research.

5.8.2 The lack of Support for Everyone Concerned

A number of participants described how the organisations they worked for or have worked for, have left them relatively unsupported when issues of grief and bereavement arose. This was also the case for participants working in managerial roles:

"...the lack of support for everybody concerned, it's just...it just wasn't there, from any agencies that the company itself, there was no – there's procedure what you do for a death you can follow out, call the police, call the – that was all written down. But after that, there's nothing. There was no training, there wasn't even – I had to bully the senior management in coming just too...you know, do a debrief with the team. They just weren't...they didn't think it was important."

(Alan).

For Alan, the repetition of this situation for a total of five deaths within the service he managed led to his retiring early from his role due to the emotional stress caused (please see *section 5.8.4*).

It is likely that the lack of support the managers and senior support staff in this research described contributed to the lack of support the support workers and PAs in this research described having received:

“you just, you just don’t know where to turn. You ask your supervisor for help, they say speak to the manager, but the manager isn’t interested, they haven’t had any training themselves and they know there is nothing they can do, so they tell you to get on with it.”

(Jane).

In fact, Jessica acknowledged this very fact and the detrimental effect it had on the service she worked for:

“...no one came. We had two deaths in six months and no one came. (The organisation) are supposed to be Christian – what’s Christian about leaving a whole team to cope on their own?”

(Jessica).

However, whilst this situation was viewed negatively by some participants, some others talk about the lack of support they have received being the catalyst for drawing their staff team together to support each other:

“Do you know what, I am really lucky, we have got a really good staff team. Through all of, like, the issues and the in-bitching that you get in any staff team – you know, there’s 26 of us, it’s never going to be great, because there are lots of us. Actually in situations like that, everybody does pull together, and everybody grieves together, and everybody supports all of the customers together. When you’re left on your own to cope, that’s what needs to happen...I am lucky that I have that.”

(Claire).

Although this appears to be a positive outcome for Claire and her colleagues, it has arisen from a terrible situation where all the support staff were left on their own to cope with providing bereavement support. The situation only arose because the staff team had the insight to realise what was happening and decided to talk to one another about

it, something that is unlikely to happen in all workplaces. Claire confirms this by stating that she is 'lucky' to work with the team that she does. In fact, Kim talks openly about how the lack of support in her workplace has left some of her colleagues feeling isolated with a number of unresolved issues simmering under the surface:

"...because I only come in and out, I pick up on the little bits and pieces that people say. There is a lot that was never said and the weight, the guilt some people carry is huge. It doesn't raise its head very often, but it's there. It's bubbling...what'll happen when someone else dies – I dread to think"

(Kim).

This situation implies that there is a huge emotional impact upon support staff if they are left unsupported in providing bereavement support, which is explored in greater detail in *section 5.8.4*.

Finally, although participants felt relatively unsupported when situations relating to grief and bereavement arose in their workplace, one participant praised the support they received from their line manager:

"Without Philippa, I don't know what I would have done, her husband's a vicar. So he suggested, 'Well why don't you do a service in a local church, round about the same sort of time as the funeral'. And I didn't know churches did things like that. I don't know, I'm not religious, sort of thing. But you can just go to the church, explain the situation, the local priest, vicar, whatever, says yeah, we could do that. That knowledge was invaluable"

(John).

It is good to hear positive stories of participants being supported by their line managers, although the outcome of this support only appears to have been successful because John and his line manager both drew on their own resources to make this happen. This was a common situation for a number of participants as shall be explored in the following section.

5.8.3 Drawing on our own Resources

Drawing on their own resources was a common theme to the bereavement support participants described providing in their interviews. It seems that participants frequently did what they could with the resources they had in order to do the best they could for the people they support, in spite of the lack of support they received from those in more senior positions to them.

The resources participants describe using, were predominantly emotional resources:

“you know, if you explain to some of the folks, you say, 'Oh, well I've lost my parents as well', they're like, 'Oh right. Anyway, with my mum and dad' – you know? And, well you then have to delve into your stuff to make what they say seem ok. (Steve).

time:

“So he went to the funeral, and I couldn't go, I can't remember why. So I went round and made his tea that evening, because they were saying he wouldn't get any tea, because they couldn't rearrange his support, and he wouldn't be back in time. So I went round and made his tea, and so I sat and chatted to him. And the only support he got was from me, to be honest, and his friends - his in-house support did nothing.”

(Chloe).

and personal connections and contacts:

“Not everyone is so lucky. Not everyone's manager's husband is a vicar. I really would have been lost without that.”

(John).

Drawing on these elements of themselves, whilst done with the best of intentions and to make the best of a difficult situation, appears to have compounded the emotional impact providing bereavement support in an unsupportive environment has upon participants.

This is explored in greater detail in the following section.

5.8.4 *Box it up and keep it Closed!*

The lack of support participants described receiving when faced with providing bereavement support and the subsequent drain on their own resources, appears to have had a negative effect on their emotional and mental health. A common issue for participants was that the support they had to provide brought up their own feelings of grief from their own personal losses:

“And it's kind of like –it doesn't mean that it doesn't affect us, and, you know, it brings up those things as well. So, I think it's kind of like, sometimes we're not only dealing with that person's kind of issues, we're also dealing with some of our old stuff as well, and things”

(Steve).

Leading some participants to have difficult feelings about the work they were having to do and developing 'unhealthy' coping strategies:

“So that's why I get the hammer and nails out and just make sure that the box is really strong. Change it from wood to metal and make sure that it is really securely shut. Box it up and keep it closed.”

(Dom).

Whilst the lack of support some participants received from those in more senior positions than them, led them to leave their role:

“the fact that I was told I had to find my own support, counselling, like. I went to the GP and manager to get a referral, after a bit of a wait, but then was told by (the company) that I couldn't have the time off unless it was unpaid. I tried for a while, but I couldn't cope, I needed to work it all out. I needed the space and time.”

(Alan).

This situation needs to change, and Kim offers an insight into how this change might be achieved through a reflection on how bereavement support work is done within older people's settings:

“it happens almost every week in the winter. It’s normal to talk about someone not being there anymore. It is all quite open. The residents’ sort of expect it. There’s sort of an unspoken knowledge that people die, it’s normal and we support each other as staff.”

(Kim).

Thinking about how older people’s services deal with death and the resulting grief that the remaining residents feel, it appears that support staff in this section of the social care workforce experience death and bereavement on a regular basis within an environment that knows how to support it. In this context, staff are supported to develop the skills and confidence to provide bereavement support to the individuals they work with. From the findings in this research, learning disability support services could learn a lot from older people’s services in relation to providing bereavement support. However, this suggestion comes with a word of warning as, as Kim acknowledges, the reason why older people’s services cope so well with death and bereavement is due to the frequency with which it happens in these services, something which is currently not the case in learning disability services:

“...it doesn’t happen so often. Maybe that’s the problem. Luckily it doesn’t happen often, but then when it does, it’s a shock and it’s like it all has to be learnt, how to deal with it has to be learnt again.”

(Kim).

This is an insightful and useful observation and one to be taken heed of as the population of people with learning disabilities are living longer (Ward, 2012). Exploring the cross social care workforce learning that could be done in relation to the processes within older people’s services when issues of grief and bereavement arise could therefore be beneficial to the sector.

5.9 Being Professional

As well as the cultural and organisational challenges participants described experiencing when providing bereavement support, the notion of ‘professionalism’ was described by participants in twelve of the thirteen interviews in a way that has been

interpreted as an indirect challenge to the support they provided. Due to the size of this challenge a separate theme to explore the issues at play for participants has been created. This theme has been split into three subordinate themes; Professional boundaries; The Wild West, and; The crisis of professional identity.

5.9.1 Professional Boundaries

All eleven participants endeavoured to make sure it was recorded that they knew what was expected of them as professionals, with boundaries who had 'appropriate' relationships with those they supported:

"I do have to have those sorts of professional boundaries."

(Steve).

The majority of participants seemed to view these boundaries as being an essential part of doing support work 'right':

"I mean, the rules are there for good reason. We have had some people here who have just had no idea about how to be. Social media, Facebook in particular is a real problem. We had one woman start here who had customers as 'friends' on her Facebook after a week of being here. To me...to me that's not right. We had to put a social media policy in place after that. We have to make sure we do our drop right – make sure everyone is safe."

(Claire).

Although some questioned their usefulness when talking about the individuals they support:

"It's funny, actually, we had a training about the lines – I can't even remember the name of the training now. Professional boundaries stuff. And actually one of the questions was, you know, if a service-user invited you to their wedding, is it appropriate to go? And I think a lot of the staff thought, we have to say no, and I said, 'Well wait a minute, they all came to my wedding, why is it any different?"

They came, they had a party, we had a good laugh. Why would it be different the other way round?"

(Kim).

For Kim, the rules and policies around 'professional boundaries' do not sit in line with the values she assigns the people she works with and the human connections she has with them. Jane furthers this point by highlighting that the blanket approach with which policies and guidelines around 'professional boundaries' will never work in settings where you are working with people:

"...what I've learnt from being a support worker is actually, boundaries are different with every single person, because everybody's an individual. It's really simple. Rules are fine, but you really do have to think about the individual when you do anything."

(Jane).

Within the research community this is seen as a crucial point. For members of the advisory group, they want the support they receive to be individual and personal to them. Each of them are supported by a variety of people and have very different relationships with each of them, the thought of these relationships being regulated in the way participants describe fills them with dread as this is how their support used to be.

5.9.2 The Wild West

Although some participants openly question the notion of 'professional boundaries' within their work, the overarching message from the interviews is that these 'boundaries' are a good thing for practice and should be obeyed to ensure the safety of everyone involved. The extent to which this notion has been embodied in the workforce is highlighted in the following quote from Steve, one of the independent support workers interviewed in this research:

"...one of the things that kind of worries me at the moment, as a self-employed care worker, I have absolutely nobody checking up on me. No one – there are no overarching standards, there are no real qualifications...it worries me that we're in a kind of – it's almost like one of those wild west situations at the moment, where we're in this transition period, and kind of...as we move to a more sort of

private, individual-focused thing, we don't seem to have set up those necessary systems to sort of make sure that, everyone's OK."

(Steve).

Whilst this is only one quote from one participant, it comes from a different perspective to the rest of the participants and therefore raises some interesting points which require exploration within their own subordinate theme.

Steve, who left a job in social services because he felt the rules and regulations were affecting his ability to do his job, states that his new independent work place feels like the '*wild west*' as none of the rules, standards, or qualifications that he is used to are in place and this worries him. Furthermore, his statement '*I have absolutely no one checking up on me*' implies that he needs and wants someone to be doing this to check that he is doing everything '*OK*'.

This discussion suggests that whilst Steve did not like the rules and regulations governing his previous job in social services, without them in his new role he is worried and fearful. He appears to have embodied the notion that 'professional boundaries' within support work are necessary and have to be governed by rules, regulations, standards and qualifications, rather than his own judgement. Of course, Steve's worries may also be underpinned to a greater or lesser extent by concerns about how safeguarding issues are managed in an independent PA workforce (that is, PAs who do not work for services), which do need to be considered (see *Chapter Three*). However, his worries seem to be much more personal, suggesting he does not have confidence in his abilities to provide support to people with learning disabilities despite having worked in the field for many years and having the confidence to 'go it alone' as an independent support worker. Whether this lack of confidence has been caused by the very rules he sought to escape and is now seeking in his new role, cannot be discussed in this research due to the limited data available. However, Steve has provided an interesting insight into the complex issue of support work and PA 'professionalism' from the unique perspective of someone who has transitioned from one role to the other, that has not been explored in great detail in the literature to date.

5.9.3 *The Crisis of Professional Identity*

The situation described in *sections 5.9.1* and *5.9.2* suggests that some participants perceive there to be very clearly defined roles for support workers and PAs within services that do not overstep certain boundaries as they are the territories of other ‘professionals’ in the field. This is particularly evident in relation to the emotion work that is involved with providing bereavement support, as participants discuss the internal conflict they face in relation to what they are allowed to do ‘professionally’ when providing this support and what they feel they should be doing:

“...because we are so close to them, it was more like your family, so you kind of...maybe step over that professional line, maybe? Because you are so close to them, because they haven't had much family contact. We were their aunts, their mums, their brothers and sisters, and, you know, it was...no, it was really good, but we worried.”

(Hannah).

As Hannah suggests, the need to obey the ‘professional boundaries’ policies is at the forefront of participants’ minds when they are faced with providing emotional support to people with learning disabilities. Emotional support sits outside what these policies tell participants their role is, but the relationships they have with the individuals they support contradict what these policies say. This situation appears to cause a crisis of professional identity for the support workers and PAs involved in this research, which leads them to doubt their abilities to provide bereavement support and defer to ‘*proper professionals*’ (Jessica). Alarming, a number of participants, whilst telling clear and compelling narratives about the successful and empathetic bereavement support they have provided (*section 5.8*), quickly default to an inferior position when unpicking these narratives, stating that:

“...(I) don't really know what I am doing”

(Dom).

“he definitely needed some professional help, we were clasping at straws.”

(Hannah).

This conflict of professional identity created by the rules and regulations which govern the support worker and PA workforce within learning disability services is felt to be at the heart of why bereavement support in the UK 'is at best inconsistent and at worse non-existent' (Read and Elliott, 2007, p.177) and needs to be explored in greater detail in future research. This issue will be explored within the questionnaire data (*Chapter Six*) and discussed in greater detail in *Chapter Seven*.

5.10 Bereavement Training

Due to the conflict of professional identity participants described facing in their interviews, the lack of guidance they have received and the emotionally taxing nature of providing bereavement support, participants talked a lot about bereavement training within their interviews. In these discussions five participants discussed having received some training in the past, but this had not been particularly useful to the majority of them:

"...I mean I did some training, but it was moons ago. It was only a day. I don't think I could tell you anything about it, other than it was in an old scout hut that was really damp – it's funny what you remember!"

(Alan).

Of the participants who had not received any training (eight), seven said they would like some training, but they placed caveats on this stating that they didn't want this to be done online:

"I wouldn't want it to be done online like so much training is done now. I know it costs less, but how can you teach this stuff remotely. It's meaningless"

(Steve).

The co-researchers with support experience felt this was an important point, and agree with Kim's suggestion that:

"there could be a point to having training done online for the theory stuff, but then it needs to be in situ. With the guys as its happening."

(Kim).

They also agreed with Alan's suggestion of:

"...having a toolkit would be helpful and, I suppose, that could be done online. You know, letting us have a 'bag of tricks', but really I think it needs to be done in person, talking and sharing ideas from real lived experience like we've done here today. Just talking is helpful"

(Alan).

These suggestions of having multifaceted training for support staff could be beneficial to the workforce. Providing details of the different theories of grief, how this can manifest and different strategies, or a 'bag of tricks', for supporting these online would be useful foundation stones to in-situ training for staff at their places of work. Alan's suggestion of providing staff with space to talk about what they are facing when providing bereavement support and how they feel about this, is an important point to note, and is discussed in detail in *section 5.12*. Members of the research's advisory group felt that people with learning disabilities should be closely involved in creating and delivering this in-situ training as they are the ones who are going to be in receipt of the support. The people that Chloe works with also feel similarly, as:

"...quite a lot of people here that want to start a support agency that's user-led, where they do all the recruitment, the training and the supervision, of non-learning disabled staff who go and support people in their homes. And one of the things they put on the list of what they would consider their essential training was how to help people when someone in their life dies,"

(Chloe).

This is an interesting insight into the importance some people with learning disabilities themselves place upon staff knowing how to support them when they suffer a bereavement and suggests that service providers should consider incorporating this support into their organisations.

The thoughts participants have about bereavement support training explored in this section suggest that these individuals are engaged with their work and have clear ideas about what they need in order to develop within their roles. There is an undercurrent in these individuals' responses of wanting to receive training to ensure they are doing

bereavement support 'right' within the parameters of their roles, but this appears to be surpassed by their desire to take control of the difficult support situations they are faced with by offering tangible suggestions for improvement. That is, these participants describe providing people with learning disabilities with personalised, empathetic and creative bereavement support, but have done so with relatively few resources and limited support from their managers or supervisors. As a result, their suggestions for training can be interpreted as a proactive approach to remedying the situation in a way they can control, rather than suggesting larger system changes within their organisations or the field more broadly which are outside their control.

5.11 Looking for Confirmation and Answers

As well as exploring the usefulness of bereavement support training and offering suggestions for how this might be delivered in the future, some participants also used the interviews as a space to look for answers to their questions, solutions to their problems and confirmation that the support they were providing was 'right'. For example:

"...so we have been doing that with him for the past six months and it seems to be working, but, I don't know, what do you think. Does it sound like it's, like it's the right thing to be doing?"

(Chloe).

All Chloe, and a number of other participants, needed in this situation, was confirmation that they were doing the right thing, before continuing with their narrative. This need for reassurance and confirmation that what they are doing is right, is thought to add further weight to the suggestion that due to bereavement support sitting outside the rules and regulations assigned to their role, support workers and PAs suffer a crisis of professional identity and confidence in their ability to provide bereavement support in the 'right' way. A further example of this came from Dom who asked directly for advice about how to support the people he works with:

“So have you heard of any organisations, or places where we might be able to send our guys? It’s really difficult not knowing where to go, so anything you know would be great to take back to the team.”

(Dom).

The fact that Dom asked this question seems to highlight just how unsupported and few resources he, and many other supporters, are working with, whilst also being dedicated to finding answers to remedy the situation.

Dom’s seeking of answers within the interview also highlights that whilst participants acknowledged and appreciated their shared identity with the author/interviewer, they also saw her as a researcher with more knowledge than them who might be able to provide them with answers to their problems. This finding is in line with other research where the researched and the researcher have a shared identity, as the researcher is seen as a peer as well as the holder of knowledge who is expected to share with participants because of the shared identity (such as Muhammed *et al*, 2015). In these situations, participants were referred to the few national organisations available for them to utilise, such as PAMIS and Cruse, direct advice or opinions were not shared.

5.12 Being Involved in the Research

The final theme to be drawn from the interviews relates to the impact being involved in the research had upon participants. Towards the end of each interview a number of participants had what appeared to be a moment of clarity in their ability to direct the bereavement support processes and procedures at their place of work:

“...but there’s no after support, actually, thinking about it. And this is really making me think now that I should be putting things in place for the team to be aware around mothers’ days Christmases, birthdays, and anniversaries.”

(John).

“I’m going to go back and tell them about this. Tell them what I think we should do. Thank you, thanks for...for making me think about this. We can be doing more and - I want to”.

(Jane).

This transformative process experienced by some participants is felt to suggest that providing support workers and PAs with the space to talk and reflect upon their own experiences, skills and knowledge can allow them to improve their self-concept and in turn their confidence in their ability to provide the 'right' support effectively. Of course, the data collected in this research cannot tell whether participants acted upon the realisations presented here, but it is felt that future research could explore this discovery in light of bereavement support work, as well as support work more generally.

5.13. Summary

This chapter has explored the data collected from the interview participants. Both the quantitative and qualitative analysis of this data suggests that participants in this study have provided personalised, empathetic and creative bereavement support to the people with learning disabilities they work with within highly challenging work environments. Participants openly discussed the fact that they have provided this support with relatively little guidance from managers or service owners, having to utilise their own skills and resources to provide this support even though this can have a detrimental effect on their own mental health.

Participants came across as highly skilled at what they do and best placed to provide such intimate support in people's lives. However, when asked about the support they have provided, participants were not sure they were doing it 'right' and called for 'proper professional' support and training in this area. This situation is felt to have been caused by the low self-confidence many participants described having in relation to their abilities due to the regulation of their profession sitting in juxtaposition to the emotional support they feel they should give someone who is grieving. That is, the regulation of the support service workforce suggests that emotion work is not part of support workers or PAs' remit and should therefore be done by 'other professionals' (Skills for Care for Health, 2013). This sits in juxtaposition to the fact that support workers and PAs are faced with emotive situations every day and are in fact best placed to provide support in these situations due to the intimate nature of the relationships they have with the people they support and the position they hold within their wider support network.

As has been seen in this chapter, this situation appears to be causing support workers and PAs a crisis of professional identity that makes them to question their abilities and

request training in this area as it is the only tangible outcome to this complex support situation.

The following chapter will explore the data provided by questionnaire participants before both analyses are drawn together to be discussed in greater detail in *Chapter Seven*.

Chapter 6

The Meaning of Bereavement Support: Online Questionnaire Data

6.1 Introduction

Following on from the discussion in *Chapter Five*, this chapter presents details of the data collected from the online questionnaire. The chapter begins by re-introducing how and why the online questionnaire came about, before moving on to discuss who completed the questionnaire and their experience in the learning disability field.

From this starting point, the chapter moves on to present the results of the analysis carried out on the data. Quantitative questionnaire responses have been analysed using descriptive statistics in SPSS, whilst qualitative responses have been analysed using an interpretive narrative approach similar to that used for interview data.

6.2 Creating the Questionnaire

As discussed in *Chapter Four*, the online questionnaire came about as a result of the interest in expanding the research findings that arose in two members of the research's advisory group (Julian Goodwin and Kerrie Ford) when analysing the interview data. Both Julian and Kerrie wanted to find out more contextual information about the roles of support workers and PAs when providing bereavement support to people with learning disabilities, whilst also developing their own research skills. Due to the flexibility of the research design, this development could be facilitated, and Julian and Kerrie became co-researchers in this second phase of data collection.

Whilst the research design could accommodate this second phase of data collection, the time available was limited. As a result, an online questionnaire was used to collect responses. This method was chosen due to the speed and efficiency with which large numbers of targeted responses can be gathered (Wright, 2005).

This phase of data collection was guided by the same research questions, aims and objectives as the interview stage of data collection (please see *Chapter's One and Four*). The contents of the online questionnaire was also based upon the findings from

the interview stage of data collection, specifically the responses received to the short demographic questionnaire that interview participants completed (Appendix 20). Within this short demographic questionnaire, it was found that the lack of training around bereavement support was an issue for all participants; something Julian and Kerrie wanted to explore further via the online questionnaire.

The online questionnaire utilised a mix of both quantitative and qualitative questions to elicit information from participants. This approach was chosen to ensure that the questionnaire struck the right balance between the needs of the research to gather rich and useable data from a larger number of participants, and the needs of the participants - to share their responses in a quick and convenient way. By providing participants with a number of questions that offered a selection of answers from a predetermined list the questionnaire was not too labour intensive or time consuming, whilst ensuring the research captured the data it needed (Wright, 2005). There was also the option of being able to add a different/additional answer as well, as well as open text box responses.

The online questionnaire was created using the Bristol Online Survey system (BOS) for targeted circulation to the UK learning disability support worker and PA workforce via email, blog, forum and social media posts (Appendix 8, 29 and 30). The online questionnaire was 'live' online from the beginning of July to the end of August 2015.

6.3 Participants

Fifty-four participants followed the link to the questionnaire from either the email, blog, forum, or social media posts that were circulated (Appendix 29 and 30) and read the 'landing page' information (Appendix 31). Upon reading this information, four participants did not complete the questionnaire. The remaining fifty people completed the questionnaire, but six individuals were excluded because they did not meet the criteria of either knowing someone with a learning disability who had suffered a bereavement (three participants) or providing direct bereavement support to someone with a learning disability (two participants). One participant was excluded because they were a family carer to someone learning disability.

Although support workers and PAs were targeted to complete the questionnaire (Appendix 29 and 30), a far broader mix of individuals completed the questionnaire,

including nurses, psychologists, counsellors, therapists and a retired psychiatrist, as Figure 1 (p.101) highlights. Participants were not asked for any more specific details of their places of work in the questionnaire, but on reviewing their responses they all had direct bereavement support experience which meant they met some of the inclusion criteria for the research. Although they did not meet the criteria of having '*experience of working as a support worker or PA*' (Chapter 4, p.96).

After much consideration within the research community, it was decided that rather than lose the rich data these participants had provided, their responses would be included in the research as they added the interesting contextual information to the data collected from interview participants that the researchers were interested in. Choosing to include this data allowed for the research to remain support worker/PA focused, but with the added benefit of being able to explore their experiences within the broader learning disability landscape.

Whilst the online questionnaire data has provided the research with invaluable insights into the context in which support workers and PAs provide bereavement support to people with learning disabilities, the researchers acknowledge that this was not the data set out to be collected in this phase of the research. This may have been caused by a flaw in the choice to use an online questionnaire as a method of data collection, the design of the questionnaire or the chosen distribution methods. Some of these elements are discussed throughout the remainder of this Chapter, and in more detail in *Chapter's Seven and Nine*.

As a result of the decisions made by the research community, forty-four participant responses were analysed. The participant who had been excluded for being a family carer at the beginning of the data analysis process remained excluded after this change to the questions, as the research remained focussed on those employed to support people with learning disabilities and not family carers.

This analysis is discussed throughout the remainder of this chapter. Within this discussion, participants are referred to by the number assigned to them by BOS, as the volume of respondents meant that assigning them all with a pseudonym was not possible.

6.3.1 Who the Participants Were

As highlighted above, although support worker and PA workforces were targeted via email, social media, forum and blog posts (Appendix 29 and 30), only five support workers and no PAs completed the questionnaire. The remainder of the participants were made up of a far broader mix of individuals, including nurses, psychologists, counsellors, therapists and a retired psychiatrist as Figure 1 highlights (page 101).

The reason why so few support workers and/or PAs completed the questionnaire is unknown, but there are number of potential reasons. For example, the lack of engagement this workforce may have in their role outside of their working hours, limited computer literacy skills, and/or the limited time they have available to complete online questionnaires whilst at work. As well as the questionnaire being run over the summer months when potential participants may have been on holiday, and possible inappropriate targeting of the online questionnaire by the research team. Sadly, the reason why so few support workers and PAs engaged with the online questionnaire will never be known, but it is likely to be a combination of the workforces long working hours and limited interest in engaging in work outside of working hours. This assumption is based upon the wider literature which suggests that support workers often work long, antisocial hours (Michie and Williams, 2009), which can be assumed to decrease their interest in engaging with a work related questionnaire online outside of their working hours; especially if taken in conjunction with the finding from the interview participant data, which suggests many support workers and PAs fit their working lives around their family lives (*Chapter Five*; England, 2005; Kittay 2001). This issue is discussed further in *Chapters Seven and Nine*.

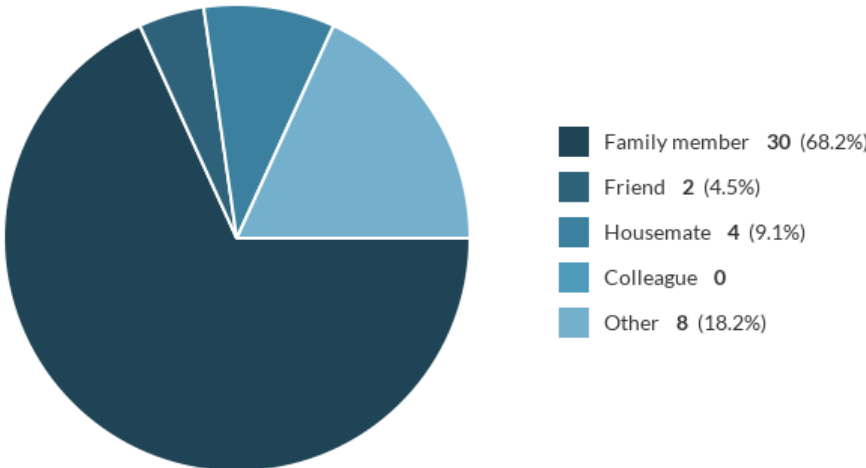
6. 4 Bereavement Support Experience

As discussed at the beginning of this chapter, all forty-four participants had known someone with a learning disability who had suffered a bereavement within the two years prior to completing the questionnaire and had directly provided them with support during that time. Twelve people felt they had provided this support on their own, whilst thirty-two felt they had provided this support with other people.

The types of bereavement the person with a learning disability had suffered, varied, but the majority of people had lost a family member, as Figure 4 highlights (below). This

finding is similar to that of other studies (Read, 1998; Ryan *et al*, 2010), and provides support for the work being done to encourage people with learning disabilities to prepare for their parents' deaths and plan for the future (Foundation for people with learning disabilities, 2013; Tuffrey-Wijne, 2013).

Figure 2. Who People with Learning Disabilities had Lost



For the participants that responded 'other' to this question, the qualitative detail they gave highlighted that they had worked in the field for a long time and therefore had supported many people through different types of bereavement, for example:

"I've supported several people and they've lost family members, flatmates, and friends"

(Participant 35).

This response was pre-empted in the questionnaire design with participants being asked to provide details of just one of their bereavement support experiences in response to the following statement:

"Please tell us about your experience of supporting someone with a learning disability through a period of bereavement. If you have supported more than one person then please provide us with an overview of your experience."

(Appendix 7).

A total of forty-two participants responded to this question. The responses ranged in length from one paragraph to two full A4 sides of text; something which surprised the research community as questionnaires are not known for providing such rich qualitative responses from participants (Wright, 2005) (please see *Chapter Seven* for a discussion of this). These responses have been analysed using a similar interpretive narrative analysis approach as used for the interview data (please see table 10, p.103).

6.5 Interpretive Narrative Analysis

As well as the statement listed above, participants were also asked to provide a qualitative response to the following question:

“Was the person with learning disabilities involved in any death rituals following the bereavement they suffered?”

(Appendix 7).

This question was asked as a result of the discussions that took place in the research interviews (*Chapter Five*) about the involvement of people with learning disabilities in the rituals that surround death (funerals, memorials etc. *section 5.8.3* and *section 5.9*). This question was directly asked to participants to prompt them to share their experiences around this issue.

The responses participants gave to both these questions were analysed in line with the research's' questions (p.143) , aims and objectives (p.17/8) using an interpretive narrative approach. However, this analysis was not blinkered by exploring the data through this lens; each questionnaire transcript was explored for all details of how participants interpreted bereavement support, their role within it and how people with learning disabilities were seen; as well as our interpretation of this data within the research group (Table 10, p.103) . Viewing the data in this way gave rise to some of the themes (*section 6.5.1*); whilst taking this analysis to the remaining advisory group member (Lisa Ponting) and the co-researchers with support experience led to themes being developed or added to.

6.5.1 Themes

Applying the interpretive narrative approach described above, led to two superordinate themes being drawn out from the qualitative questionnaire responses:

1. How people with learning disabilities are seen
2. Providing bereavement support

These superordinate themes are similar to two of those drawn from the interview data (*Chapter Five*), however their subordinate themes differ significantly. Each of these themes shall be discussed in turn in the following two sections of this chapter along with our interpretations of what the themes are telling us.

6.6 How People with Learning Disabilities are Seen

Throughout a number of the questionnaire responses reference was made to people with learning disabilities; their capabilities and understanding of the issues that surround death, grief and bereavement. Exploring these statements in their own right may provide insight into how learning disability is constructed for and by participants. There are three subordinate themes relating to this theme; Give them a chance; Do they really understand? and; The professional hierarchy.

6.6.1 Give them a Chance

Within a number of the questionnaire responses, participants talked about the people with learning disabilities they supported, or have supported, as being independent and able adults who understand the world around them and have emotional intelligence:

“I have supported quite a few people in very different situations, living independently to living in shared accommodation where one of the other tenants was terminally ill from support for loss of friends, family or staff etc. The biggest message I can give is to listen to the person. They know what they want and what they need from those who support them, if we give them the chance to be listened to.”

(Participant 74).

For this participant, the individual with the learning disability is viewed as an adult who

should be at the centre of the life they live and the support they receive. They are adults who understand the complexities of their own lives and are in touch with their emotions. They are seen as capable of directing the support they need to live the lives they choose so should be allowed to do so. For Julian and Kerrie, responses like this were interpreted as positive. Both felt that this is how they would like to be seen by their supporters, not only when they suffer a bereavement but throughout all aspects of their lives.

My Support

Why can't all supporters see people like this? I never know who is coming to my house, I can't plan my day and know what to tell them to do with them if I don't know who is coming."

Julian Goodwin, Analysis meeting, October 2nd 2015

In addition to the personal analysis of this response by Julian and Kerrie, a deeper examination of the response suggests there is a plea in participant 74's words. There is a sense of urgency and sadness in the final sentence of their response, which suggests they have witnessed many years of people with learning disabilities having no voice or control in their lives. There is a sense that the participant has despaired at watching support being given in this way and is pleading with the researchers not only view people with learning disabilities as capable in our own eyes, but to make sure other people do as well by sharing this advice in our research. This is particularly poignant as this participant worked as a support worker in the field.

6.6.2 Do they Really Understand?

Although some participants referred to people with learning disabilities as able to understand issues of bereavement and grief (like that discussed above), some participants talked about these issues being too complex for many people with learning disabilities to grasp:

"Grasping the concept of the finality varies greatly... I am never sure they understand."

(Participant 90).

For Julian and Kerrie, reading this participant's response proved challenging as they felt it was a judgement upon their abilities to understand death and therefore grieve. Both of them had had experiences of this in their own lives:

Not being seen as an adult

It happens all the time. I'm not seen as an adult. People tell me what to do. What gives them the right to treat me like that? I am an adult they should work with me to do things not baby me. "

Kerrie Ford, Analysis meeting, October 2nd 2015

However, when this response was unpicked in more detail, it was felt that rather than being a judgement upon people with learning disabilities, it actually revealed the lack of belief the participant had in their own abilities to communicate with and interpret the communication of the people they support when issues of death arose. That is, the use of the words '*I am never sure they understand*' suggests a level of doubt in the participants ability to know whether the person they are working with has understood them, not the other way around. Interestingly this response came from a support worker, which supports similar findings obtained from this research's interview participants.

6.6.3 The Professional Hierarchy

Due to the broad mix of individuals completing the questionnaire, comment was made by a number of participants in non-support worker or PA roles about how they viewed support workers and PAs in relation to bereavement support, for example:

"I have found that initially the people that support individuals with IDD want the person to have some sort of professional support for the bereavement. Though this is helpful for some people and has been used, when an extended period of time has gone by and it is impacting on the person wellbeing significantly. Grief is often clinicalised, where perhaps a more helpful approach would be to normalise the feelings and support the person in those ways, to go through the normal rituals. People often find the behaviours associated with grief, very difficult to support, and people get reduced to behaviour and somatic symptoms, rather than the emotions and feelings. I have known of people I have worked with

that have been prevented from attending funerals etc. by their staff as they have wanted to protect the person from the experience, which I don't agree with."

(Participant 03).

From analysing this response, there appear to be two different elements to the participants construction of bereavement support for people with learning disabilities, which they alternative between in their answer. Firstly, the response can be interpreted as being highly judgemental of support workers. The participant, who was a music therapist, passes judgement on the abilities of support staff to support the difficult emotions associated with grief and bereavement and openly disagrees with some of their choices. Yet in the next sentence they suggest that these staff really would be the best people to provide bereavement support to people with learning disabilities as this support does not need to be clinicalised in the way it currently is. They then return to their original critique of support staff's abilities with the statement '*(P)eople often find the behaviours associated with grief, very difficult to support*'.

Similarly, another participant, a community learning disability nurse provided the following example:

"I was able to allow the client time to talk about her bereavement, to enable her to attend the funeral and to celebrate the life of her Mother...At times her carers told the client to stop going on about it [her mother's death] and to move on, at meetings I was told that if I didn't keep mentioning her Mother she wouldn't either. But the client would ask me for nail care - this was something that her Mother had always done, at these times the client would talk about her Mother a great deal. I was saddened by my so-called colleagues approach to the client, unfortunately they provided her with such good care most of the time and knew her really well, but, I don't know, their own negative experiences of bereavement or not knowing how to deal with her sadness over-shadowed their care of this lady and how they perceived my care of her."

(Participant 61).

In unpicking these participants' responses, it can be suggested that they have embodied a professional hierarchy in their field of work, just as the participant support workers and PAs in this research have done (*Chapter Five*). These participants appear to judge the

work support staff are doing when issues of bereavement and grief arise, from a place of 'seniority', whilst actively acknowledging that support staff are the best people to provide bereavement support.

This is an interesting and important finding to have been gleaned from the questionnaire data. Of course, these participants responses cannot be said to be representative of all other professionals in the learning disability field, but the insight they have provided does add weight to the argument in *Chapter Five*, that there is a professional hierarchy in the field that is governed both by actual and implied rules upheld by its social actors. This is discussed in greater detail in *Chapter Seven*.

6.7 Providing Bereavement Support

The responses participants gave in relation to the bereavement support they have given have been divided into four subordinate themes; It takes months, sometimes years; Acknowledging grief and having conversations; Families and funerals, and; Being involved Vs Not being involved.

6.7.1 It takes Months, Sometimes Years

As with the interview participants, questionnaire participants were not asked directly what the words bereavement or grief meant to them. However, a number of participants did allude to their understanding of these concepts, such as:

"...just being with the person and allowing them to talk and tell you what they want to. Listening, sitting and holding hands. Grief takes months, sometimes years to work through. Giving each person space to do this not just in the immediate, but in the long term helps."

(Participant 62).

This response, from a learning disability nurse, demonstrates a solid understanding of the healthy processes of bereavement and grief, which they may have acquired through their training that they transfer into providing bereavement support in an individualised and empathetic manor. This response suggests the participant understands how grief

and bereavement are issues which affect everyone, but that people's responses to them will be individual. Furthermore, they appear to understand that the individual processes of grief can be lengthy and the most important thing to do when supporting someone is to provide them with the time and space to go through these processes in their own way, sometimes for a long period of time.

This response is viewed positively as it provides a valuable insight into what bereavement and grief means to the participant, and the confidence they have in their abilities to provide such support, especially in relation to physical contact. That is, the participant clearly states that '*sitting and holding hands*' whilst they talk to people who are grieving is a 'normal' thing to do when they provide bereavement support. There is no caveat placed upon this statement, no justification of 'professionalism' or clarification of 'appropriateness' which were presented by interview participants (*Chapter Five*). This finding connects with sections 6.7.3 and 6.8.4 and is discussed in greater detail in *Chapter Seven*.

6.7.2 Acknowledging Grief and Having Conversations

Like many of the interview participants, questionnaire participants had provided people with learning disabilities with bereavement support in a variety of different ways. Some had provided individual emotional support:

"Generally it's been about acknowledging the grief, having conversations about how they're feeling, sharing my experiences of grief, offering support, following up and checking in. Conversations come up again later (weeks and months) and we revisit topics again."

(Participant 35).

Whilst others had used their professional roles to set up and develop support groups for people:

"I set up a specific loss and bereavement therapy service for people with learning disabilities in 1997 in the NHS, it is still going. I now work for a charity, which provides psychotherapy to people with learning disabilities, I co-run a weekly loss and bereavement group and provide one to one therapy to others."

(Participant 37).

“I help facilitate and deliver a Bereavement support group for people with LD through my work. We talk about the different types of losses we may experience and what type of emotions they may go through. We talk about the difference between cremations and funerals and whether they attended the service or not. Discuss feelings, thoughts, wishes and dreams for the future and at the end of the course each person takes home a memory book they have helped to compile over the previous weeks. From this, sometimes the client can participate in Life Story Work which has proved to be very successful and beneficial to the client”

(Participant 23).

And others have ensured people were able to create memorials to those they had lost:

“...several adults I work with find it comforting to create a memory box or book about the deceased person and use it to talk about their grief with trusted people. This has been really useful in lots of cases.”

(Participant 51).

Some participants had also provided continued support to individuals over many years:

“...I still meet a service user at the Crematorium on the memorial date of his father’s death and have done this for a number of years as it helps him to remember and lessens any anxieties which can lead to risky behaviours.”

(Participant 64).

The types of support participants have provided people with learning disabilities was seen by both Julian and Kerrie to be positive and of high quality. Reading these responses made both Julian and Kerrie reflect on their own experiences and think about the support they would have liked when someone they loved died. Both felt that having space to talk about the person who had died (especially with their peers in a group), creating a memorial for them, and having support staff who remembered anniversaries and supported them to celebrate them, were exactly the things they have needed and wanted in their lives. However, both Julian and Kerrie felt they would like these things to

be seen as a 'normal' part of their grief supported by their support staff or PAs, rather than something that needs to be managed within a behaviour management system as is implied by participant 64, or by 'other' professionals, such as therapists.

In analysing the way participants have provided bereavement support it was noticed that a lot of the work they had done required the involvement of staff over a long period of time. That is, facilitating a support group and remembering anniversaries requires staff to be involved in someone's life for many years. Of course, it is known that this is necessary for effective bereavement support to be given as grief takes places over many months and years, but Julian and Kerrie felt that having people who are paid to be in people's lives working with them for long periods of time would be rare – especially when thinking about support workers and/or PAs. As a result, they felt that a lot can be learnt from questionnaire participants about how to give effective bereavement support, especially with regards to the importance of relationships and their longevity in people's lives. If support workers and PAs are seen as best placed to provide effective bereavement support they not only need the confidence to give this support, which is supported by the wider learning disability field as well, they need to work with the same people for a significant amount of time in order for this support to be effective:

“In general, I find those adults with good and consistent team of support workers / carers willing to be open about bereavement and grief; cope better than those with inconsistent and / or ever changing support.”

(Participant 51).

6.7.3 Families and Funerals

All questionnaire participants explored how the people with learning disabilities they had supported had been involved in the funerals and memorials of the people who had died in their lives. A number of participants provided historical context to this issue, for example:

“In some early cases the family or management staff excluded the individual with learning disabilities from the death rituals. I have worked in the field a long time so I have seen it change. I remember when people were routinely excluded from

anything to do with the death, not being told, no funerals, nothing. Just left. One day their mum, or whoever, was there, the next they weren't and nothing was said. We all knew, we had to, but we never said anything and people certainly never went to the funeral."

(Participant 66).

This response is in line with that of participant 03 (mentioned previously) who suggested that staff often stop individuals going to funerals because they cause too much upset. These answers were particularly difficult to read for Julian and Kerrie as they resonated with their own experiences of not being able to attend family funerals in their pasts:

Funerals

I remember not being able to go to a funeral. I was a lot younger, but I was an adult. I just wasn't allowed to go. Mum went, but I couldn't. I've never known why.

Kerrie Ford, Analysis meeting, 30th October 2015

Although, these historical reflections were difficult to read, a number of participants did talk about how things have changed and how the people they have supported do go to funerals and memorials now. For example:

"In recent years, things have improved, with more people with LD being involved in funerals"

(Participant 66).

"Most of the individuals I have supported have been fully involved in family rituals"

(Participant 36).

With family members actively engaging their learning disabled relative in the process of arranging the funeral:

“The person arranging the funeral kept in touch with J and myself so J knew what was being done and he was consulted every step of the way so it was done with his agreement and knowledge.”

(Participant 88).

“The individual was involved in the planning and organising of the ceremony, this was really important to them”

(Participant 95).

“...they helped to choose the hymns and the flowers and what to eat afterwards”

(Participant 62).

And support staff providing proactive support at this time:

“...we are committed to ensuring the person with a learning disability is as involved as possible”

(Participant 97).

These responses were interpreted to be positive as they demonstrate how far things have come from the past. The lived experiences of Julian, Kerrie and Lisa confirm participants historical responses to this question, so the responses providing examples of how people with learning disabilities are now not just involved, but actively involved in the planning and organising of funerals is a marked improvement on the past. The proactive actions of support staff in ensuring the individuals they support are involved in these services also shows an awareness of the importance of these rituals in the grieving process that did not exist historically. In exploring this data, the fact that support staff are thought to find providing this sort of practical support easier than providing emotional support was discussed, but in this research it does not appear the two types of support can be separated. From Julian and Kerrie’s perspective, the greatest part of being supported at a funeral after the practicalities of getting there and gaining access to the building, is to do with the emotional elements of grieving in an environment where this is acceptable and expected. Sadly, this research cannot comment further on this issue as participants were not asked for more detail about their experiences of providing support at funerals, but would recommend future research in this area would be useful.

As well as participants talking about individuals with learning disabilities being actively involved in the funeral and memorial services they attended, some also provided details of how the individuals they supported took charge of their own grief around these services:

“...some were invited to attend but chose not to attend”

(Participant 51).

“...they were all invited, but they did a vote and decided not to attend.”

(Participant 50).

Instead choosing to remember those who have died in their own ways:

“...they stayed at home and we planted a tree in the garden. Then we had tea and cake and talked, in the garden near the tree. It was quite beautiful. It’s what Terry would have wanted. It was certainly what we all needed.”

(Participant 50).

“...they were involved in planning their own remembrance wake as they choose not to go to the big family wake and making a memory box etc.”

(Participant 74).

These responses further highlight just how far some bereavement support has come for some people with learning disabilities. Not only have people been invited to services they would have been excluded from in recent history, they have been able to choose whether they would like to attend these services and been listened to. They have also been able to hold memorials of their own, to remember the person they have lost in a way that feels appropriate to them and their own grieving needs. The research community felt that these responses highlight ‘best practice’ when talking about what bereavement support should look like. These responses were also interpreted as portraying a sense of ‘togetherness’ in the support services being discussed. For example, the sentence *‘It was certainly what we all needed’* suggests everyone was

involved and benefited from the way Terry's life was celebrated and remembered by this group of people. There is no 'us and them' implied between the people with learning disabilities and staff in this process, it just describes a group of people who have lost someone important to them who were able to remember and mourn this loss in a positive way.

However, whilst the majority of participants provided positive details of how the people with learning disabilities they worked are actively involved in mourning rituals, some participants did not have such positive stories. Some participants described how individuals were not allowed to attend funerals due to familial wishes:

"In most of the cases they were excluded from all funerals etc. due to the families' wishes"

(Participant 13).

"At times family members do not feel that this is appropriate for them to attend as they believe that this may be "upsetting or distressing" for the individual so they don't invite them."

(Participant 97).

With some families placing individuals into respite care whilst the funerals and other rituals took place:

"...in our service we support a number of people with intellectual disability who have been put with us for respite whilst family members attend the funeral."

(Participant 59).

And not telling their relatives about the death of a loved one until after the funeral had taken place:

"There have been one or two instances when the person with a learning disability has not been informed until after the service."

(Participant 64).

“Additionally, in some cases other family members hid the fact of a death for quite some time with lies”

(Participant 13).

Each of these responses were difficult to read as both Julian and Kerrie had experience of not being allowed to attend funerals due to their family’s wishes, and the author had experience of supporting someone who was excluded from the funeral of their housemate due to the housemate’s family’s wishes. However, it was felt in the research community that each of these responses, which came from support workers, a learning disability nurse, therapist and psychologist, agree that excluding someone from funerals and memorials is a negative thing. That is, not one of the participants suggest that the families have done the right thing by excluding and actively lying to the individual with learning disabilities about these rituals. This highlights the knowledge participants have of the importance of being involved in these rituals and the role they play in the grieving process, whilst also highlighting the real-world challenges support workers and PAs face when trying to support this to happen.

Furthermore, in analysing these responses, the reasons why families may not want their relative with learning disabilities to attend a funeral, such as not wanting to upset them, their concerns about the person’s ability to understand what was happening, the family’s desire to grieve without the responsibility of ‘managing’ the relative with a learning disability, and not wanting to cause themselves upset, were explored. In the context of this research, the data cannot be unpicked in relation to these issues as it was not the focus of the questions asked, but Julian and Kerrie felt that families should allow their relatives with learning disabilities to know their relative has died and give them the choice to attend the funeral or memorial. They felt this should be the case no matter what the family wants; the person with learning disabilities has rights and they can be supported by support staff, who this research has shown are happy and able to provide this sort of support, to attend.

From analysing this data, it seems that for a lot of people with learning disabilities involvement in funerals and memorials has, for the most part, improved drastically from the historical perspective provided at the beginning of this section, but there are still pockets where things could be improved. The tensions between familial wishes, individual need and support requires sensitive and focussed research, which reaches

beyond the scope of the work presented here. The work of the Foundation for People with Learning Disabilities (2013), Tuffrey-Wijne (2013) and others is making strides in this area, but more work does need to be done in order to equip those working in the field with the resources to manage these tensions on the ground. By exploring these tensions in this way will help improve support staff confidence in their abilities to manage these issues when faced with them, as when support staff are confident the support they provide appears to be second to none:

“The people we support are always invited to take part or attend in the process and some accept whilst others want no involvement. Those that do are supported by staff throughout the ceremonies so that the family members can concentrate on what is happening on the day. For the friends and staff that they have lost this normally entails them going to the service and the wake. Some want to purchase flowers and we have had some that have wanted to say some words about the person that has passed, they are supported in whatever they want to do”

(Participant 06).

6.7.4 Being Involved Vs Not Being Involved

As has been alluded to throughout this chapter, the notions of professionalism, boundaries and relationships were raised by questionnaire participants. Interestingly, the way in which these issues were alluded to by participants who were not support workers differs greatly to those who were support workers. For example, a number of questionnaire participants who were not support workers wrote openly about emotionally engaging with individuals who are grieving with no caveats placed on what was being said:

“Generally it’s been about acknowledging the grief, having conversations about how they’re feeling, sharing my experiences of grief, offering support, following up and checking in. Conversations come up again later (weeks and months) and we revisit topics again.”

(Participant 35).

Whilst those who were support workers alluded to not wanting to engage in this way with the people they support because doing so would be seen as 'unprofessional':

"I try not to get too involved though. It's hard not to, it's human to want to get involved, but I try to keep my distance. It's hard though, I think. It is difficult as we are not trained in counselling and I feel this is what the individual needed. It is very hard to establish at times how they were really feeling. That's why they need a counsellor to work that out."

(Participant 22).

The difference between these two participant responses emphasises the points made in sections 6.6.3 and 6.7.1 and in *Chapter Five* about how being 'professional' is seen and embodied by support workers and others working in the learning disability field.

For example, in participant 22's response they imply that getting '*too involved*' with the people they support is something they are not allowed to do. They do not explicitly say why this is the case, but their response can be interpreted to mean that they felt they are not allowed to get '*too involved*' as this is not part of their role. They seem to view, being '*too involved*' as something only trained counsellors (and other 'professionals') can do, so support workers have to keep their distance in order to be 'professional' within their role. Yet in contrast, their response is full of words which highlight the difficulty they have with following this 'professional' rule. For example, they frequently use the words '*hard*' and '*difficult*' to describe what they are talking about, which suggests they struggle with what they feel is the 'right' thing to do and what is the 'professional' thing to do. Discussing this issue in this way, makes this participant appear confused, uncertain and lacking in confidence about their role and what they feel about it. Conversely, participant 35's response comes across as confident and secure in the role they have the work they do. This participant is a therapist, who does not question what is the 'right' or 'wrong' in their practice and does not place a caveat on their mentioning of engaging emotionally with individuals they support.

From exploring this data, and the data within sections 6.6.3 and 6.7.1, it seems that participant support staff lack the confidence to provide bereavement support to people with learning disabilities, but that this lack of confidence is in part caused by the 'professional hierarchy' within the field and the notion of what is deemed to be

'professional' conduct at different levels of this hierarchy, which is embodied by those working in the field. However, in contrast to this, a number of 'other' professionals involved in this research appear to feel that support staff really are the best people to provide bereavement support in the first instance as they know people well and are often centrally located within their social support networks. Yet, these professionals seem unable or unwilling to share the knowledge they have with these support staff to help them gain the skills and confidence to provide this support. The support staff involved in this research appear to be acutely aware of the dynamics at play in the workforce, as the role they currently have appears to go against their natural instincts to engage with emotional support when issues of grief and bereavement arise. They seem to resolve this internal conflict by assigning blame for their lack of emotionally engaging with the people support on the tangible issue of training. Participants were directly asked about this issue in the questionnaire, and their responses are explored in the following section.

6.8 Bereavement Support Training

As with the interview participants, the final set of questions questionnaire participants were asked related to whether they had received any grief and bereavement training in relation to their work. Thirty-three participants had (four were support workers, six were managers), ten hadn't (one was a support worker, eight were managers), and one wasn't sure. It is interesting that the majority of those who had not received any training are those working in the frontline of services for people with learning disabilities, whilst those in other 'professional' roles had received such training.

6.8.1 Those who had Received Training

Of the thirty-three participants who had received some grief and bereavement support training, the majority (twenty-five participants) had done this training before they had had to provide anyone with a learning disability with any bereavement support in practice. Of these only one support worker had received this training at this time, but five of the managers had. Three undertook their training at the same time as having to provide bereavement support in practice (including one support worker), whilst the

remaining five participants received their training after they had had to provide bereavement support in practice (including two support workers and one manager). The content of the training these participants had received was varied and included a range of general grief and bereavement theories, grief and bereavement theories as they relate to people with learning disabilities, practical tips on how to provide bereavement support to people with learning disabilities and links to resources.

Due to the thorough nature of the grief and bereavement training these participants had received, it is unsurprising to find that twenty-eight of the thirty-three participants felt it was useful to their work (including four support workers and four managers), and four thought it was partially useful (including one manager). However, one participant, a service manager wasn't sure if it the training had been useful or not.

6.8.1.1 Enabling Practice with Confidence

The twenty-eight participants who found the grief and bereavement training they had received useful provided some qualitative detail to this response. Generally, the training was seen as useful, because it had given informative and practical advice participants could utilise:

“Thinking about concrete ways to support people, such as memory box. Access to websites with accessible grief booklets. Thinking about ways in which grief might manifest differently in this population.

(Participant 79).

Or allowed them to develop their confidence in dealing with grief and bereavement issues in their work:

“...development of skills over time adapting general approaches and grief theories with confidence to meet individual need.”

(Participant 73).

“It has enabled me to practice with confidence”

(Participant 23).

Several participants also suggested that the training they had done allowed them to take the time out of their everyday working lives to think about how unique death, grief and bereavement experiences are and think about how to apply this to the people with learning disabilities they support:

“As grief is unique to each individual it cannot be really trained, it’s about the level of empathy that you can reach as a worker. The best part of the training was learning about anticipatory grief and how that effects people with an intellectual disability. Having the time and space and time to think about this was really helpful”

(Participant 08).

Two participants who received their grief and bereavement training after having to provide this support to people with learning disabilities, highlighted how useful this training was due to its bespoke nature:

“Bespoke and we were able to reflect on our own experiences and those of the people we support. This is was really helpful, having this time to think and talk together made me think about how I would do it again...I hope I don’t have to, but I feel better about it now if I do.”

(Participant 61).

These last two quotes resonate with the findings from the interview data (*Chapter Five*) around the issue of how to provide effective training to those working at the frontline of services. Providing individualised, bespoke training which allows attendees to reflect on the way they work seems to be a vital element of such training from the view point of those who attend. This will be discussed in greater detail in *Chapter Seven*.

6.8.1.2 Not the Right Audience

The five participants who found the training they had done to only be ‘partially’ useful or ‘weren’t sure’ if was useful (including two managers), stated this was because it was not tailored to people with learning disabilities:

“It was not really aimed at helping young people with limited verbal communication skills”

(Participant 62).

Which led some participants to taking what they were told in training and adding to it with their own research in order to make it applicable to their work:

“I took what I learnt and explored the subject myself. With my experience of working with people with LD's I created my own response toolkit, but due to my workload this has been hard work and the toolkit is still in development. I hope it will be useful to other people as well as me when I do get it finished.”

(Participant 29).

Although this is not a good situation to be in, as training should be targeted to the right audience, these responses highlight how engaged the people who have taken part in this research are about improving bereavement support for people with learning disabilities. They are willing to spend time in their busy working lives to do their own research and develop toolkits for themselves and others working in the field.

6.8.1.3 Resources, Information and Sharing

Although only twenty-eight of the thirty-three participants who had received training said that this training had been useful, when all thirty-three were asked whether they had used any of their training in their work, thirty-two of them said they had. The one participant, a manager, who wasn't sure whether the training they had received had been useful was the one who had not used anything from the training in their work.

Participants had used a variety of practical elements from their training, such as:

“Some good resources, especially online have been used.”

(Participant 14).

“Using pictures to explore feelings.”

(Participant 83).

“The pictures/creative activities etc. as a communication tool if appropriate can be useful”

(Participant 23).

Whilst others had applied their altered understanding of grief and bereavement issues to help support the people with learning disabilities they worked with:

“To support someone in their bereavement I need to step back and let them grieve in their own way. We cannot put our beliefs into the situation.”

(Participant 88).

“...allowing the person time to talk about how they are feeling and reassuring that it is ok to be upset and support during periods of tearfulness.”

(Participant 73).

And some participants had used their new knowledge to educate others:

“Encouraging parent/carers to talk about impending loss/loss with service users, encouraging them to be part of the process to some extent to prepare them for the inevitable and enabling them to grieve which is a painful but normal process rather than trying to protect them from it which can lead to confusion.”

(Participant 38).

“Used information to assist others (without learning disabilities) to understand 'normal' process of grief”

(Participant 72).

Whilst others had used their training in a number of ways:

“Since the training the people we support have lost a housemate as well as some of them losing family members and we have been able to support them in whatever way they needed. Once person who lost their Dad was supporting to attend the family’s funeral and wake with staff support even if she appeared not to understand another was supported in the house and although informed didn't

show any understanding of what had happened but we documented anything that could have signs of grief such as increased behaviours around the time. All the people we support had involvement in losing their housemate as he was a large character and loved by all. Everyone was offered the opportunity to help with the ceremonies in some way if they wanted and to talk about the person in a way they wanted. Even after the ceremony was finished we had a tree planted and his ashes spread on the grounds and those that wanted to help again did.”

(Participant 06).

The breadth and depth of the way participants describe how they have used their training highlights just how useful training can be in increasing the confidence, skills and abilities of those employed to support people with learning disabilities through periods of grief and bereavement. However, as so few of the participants who have received this training were support workers or PAs this could be an indicator as to why so few members of this workforce feel confident enough or able to provide bereavement support to the people they work with day to day. In addition, this situation further highlights the prevalence of the ‘professional hierarchy’ of roles within the learning disability field as support services do not appear to see investing in bereavement support training to be of importance for support staff as this is the job of another ‘professional;’. This is in spite of support staff calling for this training if it is effective.

6.8.2 Those who had not Received Training

Of the ten participants who had not received any grief and bereavement training (one support worker and eight managers) and the one participant who wasn’t sure if they had received any training, all eleven wanted to receive some training in this area.

When asked what they would like this training to consist of, they wanted to receive training that included information about general grief and bereavement theories, grief and bereavement theories in relation to people with learning disabilities, tips for providing bereavement support and resources to use when providing this support.

In addition, two participants wanted to include ‘other’ elements in their training, such as:

“...bereavement and ethnicity in the field of learning disabilities.”

(Participant 51).

Combining this list with the elements of training that have been successfully used by other questionnaire participants and the ideas discussed by interview participants (*Chapter Five*), may provide a good basis for the development of a training programme for support workers and PAs. However, this training would need to be bespoke to the needs of the individuals receiving it and carried out in parallel to alterations within the field more generally to improve the hierarchy. This will be discussed in greater detail in *Chapter Seven*.

6.9 Summary

This chapter has explored the data collected from the online questionnaires which ran from July to August 2015. The participants who completed this questionnaire varied from the support workers and PAs it was intended for, with only five support workers completing it, along with a variety of nurses, psychiatrists, social workers and therapists. It is unclear why, so few support workers and no PAs completed the questionnaire, but the wider literature suggests that this may be due to the long antisocial hours they work (Michie and Williams, 2009), which can be assumed to decrease their interest in engaging with a work-related questionnaire online outside of their working hours (England, 2005; Kittay 2001). Additionally, the questionnaire being run over the summer months (July to August) may have had an impact on responses as many potential participants may have been on holiday, and the questionnaire may not have been distributed as widely or as targeted as thought by the research team. Piloting the questionnaire for a short period of time might have helped highlight these issues to the research team and would be recommended to studies in the future, but due to the short period of time available was not possible in this research. As a result, a rather different group of participants completed the questionnaire, but their rich and diverse responses have echoed and added to those of the interview participants to strengthen this research's findings.

Analysing the questionnaire responses has further highlighted the impact the notions of 'professionalism', and 'professional hierarchy' has on the learning disability workforce.

Questionnaire participants who were support workers expressed a lack of confidence in their ability to provide bereavement support appropriately, blaming their lack of emotional engagement on the tangible issue of 'lack of training' and deferring to other 'professionals' to provide this support as result. The questionnaire participants who worked in these 'professional' roles expressed judgements upon the lack of support, support workers give to people with learning disabilities when they are grieving, as they know that they are the best people to provide this support. However, none of these participants discussed ways of sharing their knowledge with support workers and/or PAs in order to improve this situation in their responses. Furthermore, it is notable that participants who worked in other 'professional' roles did not express any self-doubt or question their ability to provide bereavement support, they just described what they do. They did not place caveats on the emotional and physical support they gave people in their responses, nor did they mention issues surrounding the 'appropriateness' of their conduct. This is in stark contrast to the way both questionnaire and interview participants who were support workers or PAs (*Chapter Five*) explored these issues.

Questionnaire participants were asked directly about their experience of receiving bereavement support training during their careers, with those who had received such training providing confident responses to the questions about the support they had given people with learning disabilities. Interestingly, however the majority of participants who had received this training were 'other professionals' and not support workers. This finding highlights a key message to come from this data regarding the 'professional hierarchy' within the learning disability workforce as it suggests that support services do not see bereavement support training to be of importance to support staff as this is the job of another 'professional;'. This is in spite of support staff calling for this training if it is effective. Whilst the data collected in this phase of the research cannot be said to be representative of the learning disabilities workforce as a whole, due to the self-selecting nature of the participants, this finding goes some way to explain, for these participants at least, why those working in 'other' roles appear more confident in their ability to provide bereavement support to people with learning disabilities.

As a result of the analysis presented in this chapter, the issues of professional identity, hierarchy and confidence within the learning disability workforce and the dynamics at play between the different 'professions' in this field, are key elements to understand in relation to why bereavement support for people with learning disabilities in the UK is in

the state it is currently in. This will be explored, in line with interview data (*Chapter Five*) in *Chapter Seven*.

Chapter 7

Discussion

7.1 Introduction

This chapter discusses the findings of the research presented in Chapters *Five* and *Six* in relation to the literature reviewed in *Chapter Three*. This discussion is framed by the research questions that have guided this research.

Discussion begins with a reminder of these questions, before moving on to discuss how they have been ‘answered’ by the findings of the research. Throughout this discussion, the study’s underpinning theories; The Dual Process Model of Grief (Stroebe and Schut, 1995), the Social Construct Model of Disability (Barnes, 2003), and Care Worker Theory (England, 2005) will be used to explore the data.

7.2 The Research Questions, Aims and Objectives

7.2.1 *The Research Questions*

As discussed in Chapters *Four* and *Six*, the concurrent data collected in this research was guided by the following research questions:

1. How do support workers and PAs view the bereavement support they have provided someone with a learning disability?
2. What does providing bereavement support to someone with a learning disability involve?
3. Do support workers and PAs receive training to provide bereavement support to people with learning disabilities?
4. What impact does providing bereavement support to someone with a learning disability have upon support worker and PA emotional and mental health?
5. Do support workers and PAs have any thoughts about how bereavement support for people with learning disabilities should be done in the future?

Whilst the data collected in the two stages of data collection; participant interviews and the online questionnaire, was gathered from different sources; support workers/PAs and a range of other professionals from the learning disability field, the main focus of the research was upon the experiences of support workers and PAs. That is, the research aimed to understand, from the viewpoint of those working in the learning disability field, what providing bereavement support to people with learning disabilities involves for support workers and/or PAs, what impact providing this support has upon them as workers, what training, if any, they had received and their recommendations for the future.

7.2.2 Aims

As the discussion above suggests, the research presented in this thesis aimed to explore the phenomenon of bereavement support for people with learning disabilities from the view point of support workers and PAs in the UK. It further aimed to uncover what skills these support workers and PAs utilised when providing this support, where they learnt these skills, what impact this support had upon their own emotional and psychological health, as well as their sense of professional self.

The study also aimed to highlight how support work in the field of learning disabilities is changing by exploring how the personalisation agenda is affecting everyday support work through an examination of how bereavement support is done in different support settings; residential care homes, supported living facilities and those employed under Personal Budgets or Direct Payments (CCDA, 1996).

Additionally, the study aimed to provide support workers and PAs with a voice in the literature through their 'employment' within an inclusive participatory research study. As noted by Needham (2008), 'staff on the frontlines of public services are recognised to have a distinctive voice and expertise as a result of regular interaction with service users' yet they are often marginalised within the research literature (p.222/3).

7.2.2 Objectives

In order to achieve these aims, the research had three objectives:

1. To explore the phenomenon of bereavement support from the perspective of the support workers and PAs who provide it in the UK.
2. To involve and listen to support workers directly within an inclusive participatory research model.
3. To involve and be guided by the lived experiences of a group of people with learning disabilities within an inclusive participatory research model.

Before discussing how the findings of this research have begun to answer its overarching research questions and, in turn, meet its aims and objectives, it is felt important to explore, in greater detail, the impact the concurrent approach to data collection had upon the research findings and how this is dealt with in the remainder of the thesis.

As has been discussed in previous chapters of this thesis, this research aimed to explore the phenomenon of bereavement support for people with learning disabilities from the viewpoint of support workers and PAs in the UK who provide this support. Both phases of data collection (interviews and online questionnaire) were advertised to these populations via the same outlets (Appendix 8 and 27) based upon the advice of the co-researchers with support experience within the research community, but very different populations selected themselves to complete the online questionnaire. That is, whilst the recruitment information (Appendix 29 and 30) and 'landing page' information (Appendix 31) for the questionnaire stated who it was intended for, thirty-nine 'other' professionals such as learning disability nurses, therapists, counsellors, and psychologists chose to fill it in along with only five support workers. No PAs chose to complete the questionnaire. This is an interesting finding for two reasons. Firstly, it might highlight that support workers and PAs do not engage with online questionnaires as a way of sharing their stories. It is likely that support workers and PAs saw the request for questionnaire participants as the same mediums for recruitment were used for interview participants (Appendix 8 and 27), yet only five chose to follow the link and complete the questionnaire (there may have been more who looked at the link but did not continue with the questionnaire. The research team have no way of knowing whether this was the case from the data captured).

There are many reasons why support workers and PAs may not have engaged with the online questionnaire. For example, the literature suggests that support staff work long,

anti-social hours (Michie and Williams, 2009) so spending time outside of these hours filling in a questionnaire about work may not be something they want to do, especially as many support staff are women who fit their working life around their busy family lives (*Chapter Five*; Kittay, 2001; England, 2005). Completing the questionnaire outside of working hours is likely to have been the only option available to potential participants as support staff have fast passed roles which do not afford them the time to utilise workplace computers (if there are any) for anything other than to complete their daily notes (if required) (Burton, 1993). This situation not only leads to any online research participation encroaching on their personal time, it also requires them to use their own devices to participate. Due to the low incomes many support staff have (England, 2005), it is possible that the devices they have access to at home might also be a determining factor in their decision not to complete the questionnaire online. That is, it is likely that many support staff only have access to Smartphones and/or Tablets at home which really are not conducive to completing questionnaires which require a substantive amount of typing, due to their small screens and keys. Additionally, the literacy of support workers and PAs might have had an effect on their lack of engagement with the questionnaire. The literature suggests that a large number of the support worker and PA workforce have low educational attainment (Brown-Wilson, 2017), which may have had an impact upon their ability, or perceived ability, to complete a questionnaire online with the details they would like to provide. From the participants interviewed in this research (*Chapter Five*) the educational attainment of some support workers and PAs is much higher than this literature would suggest, but our sample was a small, self-selecting, purposive one which is not representative of the wider workforce (Brown-Wilson, 2017). Furthermore, from the interviews carried out in this research, the bereavement support experiences of support workers and PAs are complicated and require a lot of discussion. To be able to get these details across in a written response would require the participant to have a great deal of confidence in their ability to communicate these details in a written format. It is therefore possible that a combination of these factors led to so few support workers and no PAs completing the questionnaire online.

However, thirty-nine 'other' professionals did complete the questionnaire, which leads to the second reason why this finding is an interesting one. As previously noted, the questionnaire was advertised via outlets specifically targeted at support workers and PAs (Appendix 8), which stated that it was intended for support workers and PAs. However, these 'other' professionals felt it was appropriate for them to complete the

questionnaire anyway. This seems to suggest that the wider learning disability field acknowledges that bereavement support is an issue which needs attention and greater understanding. Each of these 'other' professionals wanted to tell the research about their experiences, in great detail, which can be interpreted as a positive endorsement of the research. These professionals' choice to share their experiences via an online questionnaire, rather than coming forward in the interview phase, which it is presumed they will have been aware of due to the same advertising channels being utilised (Appendix 8 and 27), can also be seen to highlight the different resources available to those working in different areas of the learning disability field, such as time and access to IT.

In reflecting on why support workers did not engage with the online questionnaire whilst 'other' professionals did, the team considered whether rigorously piloting the questionnaire with support workers and PAs prior to going 'live' online might have altered this outcome. That is, would piloting the questionnaire have led to the questionnaire being administered differently, such as via targeted emails or post, or the method not being used at all? In reflecting on this question, the research team felt that whilst running a pilot with the target population may have been beneficial, and is recommended to future studies, doing so would not have necessarily safeguarded against the outcome in this research and may in fact have limited the data collected. That is, running a pilot of any data collection method is both time consuming and costly; two commodities this research was not rich in due to it being a self-funded PhD study, so doing so would have limited the time available to collect data from participants. However, if the research were to be done again a pilot would be undertaken and is recommended to other researchers.

Although piloting is recommended to ensure data collection methods are fit for purpose and will elicit responses from intended participants, the data collected from the unpiloted online questionnaires in this research has been invaluable. The data this method elicited from a broad mix of participants spoke to the research's central questions (above) and added rich contextual information about the provision of bereavement support for people with learning disabilities in the UK that would not have been gathered otherwise.

As a result, the research team conclude that the choice to use an online questionnaire for the second phase of data collection in this research was the right thing to do within

its timescales, financial limitations and aims (Wright, 2005). However, they would recommend piloting data collection methods to other research, especially if considering online questionnaires to elicit responses from support workers and/or PAs. Piloting would be recommended for future studies.

7.3 How do Support Workers and PAs view the Bereavement Support they have Provided Someone with a Learning Disability?

The academic literature relating to the bereavement support, support workers and PAs provide people with learning disabilities presents two opposing views. The first, and seemingly dominant view, is that whilst support staff accept that people with learning disabilities grieve at the time of bereavement (Reynolds *et al*, 2008), they are not best placed to provide the support needed at these times as they are often unable to identify the impact this bereavement has upon people with learning disabilities (Arthur 2003; Read and Elliott, 2007; Gilrane-McGarry and Taggart, 2007; Blackman, 2008). These findings are suggested to provide an explanation for Read and Elliott's (2007) finding that bereavement support for people with learning disabilities in the UK 'is at best inconsistent and at worst non-existent' (Read and Elliott, 2007, p.177), as this lack of support staff awareness can lead to cases of 'diagnostic overshadowing' (Gentile and Hubner; 2005; Dowling *et al*, 2006), people being denied the knowledge of a loved one's death and the associated mourning rituals (Forrester-Jones, 2013, Heslop *et al*, 2014; Mason and Dowling, 2016) and the resulting cases of complicated grief (Summers and Witts, 2003; Dodd *et al*, 2008).

The second, and somewhat contrasting view, presented by a burgeoning body of literature, suggests that support staff are able to identify the impact bereavement has upon the emotional lives of the people with learning disabilities they support, but are unable to provide all the support they need as they are let down by the resources available to them in the services they work for (Mencap, 2007 and 2012; Gilrane-McGarry and Taggart, 2007; Ryan *et al*, 2010; Handley and Hutchinson, 2013; Heslop *et al*, 2013).

The findings of the research presented in this thesis fall in line with this second view in the wider literature, as the support workers and PAs involved were all engaged and

passionate about the issues surrounding bereavement support for the people with learning disabilities they worked with, but suggest they have been let down by the organisations they work for when it comes to providing this support. However, it is important to note that these participants may not be representative of the wider learning disability workforce due to their self-selected nature (please see *Chapter Nine* for a discussion of this issue).

All of the participant support workers and PAs in this research, acknowledged that grief is a multifaceted issue and for many people with learning disabilities with both material and emotional affects, which need to be considered in the support that is provided. For example, a number of participants discussed the fact that for many people with learning disabilities the deaths they experience in their lives often lead to material losses or changes in their lives, such as having to move out of the family home or having a new house mate move in after the death of the previous tenant, as well as the emotional loss they experience. This finding suggests that participant support workers and PAs view bereavement support for people with learning disabilities through the Dual Process Model of Grief (Stroebe and Schut, 2001) lens, as they understand that this support needs to incorporate both the material and emotional responses to bereavement.

7.4 What does Providing Bereavement Support to someone with a Learning Disability Involve?

Throughout the data collected in this research, participant support workers and PAs described providing both exceptional material and emotional support to the people with learning disabilities they work with. The data is littered with examples of tailored bereavement support that focuses on the needs and desires of the individual, providing them with the space, time and information needed to make sense of what had happened, in a compassionate and empathetic manor.

Participants talked about providing the practical elements of this support, such as taking people to funerals, creating memory boxes and developing memorials, positively. They appeared proud of the work they have done and keen to share their experiences with the research. However, when talking about providing the more emotional elements of this support, participants described feeling unsure, inadequate and unsupported in

providing this type of support. For example, a number of participants talked about the need for '*proper professionals*' (Jessica, interview participant) to be brought in to provide bereavement support because this was not their role and they were not trained to provide such support.

From the analysis of the data in this research, it is argued that providing the practical elements of bereavement support that participants describe are not done in isolation from emotional support as it is likely that people will become emotionally engaged whilst going to funerals or creating memorials. However, it must be acknowledged that this is not how participants themselves interpret this. Participants appear to view the emotional elements of bereavement support, such as sitting and talking about feelings of loss in isolation of an activity, as something that needs to be done by '*those trained to do so*' (Hannah, interview participant). This situation is assumed to have been caused for Hannah, and other participants, at least in part by the legal frameworks (HMSO 2014; Skills for Care for Health, 2013) and organisational policies which govern their work. These overarching frameworks state that adult social care workers, must remain bounded from such emotive elements of their role (point 6, Skills for Care for Health, p.3) and refer individuals to those able to provide this support (such as therapists and counsellors) should they need it.

The impact of the legal and organisational frameworks which govern support work in England was a common theme in both the interview and questionnaire data collected in this research. In addition to the direct call for 'other' professionals to undertake the emotional support required when someone with a learning disability suffers a bereavement, a number of interview participants also alluded to not wanting to '*get too close*' to those they worked with. This could include placing a caveat on what they said to make sure it was recorded that they were not getting '*too close*' to these individuals. Additionally, the PAs that were interviewed (who did not work for services) also alluded to the frameworks which govern support staff by expressing concern for the limited reach they had to those working in their roles. Interestingly, both the PAs that discussed this point in their interviews had previously worked for services and had left due to the impact they felt the legal (HMSO, 2014; Skills for Care for Health, 2013) and organisational policies that governed their role had upon their ability to do their jobs. Interestingly, these are the same frameworks and policies they were calling for in their new roles in order to feel secure.

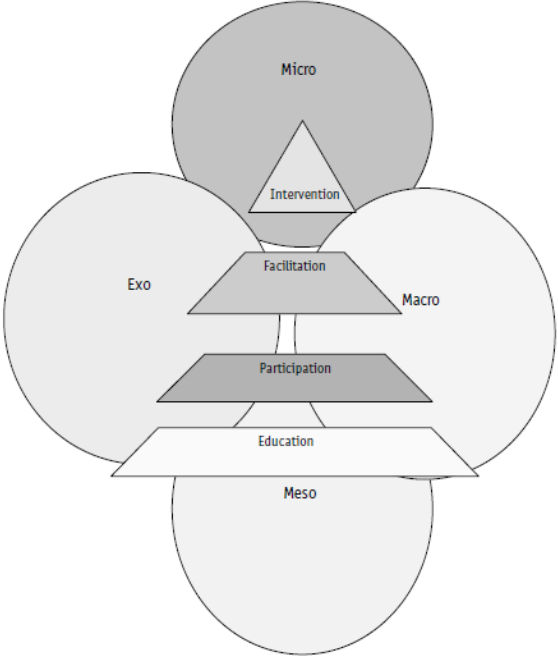
For questionnaire participants who worked in 'other' roles in the learning disability field, they also alluded to the impact the legal frameworks (HMSO, 2014; Skills for Care for Health, 2013) and organisational policies had upon the bereavement support provided by support workers and/or PAs to people with learning disabilities. For example, a number of these 'other' professionals were critical of the work support workers and PAs do, whilst also expressing their frustration at what they viewed as being too many people with learning disabilities being referred to therapeutic services due to the lack of support they receive at home. These findings appear to contradict one another as they suggest that 'other' professionals in the learning disability field do not think that support staff have the knowledge, skills or ability to provide bereavement support, whilst also suggesting that these staff really are the ones who should be providing this support, not specialist services.

This insight into the way bereavement support is done and experienced by participants who have worked in different areas of the learning disabilities field, presents a confused and hierarchical picture which have perhaps arisen from the embodiment of the frameworks which govern the field by those employed within it (HMSO, 2014; Skills for Care for Health, 2013).

As discussed in *Chapter Three*, both the Care Act (2014), and the Code of Conduct (Skills for Care for Health, 2013) which govern the role of support staff in England, appear to have taken their stance of ensuring that support staff remain boundaried from those they support from the wider literature which suggests that engaging in emotionally taxing tasks is likely to cause high levels of work related stress and increase staff turnover (Bloom, 2005; England, 2005; Handley and Hutchinson, 2013; O'Driscoll, 2015, and Skills for Care, 2017). Rather than the literature which suggests that being a supporter is a social relationship, and that by denying those providing this support with the autonomy to engage with the emotional elements of this role may cause the same work related stress and increased turnover that it was trying to avoid (Kittay, 2001). When applied to the specific context of providing bereavement support, these frameworks also fail to acknowledge Read's (2005) work which suggests that for bereavement support to be consistent and effective for people with learning disabilities, a variety of people may be required to provide this support at different times; including support workers and/or PAs. Read's (2005; Read and Elliott, 2007) model of

bereavement support for people with learning disabilities sets out four different levels in which this support can be delivered, as shown Figure 3.

Figure 3. Read’s Model of Bereavement Support for People with Learning Disabilities



(Read and Elliott, 2007, p. 178)

Support staff fall into the Meso level of this model, which Read and Elliott (2007) suggest needs to interact with the Exo level (National organisations and initiatives) and Macro level (the organisations they work for and the other organisations providing support, including specialist counsellors) to feel confident and comfortable with providing bereavement support to people with learning disabilities when it is required.

The findings of the research presented in this thesis add weight to Read’s model (2005; Read and Elliott, 2007), as support staff have been found to play a pivotal role in the provision of bereavement support for the people with learning disabilities on a daily basis, yet question their ability to provide this support due to their role’s interaction with the Macro (organisational policies and ‘other’ professionals) and Exo levels (Care Act (2014) and Code of Conduct (Skills for Care for Health (2013)) of this supports

provision. The data collected from 'other' professionals in the online questionnaire reinforce this finding.

Not only is this situation causing participant support workers and PAs to lack confidence in their abilities to provide bereavement support, it is also causing them suffer a crisis of professional identity and, in a bid to rectify the turmoil this causes them, to construct the identity of the people with learning disabilities they support within the Medical Model of Disability (WHO, 1980; Oliver, 1996). That is, within the interview data, support workers and PAs appear to see people with learning disabilities as either unable to understand the issues that surround death, dying and bereavement, or are able to understand these issues in spite of having a learning disability. This is an alarming finding, which is explored further in the following section.

7.5 What Impact does Providing Bereavement Support to Someone with a Learning Disability have upon Support Worker and PA Emotional and Mental Health?

The Commodification of Emotion Framework (England, 2005), suggests that due to the rise of capitalism in the market place, a number of employees in a variety of sectors are regularly asked to 'perform' different emotions to the ones they are feeling inwardly. This framework has been developed from Hochschild's work (1983), which suggested that in emerging capitalist markets, workers use their ability to perform the emotions that a job requires, whilst feeling something completely different, as 'currency' in the workplace (Fischer, 2009).

When this framework is applied to the provision of bereavement support for people with learning disabilities in the UK, it appears that for the participant support workers and PAs they are 'performing' different emotions to the ones they are feeling, due to their role's interaction with the legal frameworks (HMSO, 2014; Skills for Care for Health, 2013) (Macro level) and organisational policies which govern their work (Meso level). As described in the previous section, participant support staff are able to describe the exemplary bereavement support they have provided people with learning disabilities with compassion and empathy, whilst also expressing doubt in their ability to provide this support correctly.

This is an alarming finding for two reasons. Firstly, it appears to be causing a number of participants to experience cognitive dissonance, which if left unsupported the literature suggests will lead to high work-related stress levels and staff turnover (England, 2005). This was made explicitly clear by Alan, an interview participant, who had been forced to retire early from the supported living service he used to manage due to the emotional impact having to perform different emotions to the ones he was feeling for the five deaths he experienced in his service within a year, had upon him. And Dom, another interview participant, who spent most of his career as a support worker ‘*boxing...up*’ his emotions until this became too much and he left the field completely.

Secondly, as has been introduced in *section 7.4*, the cognitive dissonance the support workers and PAs involved in this research appear feel is often expressed in conversation as an ‘othering’ of people with learning disabilities and their ability to comprehend grief and bereavement. This not only puts support workers and PAs at risk of being viewed as holding Medical or Individualised Model of Disability (WHO, 1980; Oliver, 1996) views about those they support, but is also likely to perpetuate the situation which led to the creation of the legal and organisational frameworks in the first place.

When each of the factors discussed in the last three sections (7.3, 7.4, and 7.5) are combined a complex picture is created, which offers new insight into the reason why bereavement support for people with learning disabilities ‘is at best inconsistent and at worst non-existent’ in the UK (Read and Elliott, 2007, p.177). That is, from the data collected in this research it appears that the legal frameworks which govern support staff and state they must remain boundaried from those they support sits juxtaposed to the realities of the work they do and in conflict with the model of bereavement support for people with learning disabilities that Read proposes (2005; Read and Elliott, 2007). These frameworks create a division in the workforce between those who can provide emotional support to people with learning disabilities (such as specialist counsellors) and those who cannot (support workers and PAs), which has been embodied by the workforce involved in this research to the detriment of their confidence and professional identity. The support the people with learning disabilities they have worked with is also likely to have suffered as a result of this situation, as a number of participant support workers and PAs have looked for, but have been unable to find, specialist bereavement counselling for those they support (Royal College for Psychiatrists, 2004 and 2006). If

this situation is widespread within the sector then it starts to become clear why many people with learning disabilities in the UK are left with little or no support when they suffer a bereavement. Not only does this have a negative effect on those involved, it can also be suggested to have an effect on how wider society views people with learning disabilities as able individuals who do understand the complexity of death, grief and bereavement and should be afforded the ability to take control of their bereavement support needs.

7.6 Do Support Workers and PAs Receive Training to Provide Bereavement Support to People with Learning Disabilities?

The issues of bereavement support training for support staff was one of the key drivers to this research being undertaken. Much of the literature available in relation to bereavement support for people with learning disabilities is self-serving in that it ‘tests’ out a particular training model (Dowling *et al*, 2006; Reynolds *et al*, 2010), or recommends that such training is implemented as a result of its work (Oswin, 1991; Read and Elliott, 2007; Blackman, 2008; Handley and Hutchinson, 2013; O’Driscoll, 2015).

However, this research, whether testing out a model or recommending one, is based upon limited empirical evidence that such training is either wanted or useful to those undertaking it. It is also based upon the premise that there is an inherent belief system which all of society assigns to and that this is the ‘right’ system to use to support someone with a learning disability; a situation that the wider literature states is not the case (Nagraj and Barclay, 2009).

The data collected in this research suggests that support workers and PAs are not given bereavement support training as a matter of course. The reasons for this are unknown, but it may be due to the interaction their role has with the Exo and Macro levels of Read’s model of bereavement support for people with learning disabilities (2005, Read and Elliott, 2007) (the organisations they work for and national policies and standards). That is, as the legal frameworks (HMSO, 2014; Skills for Care for Health, 2013) which govern the role of support staff and are embedded in organisational policies, expect support staff to remain boundaried from the emotional elements of their role, then training and

supervision for this type of work is not going to be invested in by support organisations. Especially within the austere context in which this research was carried out, where services are unlikely to be investing in training that is not statutory for its workforce (Equality and Human Rights Commission, 2017).

For the staff in this research who had received some bereavement support training their experiences of this were mixed. For some the training had been useful as it provided them with the knowledge they wanted about models of grief and the way some people might react. However, these positive experiences were limited, as the majority of participant support workers and PAs, either felt that the training was not relevant to the people with learning disabilities they supported or did not provide them with anything useful to put in place whilst at work. Another issue that arose out of this data, was the fact that for these participants they weren't sure if they had used anything from the training session at work. The reasons for this are unknown, but are felt to possibly be due to the fact the training sessions were done in isolation to the participants practice, took place on one day, with no refresher or updates.

7.7 Do Support Workers and PAs have any Thoughts about how Bereavement Support for People with Learning Disabilities Should be done in the Future?

In line with the training experiences participants had, a number of them recommended that training for staff was essential. This is an interesting finding when considered in light of the experiences these staff have and may in part be due to their desire to be seen to be doing the right thing professionally. However, when staff were encouraged to expand on this suggestion it became clear that participants were not recommending training like that which they have received or is cited in the literature.

Participant support workers and PAs, recommend that all support staff receive training about bereavement support that is tailored and appropriate to their place of work. Participants were explicit in their recommendation that this training should not be done online at any cost, as this is too emotive a subject to be carried out in this way.

Participants suggest that training should cover models of grief and the processes that people might go through when they have suffered a loss, before moving on to specific issues that might be faced within the participants place of work. This second element of the training is suggested by participants to be carried out in situ to ensure the trainer tailors the training precisely to the place in which it is likely to be carried out.

Participants also requested that this section of the training provide them with a 'box of tricks' to use in the future.

Participants recommended a third element to the training, which allowed them as individuals to reflect on their own emotions around the issues that can brought up when providing bereavement support. This element arose as a result of the participants being involved in the research where they were provided the space and time to talk about these issues. A number of participants commented that going through this process allowed them to develop as support workers or PAs and gave them confidence in their abilities.

In light of the discussion presented in *sections 7.3 to 7.5*, this last element of the training recommendations is of paramount importance as if support workers and PAs are more confident in their abilities then changes may begin to be seen in the prevailing governance culture of learning disabilities support services.

Finally, it is important to note that the importance of effective training being implemented to improve bereavement support for people with learning disabilities, is also of paramount importance to people with learning disabilities themselves. As Chloe, an interview participant, suggests that the people with learning disabilities she works with are working on ensuring bereavement support training is provided within the induction training of all new support staff within the Local Authority where she is based.

7.8 Summary

Due to the actively engaged and educated nature of the support workers and PAs involved in this research, and the detailed responses provided by a myriad of 'other professionals' in the field the data collected in this research has provided a foundation of the rich and diverse discussion presented in this chapter.

This discussion has highlighted the complex and seemingly hierarchical nature of the world of learning disability services in the UK and the impact this has upon those who work at the front line of these services. The legal (HMSO, 2014; Skills for Care for Health, 2013) and organisational frameworks that govern support staff state they must remain boundaried from those they support (point 6, Skills for Care for Health, 2013, p.3) and therefore not engaged in the emotional elements of their lives.

Policy makers and support organisations appear to have put these frameworks in place in a bid to protect support staff from having to engage with the emotionally taxing elements of their role which can lead to high staff turnover (Bloom, 2005; England, 2005; Handley and Hutchinson, 2013; and O'Driscoll, 2015). However, what this situation appears to do is cause support staff to experience cognitive dissonance due to the commodification of the emotions they are feeling when doing this work every day. In turn, this appears to cause support staff to construct the identity of people with learning disabilities when they have suffered a bereavement within the medical/individual model of disability due to how they have to construct their own identity in order to remedy the conflict of their own emotions caused by the rules of their role.

Chapter 8

Doing Research Inclusively: Reflections



“The best bit about doing this research? The cake!”

(Kerrie Ford, Research Journal Entry, 3rd August 2015)

8.1 Introduction

This chapter explores how this research was carried out using an inclusive participatory approach. It was written collectively by the researchers with learning disabilities involved in this research, using a format developed to teach students in the School for Policy Studies, University of Bristol about our approach.

As discussed in *Chapter Two*, inclusive research projects are best explained to those outside the project through analogies, due to the complexities of using such an approach (Facer and Enright, 2016). This research was no different, and as a result, the analogy of baking a cake has been chosen to explain how the research was carried out. This analogy was chosen as cake was an important part of the research meetings, as Kerrie’s quote above highlights.

Cake played such an important role in the meetings for two reasons. Firstly, as I was unable to financially reward advisory group and co-researchers for their time on the project providing tea and cake within each research meeting was one method of ‘payment’ I could provide. Secondly, and more importantly, the cake I provided took on its own identity within research meetings as a warm and compassionate group member

who sat in the middle of the room providing us with a focus for our attention when our conversations became too difficult and we needed a break. Choosing which cake to have at each meeting also provided opportunity for our research team to bond over something other than our bereavement support experiences as we took it in turns to choose our favourite cakes, sharing with the rest of the group why we liked it and the memories it evoked.

It was not until the end of our time working together that we realised how important the cake had been to us during the research. As a result, the analogy of baking a cake as a way of sharing with others how we did this research was developed. This chapter is set out using this analogy, with each of the ingredients discussed before being brought together as a whole cake at the end.

8.2 Butter and Sugar– The Good Bits

Completing this research was full of ‘good bits.’ Having the input, insight and guidance of people with learning disabilities and those with support work experience meant that this research developed into the rich piece of work presented in this thesis. But getting the research to this point took a great deal of practical, intellectual and emotional investment from all involved (Walmsley and Johnson, 2003; Facer and Enright, 2016). Everyone had to engage with the purpose of the research and their role within it, communicating with others about the work they were doing to ensure that the outcomes of the research were met. This is an essential element of all research which has multiple groups working within it, such as within inclusive participatory research, but is especially true within projects which focus on difficult subjects to ensure trust develops and expectations are managed.

I aimed to foster the need for honest communication within this research from the outset with clear details about group roles and expectations in the advisory group and co-researcher recruitment information (Appendix 9, 16, and 17) and information sheets (Appendix 9 and 10). I was clear within this information that this research was being carried out as a piece of PhD research so I would therefore have the ‘final say’ on all decisions within the project, but that we would work together to plan, carry out, analyse and write up the research together as far as was reasonably practicable (Appendix 9

and 10). By explaining this to the advisory group and co-researchers in this way, I aimed to highlight that whilst I had to take 'control' of certain decisions, the power within the research community was a fluid concept which would change and evolve throughout the research as the project developed (Woelders *et al*, 2015).

By providing these very clear boundaries from the outset, I aimed to ensure that advisory group members and co-researchers understood their roles within the research and how they were expected to communicate with the rest of the community. This not only allowed great ideas and approaches to the research to develop, but also ensured group members knew what was expected of them so that no one person or group was taking on 'too much' work or responsibility in the research.

The key to this being successful however, was down to my continued focus on facilitating clear communication between the groups, acting as a 'go between' between them, encouraging reflective practice within each group and remaining flexible to the evolving social roles different individuals were developing as the research progressed (VanderPlaat, 1999; Baur and Abma, 2014) (I will discuss my role in greater detail in *section 8.3*).

As described in Chapters *Two* and *Four*, the advisory group, the co-researchers with support experience and the co-researchers with learning disabilities met independently of one another apart from on one occasion. I felt this was important to ensure everyone had clear roles in the research with clear expectations that allowed the groups to bond and trust to develop, it was not a decision based on power. I felt this was of paramount importance in this research as talking about death, dying and bereavement is a difficult task, especially when being asked to share experiences of this from your own life with a group of other researchers. If the different groups had met with one another it may have been more difficult for the advisory group and co-researchers with learning disabilities to share their lived experiences of receiving bereavement support with people who have provided it, although not to them, in the past. Just as it may have been difficult for the co-researchers with support experience to share their experiences of providing bereavement support with people who had been in receipt of such support in the past.

Had the two groups met together, tensions may have arisen between group members which would have been unhelpful to both the individuals involved and the research. By

meeting separately, the advisory group and co-researchers with learning disabilities were able to develop their trust with one another to the extent that they were able to discuss their lived experiences of receiving bereavement support and the co-researchers with support experience were able to do the same for their lived experiences of providing such support. This was not only beneficial to the individual group members, but also helped meet the objectives of this research;

1. To explore the phenomenon of bereavement support from the perspective of the support workers and PAs who provide it in the UK.
2. To involve and listen to support workers directly within an inclusive participatory research model.
3. To involve and be guided by the lived experiences of a group of people with learning disabilities within an inclusive participatory research model.

However, whilst each group worked together to help develop the research, they had to communicate with one another to ensure the research ideas were known by all involved. After all, those working on the research only existed in the research in relation to one another (Baur and Abma, 2014). As a result, I acted as a 'go between' between the groups sharing the ideas, data collection tools, and data analysis done in one group with the other and vice versa. This was extra work for me, but necessary to ensure the research process ran smoothly.

As well as communicating with one another, I also asked all community members to communicate with me via reflective research diaries (Appendix 9, 10, 11, and 12). This not only provided valuable insights into the way different people viewed how the research had grown, which has guided much of the writing in this chapter, but also allowed individuals to develop as researchers. This development was particularly noticeable for the two advisory group members, Julian and Kerrie, who evolved into co-researchers in the project. Through their working together and developing into confident advisory group members they had developed a 'valued social role' (Atkinson and Williams, 1990), which allowed them the confidence to become co-researchers. I view the ability for this to happen within this project, as one of the greatest 'good bits' to come out of the research. The approach we used allowed fluidity of identity, power and roles within the research community, which led to personal liberation for these two members

in particular (Bergold and Thomas, 2012) and added a great richness to the research that just would not have been present had a different approach been used (Woelders *et al*, 2015). However, it is important to note that whilst Julian and Kerrie had developed the confidence to become co-researchers through their involvement in the advisory group, their motivation for becoming co-researchers was hinged on the tension that arose around their reduced involvement in the research as the project progressed. Since they had been so heavily involved in the research for the first few months they had become invested in the process and wanted to continue this into the research's outcomes.

8.3 Eggs – What Binds it all Together

As has been alluded in *section 8.2*, my role is what held the research together and made it work. As discussed in *Chapter Two* the research was born out of the central point; my PhD research. It was a research project which grew out of my professional experience and motivations for completing such a study. Without these ideas and the work I did to develop the title, explore the literature and gain ethical approval for the work, the research would not have happened.

However, as has been highlighted throughout this thesis, this did not give me complete control of the research process. I left the ethics form (Appendix 1) as open as possible in order to allow those working with me on the research to decide what data we needed to collect, from whom and how.

Although I left the big research decisions open, I did have a number of roles within the research to ensure it progressed smoothly and to schedule. I was the organiser of all meetings, ensuring that an accessible space was available on a day and at a time that everyone could make, booked transportation for those who needed it, organised the tea and cake, prepared the meeting agenda and any reading material for group members in advance of the meeting and was there to greet people when they arrived. Once the meeting began, I was often the meeting chair, ensuring we stuck to the agenda, covered the items we needed to cover and took breaks when we needed them. Within these meetings I was also sometimes the educator; sharing information from the literature or

explaining the University research processes, and sometimes I was the learner; hearing stories and ideas from the group to apply to the research.

Without my input I do not think the research would be in the shape it is now. I do not think this is due to power as I do not see my role as being in any way 'superior' to other members of the research community. Rather, due to my position as a PhD student, I was able to help navigate a number of the research processes for the community which they would have found extremely difficult without this status. Having to use my log in to host the online questionnaire on the BOS system is a good example of this (*Chapter Two*). I therefore see myself as having been a research navigator and facilitator within this research, which allowed it to develop into the final form presented in this thesis.

There is a lot of debate in the research literature about the tension caused within inclusive and/or participatory research projects (Williams, 1999; Walmsley and Johnson, 2003; Woelders *et al*, 2015), especially with regard to the role non-learning disabled researchers have in this work. Prior to carrying out this research I was aware of these tensions, but due to the approach I had chosen to use, the role this being a PhD study had upon this approach and my decision to communicate honestly with all members of the research community, I did not feel that they should take up too much of my focus in the research. This is not to say they weren't omnipresent in my mind throughout the lifespan of the research, I just chose not to tie myself in the epistemological and philosophical knots so many social research projects seem to. For example, it was clear to me and those involved in the research community, that our inclusive participatory approach to the research did not imply emancipation (Walmsley and Johnson, 2003) so the tensions which arise in some other participatory studies (Facer and Enright, 2016) around the issues of control for the marginalised groups involved in the research did not arise in this research, especially as I communicated honestly with each group about all of our roles (Appendix 9, 10, 11, and 12).

Working in this way appears to have worked well, as Rowena's reflection in her journal suggests:

Vicky

“This was really Vicky’s research, but she didn’t make it feel like it. She helped us to be researchers throughout the project. It has been great to work with her and the things we have found out are great. I will use them in my work when I am qualified.”

Rowena, Research Journal entry, 3rd Nov 2015

However, it is important to note that although I tried my best to manage the research and all of its community members, I did not do this perfectly. For example:

Research diaries

“I think it would have been nice for you to help us write the diaries”

Kerrie Ford, Reflection meeting, 4th December 2015

This is something that I need to take on board for future research projects, not only in relation to supporting those working with me being reflective researchers, but also in relation to ensuring that those working with me are comfortable talking to me about things they are finding difficult. I endeavoured to foster this sort of communication throughout the lifespan of the research, but reading that Kerrie would have liked some help with her keep her research diary right at the end of the research project suggests I didn’t. This is discussed in greater detail in *section 8.7.2*

8.4 Flour – What needs to be there to make it Work

As has been introduced in *section 8.3*, a number of things need to be in place for an inclusive participatory research study to happen. The things that had to be in place to make this research work are not dissimilar to those needed in other projects (such as, Facer and Enright, 2016), and include space, time, money and supervision.

8.4.1 Space

In order for this research to be successful we had to have accessible research space within the University of Bristol to meet to discuss our work, analyse our data and write sections of this thesis. This required having access to rooms which were not only quiet but also fully wheelchair accessible and networked to the University servers. The rooms also needed to be ones which we were able to eat and drink in (a number of university meeting rooms do not allow this) whilst also being located near to accessible toilets and with clear access to the main reception of the School for Policy Studies for transportation and in case of a Fire Alarm. As will be discussed in *section 8.7.1*, these requirements were not always easy to meet.

8.4.2 Time

Within every research project time is of the essence, there are deadlines to be met by funders and governing bodies. In this research the completion of the research was stipulated by the length of time allowed to complete a PhD. However, as I have completed this PhD on a part-time basis the time pressure was not as intense as it would have been had I completed it on a full-time basis. Yet, because I chose to use an inclusive participatory method, the time actually needed to set up the research, including; recruiting advisory group members and co-researchers (please see Chapters *Two* and *Four*, Appendix 9, 10, 17, and 18), getting them up to speed with the relevant research literature (Appendix 2 and 13), teaching them about different approaches to social research that we might want to employ (Appendix 3) , making decisions about which of these to use in the research and obtaining ethical clearance for these methods (please see Chapters *Two* and *Four*), took a lot longer than it would have done had I done it alone.

This process was further drawn out due to the time it takes to translate research literature and traditional research documentation (ethics forms etc.) into an 'easy read' format as very few of these documents are published in this format (please see *section 8.7* for a discussion of this issue).

At the point at which I began working with the advisory group I had worked in easy information at the NFCDS for two years so had experience of working in this way. However, I still underestimated how much time it would take me to translate the information I needed in order to share it with the advisory group (Appendix 2 and 3). I also underestimated how much time it would take to ensure that the advisory group understood the information I was providing them with and were able to make an informed decision about the data collection methods we would use. My main underestimation with this was the amount of time at the start of each meeting that would be taken up by recapping on what we had covered in the last meeting. At the data analysis stage, I also underestimated how many breaks we would need whilst working with the data due to the level of detail we went into in our discussions and the impact this had upon different group members. A situation which led to us having to have more meetings than expected around data analysis.

Time is often discussed as an important element to be considered in inclusive and/or participatory research (Walmsley and Johnson, 2003, Facer and Enright, 2016), but with my years of experience as both a support worker and PA and my experience in creating 'easy information', I naïvely thought I had factored in enough time within the research. On reflection, this was the first time I had supported people with learning disabilities in a research setting, so I see this is an important lesson in my development as a researcher.

In addition to the time needed to work with the advisory group effectively, the amount of time the co-researchers with support experience had available to work on the research was also an issue. As has been discussed in Chapters *Two*, *Four* and *Seven*, recruiting the co-researchers with support experience was a difficult and prolonged task, which resulted in two Master's Students in Social Work from the University of Bristol taking on this role. Due to the timing of the research within these students' studies they had limited time available to them as they were on placement whilst also having to complete assignments. This led to a limited number of face-to-face research meetings taking place after the initial few months together. These first few months did allow us to lay firm foundations, which was beneficial, but having to communicate via email or on a one-to-one basis from that point onwards was difficult and I feel detrimental to the research in so much as we could not collectively analyse the data and come to conclusions together.

As a result, I would recommend all research which uses different groups to complete its work to factor in more time than you feel is probably necessary to complete the work required.

8.4.3 Money

Relationships

“I wanted to help Vicky. It doesn’t matter that I wasn’t paid”

Lisa Ponting, Reflection meeting, 4th December 2015

Lisa’s quote, above, raises another power related issue in this research; payment. The issue of pay in inclusive and participatory research is also one which is widely discussed in the research literature (Williams, 1999; Walmsley and Johnson, 2003; Read and Prothero, 2011; Morgan *et al*, 2014). It is widely argued that those who work as researchers or advisors should be paid ‘normal’ rates of pay for this work (Williams, 1999), yet the majority of inclusive and participatory projects are carried out on limited budgets where the ability to pay anyone without relevant research qualifications is not provided by funding bodies (Walmsley and Johnson, 2003). The ethical and social practice issues raised by this situation reach far beyond the scope of the discussion here, however the issue of payment is one that caused me great issue from the beginning of this research process.

Funding Reflection

Not being able to pay the groups for their time helping me conduct the research is difficult. I’m not being paid, in fact I am paying to do it, but if it’s successful I will get a PhD and they don’t get anything. If I can’t pay them, what can I give them? I’ve discussed this in supervision and we have talked about lots of ideas. Payment might actually be detrimental to the advisory group members, but not being able to give them anything feels wrong.

Research Journal entry, 8th March 2013

As the quote from my own research journal above suggests, I felt a huge amount of guilt towards both the advisory group and co-researchers for not being able to pay them for the vast amount of time they were giving up to do the research. As the quote suggests, I

was not being paid to undertake the research either, in fact, I was paying to do it, but I felt a huge sense of guilt about the benefits I would receive from completing the research being perceived as far outweighing the two groups would receive.

In a bid to remedy this situation, both for my own conscience and for those in the research community, I decided that honesty was the way forward to dealing with this situation and agreed with them to pay their transport costs to and from research meetings, provide them with refreshments at each research meeting, and offered them ongoing support at the end of the research process to write about the work we'd done to be submitted for publication or conferences (Appendix 9, 10, 11, and 12). This was agreeable with all involved, and the provision of cake at each research meeting became the symbol of how we worked.

Cake

“The best bit of about being involved in the research? The cake!! Vicky always make good cake for our meetings. It’s on the table when we get to the meeting and we eat it whilst we talk. I like having it there. We can stop to eat cake and have a drink whenever we want to. If things get hard I like having something else to do.”

Kerrie Ford, Research Journal entry, 3rd August 2015

However, this also raised its own issues, as I had to pay for the cake (or its ingredients) for each meeting and the transportation costs for community members. There were small pots of research money available within NFCDS to help pay for small sections of these costs throughout the research, but due to the length of time we were meeting and the number of meetings we had this was not always possible. There are always financial pressures in research and covering costs and providing fair payment are all issues which need to be taken seriously (Williams, 1999; Walmsley and Johnson, 2003; Woelders *et al*, 2015; Facer and Enright, 2016). If I were to do this research again, I would seek funding to support the work more thoroughly than I did.

8.4.4 Supervision

My role within the research was to hold it all together, but I could not have done this without supervision. As already noted, this was my first time working on an inclusive participatory project and also my first time leading a project on my own. I needed support and guidance to help navigate the process both in terms of how the research was progressing in line with the expectations of completing a PhD and also practically in relation to the systems in the University. Without this supervision the research would not be in the shape it is today, so I would recommend that all researchers working in this way put a supervision structure in place to ensure they are supported throughout the process whilst they are supporting others.

8.5 Baking Powder – Taking on a life of its Own

As the discussion in this chapter so far has highlighted, this research took on a life of its own because of the approach we used. My initial idea of carrying out research into the bereavement support experiences of learning disabilities support staff, developed and grew as the advisory group, co-researchers with support experience and co-researchers with learning disabilities, learnt new skills and gained the confidence to help shape the research into the format it is today.

Without the input of both of these groups of people, in their groups and as individuals, the ideas which led to the data collection methods used (chapters *Four*, *Five* and *Six*, and section 8.10) would not be as they are.

The confidence the research community gained from the clear guidance set out at the beginning of the research process (Appendix 9, 10, 16, and 17) allowed the groups to cultivate their understanding of the research literature in line with their own lived experiences, and develop the questions we should ask, who we should ask them to, where we should find these people and how we should analyse what they said, in line with the gaps they identified.

I do not feel the rich and diverse findings presented in this thesis would have been collected had I not employed an inclusive participatory approach to carry out this

research. Certainly, I am confident that the online questionnaire would not have been developed and run, had I not been working with Julian and Kerrie.

8.6 Chocolate Buttons – The Participants

As has been discussed in *section 8.5* (and in Chapters *Four, Five* and *Six*) the participants in this research were chosen as a result of conversations with all members of the research community. We worked together to decide what questions we wanted to ask, how we wanted to ask them, who we wanted to ask them to and how we were going to analyse the answers. Initially all of these things were decided by the co-researchers with support experience and I before asking the advisory group for their thoughts and suggestions. Due to the advisory group's experience of trying to recruit the co-researchers with support experience they were able to offer valuable information about avoiding the use of focus groups as a data collection due to the inability of support workers and PAs to attend such groups due to their long, anti-social working hours (Michie and Williams, 2009). In addition, due to the co-researcher's recent experiences of working in learning disability services we decided not to use telephone interviews due to the impersonal and sometimes intimidating nature of talking about sensitive work matters over the phone. As a result of these insights, that I would not have had had I worked alone on this research, we decided to conduct one-to-one interviews with participants rather than utilise any other method. It was also decided, for continuity that I would conduct each of the interviews and the initial stages of analysis alone, but that the themes I drew out of the data would be analysed further by both the co-researchers with support experience and then the advisory group. Had this process not taken place then the second stage of the data collection, the questionnaire, would not have occurred and the rich data collected would not have been able to be explored.

However, whilst this process is felt to be positive, comments like the one below, highlight that although the way we collected the data was the most practical, it would have been nice for the community to have been more involved in meeting the interview participants and doing the interviews.

Participants

It would have been nice to meet some of the participants. Their stories are so interesting and I would have liked to have heard them first hand. I would also have liked the experience. I haven't really done any research interviews on my own and this would have been a good time to practice my skills. I know this wasn't really practical for consistency in such a small study, but it would have been nice. I am going to try and get some more experience in another project soon as I really want to do some interviews

Ben Harrington, Reflective Journal entry, 12th August 2015

Ben's point is an interesting one and relates to the tensions that arise in inclusive participatory research that have been alluded to already in this chapter. However, it also raises the extra tension that was present in this research; that this was a PhD study. I had explained this at the outset and emphasised that I would have to have the 'final say' on research decisions due to the expectations of a PhD piece of research (Appendix 9, 10, 17, and 18), and they all agreed to this. However, in reality, when you become involved in a research project you become invested in it and not being able to carry out some of the tasks becomes difficult. This is something which is seldom written about in the research literature about doing inclusive and/or participatory research as so little PhD research is done in this way. This issue was therefore one of the 'sticky bits' that is discussed in *section 8.7*, below

8.7 Jam – The Sticky Bits

"In other words, what makes these projects strong is also what makes them difficult, hard work and meaningful. Which is why they are so often fraught and tense collaborations; if it feels too easy, you probably aren't doing it right."

(Farce and Enright, 2016, p. 79).

Although this research was filled with plenty of good bits, and took on an exciting life of its own, there were a number of 'sticky bits' that made the journey less than smooth. Some of these 'sticky bits' were due to the process of doing research generally and because this was a PhD study; whilst others were due to the relationships which developed in the research process and the expectations held by those in these relationships.

8.7.1 Research Processes

As has been alluded to in a number of the previous sections of this chapter, there were several things which caused issue within this research which were due to the traditional, positivist surroundings in which it was carried out.

8.7.1.1 Easy Information

Broadly speaking, research carried out into bereavement support for people with learning disabilities is not disseminated in an accessible format. The majority of work is published in academic journals in a non-accessible format, which are only accessible to people with the IT skills and/or academic status to find them. If people with learning disabilities are to be able to undertake research that matters to them and makes a difference to the world around them, then the academic world needs to begin presenting research information in formats that are accessible to those it is about. Talking about research findings on film and publishing them on YouTube or other video platforms would help remedy this situation.

As previously discussed, I remedied this situation through translating the research literature I provided the advisory group with at the start of the research, myself (Appendix 2). However, as you will be able to see from Appendix 2, there is a lack of Photosymbols in the translation I created as there were very few Symbols available which accurately represented the issues surrounding death, dying and bereavement being discussed. This is something which needs to be rectified if research is to be written about in an accessible format. We cannot demand that accessible information is available if the organisations which are there to facilitate this communication do not provide the Symbols required to make it so.

8.7.1.2 The Systems we had to Use

In addition to research literature not being accessible a number of research procedures are also not. One of the greatest challenges we faced during the lifespan of the

research was completing an Ethics Form for carrying out the questionnaires (Appendix 28):

Ethics

“I think this ethics form is very complicated...I think everyone should have a chance to try and this form should be put into easy information for people to read.”

Kerrie Ford, Research Journal entry, 11th June 2015

The Ethics Form used within the School for Policy Studies, University of Bristol is standardised for all research projects (Appendix 1 and 28). Not only is the format of the form not accessible in font, size or layout, it also has no accessible guidance, and in no way allows for the complexities and intricacies of inclusive participatory research studies to be written about due to the limited word count available. This made the process really difficult for the co-researchers with learning disabilities and myself, as it meant that we had to discuss everything together before I condensed these discussions down into an acceptable response in each section of the form. This process felt incredibly disabling to the research. If research of this sort is to be meaningful, it needs to be carried out by those whom it directly effects, but in order for this to happen the forms and processes that research funders and responsible bodies put in place need to be accessible to these groups. We believe that in doing so it will make it easier for all involved.

In addition to the Ethics Form we had to complete to carry out the online questionnaire (Appendix 28), the system the University of Bristol said we had to use to host this questionnaire online, was also inaccessible to the co-researchers with learning disabilities. This system, the Bristol Online Survey system (BOS), is only available to members of University of Bristol staff and students with an approved email address. Neither Kerrie nor Julian had such an email address, so I had to create the questionnaire online connected to my email address. This did not cause too many issues within this research as it was agreed prior to discovering that a specific type of email address had to be used with the system that I would take on the administration duties for the questionnaire as neither Kerrie nor Julian had sufficient internet access or IT skills to manage these tasks outside of group meetings. However, it did raise the

point that if people with learning disabilities, or other marginalised groups, are going to work on University run projects they need to be given fully 'Honorary Staff Status' within the University in order access systems such as BOS. Doing so would give them the appropriate privileges, such as an email address, to be researchers. I did not foresee this being an issue at the start of the research process, but will ensure I put this status in place for individuals on future projects I work on

As with the Ethics Form, it would also have been useful to have accessible guidance available on how to use each of the University's systems to ensure that all members of staff are able to use them. The BOS system did not have any accessible instructions, which meant that when Kerrie, Julian and I created the questionnaire together online, using my sign in, I had to read the instructions and translate them for Kerrie and Julian as we went. This was not an easy task and having accessible guidelines would have made this process easier and less disabling for all involved.

Additionally, this issue also highlighted that having access to the internet for many marginalised groups in society cannot be taken for granted. Of the co-researchers with learning disabilities, Kerrie did not have access to the internet other than when she came into University where she could have support to use it; whilst Julian did have access at home via a laptop but was only able to use the sites he knew how to use and was not confident to use any others without support. This is something that needs to be acknowledged when working with marginalised groups and factored into the costing of projects in relation to equipment, training and time.

8.7.1.3 Funding

The final process related 'sticky bit' we faced related to funding. This issue has been discussed in *section 8.4.3*, but it is felt important to mention again to reiterate and expand on the points already made.

As I have already noted, I had no funding to carry out this research, therefore any money spent to cover expenses was either my own or from small pockets of funding available through my supervisors within NFCDS. Money is certainly an enabler within research and without it, it is difficult to run projects (Farce and Enright, 2016). However,

it is possible to manage with only small amounts of money to make a project work, as this project has proved.

I do not think having funding to do this research would have made the quality of the work higher, as is argued by some (Farce and Enright, 2016). It may have let the work happen more quickly and allow us to create the DVD we wanted to create as an output (please see *section 8.8*). But I do not think that having more money would have made the quality of the research done, the questions asked or the findings gathered, a higher standard.

In fact, I have wondered whether if money had been involved in the research whether there would have been more tensions in and possibly between different groups involved in the research. That is, with no money being paid to any members of the community there were no issues of people being paid more due to their role or experience as could have been the case if we had been being paid. For example, as this is my PhD research and was, effectively the lead researcher it is likely that I would have been paid more than the others involved in the research. This would have, on paper been fair, but in reality would have felt wrong and could have born resentment from community members as I was gaining more from their involvement in the research both financially and in future career prospects.

Additionally, it has to be acknowledged that for the advisory group, being paid may have had a detrimental effect on their benefit payments. As is noted by (Walmsley and Johnson, 2003; Mencap, 2015) one of the biggest barriers to people with learning disabilities being researchers, or workers of any sort, in their own right is the complex benefits system under which so many of them live. The varied rules and regulations which govern the myriad of benefits people receive places limits on the amount of money or number of hours they are able to work before these benefits get stopped. Of course, this issue is one which reaches far beyond the scope of this discussion or the thesis as a whole, but it is an issue which needs addressing as it has been acknowledged in the research and professional literature for many years.

One way of rectifying this situation within this research would have been to create a 'gift economy' (Farce and Enright, 2016) as many studies do, where advisory group members and co-researchers were 'paid' with gift vouchers that they would not have

had to claim as income. Unfortunately, due to their being no funding at all to complete this research creating this economy and the debates this raises (Farce and Enright, 2016), was not possible.

8.7.2 Relationships

As well as the procedural challenges which made the research difficult at times there were a number of relational issues which caused sticking points as well.

Relationships

“I wanted to help Vicky. It doesn’t matter that I wasn’t paid”

Lisa Ponting, Reflection meeting, 4th December 2015

As Lisa’s quote suggests, due to the advisory group members knowing me prior to becoming involved in the research, they might have felt obliged to get involved in the research.

The obligation people feel to becoming involved in research when they know the person asking them to do so, especially if they are people with learning disabilities, is widely noted in the literature (Gates, 2007; Bowden *et al*, 2011; Read and Prothero, 2011; Morgan *et al*, 2014). As I became aware of this issue within this research, I took stock of the situation and decided to address the issue head on with individual group members before they agreed to become advisory group members (Appendix 9, 11, and 14). I was also conscious of the issue at each group meeting and regularly checked in with individuals about their happiness to continue with the work. By owning and talking about the issue with the group I aimed to rebalance the power I had in the research relationship, by providing the space to opt out or discuss the issue with me. I also reflected upon the issue privately within my research diary to ensure the issue manifested itself positively.

However, one issue I did not foresee and became a problem within advisory group meetings was the presence of a support worker working with one of the group members at the meetings. This situation arose as a number of meetings fell on the days this

member received their PA support. This was fine with the group member, but what became apparent was that having this PA in the meeting altered the dynamic in the room for the duration of the meeting. Having someone present in the room who we did not know altered the trust and openness that developed in the group, which was detrimental to the meetings. This situation was exacerbated by the fact that on each occasion the PA who came with the group member was different on each visit so we could not develop a relationship with them.

We spoke to the group member about this issue and decided that we would alter our group meetings to a day and time which did not clash with their support hours (as well as rectifying the problems this had within our work it also meant that the group member was able to use their support hours for other activities that they needed support with, rather than our research meetings which they did not need support for). In addition, when the meeting day had been moved, we discussed the issues that arise in people's lives as a result of having a different PA each day or week. We talked openly about how it feels to not know who is coming to support you and how this feels when things are difficult in people's lives; such as when they've suffered a bereavement. Advisory group members talked about their experiences of this and their opinions differed of how it has made them feel in the past; all three group members had experience of people they didn't really know coming to support them when someone they love had died. Julian felt that having different people didn't bother him:

"...it means I can just get on with life. Having someone who doesn't know me means they didn't ask about mum, we just did what I needed to do. People who knew me made me think about it all the time. I didn't want to think about it all the time"

Whilst Lisa said it was really hard:

"They don't know me or how I like to do things. I can't talk to someone about things if they don't know me, they don't know about my life. They won't know who I have lost or what they meant. I need someone who knows me."

Having this conversation, whilst born out of a difficult situation and a delicate one to manage in the group, was useful to the research. It emphasised how personal support

relationships are and how individualised they need to be. Having power and control over the support they have was most important to the group members, especially when issues of bereavement arose in their lives.

I took the key elements of this conversation, with the advisory group's consent, to the co-researchers and we discussed from our experience what it feels like to be the PA or supporter who is coming in and out of people's lives without really knowing them well. This conversation revealed that just as people receiving support want control, so do those giving the support. This echoes the findings of the interview and questionnaire participants who wanted to have control over the work they were doing and with whom. Control therefore seems to be a key element to improving support services from both the point of view of people with learning disabilities and those providing their support. The introduction of Direct Payments and Personal Budgets (Skills for Care, 2014) are going some way to address this for people with learning disabilities, but little is being done for support workers and PAs in this arena.

As well as managing the practical elements of the research relationships, a number of tensions arose with regards to the expectations of the groups. I tried, from the outset to manage expectations of the groups by being honest in the recruitment information (Appendix 9 and 10) and initial meetings (*Chapter Two* and *Four*), however as the project grew, the investment of the group members increased and the expectations they had about their involvement. This mainly related to the advisory group who it seemed had a much deeper investment in the project than the co-researchers with support experience, probably because they had such bad experiences of bereavement support themselves. I ensured that I talked with the group throughout the project about their roles and the amount of work that was needed or required of them. However, when it came to analysing the interview data the group became quite angry that they were the last to be asked about its meaning; even though I had communicated with them that this is how it would be from the outset. This situation and the ensuing discussion which took place is what led to Julian and Kerrie becoming co-researchers in their own right, and the online questionnaire becoming a concurrent data collection method which was instigated, managed and analysed with these individuals from start to finish. This data has been a great addition to the research, but it was only able to be collected due to the time available in the research. Had this time not been available the tensions caused by the expectations of the advisory group might have caused greater issues.

8.8 Icing – Making it Presentable

Disseminating PhD research when using an inclusive participatory approach is a difficult task. The requirements and expectations of completing a PhD and the research community sit, in many ways, in opposition to one another. Both the advisory group, co-researchers with learning disabilities, and co-researchers with support experience would have liked to have made a film of this research to explain to other people what we have done, how we have done it and what we have found out.

The community wanted to use this method for two reasons. Firstly, because it would enable all members of the community to be involved in telling people about the work, and secondly because it would reach more people than this thesis ever will. This second point is especially true for people with learning disabilities, and possibly their families and supporters as well. Film is felt to be the most accessible form of communication available as it uses spoken words, written words and pictures to get a message across to the audience. It is also a short and quick way of getting relatively complex messages across in a way that people can view again and again if they do not understand the information first time.

I really liked this idea and, in my role supporting the Information Officer within NFCDS (Julian Goodwin), film increasingly became the dissemination method requested by a number of funded studies for translating their findings to audiences, especially those outside academia. Unfortunately, as making a film would not have met the criteria for completing the PhD we were not create one due to the amount of money and time it would have taken up. Instead I have written this thesis using as easy to understand words as possible, have used an easy to read typeface, have not underlined any of my chapter titles, headings or sub-headings. I have also read through each chapter with either Julian, Kerrie or Lisa to ensure the content makes sense to them and is an accurate representation of what occurred in the research. This in no way makes this thesis accessible as the size of the writing is far too small (for it to be accessible it would need to be a minimum of size 16), the layout is not easy to read and there are no pictures (either Photosymbols or change symbols) to help people read the words. This is a regret I have about the thesis, but I feel I have done all I can in regards to the accessibility of the work we have done being represented in this thesis whilst also meeting the requirements of completing the PhD.

However, once the PhD is achieved, the researchers with learning disabilities planning to raise funds to create a film of our work, which we will publish and show at conferences both academic and for learning disability professionals. We are also hoping to write an accessible paper to publish about the way we have done our work and the tensions we have faced in completing an inclusive participatory PhD study, for future researchers to refer to and learn from. We have also begun work on running Death Cafés for people with learning disabilities, which is discussed in greater detail in *section 8.10*, below.

Ending

“I have learnt a lot about death and bereavement doing this research. I wanted to do the research as I wanted to know more. I didn’t know much before. It’s been hard, I want to know it’s OK...what I feel is right...I do now. It’s better”

Lisa Ponting, Research Journal entry, 27th November 2015

8.9 Jelly Tots –The Brilliant Ideas

Throughout the lifespan of this research there were a number of ‘brilliant ideas’ born out of the inclusive participatory approach we used. Working together and talking in group meetings in the way we did allowed for the evolution of our data collection methods within the research which would not have happened without us working together in this way. This has been discussed in various ways throughout this thesis, but I wanted to emphasise again that the ideas of both Kerrie and Julian to expand the research findings through an online questionnaire was one of the greatest ideas of the research.

The second most significant ‘brilliant idea’ to come out of working within an inclusive participatory way was the suggestion of Kerrie and Lisa to run an exclusive Death Café for people with learning disabilities. A Death Café is a not for profit café run by volunteers to provide people, often strangers to one another, a space to talk about death, dying and bereavement over tea and cake (Underwood, 2016). Kerrie and Lisa suggested this idea in the last group meeting we had together in 2015 where we reflected on the research process together. At this time, the Death Café movement was regularly on the local news as there was a ‘Festival of Death’ being held at one of the

city centre museums. Kerrie and Lisa had seen/heard this news and had decided that what we had been doing throughout our research meetings was like a Death Café. That is, as they saw it, we came together on a regular basis to talk about death, dying and bereavement in a safe and supportive environment which included tea and cake. Of course, our meetings had a research focus, but we shared and unpicked our own experiences of death, dying and bereavement in our own lives throughout the duration of the advisory groups involvement in the research; after all their experiences were the reason I had asked them to be involved in the research in the first place.

As Lisa's quote, on the previous page, suggests, her motivation for being involved in this research was to learn more about the issues of death and bereavement that she had not learnt and was not supported to learn about within her support networks at home now. This motivation not only went against what I thought I should be 'giving' advisory group members, co-researchers with learning disabilities, and co-researchers with support experience, but also highlights that people with learning disabilities are aware of their own bereavement support needs and want to talk, share and debate their feelings around this issue in a group forum just as many people without learning disabilities do.

As a result of these discussions, the first ever Death Café exclusively for people with learning disabilities has been piloted in Bristol. The development and running of this Café reaches far beyond the scope of this discussion, which we will publish details of via other mediums in the future. But needless to say, this development is an outcome of this research that was not intended and one which will hopefully improve bereavement support for people with learning disabilities in the future by allowing them to take control of the situation through the information they glean from conversations within the Death Café. We intend to develop and expand the Death Café movement for people with learning disabilities towards the end of 2017. As a result of this development, we want to recommend that future research in the area of bereavement support for people with learning disabilities begins to focus on the power people with learning disabilities have to begin improving the support they receive by equipping them with the knowledge and confidence to ask for this. As well as providing them with a space to incorporate the often lacking peer support in their social networks (Reinders, 2010).

8.10 The Completed Cake

As the discussion in this chapter has highlighted, completing this research has been an interesting, complex and messy process, but the completed cake is one which not only informs us about bereavement support for people with learning disabilities, but also about the wider issues of using inclusive participatory approaches within PhD research.

Completing the research using an inclusive participatory approach has led to these rich and diverse outcomes which we do not feel could have been achieved without using such an approach. It has been an emotive and challenging process at times and the conflicting perspectives and expectations within the research community has caused some tensions. These tensions have arisen as the issues being discussed were not abstract, but embodied in the community and its individual members due to their personal investments in the research (Facer and Enright, 2016). Working together with one another in an honest, clear and effective way was the only way we overcame these tensions to create the insightful piece of research presented in this thesis.

Chapter 9

Conclusions and Recommendations

9.1 Introduction

This chapter draws the discussion presented in this thesis to a close. It brings the elements explored in each chapter together and presents the conclusions that have been drawn from the data collected. Within this discussion, reference is made to the role the inclusive participatory approach used in this research has had upon the conclusions that have been drawn. The chapter draws to a close with a list of recommendations for future research and practice in the world of bereavement support for people with learning disabilities.

9.2 Bereavement Support for People with Learning Disabilities

Bereavement support for adults with learning disabilities in the UK has been described as at 'at best inconsistent and at worst non-existent' (Read and Elliott, 2007, p.177). The literature suggests that learning disability support organisations perpetuate this situation as they widely fail to provide appropriate bereavement support to people with learning disabilities (Murray *et al*, 2000) as their staff are unable to identify the impact bereavement has upon these individuals (Arthur 2003; Read and Elliott, 2007). As a result, much of the research literature available, recommends that support staff undertake bereavement training in order to remedy this situation (Reynolds *et al*, 2008; Handley and Hutchinson, 2013). However, this recommendation is based on limited empirical evidence which suggests that such training would be useful. That is, the empirical research which has led to the suggestion that training will rectify the poor provision of bereavement support in the UK, by its own admission fails to evidence the effectiveness of this training in their own findings (for example, Reynolds *et al*, 2008). Furthermore, this recommendation also goes against the small body of research which suggests that support staff are aware of the bereavement support needs of those they support but are let down by the system they work within (Mencap, 2012; Heslop *et al*, 2013).

As a result, the research presented in this thesis aimed to explore, in greater detail than has been done in previous research, the bereavement support experiences of support workers and PAs in the UK. It aimed to do this within an inclusive participatory model where a group of people with support work experience helped carry out the research and a group of people with learning disabilities advised the work we did.

By utilising an interpretive narrative approach to analyse the thirteen interview and forty-four questionnaire responses, a complex and hierarchical picture of how emotional support is provided to people with learning disabilities within services has been uncovered. This picture has seldom been seen in the research literature to date and uncovering it offers new insight into why bereavement support for people with learning disabilities is suggested to be 'at best inconsistent and at worst non-existent' (Read and Elliott, 2007, p.177). However, it is important to note that the participants who aided this discovery were not representative of the wider learning disability support workforce. They were a highly engaged and educated group of individuals who chose to take part in a research project about bereavement support, not a random sample of those working in the field (please see *section 9.4 for a more detailed discussion of this point*).

All fifty-seven participants in this research acknowledged that people with learning disabilities grieve when someone important in their lives dies. But more than this, all the participants expressed an understanding of the impact these losses can have upon people with learning disabilities material existence as well as their emotional wellbeing. That is, they acknowledged that for many people with learning disabilities when someone important in their life dies this often results in a tangible change in their lives such as having to move to a new house or having someone new move into the place they call home. This not only demonstrates that support staff, and the 'other' professionals involved in this research, have an understanding of the Dual Process Model of Grief (Stroebe and Schut, 2001), but that they apply this to the work they do when someone they support is grieving.

Furthermore, all the participants in this research acknowledged the role they play in the social networks of the people they support and as a result felt a deep sense of empathy and compassion towards them when they suffered a loss. All the support workers and PAs involved in the research expressed an almost instinctive response to this situation

and provided examples of what can be interpreted as being exemplary bereavement support to these individuals

However, when discussing the emotional elements of this support these participants did so with both a sense of caution and uncertainty. They wanted to ensure that they came across as being 'professional' and not getting 'too close' to those they worked with when providing this support, whilst also expressing a concern that they weren't doing this support 'right'.

Unpicking these findings within Read's model of bereavement support for people with learning disabilities (2005; Read and Elliott, 2007) has revealed that the interaction the role of support worker and PA has with the Exo (organisational) and Macro (national) levels of support provision in the UK may, at least in part, provide an explanation for these participants experiences. That is, the data gathered in this research suggests that support workers and PAs are expected to carry out the practical elements of bereavement support, such as going to funerals and creating memorials, but are instructed by the national (HMSO, 2014; Skills for Care for Health, 2013) (Macro level) and organisational level policies (Exo level) which govern their roles not to engage with the emotional elements of this work, instead referring people to specialist counselling services as required (Exo level). However, providing practical bereavement support is not likely to be done in isolation of emotional support, as going to a funeral and creating memorials are emotive activities for many people, so support staff expressed having to provide emotional support at these times out of sight of management, with little training and limited support for their own health and wellbeing. These findings suggest that the participants in this research appear to have embodied the Exo and Macro regulations which govern their work, as a framework which tells them what they must not do, more than what they must do

The Exo and Marco frameworks which govern the provision of support for people with learning disabilities appear to have taken their lead from the literature which suggests that engaging in the emotive elements of their work will lead support staff to experience high levels of work related stress, which is likely to increase turnover (Bloom, 2005; England, 2005; Handley and Hutchinson, 2013; O'Driscoll, 2015). Rather than that which acknowledges that being a supporter is a social relationship, 'it can only be undertaken in the context of another person' (Payne, 2005, p.184) and by denying

support staff the autonomy to engage with the emotive elements of their role in these frameworks creates the very situation they were trying to avoid; high stress levels and turnover (Kittay, 2001). This was particularly evident in this research with interview participant Alan who, due to the large number of deaths in the service he worked for and the lack of support he received to support with people with learning disabilities left behind, took early retirement due to stress the situation caused him.

Furthermore, this situation appears to be forcing participants to construct the abilities of people with learning disabilities to understand the issues of bereavement and grief within a Medical or Individual Model of Disability (Oliver, 1996) as that is how they are forced to co-construct their own identities within this context. The Exo and Macro level frameworks which govern support workers appear to force participants to see emotionally taxing tasks, such as providing bereavement support, as something which they are not capable of doing so has to be carried out '*proper professionals*' (Jessica, interview participant) within a clinicalised setting. Therefore, forcing participants to construct the bereavement support needs of people with learning disabilities as something 'different' to that of their own, which can only be managed within clinical (medical) services. However, many participants expressed concern about the lack of such services for people with learning disabilities and actively asked the interviewer whether she could refer them to any services she knew of.

This complex and hierarchical picture of support services for people with learning disabilities and specifically how bereavement support is provided within this context, sheds light on why some people with learning disabilities are left alone and unsupported when someone they love dies (Read and Elliott, 2007; Blackman, 2008). More research is required to explore this finding further from the view point of support workers, PAs, service providers, policy makers and specialist counselling services. Work which brings the voices of people with learning disabilities to the fore would also be beneficial.

9.3 Inclusive Participatory Research

The rich and insightful findings obtained in this research could not have been gathered without using an inclusive participatory approach. This approach was chosen for two

reasons, firstly to provide both support workers/PAs and people with learning disabilities with a space in the research literature to have their voices heard. And secondly to ensure that the questions being asked, and the medium used to ask them (interview, questionnaire, focus groups etc.) was appropriate to current learning disability services in the UK.

The focus of the research was upon the experiences of support workers and PAs providing bereavement support, so it was felt important to have people with experience of working in those roles as co-researchers. However, to ensure the needs of people with learning disabilities were at the heart of the research it was important to also have a group of people with learning disabilities advising the study. Both of these groups offered different perspectives on the research and how it should be conducted, so it was vital they were both included throughout the lifespan of the work (Leece and Peace, 2010; Ahlstrom and Wadensten, 2010).

The flexibility of working with these groups within an inclusive participatory approach allowed the research to grow in a way that it would not have done had it been completed by a lone researcher. For example, the different perspectives members of the research advisory group brought to the fore, led to the development of the concurrent stage of data collection via an online questionnaire. This development not only allowed for data to be collected that would not have been exposed had only interviews been carried out, but also shows how empowering working in research can be for people with learning disabilities (Walmsley and Johnson, 2003).

As a result, social research which explores issues affecting the lives of people within services, both as the receivers and providers of support, should, as far as reasonably practicable, utilise an inclusive participatory approach where possible. As the insight and richness of the data that this work collects will prove invaluable to the lives of the people involved.

This is not to say that carrying out research in this way is easy; far from it. It takes a huge amount of time, effort, planning and managing to run a successful inclusive participatory research project. However, the biggest challenge of all seems to be carrying out the research within systems which are still geared towards 'traditional' academic research approaches. The accessibility of forms, availability of suitable

research spaces, timescales to work within, and output expectations are not geared towards untraditional research teams. This is something which needs to change.

9.4 Strengths and Limitations

This research was built upon previous work in the fields of 'thanatology', 'disability', 'grief', and 'learning disability practice'. This body of work was reviewed within a research community made up of people with learning disabilities and those with previous support work experience (p. xviii). Reviewing the literature in this way allowed the important questions to those directly affected by the issue of bereavement support to guide the research. This community also analysed and advanced the research in line with their interpretations of the data collected and advised on the presentation of these findings in this thesis.

However, small scale qualitative research projects are not generalisable, and the research presented in this thesis is no different. Participants were selected using purposive or self-selecting sampling, both methods which limit the generalisability of the data gathered due to their unrepresentative nature (Sharma, 2017; Lavrakas, 2008). However, this research did not set out to be either generalisable or representative, but rather sought expert participants who met a particular set of criteria (p. 83 and p.96) to explore the phenomenon of bereavement support from their own lived experience. Utilising purposive and self-selecting sampling allowed such participants to be recruited quickly and with limited bias (Etikan *et al*, 2016), in order to provide the research with the rich data needed to undertake the interpretive narrative analysis presented in this thesis. In doing so, this research does provide useful findings which the learning disability sector should utilise in the future. However, it must be acknowledged that these findings have come from a non-ethnically diverse and highly educated population.

Furthermore, the views of people with learning disabilities, other than those who advised the study, have not been addressed in this research, which is something that needs to be addressed in future research.

9.5 Recommendations

As a result of the conclusions that have been drawn from the research data presented in this thesis, there are a number of recommendations which could help these findings influence future practice. Of course, a number of the conclusions require large, systematic and cultural changes to occur within learning disability support services and research, which are not going to happen quickly. However, the small and practical recommendations listed here may help bring about a step change that will prompt the larger changes to occur in the future.

9.5.1 Recommendations for Support Services

- Support services need to take heed of the findings of this research and put protocols in place to ensure support staff feel supported by their superiors when issues of grief and bereavement occur in the work place.
- Conversations about death should become part of someone's support relationship. When someone moves into a new home, or has a new PA, a conversation about how to manage grief and bereavement should take place just as conversations about palliative care are now common place within many support organisations.
- In a bid to improve both the confidence of support staff, and the culture of not allowing support staff to engage in emotional support work, training is recommended. However, this training must be provided in situ and be specific to the context in which the support is likely to be given. Remote, generic training will not be beneficial to support staff or the current situation within support services.

9.5.2 Recommendations for People with Learning Disabilities

- People with learning disabilities need support to develop their social networks outside of their paid support networks. Doing so will help increase their

confidence in understanding issues, such as bereavement and grief, and in their ability to ask for help when they need it.

The creation of an exclusive Death Café, which provides a safe and friendly environment to discuss the issues of death, grief and bereavement, for people with learning disabilities is one of the ways to facilitate this happening.

- Few studies have been done which explore the bereavement support experiences of people with learning disabilities directly. This needs to change to ensure that the developments and recommendations of studies about bereavement support are reflective of the wishes of those in receipt of this support.

9.5.3 Recommendations for Research

- Inclusive participatory approaches need to be used more widely within social research especially within projects which focus on the support, services and lives of marginalised groups of people, such as people with learning disabilities.

Having the voices of both those who receive support and those who provide it, guiding the research process adds a depth and richness to the research outcomes, which would not be there without their input. Their presence also helps ensure the impact of the research is upon those it concerns as they have access to these populations in a way 'traditional' research does not.

- Research funders and hosts, such as Universities, need to adjust their systems, protocols, and guidance to allow different groups with different communication needs to take control of research process without the need for interpreters.
- Research into bereavement support for people with learning disabilities needs to be carried out with a focus upon the views of people with learning disabilities themselves. To date, there is little work in this area which provides them with a voice in the research landscape.

- One participant alluded to the cross-social care learning that could be done between older people's services and learning disability services. This could be a beneficial avenue to explore in future research.

Epilogue

The research presented in this thesis was born from the personal and professional journey I had gone on as a learning disability support worker and PA in the years preceding its completion. I had worked with a number of people who had suffered bereavements during my time with them but had been unable to support them effectively due to my inexperience and the culture within the organisations I worked for. For many years I carried a great sense of guilt about the part I played in these situations and wanted to conduct this research as both a remedy to these feelings and to ensure that other support workers and/or PAs don't have to experience them in the future.

Of course, it can be argued, and probably will be by some, that due to my ontological position this research is biased and therefore not valid. However, accusations of researcher bias plagues much qualitative research (Smith and Noble, 2014) and I believe that by providing an honest discussion of my position at the beginning of this thesis helps allay some of these claims for readers. Furthermore, I hope that the discussion of my position as an insider of the world being researched makes it clear that this is one of this research's greatest strengths. By sharing an identity with research participants, applying appropriate data collection methods (semi-structured narrative interviews and an online questionnaire) and carrying out interpretative narrative analysis on their data not only makes this research valid and reliable, it also provides a unique insight into the currently under researched world of bereavement support for people with learning disabilities as understood by those providing this support within intimate care relationships.

As well as the valuable insight this research provides the wider world, the impact it has had upon my professional sense of self has been far greater than I could have imagined at the outset.

The research presented in this thesis today, is somewhat different to that which I envisaged seven years ago at the project's outset. My decision to employ a group of people with learning disabilities as research advisors and individuals with support work experience as co-researchers, allowed the research to evolve from my original ideas to the wonderfully detailed and intricate work described in this thesis. Working together in this way has allowed us to unpick the issue of bereavement support for people with

learning disabilities in a way not previously seen in academic or professional literature, which may be beneficial to those working in the learning disability field. It is my intention to ensure that the research reaches support workers and PAs to who may be feeling isolated and alone when issues of bereavement arise in their working lives. I say this, as I have found talking to other support workers and PAs about the issue of bereavement support has allowed me to see that I am not alone in feeling like I haven't done quite enough when supporting someone through a bereavement in the past, and this has given me strength. I will endeavour to make sure this research reaches them.

As well as not feeling alone, I would like other support workers and PAs to read this research or its outputs and realise that the reason they maybe feel this way is because of the culture they work in. Through unpicking the experiences of the support workers and PAs involved in this research, the issue of power, which appears to so greatly affect support workers and PAs confidence, has been uncovered. Uncovering this issue exposed part of my identity as a support worker that I was not aware of; the knowledge that I was quite often the best person to make a judgement on the bereavement support someone I was working with needed but was relatively powerless to provide this support due to the prevailing culture in my workplace. Hearing similar experiences being spoken about by a number of other support worker and PA participants, and confirmed by those who saw themselves as working higher up the 'professional hierarchy', really struck a chord with me.

Exposing this part of myself allowed me to reflect on the guilt I had been carrying about the bereavement support I had given in the past in a new way. The sense of personal responsibility I had assigned to the feeling could be set free to a certain extent, as I realised that the culture, both within the organisations I worked for and the field I was working in more generally, would not have allowed me to do much more than I had as it did not see me as being capable of it.

This realisation had a transformative effect on me and as a result, I have chosen to leave my previous role as a PA within a traditional setting and now work within a variety of inclusive and co-produced research projects with people with learning disabilities at NFCDS. I made this change as I experienced first-hand the impact inclusive research can have in driving forward cultural change within the adult social care workforce.

Without the methodology I employed to complete this research and the findings it has uncovered, I do not think I would have grown in strength and confidence in the way I have and I do not think I would have the career I now have. For this, I am extremely grateful, and I will forever be indebted to both my co-researchers Ben and Rowena; and my advisory group Julian, Kerrie and Lisa. As well as each of my Supervisors who have supported me along my journey, especially Professor Val Williams who has been by my side from start to finish, as well as Anna Marriott and Professor David Abbott who have both been wonderful Supervisors at different stages of my work.

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Appendix

Appendix

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Please note that the documents presented in this appendix are in their original format.

Appendix One Ethics Form

SCHOOL FOR POLICY STUDIES: RESEARCH ETHICS COMMITTEE APPLICATION FORM

- This proforma must be completed for each piece of research carried out by members of the School for Policy Studies, both staff and doctoral postgraduate students.
- See the Ethics Procedures document for clarification of the process.
- All research **must** be ethically reviewed before any fieldwork is conducted, regardless of source of funding.
- See the School's policy and guidelines relating to research ethics and data protection, to which the project is required to conform.
- Please stick to the word limit provided. Do **not** attach your funding application or research proposal.

Key project details:

1. Proposer's Name

2. Project Title

3. Project start date End date

Who needs to provide Research Ethics Committee approval for your project?

The SPS REC will only consider those research ethics applications which do not require submission elsewhere. As such, you should make sure that your proposed research does not fall within the jurisdiction of the NRES system:

<http://www.nres.nhs.uk/applications/approval-requirements/ethical-review-requirements/>

If you are not sure where you should apply please discuss it with either the chair of the committee or the Faculty Ethics Officer who is based in RED.

Currently NRES are not expected to consider applications in respect of activities that are not research: ie. clinical audit, service evaluation and public health surveillance. In addition REC review is not normally required for research involving NHS or social care staff recruited as research participants by virtue of their professional role. Social care research projects which are funded by the Department of Health, must always be reviewed by a REC within the Research Ethics Service for England. Similarly research which accesses unanonymised patient records must be reviewed by a REC and NIGB.

Do you need additional insurance to carry out your research?

Whilst staff and doctoral students will normally be covered by the University's indemnity insurance there are some situations where it will need to be checked with the insurer. If you are conducting research with: Pregnant research subjects or children under 5 you should email: insurance-enquiries@bristol.ac.uk

In addition, if you are working or travelling overseas you should take advantage of the university travel insurance.

Do you need a Criminal Records Bureau Check?

Please see the current guidance to determine whether you are required to obtain a CRB check:

<http://webarchive.nationalarchives.gov.uk/+http://www.homeoffice.gov.uk/publications/agencies-public-bodies/crb/about-the-crb/eligible-positions-guide?view=Binary>

If you think you need a CRB check, employed staff should contact Personnel, all students should check the University counter signatories page for information: <http://www.bristol.ac.uk/secretary/legal/disclosure/countersigns.html>

4. If your research project requires REC approval elsewhere please tell us which committee, this includes where co- researchers are applying for approval at another institution.
Please provide us with a copy of your approval letter for our records when it is available.

N/A

5. Have all subcontractors you are using for this project (including transcribers, interpreters, and co-researchers not formally employed at Bristol University) agreed to be bound by the School's requirements for ethical research practice?

Yes

No/Not yet

Not applicable

X

Note: You must ensure that written agreement is secured before they start to work

6. If you are a PhD/doctoral student please tell us the name of your research supervisor

Dr Val Williams and Anna Marriott

ETHICAL RESEARCH PROFORMA

The following set of questions is intended to provide the School Research Ethics Committee with enough information to determine the risks and benefits associated with your research. You should use these questions to assist in identifying the ethical considerations which are important to your research. You should identify any relevant risks and how you intend to deal with them. Whilst the REC does not comment on the methodological design of your study, it will consider whether the design of your study is likely to produce the benefits you anticipate. **Please avoid copying and pasting large parts of research bids or proposals which do not directly answer the questions.** Please also avoid using *unexplained* acronyms, abbreviations or jargon.

1. **EXPECTED DURATION OF RESEARCH ACTIVITY:** Please tell us how long each researcher will be working on fieldwork/research activity. For example, conducting interviews between Feb 12 – July 2012. Also tell us how long participant involvement will be. For example: Interviewing 25 professional participants X2 for a maximum of 1 hour per interview.

The proposed project will employ a Community Action Research (C.A.R) approach. As a result, research activities will begin at different stages for different members of the research community.

The research community will consist of a research advisory group of adults with learning disabilities, a group of co-researchers who are employed as support workers in the learning disabilities field and myself. These groups are central to the project as I aim to understand how bereavement support is done from those working at the front line of practice. Providing support workers with the opportunity to conduct research will provide professional insight into bereavement support work, allow a shared identity with research participants to develop and give them with a voice in the research and professional literature. The research advisory group will advise on the research questions from their lived experience and assist with the dissemination of the findings using 'easy-English' and pictures.

Below are details of the roles each community member will take on within the project.

Victoria Mason

Part-time PhD student and research facilitator leading all aspects of the project.

Research Advisory group

The research advisory group will consist of 3 people with learning disabilities who are associates of NFRC. This group will be asked to attend a advisory group meeting once every 3 months for the duration of the research project (7 meetings in total). These meetings will not last longer than 2 hours at any one time. The role of the advisory group will be

- to provide co-researchers with informal training on conducting research inclusively;
- to advise on the questions to ask participants;
- to assist with writing an 'easy-English' report of the research findings;
- to assist with the dissemination of this report

These points will be agreed by the group and I at our first meeting and documented in the Research Advisory Group Research Agreement.

Co-researchers

A group of 3-4 support workers who are employed in the learning disabilities field will meet with me once a month for the duration of the research project (19 meetings in total). These meetings will not last longer than 2 hours at any one time. Some of this group will be offered the choice of collecting data by assisting with focus groups and/or interviewing

participant support workers. The roles and responsibilities of the co-researchers within the proposed project will be agreed by the co-researchers and I at their first meeting and documented in the 'Co-researchers Research Agreement'

Participants

We aim to recruit 10 – 12 participants from the South West Region who will take part in a short series (2-3) of small focus groups (5-6 participants) and in-depth qualitative interviews. Each data collection session will last no longer than 2 hours at any one time.

2. **IDENTITY & EXPERIENCE OF (CO) RESEARCHERS:** Please give a list of names, positions, qualifications, previous research experience, and functions in the proposed research of all those who will be in contact with participants.

1. Victoria Mason

Qualifications

PhD Student (part-time)

Post Graduate Diploma in Social Research Methods (pending 2012)

MA Social Policy (with Merit)

BSc (Hons) Social Care with Psychology (1st class)

NVQ Level 3 Promoting Independence

Research Experience

I have undertaken two small scale studies as part of my BSc and MA degrees. In these studies survey, observation and in-depth qualitative interview data were collected and analysed utilising SPSS software and thematic analysis. In my paid employment at the University of Bristol, I have run a small focus group for people with learning disabilities as part of the Office for Disability Issues 'Fulfilling Potential' project and assisted three individuals with learning disabilities to plan a collaborative piece of research. I have also supported these individuals to participate in a number of projects around the UK including; attending focus groups, being interviewed and completing questionnaires.

Professional Experience

I have worked as a support worker in the field of learning disabilities for the past 11 years. I have worked in the UK and USA supporting individuals within residential, day centre, college, employment and vacation settings. The experience I have gained in these roles inspired the proposed project and provides me with an invaluable insight into the world of support work and gives me a shared identity with my co-researchers and participant

Function in Proposed Project

Within the proposed project I will be the research facilitator; I will work with my co-researchers to develop the research questions, the methods and the analysis to be undertaken. Furthermore, as I have research training and experience, it will be my job to assist the group to understand the relevant aspects of social research and apply them. As a PGR student, I have successfully completed my PG Diploma in social research methods over the last two years. I will make it clear to my co-researchers that I will share what I can of my knowledge with them and they will be invited to a one-day workshop run as the first part of the Inclusive Research unit in the MSc Disability Studies. This will not of course constitute a research qualification but the group will be given the opportunity to learn about routes into research methods training within the School for Policy Studies. To ensure that I am fully equipped to share my research knowledge with my co-researchers I will undertake a teacher training course within the Graduate School of Education in the autumn 2012.

As the research facilitator, I will also encourage my co-researchers to participate in discussions, promote mutual understanding and ensure shared responsibility is cultivated. I will endeavour to be 'content neutral' in this role to ensure inclusivity; however as the instigator of the research my role cannot be completely neutral.

2. Three or four co-researchers will be recruited to undertake the proposed project with me. These individuals will be recruited from Bristol based learning disabilities services that already have a working relationship with NFRC (Brandon Trust, Mencap, Home Farm Trust, and United Response). I will send a letter, with Val Williams and Anna Marriott's support, to the personnel development and training departments of these services, to introduce the project and seek permission to contact their support workers/personal assistants as potential co-researchers. With permission granted a 'Co-researcher Information Sheet' will be sent to support workers/personal assistants inviting them to an information session at the University. After individuals have attended the information session they will be provided with an 'Expression of Interest Form'. From the individuals who express an interest in becoming a co-researcher I will recruit a maximum of 4 co-researchers.

Qualifications

My co-researchers do not require specific formal or professional qualifications to take part in the project. Their membership in the learning disabilities support worker/personal assistant community, an interest in bereavement support and a desire to learn new skills are their 'qualifications' for taking part.

Research Experience

As highlighted in the previous section, my co-researchers do not have to have any specific research experience to take part in the project. Their role is to provide professional insight into support work and bereavement in the learning disabilities field and to share an identity with research participants. I will work with the group to identify areas where research training is needed and I will share what I can of my research knowledge with them. My supervisors (Val Williams and Anna Marriott) will be available to provide specific research training, such as interview technique, and the research advisory group will provide training on using 'easy-English'. The group will be invited to a one-day workshop which is run as the first part of the Inclusive Research unit in the MSc Disability Studies. This research training will not of course constitute a research qualification. If they wish, they will be given the opportunity to learn about routes into research methods training within the School for Policy Studies

Function in the Proposed Project

My co-researchers will work with me to develop the research questions, the methods to be applied to answer these questions, conduct the field work and carry out the analysis. There is a possibility that my co-researchers could know participants and the individuals they have supported through a bereavement. In order to limit this, participants will be recruited from outside the Bristol area, yet if they do know potential participants, they will be excluded from the study.

My co-researchers will also be involved in the dissemination of research findings within the university, to research participants and the wider fields of social care, social work, death and bereavement.

3. A Research Advisory Group of three adults with learning disabilities will also take part in the research. These individuals are associates of NFRC who have been involved in many research projects.

Qualifications

My Research Advisory Group do not have any formal research qualifications; their experience of living with a learning disability combined with the work they have done advising, conducting and teaching about learning disabilities research are their 'qualifications' for joining the group. Collectively the group have carried out research within NFRC such as the 'Getting good support' project with Val Williams; taught on the Inclusive Research module within the MSc in Disability Studies; and developed a video based dissemination webpage for NFRC research.

Research Experience

As highlighted above, all three individuals have advised on a number of research projects, carried out their own research, spoken at conferences about their research and taught on the MSc in Disability Studies.

Function in the Proposed Project

The advisory group will advise my co-researchers and I on aspects of the research project. They will assist with the research training before advising and commenting on the research questions, the conclusions drawn and the methods of dissemination. The group will be made fully aware of the sensitive nature of the proposed research from the outset and will be advised of the support they have available to them as associates of NFRC at the first group meeting. At the first Group meeting, the Group and I will complete and sign a Research Agreement listing our roles and responsibilities to one another and the project. The Group will not have contact with research participants however it is possible that they may know participants and those they have supported through a bereavement from their familiarity with local learning disability services. In order to limit this, participants will be recruited from outside the Bristol area and all data will be anonymised before the Group review it. However, if the Group identify participants and/or those they support they will not be included in the research.

3. **STUDY AIMS/OBJECTIVES [maximum of 200 words]:** Please provide the aims and objectives of your research.

Aim

The proposed project aims to explore how support workers support adults with learning disabilities through a period of bereavement.

Objectives

1. to explore support workers' experience and needs for training in bereavement support;
2. to involve and listen to support workers directly within an action research model;
3. to build a research community around the notion of bereavement support, to suggest ways of improving practice

Rationale

Research suggests that bereavement support for people with learning disabilities is 'at best inconsistent' (Read and Elliott, 2007) with some support workers unable to identify the impact bereavement has upon those they support (Dowling *et al*, 2006). Dowling *et al* (2006) therefore suggest the majority of support workers would benefit from bereavement training.

This suggestion raises questions about English society's view of bereavement and its assumptions about people with learning disabilities. The suggestion that support workers require bereavement training implies an inherent belief system and a 'correct' method of bereavement support. Furthermore, current research criticises support workers without providing them with a voice in the literature (Bloom, 2005).

This project aims to explore these points from the viewpoint of those working on the front line of practice. In the ever evolving social care system with its focus on evidence based practice, providing support workers with the opportunity to conduct as well as participate in the project will provide invaluable knowledge for the field.

Bloom, J. (2005). Breaking Bad News. In: G. Grant., P. Goward., M. Richardson and P. Ramacharan (eds). *Learning Disability: A life cycle approach to valuing people*. Berkshire: Open University Press

Dowling, S., Hubert, J., White, S., and Hollins, S. (2006). Bereaved adults with intellectual disabilities: a combined randomized controlled trial and qualitative study of two community-based interventions. *Journal of Intellectual Disability Research*, Vol. 50, (4), pp.277-287

Red, S. and Elliott, D. (2007). Exploring a continuum of support for bereaved people with intellectual disabilities: A strategic approach. *Journal of Intellectual Disabilities*. Vol. 11, (2), pp.167 – 181

4. **RESEARCH METHODS AND SAMPLING STRATEGY [maximum of 300 words]:** Please tell us what you propose to do in your research and how individual participants, or groups of participants, will be identified and sampled. Please also tell us what is expected of research participants who consent to take part (Please note that recruitment procedures are covered in question 8)

10 -12 participants who are support workers/personal assistants to adults with learning disabilities in the South West Region will be recruited for the project.

- Contact will be made with learning disabilities organisations who have a working relationship with NFRC to inform them of the project and seek their consent to contact their support workers/personal assistants as potential participants.

- Potential participants will then be sent an introductory P.I.S.
- Those who are interested in participating will contact me via the 'Expression of Interest' form attached to the introductory P.I.S.
- 10-12 participants will be selected from those who are interested in taking part. If only 10 or 12 individuals make contact they will be recruited. If more than 10 -12 individuals make contact each individual will be assigned a number and a maximum of 12 individuals will be selected at random.
- A P.I.S and consent form will be circulated to selected participants before data collection begins
- Consent will be gained from participants at the start of data collection. The P.I.S (Appendix 9) will be discussed prior to consent forms being signed to ensure it is understood and that participants are able to ask questions.
- Data will be collected from participants via a short series (2-3) of small (5-6) focus groups and in- depth qualitative interviews lasting no longer than 2 hours in length.
- The data will be analysed.
- The data will be taken back to participants for validation
- The findings will be written up
- PhD thesis submitted to the University of Bristol
- Dissemination of research findings to the field of learning disabilities, disability, death and bereavement via publication in professional and/or academic journal and presentation at professional and/or academic conferences.

5. **POTENTIAL BENEFITS AND TO WHOM: [maximum 100 words]** Tell us briefly what the main benefits of the research are and to whom.

The proposed research will benefit the learning disabilities field; providing professionals and academics with a broader understanding of how support workers support people with learning disabilities through a period of bereavement on a day to day basis and whether training is necessary and appropriate. It will further benefit the fields of disability, social work, social care, death, bereavement and counselling research and practice.

Furthermore, the research will benefit my co-researchers, their professional development and practice. They will develop research skills and bereavement knowledge that will transfer to practice and benefit the individuals they support and the services they work for.

6. **POTENTIAL RISKS/HARM TO PARTICIPANTS [maximum of 100 words]:** What potential risks are there to the participants and how will you address them? List any potential physical or psychological dangers that can be anticipated? You may find it useful to conduct a more formal risk assessment prior to conducting your fieldwork. The University has an example of risk assessment form

RISK	HOW IT WILL BE ADDRESSED
Participants may become upset when discussing bereavement	<ol style="list-style-type: none"> 1. Participants will be made aware of the potential risk in the P.I.S and consent form. 2. If participants do become upset data collection will be stopped and I will support them. 3. Participants will be provided with an information sheet at the end of the data collection process providing them with information about sources of support.
	<ol style="list-style-type: none"> 1. Participants will be informed of the nature of the

Participants may feel professional practice is judged

their study and the intended outcomes in the P.I.S and consent form.
2. Pseudonyms will be used to ensure confidentiality of identity.

the P.I.S and confidentiality of identity.

7. **RESEARCHER SAFETY [maximum of 200 words]:** What risks could the researchers be exposed to during this research project? If you are conducting research in individual's homes or potentially dangerous places then a researcher safety protocol is mandatory. Examples of safety protocols are available in the guidance.

My co-researchers and I will be required to reflect on our own professional experience of supporting people with learning disabilities through bereavement. Reflecting in this way may be distressing and could cause our own personal bereavement experiences to be brought up. At our first researchers meeting we will agree how we will support each other through this process. I will also provide my co-researchers with details of local counselling services they can contact should they feel they need professional support.

We will also be exposed to the experiences of participant support workers, which may be distressing. Furthermore, participants could become distressed whilst disclosing this information which could potentially put us at risk. Data will not be collected by a lone researcher to ensure safety. Focus groups and one-to-one interviews will be carried out on University premises and I will work with a co-researcher on all occasions.

The research advisory group may experience some distress in reflecting upon their bereavement experiences and in reviewing participant data. Group members will be made aware of this risk prior to agreeing to take part and as associates of NFRC will have access to the Staff Counselling Service should they require it. Furthermore, the group will never be alone when exploring research data, they will work with my co-researchers and I and all the data will be anonymised.

8. **RECRUITMENT PROCEDURES [maximum of 400 words]:** How are you going to access participants? Are there any gatekeepers involved? Is there any sense in which respondents might be "obliged" to participate (for example because their manager will know, or because they are a service user and their service will know), if so how will this be dealt with.

Accessing the 10-12 participants in the proposed project will be a two-tier process. Participants will be sought for their professional experience and skills from South West based learning disability services who have a working relationship with NFRC. Initial contact will be through their place of work with the individuals who run the work place (service providers/Managers) being gatekeepers (tier one).

My co-researchers and I will contact service providers to introduce the research project and seek consent from them to make contact with their support staff as potential participants. Recruiting participants from outside the Bristol area will reduce the likelihood of my co-researchers, the advisory group and I knowing participants and those whom they have supported through a bereavement.

With consent sought from the organisation, an introductory P.I.S will then be sent to their support staff/personal assistants (tier two). This P.I.S will provide information of the project and an 'Expression of Interest' in participation form.

Potential participant support workers will be aware of their employers giving permission for them to participate in the proposed project. There is therefore a concern that potential participants will feel obliged to take part in the study to protect their professional integrity. Participation will be entirely voluntary and confidential which will be made clear to all potential participants in the introductory P.I.S, P.I.S., and consent form and at the start of data collection.

9. **INFORMED CONSENT [maximum of 200 words]:** How will this be obtained? Whilst in many cases written consent is preferable, where this is not possible or appropriate this should be **clearly justified**. An age and ability appropriate participant information sheet (PIS) setting out factors relevant to the interests of participants in the study must be handed to them in advance of seeking consent (see materials table for list of what should be included). If you are proposing to adopt an approach in which informed consent is not sought you must explain in detail why this is not considered to be appropriate. If you are planning to use photographic or video images in your method then additional/separate consent should be sought from participants which adheres to the relevant data protection legislation.

Please tick the box to confirm that you will keep evidence of the consent forms (either actual forms or digitally scanned forms) in accordance with the data protection legislation, securely for ten years.

Written consent forms will be completed by all participants. This form will be circulated to those who express an interest in taking part in the project along with a P.I.S prior to them agreeing to take part. My co-researchers and I will go through the consent form and P.I.S. with participants prior to data collection to ensure it is understood and to provide participants with an opportunity to ask questions.

10. **DATA PROTECTION:** All applicants should regularly take the data protection on-line tutorial provided by the University in order to ensure they are aware of the requirements of current data protection legislation. University policy is that “personal data can be sent abroad if the data subject gives unambiguous written consent. Staff should seek permission from the University Secretary prior to sending personal data outside of the EEA”. Any breach of the University data protection responsibilities could lead to disciplinary action.

Have you taken the mandatory University data protection on-line tutorial in the last 12 months Yes
https://www.bris.ac.uk/is/media/training/uobonly/datasecurity/page_01.htm

Do you plan to send any information/data, which could be used to identify a living person, to anybody who works in a country that is not part of the European Union? Yes No
 (see http://www.ico.gov.uk/for_organisations/data_protection/the_guide/principle_8.aspx)

If YES please list the country or countries:

11. CONFIDENTIALITY AND ANONYMITY:

	YES	NO
All my data will be stored on a password protected server	X	
I will only transfer unanonymised data if it is encrypted (For advice on encryption see: http://www.bristol.ac.uk/infosec/uobdata/encrypt/device/)	X	
If there is a potential for participants to disclose illegal activity or harm to others you will need to provide a confidentiality protocol.	X	

Please confirm that you warned participants on the information and consent forms that there are limits to confidentiality and that at the end of the project data will be stored for 10 years on appropriate storage facility. <https://www.acrc.bris.ac.uk/acrc/storage.htm>

Confirmed

12. **SHARING DATA AND DISSEMINATION OF FINDINGS [maximum 200 words]:** Are you planning to send copies of data to participants for them to check/comment on? If so, in what format and under what conditions? What is the anticipated use of the data, forms of publication and dissemination of findings etc.? If you plan to archive your interview transcripts then ensure that consent is obtained.

Participant validation is vital in social research and the data collected in the proposed project will be returned to participants upon analysis before write-up and dissemination. Focus group data will be

taken back to the group for them to read, comment on and remove details they do not want to be included in the final report. The findings from one-to-one interviews will also be taken back to the individual participant for validation.

The validated findings will form the basis of my PhD thesis; published articles to be submitted to journals such as Learning Disability Practice, Journal of Learning Disability and Death Studies; and conferences related to the field, such as Learning Disability Today, Innovations in Qualitative Research Conference and Cruse Bereavement Annual Conference.

Research participants will consent to their data being used in this way and all data collected will be archived for 10 years, in accordance with data protection guidelines.

13. **ADDITIONAL INFORMATION:** Please identify which of the following documents, and how many, you will be submitting within your application: Guidance is given at the end of this document (appendix 1) on what each of these additional materials might contain.

ADDITIONAL MATERIAL	NUMBER OF DOCUMENTS:
Participants information sheet (s)	X
Consent form (s)	X
Confidentiality protocol	X
Researcher safety protocol	-
Recruitment letters/posters/leaflets	X
Photo method information sheet	-
Photo method consent form	-
Risk assessment form	-
Support information for participant	X
3 rd party confidentiality agreement	-
Other information	X

Please DO NOT send your research proposal or research bid as the committee will not look at this.

SUBMITTING & REVIEWING YOUR PROPOSAL:

To submit your application you should create a **single PDF document** which contains your application form and all additional material and submit this information to the SPS REC admin. Zaheda Tariq, Zaheda.Anwar@bristol.ac.uk
 If you are having problems with this then please contact Zaheda to discuss.

Your form will then be circulated to the SPS Research Ethics Committee who will review your proposal on the basis of the information provided in this single PDF document. The likely response time is outlined in the „Ethics Procedures“ document. For staff applications we try to turn these around in 2-3 weeks. Doctoral student applications should be submitted by the relevant meeting deadline and will be turned around in 4 weeks.

Should the committee have any questions or queries after reviewing your application, the chair will contact you directly. If the committee makes any recommendations you should confirm, in writing, that you will adhere to these recommendations before receiving approval for your project.

Should your research change following approval it is **your responsibility** to inform the committee in writing and seek clarification about whether the changes in circumstance require further ethical consideration.

Failure to obtain Ethical Approval for research is considered research misconduct by the University and is dealt with under their current misconduct rules.

What research tell us

The Past

For a long time it was thought people with learning disabilities did not grieve when someone they loved died.

Maureen Oswin wrote a book in 1981 about people with learning disabilities and grief.

This book showed that people with learning disabilities do grieve when someone they love dies.

But this book did not change how people with learning disabilities were supported when someone they loved died.

Now

People with learning disabilities are now seen as able to grieve when someone they love dies.

But how they grieve is still seen as '*different*' to how people without learning disabilities grieve.

Ideas about grief

There are lots of ideas about how people grieve when someone they love dies.

These ideas have only been looked at with people who do not have learning disabilities.

Research shows that 9 out of 10 people without learning disabilities will cope with the death of a loved one by talking to their friends and family.

Those people that don't cope with their loss in this way, suffer from **'complicated grief'**.

Complicated grief means that someone is still very sad for a long time after the person they love has died. Their sadness will affect their everyday life so they won't be able to go to college or work and seeing friends and family might be hard.

For people with **complicated grief** they will need to see a professional to help them. This might be a counsellor or a psychiatrist.

People with Learning Disabilities

Research shows that people with learning disabilities are more likely to experience **complicated grief** than those without learning disabilities.

The support people with learning disabilities get when someone they love dies is one of the reasons why they experience **complicated grief**.

Dr Sue Read has done a lot of research about the support people with learning disabilities get when they are grieving.

Sue says that people with learning disabilities do not always get the support they need.

She says that people who are paid to support people with learning disabilities do not do this part of their job very well.

Research done by other people has said the same thing.

Support staff and Personal Assistants

The research done by Dr Sue Read says that support staff need training about grief for people with learning disabilities.

She has done some work training support staff and has written about it.

She says that going on a training course made staff feel more confident in supporting people with learning disabilities when they are grieving.

Research done by other people has found the same thing.

But this research doesn't look at what support staff were doing when supporting people in times of grief before doing the training course.

And it doesn't look at the other ideas about grief that have been looked at for people without learning disabilities.

Dr Sue Read's research also doesn't look at how long support staff remember what they learn at the training course.

And it also doesn't look at how support staff use what they learn in supporting people through times of grief on a daily basis.

Appendix Three

Research Skills – Advisory Group

Research skills – training day outline

1. What are the important questions we want to ask?
2. Who do we want to ask these questions to?
3. How do we want to ask them? - focus groups, interviews (face-to-face/phone), questionnaire?
4. Where will we find them?
5. Who will ask them the questions? Vicky, Co-researchers?
6. What will we do with the answers?

Appendix Four

Co-researcher Recruitment Locations– First Round

Organisations

Brandon Trust
Home Farm Trust
Mencap
Mind
Options Support
WECIL

Social Media

Facebook

- Bristol PA Group
- The Misfits Theatre Company Page
- WECIL Page
- Mencap Bristol Page
- Bristol Mind Page

Twitter

- NFCDS Twitter Account
- School for Policy Studies Twitter account
- Victoria's personal/academic Twitter account

Forums

Choice Forum

Appendix Five

Co-research Recruitment Locations – Second Round

- NFCDS – MSc Student group via Professor Val Williams
- SPS - MSc Social Work Students via Dr Barbara Teater

Appendix Six

Interview Schedule

Indicative Interview Questions

About you

1. Who you are
 - a. How long have you worked with people with learning disabilities?
 - b. Where do you currently work?
 - c. What is your job title?
 - d. How long have you worked there?
 - e. How many people live there?
 - f. How many people do you support in an average day?
 - g. What type of learning disabilities do the people have?
 - h. If a PA, how many hours a week does the person you PA for receive?

2. Does your place of work have a bereavement and grief policy?
 - a. Yes - Do you know what it is? Is it useful? Have you ever used/referred to it?
 - b. No – Do you think it should? Would it be helpful?

If working in PA setting employed by one person: Have you talked about their feelings towards death and bereavement and the type of support they would like to have?

- a. Yes – can you tell me about that? How did the subject come up? How did you talk about it? How did that make you feel? What conclusions did you come to?
- b. No – Do you think this is something that would be good to talk about? How would you feel about bringing this up with them? How do you think the talk would go?

Bereavement support experience

3. Tell me about your experience of supporting someone with a learning disability through a period of bereavement
 - a. How long ago was this experience?
 - b. Who was this person?
 - i. Gender
 - ii. Age?
 - iii. Learning disability?
 - iv. Any other disability?
 - c. How long had you supported them prior to the bereavement?
 - d. Who had died?
 - e. How did they die?
 - i. Expected?
 - ii. Unexpected?
 - f. How did the person with learning disabilities find out?
 - i. Prepared?
 - ii. Told about it afterwards?
 1. Who told them?
 2. How were they told?
 - g. Involvement in the death
 - i. Did they go to the funeral?

- ii. Involved in other death rituals?
 - h. How involved were the persons family? Did this have an impact on the situation? Did it impact on how you supported them?
- 4. How did you support them?
 - a. What did you do?
 - b. Who else was involved? Family/Friends/other supporters?
 - i. How did this work?
 - c. How confident did you feel in doing this?
 - d. How did this make you feel?
 - i. Did you also know the person who had died? Were you grieving as well?
 - ii. How did you show your emotions to the people you were supporting? How did they respond to this?
 - iii. What support did you get from the place where you work?
 - 1. Was this helpful?
 - 2. Did you feel emotionally supported?
 - 3. Is there peer support where you work
 - iv. If a manager/senior role/PA self-managing – did you feel supported? Who supported you?
 - e. How do you think this support was received by the individual you supported? Was it helpful/not helpful? Could you have done it differently?
 - f. How was your relationship with the individual afterwards/?
- 5. What resources did you use –
 - a. personal/professional/physical?
 - b. Were the people with learning disabilities offered any support?
 - c. If the person who passed away was someone who lived in the same facility as the bereaved individual, how long was the bed empty?
 - d. How was this taken by everyone who lived there?
 - e. Should it have been longer/shorter?
- 6. What do think could be done to improve practice?
- 7. Had you ever had any bereavement or grief training prior to actually supporting someone?
 - a. Yes- What was this training? How long before doing it was it? Did you use anything you learnt in the training at the time? Have you had any more training since?
 - b. No – Do you think it could have been useful? What do you think the training could have covered? Have you received any training since? What did this consist of?
- 8. Have you supported anyone else?
 - a. Yes – how did your first experience help? Did you change anything?
 - b. No- What do you think you would do now if you did?

Appendix Seven
Online Questionnaire

1. Do you know adults with learning disabilities who have been bereaved?

- Yes – *Please go to questions 2*
- No - *Thank you for your time.*

2. Do you feel that you provided these individuals with support through their bereavement?

- Yes
- Yes, along with others
- No
- Not sure

3. What is your current job title?

4. Please tell us about your experience of supporting someone with a learning disability through a period of bereavement. If you have supported more than one person then please provide us with an overview of your experience.

5. Who had the person with learning disabilities lost to this bereavement?

- Family member
- Friend
- Housemate
- Colleague
- Other (*please specify*)

6. What involvement did the individual with learning disabilities have in any death rituals? i.e did they attend any religious ceremonies related to the death? Were they involved in any family rituals? Were they invited to be involved in these rituals but refused to take part?

7. Have you had any training about bereavement and grief in relation to your work?

- Yes – please go to question 8
- No - please go to question 12
- Not sure – please go to question 12

8. When did you do this training?

- Before you had to provide bereavement support
- During providing this bereavement support
- After providing the bereavement support

9. What did this training cover? (please tick all that apply)

- General grief theories
- General bereavement theories
- Grief theories in relation to people with learning disabilities
- Bereavement theories in relation to people with learning disabilities
- Practical tips on how to support someone with learning disabilities at this time
- Information about resources for people with learning disabilities
- Other (please provide details)

10. Was this training useful?

- Yes
- In part
- No
- Not sure

Please tell us why this was the case

11. Have you used anything you learnt in the training in your day to day work?

- Yes
- No
- Not sure

Please tell us why this was the case

Thank you for taking the time to answer these questions. Please go to question 14.

12. Would you like to receive any training?

- Yes – *please go to question 13*
- No – *please go to question 14*
- Not sure - *please go to question 14*

13. What would you like this training to consist of?

- General grief theories
- General bereavement theories
- Grief theories in relation to people with learning disabilities
- Bereavement theories in relation to people with learning disabilities
- Practical tips on how to support someone with learning disabilities at this time
- Information about resources for people with learning disabilities
- Other (*please provide details*)

Thank you for taking the time to answer these questions. Please go to question 14

Demographic information about you

14. Are you?

- Male
 - Female
 - Other (*please specify*)
-

15. What is your age?

- 18-24 years old
 - 25-34 years old
 - 35-44 years old
 - 45-54 years old
 - 55-64 years old
 - 65-74 years old
 - Other
-

16. What is your ethnic group?

Please choose 1 option that best describes your ethnic group or background

White

- English/Welsh/Scottish/Northern Irish/British
 - Irish
 - Gypsy or Irish Traveller
 - Any other White background, (*please specify*)
-

Mixed/Multiple ethnic groups

- White and Black Caribbean
 - White and Black African
 - White and Asian
 - Any other Mixed/Multiple ethnic background, (*please specify*)
-

Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, (*please specify*)

Black/ African/Caribbean/Black British

- African
 - Caribbean
 - Any other Black/African/Caribbean background, *(please specify)*
-

Other ethnic group

- Arab
 - Any other ethnic group, *(please specify)*
-

17. Do you consider yourself to have a disability?

- Yes
- No
- Prefer not to say

18. What is your sexual orientation?

- Heterosexual
 - Bisexual
 - Homosexual
 - Other *(please specify)*
-

- Prefer not to say

19. What is the highest level of education you have completed?

(If currently enrolled, what is the highest qualification you have received?)

- No schooling completed
- GCSE's/CSE's
- AS Levels
- A Level
- Trade/technical/vocational training *(please specify)*

-
- Bachelor's degree
 - Master's degree
 - Professional degree
 - Doctorate degree
 - Other (*please specify*)
-

Thank you for taking the time to complete this survey.

Appendix Eight

Social Media Used for Online Questionnaire Participant Recruitment

Organisations

Brandon Trust

Home Farm Trust

Mencap

Mind
Options Support
WECIL

Social Media

Facebook

- Bristol PA Group
- The Misfits Theatre Company Page
- WECIL Page
- Mencap Bristol Page
- Bristol Mind Page

Twitter

- NFCDS Twitter Account
- School for Policy Studies Twitter account
- Victoria's personal/academic Twitter account

Forums

Choice Forum

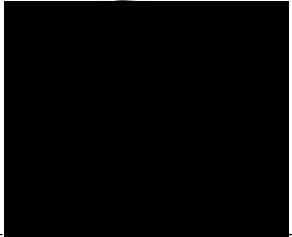
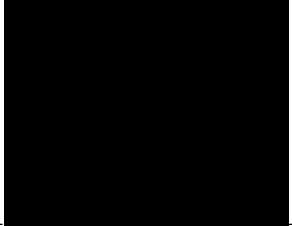
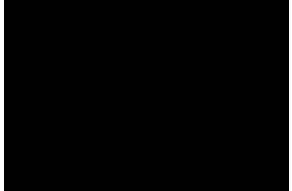
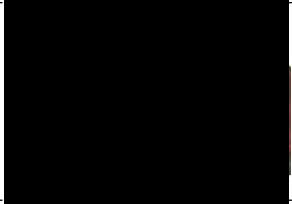
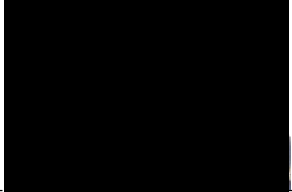
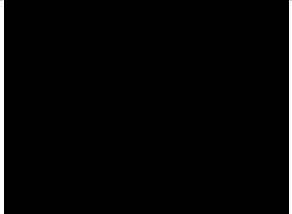
Appendix Nine

Advisory Group Information Sheet

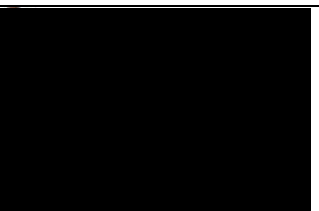
Bereavement Support for People with Learning Disabilities

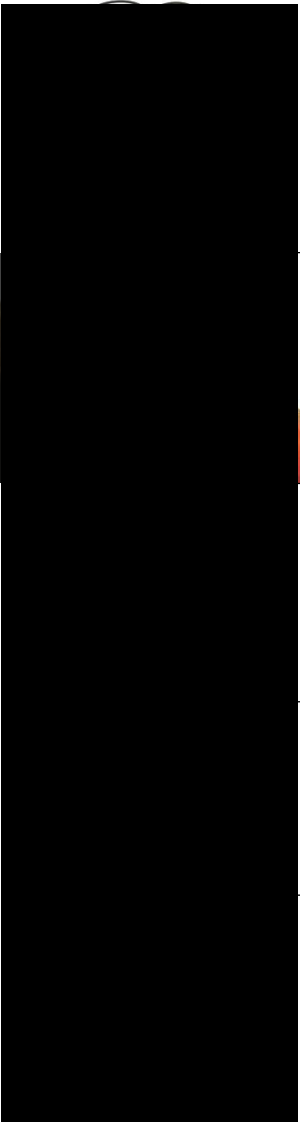
Information about the research

What is the research about?

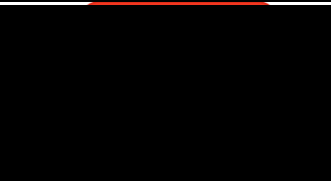
	<p>Vicky is doing some research about how people with learning disabilities are supported when someone they love dies</p>
	<p>She is doing this research as part of her studies at the Norah Fry Research Centre.</p>
	<p>Vicky will be doing this research with a group of Co-researches.</p>
	<p>Vicky and her Co-researchers will do some focus groups with Support Workers and Personal Assistants to find out about the work they do.</p>
	<p>Vicky will also talk to some of these people on their own.</p>
	<p>What people say will help us understand what support people with learning disabilities get when someone they love dies.</p>

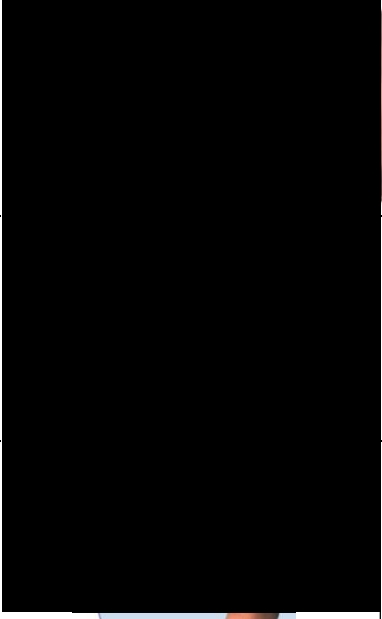
What can I do to help the research?

	<p>Vicky would like to set-up a Research Advisory group</p>
---	--

	<p>This Group will help Vicky and her Co-researchers think about how to do the research,</p>
	<p>They will help Vicky pick her co-researchers,</p>
	<p>They will help the researchers decide what questions to ask participants,</p>
	<p>They will help the researchers make sense of the information they get,</p>
	<p>And they will help the researchers get the information out to other people.</p>

What will taking part involve?

	<p>You will be asked to come to a meeting once every 3 months</p>
---	--

	These meetings will last for about 2 hours
	These meetings will be at Norah Fry Research Centre
	You will be asked to keep a diary about your time as a member of the Research Advisory group.

Is there anything I need to know?

	In the Meetings
--	------------------------

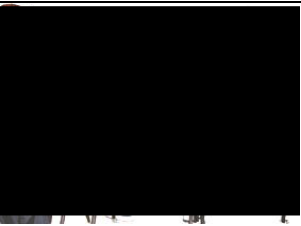
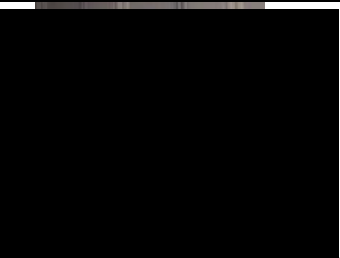
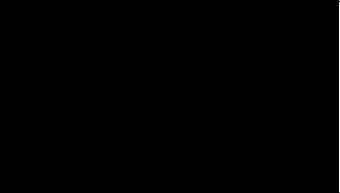
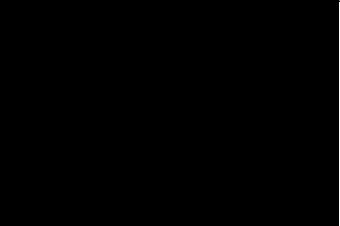
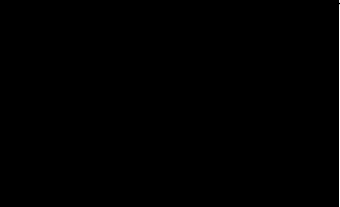
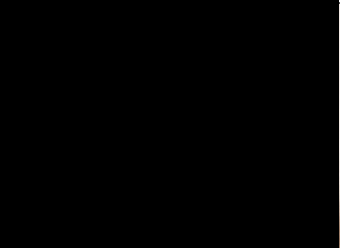
	<p>You will be asked to talk about how people with learning disabilities should be supported when someone they love dies.</p>
	<p>You will NOT be asked to talk about your own experiences of losing a loved one, but you may end up thinking of them.</p>
	<p>You may also hear some difficult stories from other people.</p>
	<p>This could make you upset</p>
	<p>Vicky will help you through this and stop the meeting. You will be able to leave the meeting if you need to.</p>
	<p>Vicky will give you a list of people who can help you after the meeting if you are still upset.</p>
	<p>You can stop being a member of the Research Advisory group at any time.</p>
	<p>The research meetings will be tape recorded. You can ask to have the recorder turned off at any time.</p>

	At the end of the research
	Vicky will write a report about the research.
	Vicky may use parts of what is said in the research meetings in the report.
	Vicky will ask you for some words from your research diary to use in the report.
	Your name will not be used in the report and Vicky will check what she writes with you before she hands in the report.
	The report will be handed in to the Norah Fry Research Centre at the end of the research.
	Some shorter pieces might also be written about the research and published. Vicky will check what she writes with you before anything is published.

What will I get for taking part?

	Vicky will pay for your transport to and from the meetings
	Vicky will provide food and drink at each of the meetings
	Vicky will give you a diary to write about your time doing the research.
	Vicky will give you Agendas, minutes and notes from each meeting
	Vicky will mention the work you did in the research report that she hands in to the Norah Fry Research Centre.
	Vicky will help you to write something about the research to be published
	Vicky will help you to speak at a conference about the research

What should I do now?

	<p>If you think you might like to become a Research Advisory group Member, please come to a meeting on...</p>
	<p>Vicky will tell you more about the research at this meeting.</p>
	<p>You will be able to ask Vicky more about the research at this meeting.</p>
	<p>Coming to this meeting does not mean you have to become a Group member unless you want to.</p>
	<p>Vicky will pay for your transport to and from the meeting</p>
	<p>Vicky will provide food and drink at this meeting.</p>

Appendix Ten

Co-researcher Information Sheet

Bereavement support for people with learning disabilities.

“People with learning disabilities are often left alone and isolated when someone they love dies, as the bereavement support available to them is at best inconsistent and at worst non-existent.”

(Read and Elliott, 2003).

Who I am

My name is Vicky Mason and I am completing my PhD into the bereavement support needs of adults with learning disabilities, at the Norah Fry Research Centre, University of Bristol. The Norah Fry Research Centre (NFRC) aims to make a positive difference to the lives of disabled children, young people and adults, particularly those with learning disabilities, through social, educational and policy related research.

I have 12 years professional and academic experience in the learning disabilities field, working with both adults and children here in the UK and abroad. I have also worked on a number of research studies that have explored issues which affect the lives of people with learning disabilities, their supporters and families.

To complete my PhD, I am looking to work with a group of individuals who have supported someone with a learning disability and a group of people with learning disabilities, to undertake my research with me.

I am currently looking to recruit individuals who would be interested in becoming a **co-researcher** to my study. I feel it is important to work in this way as front line support workers don't have a voice in the research literature and I would like my research to begin to change this. I am looking for people who:

- are currently or have been employed to support someone with a people with learning disability,
- have experience of supporting someone with a learning disability through a period of bereavement.
- would be able to come to a 2 hour research meeting, at the Norah Fry Research Centre, University of Bristol, once a month for 12 months, from **April 2014** to **March 2015**. The times and locations of which will be negotiated.

Co-researchers will work with me to recruit participants; plan, organise and facilitate focus groups with participants and analyse the findings. They will also be involved in the dissemination of the research to people with learning disabilities, their families and supporters.

What do we already know about bereavement support for people with learning disabilities?

Research into the bereavement support needs of people with learning disabilities suggests that those who are paid to support individuals do not detect or accept the impact bereavement has upon them. These studies suggest that this is due to support workers and personal assistants lacking the knowledge and skills to support someone effectively at a time of loss.

As a result, **some** death and bereavement education programs have been introduced for support staff. These programs appear to have been successful, with many paid supporters stating that they felt better equipped to support someone with a learning disability through bereavement at the end of the program.

But these education programs raise a number of interesting questions about society's view of bereavement and its assumptions about people with learning disabilities. For example, suggesting that paid supporters require training implies that people with learning disabilities experience grief differently to those without and that there is a 'correct' method of supporting them through bereavement. Furthermore, these studies fail to explore what paid supporters do on a daily basis during in a time of bereavement, before criticising their knowledge and skills.

What does this research aim to do?

My research aims to:

- explore what paid supporters do on a daily basis when supporting someone with a learning disability through bereavement.
- take the experiences of paid supporters to explore the issue of bereavement education programs for people with learning disabilities and what should be done for the future.
- Provide paid supporters with a voice in the research literature by creating a research community around the notion of bereavement support, in which they are employed to inform knowledge and future practice.

More information

What can I do to help the research?

I am looking for a small group of people who are currently employed or have been employed to support someone with a learning disability, to become co-researchers to assist her in completing the research.

Co-researchers will help me to collect data from participant support workers, personal assistants and those employed within supported living establishments.

Together we will recruit participants, plan and facilitate focus groups, jointly analyse the data and draw some conclusions on what we have found out.

A group of adults with learning disabilities, who are associated with NFRC, will form a reference group for the study. We will work with this group during the planning and analysis stages of the research.

What will being a co-researcher involve?

If you would like to become a co-researcher, this will involve coming to a research meeting once a month for the duration of 2014. We will negotiate the best times for these meetings to fit with everyone in the group.

The majority of these meetings will be held at NFRC, at the University of Bristol. However, some meetings may take place at another location in the Bristol area during the data collection phase. This location will be selected to meet the needs of everyone involved in the research, including you and the participants.

I will also ask you to keep a research diary of your time working on the project. This is good practice when undertaking social research as it allows you space to reflect and explore things that interest about the process. At the end of your involvement in the research, I will ask you to share some parts of this diary with me. You will have full control over the sections you choose to share with me. I will use these sections to explore how carrying out research collectively has affected the group and the study itself.

What else do I need to know?

Being a co-researcher could be distressing. Whilst you will not be asked to directly share your experiences of supporting people through a bereavement or your own bereavement experiences the things we are talking about may cause you to think about these things.

If you feel unable to take part in a particular meeting due to its contents, then you can leave at any time. I will help you in any way that I can at this time, and will provide you with details of people who help you after the meeting if you are still upset. Furthermore, you can choose to stop being a Co-researcher at any time and for whatever reason.

The research meetings will be tape recorded, but you can ask for this to be turned off at any time.

I will be writing a thesis about the research that I will submit to the University of Bristol to complete my PhD. I might use some of the things that are discussed in the research meetings in my thesis. I will show you what I am going to write in my thesis and you will have the chance to remove or change anything that you do not want to be reported. I will not use your name in the thesis.

Some shorter pieces might also be written about the research and published. I will again check with you what I write and you will be able to remove or change anything that you do not want to be published. Again, your names will not be used in anything that is reported.

What will I get for taking part?

I can't pay you for your time spent working as a co-researcher. However, I can pay you for any travel expenses you incur as a result of taking part. I will also provide you with refreshments at each meeting.

I will provide you with all the physical materials you will need to be involved in the research, such as a research diary.

I will introduce you to members of the NFRC team and if you would like to discuss the research degrees they offer with them, you will have the chance to have these conversations.

I will acknowledge the work you do in the thesis I submit to the University of Bristol for the completion of my PhD.

I will work with you to write an article about our experience of carrying out the research together. I will then work with you to submit this article to various academic and professional journals and conferences for possible publication.

What should I do now?

If you think you would like to become a co-researcher in this research project, please contact Vicky to confirm your attendance at the meeting on **March 12th 2014**

This will be an introductory meeting where you will be able to discuss the research and what taking part will involve. Coming to this meeting does not mean that you are committing to becoming a co-researcher. If you decide that you would rather not take part, that is fine and you can let Vicky know at any time.

Telephone Number: [REDACTED]

Email: mhvam@bristol.ac.uk

Appendix Eleven
Advisory Group Consent Form

Bereavement support for people with learning disabilities: PhD Research Study.

Research Advisory group Consent form

Tick

	I have read the Information Sheet about this research.	<input type="checkbox"/>
	I have talked to Vicky about the Information Sheet and have been able to ask questions about the research.	<input type="checkbox"/>
	I understand that this is a piece of research that Vicky is doing as part of her studies at the Norah Fry Research Centre.	<input type="checkbox"/>
	I understand the information about the research and would like to be part of the Research Advisory Group	<input type="checkbox"/>
	I agree that Vicky can record what I say at our research meetings, but I can ask her to turn off the recorder at any time.	<input type="checkbox"/>
	Vicky will keep the recording of what I say in a safe place.	<input type="checkbox"/>
	I will keep a research diary about my time in the Research Advisory Group	<input type="checkbox"/>
	I understand that some of the things I say in the research meetings and write down in my research diary might be used in the report Vicky writes about the research. I will be able to check	<input type="checkbox"/>

[Redacted]	what Vicky writes in the report before she hands it in and my name will not be used.	
	I understand that some shorter pieces might be written and published about the research. I will be able to check what Vicky writes before it is published and my name will not be used.	<input type="checkbox"/>
	I understand that I can change my mind about being in the Research Advisory Group at any time.	<input type="checkbox"/>
[Redacted]	I know that I will not be paid for being a member of the Research Advisory Group, but will have any travel costs paid for.	<input type="checkbox"/>



Name (please print)



Signed.....

Date.....

Appendix Twelve

Co-researcher Consent Form

**Bereavement support for people with learning disabilities:
PhD Research Study.**

Co-researchers

Consent form

Tick

	I have read the Information Sheet about this research.	<input type="checkbox"/>
	I have talked to Vicky about the Information Sheet and have been able to ask questions about the research.	<input type="checkbox"/>
	I understand that this is a piece of research that Vicky is doing as part of her studies at the Norah Fry Research Centre.	<input type="checkbox"/>
	I understand the information about the research and would like to be a Co-researcher	<input type="checkbox"/>
	I agree that Vicky can record what I say at our research meetings, but I can ask her to turn off the recorder at any time.	<input type="checkbox"/>
	Vicky will keep the recording of what I say in a safe place.	<input type="checkbox"/>
	I will keep a research diary about my time as a co-researcher	<input type="checkbox"/>
	I understand that some of the things I say in the research meetings and write down in my research diary might be used in the report Vicky writes about the research. I will be able to check what Vicky writes in the report before she hands it in and my name will not be used.	<input type="checkbox"/>

	I understand that some shorter pieces might be written and published about the research. I will be able to check what Vicky writes before it is published and my name will not be used.	<input type="checkbox"/>
	I understand that I can change my mind about being in a co-researcher at any time.	<input type="checkbox"/>
	I know that I will not be paid for being a co-researcher, but will have any travel costs paid for.	<input type="checkbox"/>



Name (please print)



Signed.....

Date.....

Appendix Thirteen
Co-research Literature

Bereavement and Grief

“Grief is a universal part of the human experience”
(Floyd, 2008).

Grief is a universal, but unique phenomenon (Nagraj and Barclay, 2009). We will all experience periods of bereavement in our lives and will grieve for these losses in a personal way (Gilbert,

1996). Bereavement is commonly defined as the process of suffering after loss, whilst grief is the psychological, emotional and physical response to this loss (Kübler-Ross, 1969). Our culture, gender and belief structures are often predetermining factors to the grief we feel (McCabe, 2003). As is our relationship to the object we have lost and how it was lost (Tesik, 2013).

The demonization of death

Death has been removed from Western society through the introduction of medical intervention, and as a result has become an obscenity not to be discussed in polite company (Gorer, 1955). This has led to British society having a poor dialogue with death (Kübler-Ross, 1969). We are exposed to death in the literature we read and the media we consume (Smith, 1995) but when we experience death within our own social circle we are

“...without adequate guidance as to how to treat death and bereavement and without social help in living through and coming to terms with the grief and mourning which are inevitable responses in human beings to the death of someone whom they have loved.”
(Gorer, 1977, p.110)

Society's poor dialogue with death is likely to affect the way people with learning disabilities experience grief, as those who support them do not engage with the taboo subject in conversation (Ryan *et al*, 2010).

A study carried out by Ryan *et al* (2010) suggests that people with learning disabilities often require conversations about death to take place in order to ensure they understand it and the feelings of grief they may experience should they experience it. However, this study found that the participating support staff lacked an understanding of the importance of these preparation conversations. Instead spending their time facilitating the emotional expressions of grief presented by individuals when a death occurred (Ryan *et al*, 2010).

Models of Grief

In a bid to understand the grieving process, a number of models of grief have developed over time and across disciplines. Each of these models highlight the uniqueness of grief and the range of potential responses (Parkes, 1996). No one model presides over the other, with most suggesting that the bereaved need to engage with their loss and work through it, so that life can be reordered and made meaningful again (Dent, 2005).

The Psycho-analytic model (Freud, 1917) is the most widely known, as is Kubler Ross's (1969) stage model. However, there is also Bowlby and Parkes (1970) Phases of grief model, the Four Tasks model (Worden, 1991) and the Dual Process Model (Stroebe and Schut, 1995). The Dual Process Model focuses on grief as a dynamic process, in which the bereft alternate between focusing on the loss of the person who has died (loss orientation) and avoiding that focus (restoration orientation). 'Loss orientation' incorporates the 'grief work', whilst 'restoration orientation' involves dealing with secondary losses as a result of the death, such as losing a home. Within this Model, both 'orientations' are said to be necessary for future adjustment but the importance and prevalence of each, depends upon on the circumstances of the death, personality, gender and cultural background of each bereft person. This model will guide this study.

Bereavement and Grief for people with learning disabilities

Whilst the majority of the non-learning disabled population do not require specialist support after they have suffered a loss, some authors (Elliott, 1995; Read and Elliott, 2007) argue that people with learning disabilities are more likely to require this support due to their marginalised status in British society.

Marginalised sectors of society, such as people with learning disabilities, often experience a disenfranchisement of grief as their ability to publicly mourn is not widely supported (Doka 1989). Taken together with the reluctance to hold open discussions about death, grief is not acknowledged openly at all (Conboy-Hill, 1992). Oswin (1991) terms this the 'double taboo' of death and disability, which often sees the expressions of grief made by people with learning disabilities assigned to their disability, rather than their grief.

Until as recently as 1989 (Hollins and Kloeppel, 1989) people with learning disabilities were thought to be unable to grieve at the time of bereavement (Dodd and Guerin, 2009). Oswin set out to challenge this assumption, in her seminal book 'Am I allowed to cry?' (1991), which concluded that people with learning disabilities feel the same emotions as the non-learning disabled population in times of bereavement.

It is now widely accepted that people with learning disabilities grieve at the time of bereavement (Reynolds *et al*, 2008) and that their emotional responses to grief do not differ to those of other people (Stoddart *et al*, 2002). Yet, they are still often 'forgotten' when issues of death arise (Read and Papakosta-Harvey 2004, p.192), due to society's inability to acknowledge their emotional lives (Arthur, 2003)

Supporting people with learning disabilities through a period of bereavement

Bereavement support for people with learning disabilities in the UK is said to be 'at best inconsistent and at worst non-existent', with those employed in the field said to be perpetuating this situation (Read and Elliott, 2007, p.177).

A randomised control trial carried out by Dowling *et al*, (2006), found that paid support workers are unable to identify the emotional needs of those they support and the impact bereavement has upon their lives (Dowling *et al*, 2006). This finding replicates the criticisms made by Oswin (1991) more than two decades ago.

Both Oswin (1991) and Dowling *et al* (2006) recommend support staff receive bereavement training in order to improve the service they provide. Whilst the intention of this recommendation is seen as an attempt to improve service provision, it does raise some interesting questions about how bereavement, grief and learning disability are viewed in society. For example, suggesting that support staff can be trained to undertake bereavement support, implies an inherent belief system to which all of society assigns and that this is the 'right' system in which to support people with learning disabilities.

Furthermore, the suggestion that attending a bereavement training course will improve staff knowledge of bereavement for the remainder of their career is not supported by empirical evidence. A randomised control trial carried out by Watters *et al* (2012), found that attending a one day bereavement training course did improve the knowledge of support staff immediately after the course, but conclusions for the longer term impact of this training could not be drawn.

Whilst Oswin (1991) and Dowling *et al* (2006) suggest that support staff have limited knowledge of how to support someone with a learning disability through a period of bereavement, this is based on limited evidence. Relatively little is known about the

bereavement support front line support staff do on a daily basis (Bloom, 2005), as only a small body of research has highlighted details of this work.

Studies carried out by Mencap (2007 and 2012) and Heslop *et al* (2013) suggest that learning disabilities support staff do acknowledge the bereavement needs of those they support, but are let down by the guidance and resources available to them. Additionally, the research carried out by Gilrane-McGarry and Taggart (2007), suggests that front line support staff are well equipped to provide practical bereavement support, such as involving individuals in funeral arrangements.

Yet, despite the evidence that some support staff do engage with bereavement support, many people with learning disabilities are still widely referred to grief counselling services after they suffer a loss (as highlighted above). This may be the result of support staff being let down by the resources available to them (Mencap, 2007 and 2012; Heslop *et al*, 2013), leaving them relatively little choice but to refer individuals to those deemed to have the most appropriate 'professional' knowledge at this time.

Support work

As the previous section highlights, the work of frontline support staff in the learning disabilities field is constantly scrutinised. A key agenda of this scrutiny relates to the notion of 'professionalism' (GSCC, 2010). Whilst professional regulation is commendable and indeed required in some areas of the field, it does not appear to translate well to what is known about effective bereavement support and the increasingly individualistic framework of social care. The voices of those working at the front line of services express an awareness of the 'professionalism' agenda. For example, one PA states that he sees his role as being a 'professional shadow' to the individual he works for (Clayton, 2006, p.137). The use of the term 'shadow' here fits within the personalisation agenda as it places the PA in service to the individual he works for. But the term 'professional' seems to juxtapose this relationship, detaching him from the individual he works for, when he is likely to be a key member of their social network.

Statements such as these highlight a fear amongst support staff, employed as PA's or in more traditional support worker roles, of acknowledging that in working for someone with a learning disability that you become an inevitable part of their social network. Being a supporter is to engage in a social relationship, 'it can only be undertaken in the context of another person' (Payne, 2005, p.184).

Research carried out by Williams *et al* (2009) highlights the importance of personal relationships in support work, especially for PA's. The people with learning disabilities interviewed in this study acknowledged that they became part of their PA's social network and said that this was an important part of their support relationship. However, the PA's interviewed in this study, raised concerns about the impact this relationship had on their 'professional boundaries' (Williams *et al*, 2009, p.7).

Williams *et al*'s (2009) study also found that when sensitive matters arose in their support relationship, they frequently took on the role of 'educator' (Williams *et al*, 2009). This casting presents a paradox within the personalisation agenda, as it requires the PA to assume a position of power, rather than the power being in the hands of the person with the learning disability.

Work stress and burnout

Supporting someone with a learning disability through a period of bereavement is an emotionally taxing task for support staff, which is likely to increase their work related stress levels (England, 2005). As alluded to, support workers and PA's often have to draw on their own emotional resources to support those they are in service to, as they are under resourced by their places of work (Mencap, 2007 and 2012; Heslop *et al*, 2013). This situation is likely to increase their work related stress levels, which will in turn impact the support they are able to provide.

Work stress is suggested to occur when the demands of an individual's job exceeds their internal and external resources to do that job (Folkman *et al*, 1987), whilst 'burnout' is a psychological syndrome that occurs in response to chronic, uncontrollable work stress (Maslach, *et al* 2001).

Literature from the learning disabilities field suggests that a third of direct care workers experience work related stress levels indicative of the presence of a mental health problem (Hatton and Emerson, 1993). The work of England (2005), which for the first time draws together the emerging theories of care work, suggests that this situation can be understood within the 'Commodification of emotion' framework as it highlights the emotional harm care work does to those carrying it out. This is concerning when considered in light of providing bereavement support as, as Weinberg *et al* (1983) states

"What makes burnout such a serious problem is not necessarily the fact that it is experienced by a relatively large percentage of the workforce, but that it is experienced more readily by the type of person most valued as a human service provider"
(p.251).

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Appendix Fourteen

Advisory Group Research Agreement

This document enlists the roles and responsibilities of each member of the Research Advisory Group. The list was drawn up by the group at their first meeting on 22nd November 2013

Vicky

- Vicky will lead the research
- You can contact Vicky:

Monday – Friday
10am and 4pm.
(0117) 331 0983



- Vicky will only contact you on the days and times that you provide her with.
- Vicky will arrange meetings with each member so they take place on a day and at a time that suits all of us.
- If a meeting has to be cancelled or changed, Vicky will let you know as soon as possible.
- Vicky will provide information about the meetings in a way that suits you.
- Vicky will try her best to explain things clearly to you.
- Vicky will provide information in the meeting in a way that suits you.
- Vicky will record what is said in the meetings. You can ask Vicky to turn off the recorder at any time and she will.
- Vicky will keep the recording of the meetings in a safe place.
- Vicky will use some of the recordings in the final report she writes about the research to be handed in to the Norah Fry Research Centre. She will check what she has written with you before the report is submitted and she will not use your name.

- Vicky will give you a research diary which she would like you to keep and record anything that interests you about the research.
- Vicky may use some of the words from your research diary in the final report she writes to be handed in to the Norah Fry Research Centre. She will check the words she uses with you before the report is submitted and she will not use your name
- Vicky will also keep a research diary about her experiences of working in the Research Advisory Group. Vicky will use some words from her diary in the final report she will hand in to the Norah Fry Research Centre.
- Vicky may write some shorter reports about the research to be published. She may use some of the recordings and words from the research meetings and diaries in these reports. She will check the words she uses in these before she hands them in and she will not use your name.
- If you become upset in our meetings, Vicky will stop the meeting, turn off the Dictaphone and provide you with any support you need.
- Vicky will provide you with information about people who can help you if you are upset.
- Vicky will stick to the rules that the group have created together.
- Vicky will bring drinks and snacks to the meetings.
- Vicky will pay for your transport to get to the research meetings.
- Vicky will try and help you write something about this project to be published.

- Vicky will try and help you speak at a conference about this project.
- When the work is finished, Vicky will provide members of the group with the executive summary and the plain language report.

The Group

- You will come to a meeting every 3 months (7 meetings in total)
- You will provide Vicky with details of days and times when she can contact you to arrange meetings.

Kerrie – busy every day but will reply to messages and get back to you, Monday – Friday

Julian – any day is OK to contact, and will call back if not about.

Lisa – Monday to Thursday.

- You will only contact Vicky on the days and times that she has given you.
- You will tell Vicky what the best days and times are for meetings to be held.
- If you cannot come to a meeting, you will let Vicky know as soon as possible.
- You will tell Vicky what the best way is to give you information
- You will read, with help if needed, any information Vicky sends you before a meeting. Vicky to work with Lisa on making sure she understands this information.
- You will stick to the rules that have been created by the group.
- You will keep a research diary about your experiences of being in the Research Advisory Group. You will let Vicky have some words from the diary that you are happy to share in the final report. Your name will not be used in the report and you will be able to check what Vicky writes before the report is handed in.
- You will also let Vicky have some words from the diary that you are happy to share in some shorter reports that might be published. Your name will not be used in these reports and you will be able to check what Vicky writes before the reports are published.
- If anyone becomes upset in a meeting, you understand that the meeting will be stopped and the individual will be supported.

- You will help Vicky choose some support workers and/or personal assistants who will work with her as Co-researchers in this research.
- You will help Vicky train her Co-researchers
- You will help Vicky and her Co-researchers write the questions to ask participants.
- You will help Vicky and her Co-researchers work out what it all means.
- When the research is finished, you will help Vicky tell other people about the research.

Signed.....

Print.....

Signed.....

Printed.....

Signed.....

Printed.....

Signed.....

Printed.....

Date.....

Appendix Fifteen
Advisory Group Ground Rules

These rules were written by the Research Advisory Group at their first meeting on 22nd November 2013.

1. Only one person to talk at a time.

2. We will be respectful to one another's thoughts, views and experiences.

3. If anyone wants to have the recorder to be turned off at any time we will be respectful of this and turn it off.
4. Anything that we say in the meeting, stays in the meeting room. We are not to repeat anything we say to anyone not involved in the research project.
5. We are talking about a difficult subject, people might become upset during in the meeting. We need to respect this and be considerate. People need to be given time to work through their experiences.
6. We will take a break in the meetings. The timing of the break will be decided at the start of the meeting, but more informal breaks will happen as and when we as a group feel it is needed.
7. Any snacks and drinks at the meetings will be shared equally between us all. Each meeting will have a cake made by Vicky.
8. Mobile phones to be switched off or on silent. Only to be on if needed for someone.

Appendix Sixteen

Co-researcher Recruitment Poster – First Round

Interested in research about bereavement?

Want to carry out research that will inform practice?

If the answer to either of these questions is 'yes' then you are invited to an introductory research meeting on

Wednesday 26th February 2014

From 5- 7pm

**School for Policy Studies Common Room
8 Priory Road, Bristol, BS8 2AW**

Everyone who comes along will have their travel expenses paid for.

There will be Refreshments at this meeting

What is the research about?

Vicky Mason is a PhD student at the Norah Fry Research Centre and is carrying out a study into the **bereavement support needs of adults with learning disabilities**. Vicky is currently looking for a group of individuals who work with or have worked with adults with learning disabilities and have supported someone through a period of bereavement, to become **co-researchers** in the study.

Becoming a co-researcher will require you to commit to attending a 2 hour research meeting once a month for the duration of 2014. Being a co-researcher is not a paid position and is not a route to professional development; however, it will provide you with:

- Informal research training
- Experience of conducting a unique small scale qualitative research project
- Full acknowledgement in PhD thesis, and any academic and professional publications made.

If you think this is something you might be interested in then please come along to the meeting to find out more!

Appendix Seventeen

Co-researcher Recruitment Poster – Second Round

Interested in research about bereavement?

Want to carry out research that will inform practice?

If the answer to either of these questions is 'yes' then you are invited to an introductory research meeting on:

Wednesday 23rd April 2014

From 5- 7pm

**School for Policy Studies Common Room
8 Priory Road, Bristol, BS8 2AW**

Everyone who comes along will have their travel expenses paid for.

There will be Refreshments at this meeting

What is the research about?

Vicky Mason is a PhD student at the Norah Fry Research Centre and is carrying out a study into the ***bereavement support needs of adults with learning disabilities***. Vicky is currently looking for a group of individuals who work with or have worked with adults with learning disabilities and have supported someone through a period of bereavement, to become **co-researchers** in the study.

Becoming a co-researcher will require you to commit to attending a 2 hour research meeting once a month for the duration of 2014. Being a co-researcher is not a paid position and is not a route to professional development; however, it will provide you with:

- Informal research training
- Experience of conducting a unique small scale qualitative research project
- Full acknowledgement in PhD thesis, and any academic and professional publications made.

If you think this is something you might be interested in then please come along to the meeting to find out more!

Appendix Eighteen

Co-researcher Research Agreement

This document provides details the roles and responsibilities of each member of the Research Reference Group. It was drawn up by the group at their first meeting on Monday 2nd June 2014.

Vicky

- Vicky will lead the research

- You can contact Vicky:

Monday – Friday
10am and 4pm.



- Vicky will only contact you on the days and times that you tell her are convenient for you.
- Vicky will arrange meetings with you so that they take place at a time that is convenient for you.
- Vicky will send you any information you need to read for a meeting in good time. She will also send you copies of the minutes and any actions you need to complete after each meeting.
- If a meeting has to be cancelled or changed, Vicky will let you know as soon as possible.
- Vicky will record what is said in the meetings. You can ask her to turn off the recorder at any time and she will.
- If you become upset in our meetings, Vicky will stop the meeting, turn off the Dictaphone and provide you with any support she can.
- Vicky will keep the recording of the meetings securely. A digital version of the recordings will be stored on the University of Bristol's servers, as will a transcribed version of the recordings.
- Vicky will use some parts of the recordings in her PhD thesis. She will check what she has written with you before she submits her thesis. She will not use your name in the thesis unless you want her to.

- Vicky may use some of the words from your research diary in her PhD thesis. She will check the words she uses with you before the report is submitted and she will not use your name unless you want her to.
- Vicky will also keep a research diary about her experiences of working with you as Co-researchers. Vicky will use some words from her diary in her PhD thesis.
- Vicky may write some papers about the research to be published. She may use some of the recordings and words from the research meetings and diaries in these papers. She will check the words she uses in these papers before she hands them in and she will not use your name.
- Vicky will provide you with information about people who can help you after the meetings if you are upset.
- Vicky will provide refreshments at the meetings.
- Vicky will reimburse any travel expenses you incur as a result of being a co-researcher
- Vicky will endeavour to help you write something about the research to be published. This could be something related to findings of the research or the way we have carried it out together.
- Vicky will also endeavour to help you speak at a conference about the research. Again, this could be something related to findings of the research or the way we have carried it out together.

The Group

- You will come to 12 research meetings commencing in June 2014. These meetings will be once a month at a time and location convenient to you.
- You will provide Vicky with details of days and times when she can contact you to discuss the research.

- You will only contact Vicky on the days and times that she has given you (listed at the top of this agreement).
- If you cannot come to a meeting, you will let Vicky know as soon as possible.
- You will read any information Vicky sends you to read before each meeting.
- You will complete any actions assigned to you at a meeting for the designated completion date. If you realise you are not going to be able to complete the task in time, for whatever reason, you will let Vicky know as soon as possible.
- You will keep a research diary about your experiences of being a Co-researcher. You will let Vicky have some words from the diary that you are happy to share in her PhD thesis. Your name will not be used in the thesis, unless you want it to be, and you will be able to check what Vicky writes before she submits her work.
- You will also let Vicky have some words from the diary that you are happy to share in papers that might be published in research or professional journals. Your name will not be used in these reports, unless you want it to be, and you will be able to check what Vicky writes before the reports are published.
- If anyone becomes upset in a meeting, you understand that the meeting will be stopped and the individual will be supported.
- You will work with Vicky and the Research Reference Group of people with learning disabilities throughout the lifespan of the research. The Reference Group will advise us at key junctures in the research (participant requirement, research questions, analysis and plain language dissemination).

- When the research is finished you will help Vicky disseminate the research to people with learning disabilities, their families and supporters.

Signed.....

Print.....

Signed.....

Print.....

Signed.....

Print.....

Date.....

Appendix Nineteen
Co-researcher Ground Rules

These rules were written by the Bereavement Research Group at their first meeting on Monday June 2nd 2014

1. Anything that we say in the meeting stays in the meeting room. We are not to repeat anything we say to anyone not involved in the Bereavement Research Group.

2. We will be respectful to one another's thoughts, views and experiences. This includes not cutting someone off when they are speaking.
3. We are talking about a difficult subject; it is possible that we might become upset during our researchers meetings. We need to respect this and be considerate to one another.
4. If anyone wants the Dictaphone to be turned off at any time we will be respectful of this and Vicky will turn it off immediately.
5. We will take a break in the meetings. The timing of the break will be decided at the start of the meeting, but more informal breaks will happen as and when we as a group feel it is needed.

Appendix Twenty

Interview Demographic Questionnaire

We would be really grateful if you would fill in this questionnaire about who you are and where you work. We are collecting this information to help us set the scene for bereavement support in the learning disabilities field and for no other purpose.

You do not have to answer any of the questions if you do not wish to. Please leave any questions you do not want to answer blank.

1. Are you? *(please specify)*

- Male
 - Female
 - Other *(please specify)*
-

Prefer not to say

2. What is your age?

- 18-24 years old
- 25-34 years old
- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65-74 years old
- Prefer not to say

3. What is your ethnic group?

Please choose 1 option that best describes your ethnic group or background

White

- English/Welsh/Scottish/Northern Irish/British
 - Irish
 - Gypsy or Irish Traveller
 - Any other White background, *(please specify)*
-

Mixed/Multiple ethnic groups

- White and Black Caribbean
 - White and Black African
 - White and Asian
 - 8. Any other Mixed/Multiple ethnic background, *(please specify)*
-

Asian/Asian British

- Indian
 - Pakistani
 - Bangladeshi
 - Chinese
 - Any other Asian background, *(please specify)*
-

Black/ African/Caribbean/Black British

- African
 - Caribbean
 - Any other Black/African/Caribbean background, *(please specify)*
-

Other ethnic group

- Arab
 - Any other ethnic group, *(please specify)*
-

4. Do you consider yourself to be disabled?

- Yes
- No
- Prefer not to say?

5. What is your sexual orientation?

- Heterosexual
- Bisexual
- Homosexual

- Pansexual
 - Asexual
 - Other (*please specify*)
-

- Prefer not to say

6. What is the highest level of education you have completed?
(*If currently enrolled, what is the highest qualification you have received?*)

- No schooling completed
 - GCSE's/CSE's
 - AS Levels
 - A Level
 - Trade/technical/vocational training (*please specify*)
-

- Bachelor's degree
 - Master's degree
 - Professional degree
 - Doctorate degree
 - Other (*please specify*)
-

7. How long have you worked with adults with learning disabilities? (*please specify*)

8. What is your current employment status?

- Employed full-time
 - Employed part-time
 - Self Employed
 - Other (*please specify*)
-

9. Who do you currently work for?

- A support service provider
 - An individual/individuals using direct payments
 - A Direct payments support provider
 - Other *(please specify)*
-

10. What is your current job title? *(please specify)*

11. Have you ever received any bereavement or grief training in your role?

- Yes *(please go to questions 12)*
- No *(please go to question 14)*
- Not sure *(please go to question 14)*

12. What did this training consist of? *(please describe)*

13. Have you used anything you learnt at this training in your work?

- Yes *(please tell us a little about what you have used in the space below)*
- No
- Not sure

Thank you for taking the time to complete this questionnaire

14. Would you like to receive training around this issues of grief and bereavement?

- Yes *(please tell us why in the space below)*
- No *(please tell us why in the space below)*
- Not sure

Thank you for taking the time to complete this questionnaire

Appendix Twenty-One
Interview Participant Recruitment Email

Subject: Bereavement support for adults with learning disabilities – request for interview participants

Dear...

We are the Bereavement Support Research Group based at that the Norah Fry Research Centre, University of Bristol. We are currently working on a research project entitled “Bereavement Support for Adults with Learning Disabilities”. This project aims to explore how bereavement support for adults with learning disabilities is done from the viewpoint of those who work at the front line of practice.

The research is being carried out as part of a PhD project being undertaken by Victoria Mason. Victoria is therefore the lead researcher in the project, but she is working with a research community of support workers and people with learning disabilities to conduct the research.

The research has received ethical clearance from the University of Bristol's School for Policy Studies Research Ethics Committee (available on request) and is supervised by Dr Val Williams and Professor David Abbott, Norah Fry Research Centre.

We are currently looking to recruit 10 -12 support workers/personal assistants to participate in the study. As a leading learning disability service provider/learning disability practitioner (*deleted as appropriate*) who has worked with NFRC in the past, we are writing to you to ask permission to contact your support workers (via an introductory information sheet, enclosed) to participate in the study/to ask you to consider taking part in this research by reading the enclosed information sheet (*deleted as appropriate*).

In agreeing to participate we will be asking support workers/you (*deleted as appropriate*) to attend a 60 minute in-depth qualitative interview with Victoria.

We would not ask participants/you to take time away from their/your paid employment to attend these sessions and we will reimburse them/you for their/your travel expenses (*deleted as appropriate*).

We would be grateful if you could take the time to read the enclosed research information sheet and contact Victoria via one of the methods listed on this sheet regarding your organisations/your involvement in the study.

Kind Regards

Victoria Mason and Bereavement Support Research Group

Appendix Twenty-Two
Interview Participant Recruitment Leaflet

Who We Are

My name is Victoria and I am a part-time PhD student at the Norah Fry Research Centre. I have 14 years' professional experience in the learning disability field both here in the UK and USA. I began my career as a support worker but currently work as a Personal Assistant.

I developed my PhD topic whilst working as a support worker within a day service for people with learning disabilities. I am passionate about understanding how support staff provide bereavement support and doing research which influences future practice.

In this project I am working with two co-researchers who have experience of supporting people with learning disabilities. Three individuals with learning disabilities are also advising the project.

This research has received ethical approval from the University of Bristol's School for Policy Studies Research Ethics Committee and is being supervised by Dr Val Williams.

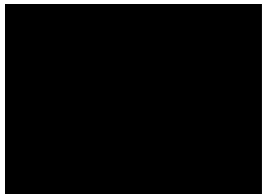
Contact Me

NFRC, 8 Priory Road
Bristol
BS8 1TZ

Email: mhvam@bristol.ac.uk

Web: <http://www.bristol.ac.uk/norahfry/about/contact/vicky-mason.html>

Bereavement Support for Adults with Learning Disabilities



University of
BRISTOL

**A PHD STUDY AT THE
NORAH FRY RESEARCH
CENTRE**

Being a Participant

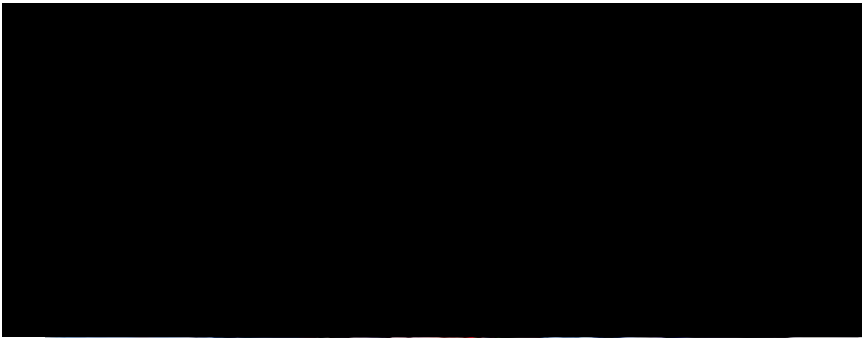
Experience

In order to participate in this research, we ask that:

- **You have worked as a support worker or personal assistant to someone with a learning disability**
- **Have supported someone (over the age of 18) with a learning disability through a bereavement**

What it will involve

Participating in this study will involve being interviewed by Victoria Mason for about an hour. She will ask you about your experience of supporting someone with a learning disability through a period of bereavement, and will explore any issues that have arisen from your experience.



The research literature suggests that support staff need to undertake training about grief for people with learning disabilities in order to improve practice (Reynolds *et al*, 2008). A small number of studies have been carried in line with this recommendation. For example, Read and Elliott (2007) conducted a study with a small group of support staff who were surveyed before and after receiving some bereavement and grief training. Results showed that receiving training improved staff confidence in their ability to support someone with a learning disability through a period of bereavement. However, studies like these do not look at what support staff were doing when supporting people in times of grief before undertaking any training. They also fail to look at how long support staff remember what they learn in training or how they use what they learn in supporting people through times of grief on a daily basis. This PhD study aims to address these omissions by exploring what support staff know about bereavement and how they provide bereavement support on a daily basis.

People with Learning Disabilities



Research shows that people with learning disabilities are more likely to experience complicated grief than those without learning disabilities.

The support people with learning disabilities get when someone they love dies is widely cited as one of the reasons why they experience complicated grief.

Dr. Sue Read has done a lot of research about the support people with learning disabilities get when they are grieving. Her work suggests that people with learning disabilities do not always get the support they need as the people who are paid to support them do not know how to support them.

Other research done in this emerging field, has demonstrated similar findings (such as Dowling *et al*, 2006).

The Research

Bereavement support for people with learning disabilities in the UK is described as 'at best inconsistent and at worst non-existent' (Read and Elliott, 2007). Research suggests that support organisations fail to provide appropriate bereavement support to people with learning disabilities (Murray *et al*, 2000) as front line support staff, are unable to identify the impact bereavement has upon those they support (Dowling *et al*, 2006, Read and Elliott, 2007). However, much of this research fails to explore the tacit knowledge support workers have about bereavement and how they put this into practice.

Research Aims

This PhD study aims to shed light on the knowledge and skills support staff have about bereavement and those they support. The study further aims to provide support workers with a voice in the research literature by:

- building a research community around the notion of bereavement

The Literature

For a long time it was widely thought that people with learning disabilities did not grieve at the time of bereavement

In 1981 Maureen Oswin began to change this, in her seminal book 'Am I allowed to Cry?' This book demonstrated, from Oswin's professional experience, that people with learning disabilities do grieve at the time of bereavement.

As a result of Oswin's book and subsequent work in the field, it is now

Theories about grief

There are lots of different theories about grief and how we experience it. The majority of these theories have been developed and applied to people who do not have learning disabilities.

Research shows that 9 out of 10 people without learning disabilities will cope with the death of a loved one by talking to their friends and family. For those people who do not cope with their loss in this way, they experience a period of 'complicated grief'.

Complicated grief results from the feelings of loss not improving over time and becoming debilitating. Painful emotions associated with grief are long lasting and severe and make it difficult to accept the loss of the individual who has died. People who experience complicated grief may also not be able to resume living their own life after their loss.

People who experience complicated grief will often need to seek professional help from a counsellor or psychiatrist.

Appendix Twenty-Three

Interview Participant Information Sheet

Research Title

Bereavement Support for Adults with Learning Disabilities

Who is carrying out the research?

Victoria Mason, a PhD student at the Norah Fry Research Centre, University of Bristol, is the lead researcher. She has a group of co-researchers working with her, each of whom have worked in the learning disabilities field. The project is supervised at the University of Bristol by Dr Val Williams and Professor David Abbott and has received full ethical approval from the University of Bristol's School for Policy Studies Research Ethics Committee (available upon request).

The research is being advised by an advisory group of people with learning disabilities who are all '*experts by experience*'. These individuals are also familiar with conducting research as they have all worked on projects carried out in the Norah Fry Research Centre over the past few years.

Victoria, her co-researchers and advisory group are working together to collect data, analyse it and disseminate the findings to the University of Bristol and the broader fields of learning disabilities, disability, death and bereavement.

What is the research about?

The research aims to explore how support workers/personal assistants support adults with learning disabilities through a period of bereavement. Research suggests that bereavement support for people with learning disabilities in England is 'at best inconsistent and worse non-existent' (Read and Elliott, 2007) with some support workers unable to identify the impact bereavement has upon those they support (Dowling *et al*, 2006). Reynolds *et al* (2008) therefore suggest that the majority of support workers would benefit from bereavement training.

These findings raise a number of interesting questions about English society's view of death and bereavement and its assumptions about people with learning disabilities. The suggestion that support workers require bereavement training implies an inherent belief system and a "correct" method of bereavement support.

Furthermore, current research criticises support workers without providing them with a voice in the literature (Bloom, 2005).

This research aims to explore these issues from the view point of those working on the front line of practice.

What will I have to do?

If you would like to take part in this research, you will be interviewed by Victoria for about an hour and no more than an hour and a half. This interview will take place at a place and time that is convenient to you. Before being interviewed you will be asked to fill in a short form to record your demographic information and a few details about your professional experience.

The interview will explore your experiences of supporting someone with a learning disability through a period of bereavement. Victoria has a number of questions she would like to ask you, which have been created by her and the research community. However, it is hoped the interview will be loosely structured and will take shape as the conversation between you and Victoria develops around your experience of the research topic.

What is good about taking part in the research?

By telling the research community about the bereavement work you have done with the people you support will help inform the academic fields of learning disability, disability, death and bereavement, as well as inform professional practice. At the moment little is known about the work support workers/personal assistants do when someone they support suffers a bereavement. The information you can provide from your professional practice is therefore vital to broaden knowledge and understanding in the field.

Are there any risks to taking part?

Yes. Taking part in any research project presents participants with risks, but taking part in one which is exploring such a sensitive topic area is likely to raise a number of issues. Firstly, talking about your professional experiences of bereavement support may bring up the feelings you felt whilst supporting someone, this could be distressing.

Should you become upset or distressed at any time please let Victoria know and the interview will stop immediately. Victoria will then provide you with the support and information you require. The session will not continue (if at all) until you are ready to do so.

Secondly, talking about your professional experiences may bring up your personal experiences of bereavement. Again this can be distressing and upsetting, so please ensure you inform Victoria as soon as you feel you need to. Victoria will again support you as best she can and provide you with the information you require. The interview will not continue (if at all) until you are ready to do so.

Thirdly, it may feel at times as if your professional practice is being judged through some of the questions being asked in the interview. You can be reassured that it is NOT. This research is NOT AN EVALUATION so your practice and knowledge is not being tested or recorded.

You will be provided with an 'Exit Information Sheet' at the end of your interview, providing you with details of local and national organisations and charities which will be able to offer you support and guidance which reach beyond the scope of the research. Victoria will be happy to chat with you about matters directly related to the project, but will not be able to provide further professional or bereavement support at the end of the data collection process.

Will taking part cost me anything

No, taking part in the research will not cost you anything. Your interview and checking session will take place at a time and location convenient to you. Unfortunately, Victoria is not able to pay you for your time, but she will reimburse your travel expenses, up to a maximum of £30 per visit (£60 for the two visits) and refreshments will be provided.

Can I change my mind about taking part in the research?

Yes. Up until the **28th August 2015** you will be able to contact Victoria (via the contact details below) and withdraw from the research. You do not have to give a reason for this withdrawal. After the **28th August 2015** you will not be able to withdraw.

Norah Fry Research Centre
School for Policy Studies
University of Bristol
8 Priory Road
Bristol
BS8 1TZ

Tel No: [REDACTED]

Email: mhvam@bristol.ac.uk

What happens at the end of the research?

Victoria will write up the research findings in her thesis to complete her PhD at the University of Bristol. Upon completion this thesis will be available at the University of Bristol Social Sciences Library.

Victoria intends to work with her research community to write an article(s) to be published in professional and/or academic journals relevant to the fields of learning disabilities, disability, death and bereavement. It is also intended that the research community will work together to present the research findings at professional and/or academic conferences relevant to the fields of learning disabilities, disability, death and bereavement.

Can I check that what I say is recorded accurately?

Yes. Victoria will contact you once your interview has been transcribed and analysis has taken place. At this point, she will arrange to meet with you again (for about an hour) to go through the findings from the things you have said and check that you are happy that they are an accurate representation. Victoria will send you this information before meeting so you are able to thoroughly read it before meeting. You will be able to remove any details you are not happy with at this point.

Will my identity be kept confidential?

Yes. You will be able to choose a pseudonym at the start of the interview process to ensure that your identity is unknown to those reading Victoria's PhD thesis and/or any other dissemination publications. However, you should be aware that those who read the report who work in the service you work for may be able to identify you.

Furthermore, it is advisable to use a pseudonym for the individuals with learning disabilities that you talk about in the data collection process, to ensure their identities are protected. Victoria will check this with you during the interview and on your second meeting.

If you do not choose a pseudonym for yourself or those you talk about in your interview, Victoria will do this for you to ensure your identities are protected. Victoria will check this with you during the interview and on your second meeting.

Will confidentiality ever have to be broken?

Yes, there are occasions where confidentiality may have to be broken. Should you tell Victoria anything which she feels highlights abuse or raises concern about the support given to people with learning disabilities, such as; your professional conduct, the conduct of those in your work place or any other matter, she will have to break confidentiality.

Should an issue arise, Victoria will take the information to Dr Val Williams at the University of Bristol. It will be Dr William's decision as to what happens next. Should this occur you will be informed and involved in the process as appropriate.

Data storage

Your interview will be recorded on a Dictaphone. This recording will be stored on the University of Bristol's secure network. This recording will be transcribed and this too will be stored on the University of Bristol secure network. Neither of these documents will be worked on outside the university network and will never be taken off site.

The demographic information sheet you complete at the start of the interview will be stored securely on the University of Bristol premises.

The data will be held for 10 years in line with University regulations and the Data Protection Act 1998.

If I don't understand something who can I ask?

If you do not understand something, please ask Victoria during the interview. She will do her best to answer your questions and provide you with clearer information.

If you have any questions after the interview please contact Victoria

Norah Fry Research Centre
School for Policy Studies
University of Bristol
8 Priory Road
Bristol
BS8 1TZ

Tel No: [REDACTED]

Email: mhvam@bristol.ac.uk

If you have any further questions and/or would like to speak to someone at the University of Bristol you can contact:

Dr Val Williams
Norah Fry Research Centre
School for Policy Studies
University of Bristol
8 Priory Road
Bristol
BS8 1TZ

Tel No: [REDACTED]
Email: val.williams@bristol.ac.uk

References

Bloom, J. (2005). Breaking Bad News. In: G. Grant, P. Ramacharan, M. Flynn, and M. Richardson (eds.) (2005). *Learning Disability: A life cycle approach to valuing people*. Berkshire: Open University Press

Dowling, S., Hubert, J., White, S., and Hollins, S. (2006). Bereaved adults with intellectual disabilities: a combined randomized controlled trial and qualitative study of two community-based interventions. *Journal of Intellectual Disability Research*, 50, (4), pp.277-287

Read, S., and Elliott, D. (2007). Exploring a continuum of support for bereaved people with intellectual disabilities: A strategic approach. *Journal of Intellectual Disabilities*, 11(2), pp. 167-181

Reynolds, S., Guerin, S., McEvoy, J., and Dodd, P. (2008). Evaluation of a Bereavement Training Program for Staff in Intellectual Disabilities Service. *Journal of Policy and Practice in Intellectual Disabilities*, 5, (1), pp.1-5

Bereavement Support for Adults with Learning Disabilities

The Research Community

Victoria Mason (PGR Dip Social Research Methods, MA, BSc) has worked with adults with learning disabilities for the past 14 years. She has worked at NFRC as Personal Assistant to the Centre's Information Officer (who has learning disabilities); has experience in facilitating focus groups and interviewing people with learning disabilities within a research setting; and has worked as a Research Assistant on number of research projects within the Centre.

Victoria is the lead researcher in this project as the research is being undertaken to complete her PhD at NFRC. However, Victoria has a research community working with her on the project:

Co-researchers

Two co-researchers are working with Victoria to complete this research. Both individuals have worked in the learning disabilities field in the past, and one has experience of working within bereavement and grief services for members of the general public.

Both co-researchers are also undertaking their Masters in Social Work within the School for Policy Studies, University of Bristol. As a result, they have a broad understanding of the issues which sit at the root of this research and are developing their research skills both within their degree programme and by working on this project.

Research Advisory group

The research is being advised by an advisory group of people with learning disabilities. The group is made up of three individuals who have been associated with NFRC for the past 10 years; Julian Goodwin, Kerrie Ford and Lisa Ponting. They are all '*experts by experience*' as they have each been supported through a period of bereavement by professional carers.

Each group member is also familiar with the process of carrying out research as they have all been involved in a number of research projects carried out at the Centre. They have conducted interviews, facilitated focus groups, analysed data and been involved with the dissemination of research to people with learning disabilities, their families and supporters.

This group have been involved in this project from shortly after its creation. They have guided the recruitment of the co-researchers (mentioned above); advised on data collection methods; and the questions to be asked. They will also be involved in the analysis of data and dissemination of the projects findings.

Research Supervisors

The research is being supervised by two academics within the Norah Fry Research Centre:

Dr Val Williams (PhD, M Ed, BA)

Val joined NFRC in 1997, as a research assistant on a project about family carers. During this time she carried out her own PhD which was an analysis of discourse based on an inclusive research project with people with learning disabilities.

Val is now a reader in Disability Studies, and is the Head of Norah Fry Research Centre.

Her research output includes projects about: families and carers, direct payments support, work and employment issues, community based day activities, mental health support needs of young people with learning disabilities, financial issues for people with learning disabilities, accessible information, Further Education for young people with learning disabilities, commissioning for new forms of support, and communication skills of personal assistants, in working with direct payments users with learning disabilities.

Professor David Abbott (LLB, MPhil, MSocSc)

David has worked at NFRC since 1999 having previously worked at Loughborough University and a London Health Authority carrying out social policy research. Much of his work has focused on issues for disabled children and young people – as well as their families and the services that support them. He has an interest in transition to adulthood, multi-agency working, and disabled children who live away from home in residential settings such as schools and colleges.

Another area of interest for David is around gay, lesbian and bisexual people with learning disabilities – their experiences, the barriers they face and the ways in which they overcome them.

Finally, David has a long standing interest in how families in the whole population think about their economic security and the risks they face in maintaining it. His work in this area has been carried out in partnership with colleagues at the Centre for Housing Policy, University of York.

Appendix Twenty-Four
Interview Participant Consent Form

Bereavement
Support for Adults with Learning Disabilities
A PhD research study
Consent form

		Tick
	I have read the information sheet about this research.	<input type="checkbox"/>
	I have been given the chance to ask the researcher(s) questions about this information.	<input type="checkbox"/>
	I understand this information and would like to participate.	<input type="checkbox"/>
	I agree to complete the Participant Questionnaire at the start of the interview. I understand that completing this information won't be tape recorded.	<input type="checkbox"/>
	I agree that the researcher(s) can record what I say, but I can ask for the recorder to be switched off at any time.	<input type="checkbox"/>
	I understand that the researcher(s) will transcribe the recording of what I say and will bring this back to me to check that it is ok before writing about it in the research.	<input type="checkbox"/>

	<p>I understand that the researcher(s) will keep the record of what I say in a safe place. Any identifying information about me (participant questionnaire, this consent form), will be stored separately to the recordings so my identity will remain anonymous. This is in accordance with the Data Protection Act 1998.</p>	<input type="checkbox"/>
	<p>I understand that Victoria Mason will write about what I have said within her PhD thesis. She will not use my name or any identifying features within it.</p>	<input type="checkbox"/>
	<p>I understand that Victoria Mason and her co-researchers and/or advisory group may write about what I have said in various research dissemination materials. Again, I understand that my name or any identifying features will not be used within these materials</p>	<input type="checkbox"/>
	<p>I have been given the opportunity to choose a pseudonym to be used in the research report for both myself and those I talk about. I understand that if I do not choose any pseudonyms, Victoria will choose them for me so that our identities are kept confidential.</p>	<input type="checkbox"/>
	<p>I know that I can change my mind about taking part in this research until the 28th August 2015 and that I do not have to have a reason.</p>	<input type="checkbox"/>

Name (please print)

Your telephone number

Your email address

Signed

Date.....

Appendix Twenty-Five
Interview Participant End of Interview Information

People who can help if you are upset

* the details presented here were altered per locality of participant*

If you feel upset by anything we have talked about during the interview today, Victoria is available to chat with you about matters directly related to the research, but she is not able to provide further professional or bereavement support. You can contact her up to and including the 28th August 2015:

Tel: [REDACTED]
Email: mhvam@bristol.ac.uk

If you feel that you need further support, here is a list of people in your local area who you can contact to talk to.
You might also find it beneficial to talk to people you know like your family, friends and/or work colleagues.

Citizens Advice Bureau

12 Broad Street, Bristol
Tel: 0117 921 1664

Cruse Bereavement Trust

9a St James Barton, Bristol, BS1 3LT
Tel : 0117 926 4045
Web Site: www.crusebereavementcare.org.uk

The Harbour

30 Frogmore Street, Bristol, BS1 5NA
Tel: 0117 9259348
Web site: www.the-harbour.co.uk
Email: info@the-harbour.co.uk

Bereavement Support for Adults with Learning Disabilities

Would you like to have a say about your experience of providing bereavement support?

If the answer is **Yes** then please read on!

A unique and exciting research project about the support **YOU** have provided someone with a learning disability is currently recruiting participants.

Victoria Mason, a PhD student at the University of Bristol and personal assistant to someone with a learning disability, is working with a group of co-researchers (who have been support workers in the learning disabilities field) to explore how **YOU** have supported someone with a learning disability through a period of bereavement. A small group of people with learning disabilities are also working on the project as members of an advisory group.

The research community are currently looking for 10 -12 support workers or personal assistants to come and talk to Victoria for **an hour** about their experience of providing bereavement support.

If you think you would like to participate in the study, please read the information on the next few pages, fill in the 'Expression of Interest Form' and return it to Victoria in the S.A.E provided or via email (mhvam@bristol.ac.uk) by May 29th 2015.

Victoria will then be in touch with further information about what taking part will involve and to arrange an interview.

Thank you

Appendix Twenty-Seven

Interview Participant Recruitment Advertising List

Organisations

Brandon Trust
Home Farm Trust
Mencap
Mind
Options Support
WECIL

Social Media

Facebook

- Bristol PA Group
- The Misfits Theatre Company Page
- WECIL Page
- Mencap Bristol Page
- Bristol Mind Page

Twitter

- NFCDS Twitter Account
- School for Policy Studies Twitter account
- Victoria's personal/academic Twitter account

Forums

Choice Forum

Appendix Twenty-Eight

Ethics Form– Online Questionnaire

SCHOOL FOR POLICY STUDIES: RESEARCH ETHICS COMMITTEE

APPLICATION FORM

- This proforma must be completed for each piece of research carried out by members of the School for Policy Studies, both staff and doctoral postgraduate students.
- See the Ethics Procedures document for clarification of the process.
- All research **must** be ethically reviewed before any fieldwork is conducted, regardless of source of funding.
- See the School's policy and guidelines relating to research ethics and data protection, to which the project is required to conform.
- Please stick to the word limit provided. **Do not** attach your funding application or research proposal.

Key project details:

1. Proposer's Name	Victoria Ann Mason		
2. Project Title	Bereavement Support for Adults with Learning Disabilities		
3. Project start date	06/2015	End date	08/2015

Who needs to provide Research Ethics Committee approval for your project?

The SPS REC will only consider those research ethics applications which do not require submission elsewhere. As such, you should make sure that your proposed research does not fall within the jurisdiction of the NRES system:

<http://www.nres.nhs.uk/applications/approval-requirements/ethical-review-requirements/>

If you are not sure where you should apply please discuss it with either the chair of the committee or the Faculty Ethics Officer who is based in RED.

Currently NRES are not expected to consider applications in respect of activities that are not research: ie. clinical audit, service evaluation and public health surveillance. In addition REC review is not normally required for research involving NHS or social care staff recruited as research participants by virtue of their professional role. Social care research projects which are funded by the Department of Health, must always be reviewed by a REC within the Research Ethics Service for England. Similarly research which accesses unanonymised patient records must be reviewed by a REC and NIGB.

Do you need additional insurance to carry out your research?

Whilst staff and doctoral students will normally be covered by the University's indemnity insurance there are some situations where it will need to be checked with the insurer. If you are conducting research with: Pregnant research subjects or children under 5 you should email: insurance-enquiries@bristol.ac.uk

In addition, if you are working or travelling overseas you should take advantage of the university travel insurance.

Do you need a Criminal Records Bureau Check?

Please see the current guidance to determine whether you are required to obtain a CRB check:

<http://webarchive.nationalarchives.gov.uk/+http://www.homeoffice.gov.uk/publications/agencies-public-bodies/crb/about-the-crb/eligible-positions-guide?view=Binary>

If you think you need a CRB check, employed staff should contact Personnel, all students should check the University countersignatories page for information: <http://www.bristol.ac.uk/secretary/legal/disclosure/countersigns.html>

4. If your research project requires REC approval elsewhere please tell us which committee, this includes where co-researchers are applying for approval at another institution.
 Please provide us with a copy of your approval letter for our records when it is available.

5. If
 for
 Yes

ot
 tice?

No/Not yet
 Not applicable

X

Note: You must ensure that written agreement is secured before they start to work

6. If you are a PhD/doctoral student please tell us the name of your research supervisor

Dr Val Williams and Professor David Abbott

ETHICAL RESEARCH PROFORMA

The following set of questions is intended to provide the School Research Ethics Committee with enough information to determine the risks and benefits associated with your research. You should use these questions to assist in identifying the ethical considerations which are important to your research. You should identify any relevant risks and how you intend to deal with them. Whilst the REC does not comment on the methodological design of your study, it will consider whether the design of your study is likely to produce the benefits you anticipate. **Please avoid copying and pasting large parts of research bids or proposals which do not directly answer the questions.** Please also avoid using *unexplained* acronyms, abbreviations or jargon.

This ethics form is being submitted as an addition to the PhD research project which gained ethical approval on the 25th July 2012. This addition has come from discussions with the project's advisory group (Research Reference Group – R.R.G) and co-researchers (Bereavement Research Group – B.R.G) about methods of data collection.

1. **EXPECTED DURATION OF RESEARCH ACTIVITY:** Please tell us how long each researcher will be working on fieldwork/research activity. For example, conducting interviews between Feb 12 – July 2012. Also tell us how long participant involvement will be. For example: Interviewing 25 professional participants X2 for a maximum of 1 hour per interview.

Research activity in this section of the research is going to consist of an online questionnaire. This questionnaire will be created using Bristol Online Survey (BOS). Information about the research, the researchers, and the questionnaire will be posted on online forums and closed Facebook groups for support workers and personal assistants in the UK (Appendix 1). This information will provide potential participants with a link to the questionnaire if they wish to complete it (Appendix 2). Consent will be given via participants clicking on a box on the questionnaire before completing it (Appendix 2). The questionnaire will be available online from the day ethical approval is received until 28th August 2015.

Victoria Mason – Collecting online questionnaire data, June 2015 – August 2015
- Analysing online questionnaire data, September 2015 – October 2015

Kerrie Ford - Analysing online questionnaire data, September 2015 – October 2015
Julian Goodwin - Analysing online questionnaire data, September 2015 – October 2015

Lisa Ponting, Ben Harrington and Rowena Wilkinson – Looking at and commenting on the analysis done by Victoria, Kerrie and Julian - November/December 2015

2. **IDENTITY & EXPERIENCE OF (CO) RESEARCHERS:** Please give a list of names, positions, qualifications, previous research experience, and functions in the proposed research of all those who will be in contact with participants.

Full details of the researchers, R.R.G and B.R.G members, their qualifications and roles can be found in the original ethics form which gained approval on 25th July 2012. A list of their names and roles are provided here for reference:

Victoria Mason – PhD student and lead researcher.
Kerrie Ford – R.R.G member and self-advocate.
Julian Goodwin – R.R.G member and self-advocate
Lisa Ponting – R.R.G member and self-advocate
Ben Harrington – B.R.G member, support worker and student
Rowena Wilkinson – B.R.G member, support worker and student

3. **STUDY AIMS/OBJECTIVES [maximum of 200 words]:** Please provide the aims and objectives of your research.

This project is exploring how support workers and personal assistant support adults with learning disabilities through a period of bereavement.

Objectives

1. to explore support workers' experience and needs for training in bereavement support;
2. to involve and listen to support workers directly within an inclusive research model;
3. to build a research community around the notion of bereavement support, to suggest ways of improving practice

Rationale

Research suggests that bereavement support for people with learning disabilities is "at best inconsistent" (Read and Elliott, 2007) with some support workers unable to identify the impact bereavement has upon those they support (Dowling *et al*, 2006). As a result, Reynolds *et al* (2008) recommend support workers undertake bereavement training in order to improve practice. However, this recommendation is based on limited empirical evidence of the tacit knowledge support workers have about bereavement and how they put this into practice.

Furthermore, this suggestion raises questions about English society's view of bereavement and its assumptions about people with learning disabilities. The suggestion that support workers require bereavement training implies an inherent belief system and a 'correct' method of bereavement support. Furthermore, current research criticises support workers without providing them with a voice in the literature (Bloom, 2005).

This project aims to explore these points from the viewpoint of those working on the front line of practice. In the ever evolving social care system with its focus on evidence based practice, providing support workers with the opportunity to conduct as well as participate in the project will provide invaluable knowledge for the field.

Bloom, J. (2005). Breaking Bad News. In: G. Grant., P. Goward., M. Richardson and P. Ramacharan (eds). *Learning Disability: A life cycle approach to valuing people*. Berkshire: Open University Press

Dowling, S., Hubert, J., White, S., and Hollins, S. (2006). Bereaved adults with intellectual disabilities: a combined randomized controlled trial and qualitative study of two community-based interventions. *Journal of Intellectual Disability Research*, Vol. 50, (4), pp.277-287

Read, S., and Elliott, D. (2007). Exploring a continuum of support for bereaved people with intellectual disabilities: A strategic approach. *Journal of Intellectual Disabilities*. Vol. 11, (2), pp. 167-181

Reynolds, S., Guerin, S., McEvoy, J. and Dodd, P. (2008). Evaluation of a Bereavement Training Program for Staff in Intellectual Disabilities Service. *Journal of Policy and Practice in Intellectual Disabilities*, 5(1), pp.1-5

<p>4. RESEARCH METHODS AND SAMPLING STRATEGY [maximum of 300 words]: Please tell us what you propose to do in your research and how individual participants, or groups of participants, will be identified and sampled. Please also tell us what is expected of research participants who consent to take part (Please note that recruitment procedures are covered in question 8)</p>

25 participant support workers and/or PA's will be recruited to complete an online questionnaire (Appendix 2)

- Contact will be made with administrators of online forums and closed Facebook groups for learning disability support workers and PA's to seek permission to post the research information and a link to the online questionnaire.
- The information and link will be posted (Appendix 1)
- Participants who are interested will click through to the questionnaire (Appendix 2). They will be given more information about the research, what will happen to the data they provide and outcomes at this point (Appendix 2). If they wish to complete the questionnaire they will give their consent via a tick box on the front page of the questionnaire. They will not be able to complete the questionnaire without ticking this box (Appendix 2).
- The questionnaire will be 'live' until the 28th August 2015.
- After this date, the data will be analysed by Victoria Mason, Kerrie Ford and Julian Goodwin
- Victoria Mason will write up the analysis
- Lisa Ponting, Ben Harrington and Rowena Wilkinson will read this write up and discuss it with Victoria, Kerrie and Julian.
- Amendments will be made.
- PhD thesis will be submitted.
- Dissemination of research findings to the field of learning disabilities, disability, death and bereavement via publication in professional and/or academic journals and presentation at professional and/or academic conferences. This will include posting a link on the forums and Facebook groups that were used to recruit participants to a report/leaflet about the researcho that they can see the outcome.

5. **POTENTIAL BENEFITS AND TO WHOM:** [maximum 100 words] Tell us briefly what the main benefits of the research are and to whom.

This research will benefit the learning disabilities field; providing professionals and academics with a broader understanding of how support workers support people with learning disabilities through a period of bereavement on a day to day basis and whether training is necessary and appropriate. It will further benefit the fields of disability, social work, social care, death, bereavement and counselling research and practice.

Furthermore, the research will benefit R.R.G and B.R.G members. It will allow them to develop their personal and professional knowledge around bereavement and grief as well as research and dissemination skills.

6. **POTENTIAL RISKS/HARM TO PARTICIPANTS** [maximum of 100 words]: What potential risks are there to the participants and how will you address them? List any potential physical or psychological dangers that can be anticipated? You may find it useful to conduct a more formal risk assessment prior to conducting your fieldwork. The University has an example of risk assessment form: <http://www.bristol.ac.uk/safety/policies/>

RISK	HOW IT WILL BE ADDRESSED
Participants may become upset when discussing bereavement	1. Participants will be made aware of the potential risk (Appendix 2).
Participants may feel their professional practice is being judged	1. Participants will be informed of the nature of the study and the intended outcomes (Appendix 1 and 2) 2. No identifying characteristics are being recorded and no names will be used.

*Add more boxes if needed.

7. **RESEARCHER SAFETY** [maximum of 200 words]: What risks could the researchers be exposed to during this research project? If you are conducting research in individual's homes or potentially dangerous places then a researcher safety protocol is mandatory. Examples of safety protocols are available in the guidance.

There is minimal risk to any of the researchers within this area of the research. The R.R.G, who came up with the idea of this method of data collection, are fully aware of their role in the project as advisory group members and that it is Victoria's PhD research and therefore she is taking the lead in this process. They are also aware that they can talk to Victoria should they become upset or distressed by their role in the research.

There is a minimal risk to Victoria herself, as she has provided her email and phone number as contact points for potential participants. She has provided her work contact details to minimize this risk along with Dr Val Williams' contact details.

8. **RECRUITMENT PROCEDURES** [maximum of 400 words]: How are you going to access participants? Are there any gatekeepers involved? Is there any sense in which respondents might be "obliged" to participate (for example because their manager will know, or because they are a service user and their service will know), if so how will this be dealt with.

Accessing potential participants will be a two tier process. They will be sought for their professional role in the learning disability field and bereavement support experience. Initial contact will be made with them via online forums and closed Facebook groups for learning disability support workers and personal assistants.

Victoria Mason, Kerrie Ford and Julian Goodwin have written Appendix 1, which will be posted on online forums and closed Facebook groups, once permission has been sought from forum/group administrators. Victoria Mason will make initial contact with Forum and Group administrators to seek permission to post the research information. With permission granted, the post will be made and those who are interested will follow the link in the post to the questionnaire.

They will be provided with more information about the research, what will happen to the data they provide and intended outcomes at this stage (Appendix 2). If after reading this information they would like to complete the questionnaire, they will have to click on the consent tick box (Appendix 2), before they can complete the questions. They will not be able to proceed to the questionnaire without ticking this box.

As all participants will be self-selecting they should not feel obliged to complete the questionnaire.

9. **INFORMED CONSENT [maximum of 200 words]:** How will this be obtained? Whilst in many cases written consent is preferable, where this is not possible or appropriate this should be **clearly justified**. An age and ability appropriate participant information sheet (PIS) setting out factors relevant to the interests of participants in the study must be handed to them in advance of seeking consent (see materials table for list of what should be included). If you are proposing to adopt an approach in which informed consent is not sought you must explain in detail why this is not considered to be appropriate. If you are planning to use photographic or video images in your method then additional/separate consent should be sought from participants which adheres to the relevant data protection legislation. Current guidance is that consent forms should ask participants to initial rather than tick the consent boxes on the consent form.

Please tick the box to confirm that you will keep evidence of the consent forms (either actual forms or digitally scanned forms) in accordance with the data protection legislation, securely for ten years.

Informed consent will be sort from participants via a tick box on the online questionnaire (Appendix 2). They will not be able to proceed with the questionnaire without giving their consent. The initial post which they will have read to have reached the questionnaire will provide them with details of the research, what will happen to the data and intended outcomes. They will be able to contact Victoria Mason via the contact details provided (Appendix 1 and 2) should they have any questions about the research.

10. **DATA PROTECTION:** All applicants should regularly take the data protection on-line tutorial provided by the University in order to ensure they are aware of the requirements of current data protection legislation. University policy is that “personal data can be sent abroad if the data subject gives unambiguous written consent. Staff should seek permission from the University Secretary prior to sending personal data outside of the EEA”. Any breach of the University data protection responsibilities could lead to disciplinary action.

Have you taken the mandatory University data protection on-line tutorial in the last 12 months Yes No
https://www.bris.ac.uk/is/media/training/uobonly/datasecurity/page_01.htm

Do you plan to send any information/data, which could be used to identify a living person, to anybody who works in a country that is not part of the European Union? es

No

(see http://www.ico.gov.uk/for_organisations/data_protection/the_guide/principle_8.aspx)

If YES please list the country or countries:

11. CONFIDENTIALITY AND ANONYMITY:

	YES	NO
All my data will be stored on a password protected server	X	
I will only transfer unanonymised data if it is encrypted (For advice on encryption see: http://www.bristol.ac.uk/infosec/uobdata/encrypt/device/)	X	
If there is a potential for participants to disclose illegal activity or harm to others you will need to provide a confidentiality protocol.	X	

Please confirm that you warned participants on the information and consent forms that there are limits to confidentiality and that at the end of the project data will be stored for 10 years on appropriate storage facility.

<https://www.acrc.bris.ac.uk/acrc/storage.htm>

Confirmed

12. SHARING DATA AND DISSEMINATION OF FINDINGS [maximum 200 words]: Are you planning to send copies of data to participants for them to check/comment on? If so, in what format and under what conditions? What is the anticipated use of the data, forms of publication and dissemination of findings etc? If you plan to archive your interview transcripts then ensure that consent is obtained.

Due to the nature of the data collection via an anonymous online questionnaire, the research community will not have contact details of participants to send copies of data for approval (participants will be made aware of this, Appendix 2). However, when the research is finished and Victoria has received her PhD, she will disseminate a short dissemination report/leaflet via the online forum and closed Facebook groups used to recruit participants in the hope that those who participated will be able to see the findings.

13. ADDITIONAL INFORMATION: Please identify which of the following documents, and how many, you will be submitting within your application: Guidance is given at the end of this document (appendix 1) on what each of these additional materials might contain.

ADDITIONAL MATERIAL	NUMBER OF DOCUMENTS:
Participants information sheet (s)	X
Consent form (s)	X
Confidentiality protocol	X
Researcher safety protocol	
Recruitment letters/posters/leaflets	X
Photo method information sheet	
Photo method consent form	
Risk assessment form	
Support information for participant	
3 rd party confidentiality agreement	
Other information	

Please DO NOT send your research proposal or research bid as the committee will not look at this.

SUBMITTING & REVIEWING YOUR PROPOSAL:

To submit your application you should create a **single PDF document** which contains your application form and all additional material and submit this information to the SPS REC admin. Zaheda Tariq, Zaheda.Anwar@bristol.ac.uk
If you are having problems with this then please contact Zaheda to discuss.

Your form will then be circulated to the SPS Research Ethics Committee who will review your proposal on the basis of the information provided in this single PDF document. The likely response time is outlined in the 'Ethics Procedures' document. For staff applications we try to turn these around in 2-3 weeks. Doctoral student applications should be submitted by the relevant meeting deadline and will be turned around in 4 weeks.

Should the committee have any questions or queries after reviewing your application, the chair will contact you directly. If the committee makes any recommendations you should confirm, in writing, that you will adhere to these recommendations before receiving approval for your project.

Should your research change following approval it is **your responsibility** to inform the committee in writing and seek clarification about whether the changes in circumstance require further ethical consideration.

Failure to obtain Ethical Approval for research is considered research misconduct by the University and is dealt with under their current misconduct rules.

Chair: e.williamson@bristol.ac.uk

Date form updated by committee: March 2012.

Appendix Twenty-Nine
Online Questionnaire Participant Recruitment Email

Email Subject: Bereavement support for adults with learning disabilities – Research Questionnaire.

Dear.....

We are writing to you with details of a unique and exciting research project we are running at the University of Bristol, about the bereavement support **YOU** have provided people with learning disabilities.

Victoria Mason, a PhD student at the University of Bristol and personal assistant to someone with a learning disability, is working with a group of co-researchers (who have been support workers in the learning disabilities field) and a small group of adults with learning disabilities, to explore how **YOU** have supported someone with a learning disability through a period of bereavement.

If you would like to tell us about your experience of offering this kind of support, please follow the link below to an online questionnaire. Your response will be anonymous.

-----LINK TO B.O.S. TO GO HERE-----

If you have any questions please contact Victoria Email: mhvam@bristol.ac.uk or Mobile: [REDACTED]
Or her Supervisor Dr Val Williams
Email: val.williams@bristol.ac.uk or Phone: [REDACTED]

Thank you
Bereavement Research Group

Bereavement Support for Adults with Learning Disabilities

Would you like to have a say about your experience of providing bereavement support?

If the answer is **Yes** then please read on!

A unique and exciting research project about the support **YOU** have provided someone with a learning disability is currently recruiting participants to complete an online questionnaire.

Victoria Mason, a PhD student at the University of Bristol and personal assistant to someone with a learning disability, is working with a group of co-researchers (who have been support workers in the learning disabilities field) and a small group of adults with learning disabilities, to explore how **YOU** have supported someone with a learning disability through a period of bereavement.

If you would like to tell us about your experience of offering this kind of support, please follow the link below to an online questionnaire. Your response will be anonymous.

-----LINK TO B.O.S. TO GO HERE-----

If you have any questions please contact Victoria Email:

mhvam@bristol.ac.uk or Mobile: [REDACTED]

Or her Supervisor Dr Val Williams

Email: val.williams@bristol.ac.uk or Phone: [REDACTED]

Thank you

Bereavement Research Grou

Appendix Thirty-One

Online Questionnaire 'landing page' Information

Bereavement Support for Adults with Learning Disabilities

Thank you for showing an interesting in taking part in this research about the support YOU have given someone with a learning disability when they have suffered a bereavement. This research is being completed by Victoria Mason as part of her PhD at the Norah Fry Research Centre, University of Bristol. Victoria is completing this research inclusively with a group of support workers and a group of people with learning disabilities.

Taking part in this research will involve completing a short questionnaire that should take about 15 minutes to complete. This questionnaire will ask you about your job and the bereavement support experience you have. It will also ask you about the training you have had in this area and your opinions of what is needed in such training. It will also ask you for some demographic information.

The answers you provide will be completely anonymous and can in no way be traced back to you. Whilst this offers you complete anonymity it does however mean that once you have completed the questionnaire and submitted it you will not be able to withdraw from the research. You are however able to stop completing the questionnaire and not submit it at any point.

What you tell us will be used to create a picture of bereavement support for people with learning disabilities at the current time and look to what can be done to influence practice in the future. No judgement is being passed on the support you have provided and/or your professional conduct. When the research is completed a link will be posted on the website you accessed this questionnaire from, to a leaflet about the research findings.

If you would like to complete the questionnaire, please consent to the information provided here by ticking the box below.

By ticking this box, I understand:

that the information I provide is anonymous and cannot be traced back to me.

that taking part in the research is voluntary and I can stop completing the questionnaire and not submit it at any point;

however, once I have submitted the questionnaire, I understand that I cannot withdraw from the research as they cannot be linked to me.

that the answers I give will be used within Victoria Mason's PhD thesis

that the data will be stored in accordance with the data protection act on a secure server at the University of Bristol.