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Bereavement and loss support for adults with
learning disabilities: An exploratory study
using Photovoice

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Abstract

Background: Loss and bereavement are devastating life experiences for all human beings belonging to any social group, and adults with learning disabilities are not exempt from the effects of loss. Recent research has shown that adults with learning disabilities understand loss and bereavement; however, there is a lack of empirical evidence to show what adults with learning disabilities believe is useful for them to cope with loss and bereavement. Literature in this field suggests that adults with learning disabilities have been generally treated as subjects in research in the field of loss and bereavement and that most of this research has been based on case studies, observations, and other people's perspectives. This qualitative research study aims to engage bereaved adults with learning disabilities as active members in research using Photovoice (a participatory methodology using photography and photographs for community-based research), to explore the experiences of loss in their lives and their perceptions of support available in the local area (Staffordshire, UK).

Methods: A preliminary Photovoice workshop was organised for 10 bereaved adults with learning disabilities - the participants of the current research - in order to provide ethical and technical training for using a camera; engage them creatively to participate in research; and provide information on the photographs they would subsequently take as part of this research. The Photovoice workshop was followed by 10 semi-structured interviews with adults with learning disabilities to identify the support available and accessed; the impact of both loss and support; and the coping strategies used following bereavement. Interviews were facilitated through discussion of participants'

photographs taken after the Photovoice workshops. Additionally, data were gathered from focus groups with advocates (who support people to speak up by discussing, understanding their issues and finding information about their situations and options available); focus groups with professional carers; and interviews with family carers, to explore key issues and support needs and roles in supporting bereaved adults at home, in an advocacy organisation, and in a care setting. In total 27 (10 bereaved adults with learning disabilities; eight advocates; six professional carers; and three family carers) participated in the current research. All data, including the photographs taken by participants, were analysed using Thematic Analysis.

Findings: The main themes emerging from the photographs taken by the bereaved adults with learning disabilities included people (the deceased family members; living family members; friends; personal assistants; support staff); a range of daily activities (such as drama; pottery; dance); and objects inside homes and outside. Thematic analysis of remaining data highlighted five main themes across the results, namely: (1) Multiple losses, (2) communications related to loss, (3) support and barriers to support, (4) impact of bereavement and (5) continuing bonds.

Conclusions: The experiences of bereaved adults with learning disabilities mirrored the usual ordinariness of types of loss as people without learning disabilities but illustrate differences in the support, communications and other events after loss. Most of these differences were owing to the stigma attached to the learning disability itself. Creative methods (such as Photovoice) together

with clear information are beneficial to engaging adults with learning disabilities in research and enabling them to share their viewpoints around sensitive topics. Overall, the benefits of using Photovoice extended beyond engaging participants, teaching them skills and collecting data, but also in providing evidence of its success that bereaved adults with learning disabilities are able to share their viewpoints on difficult topics such as loss and bereavement with the support of photographs for future research involving vulnerable groups.

Note on terminology used: The acronym AWLD is used only in this thesis to refer to adults with learning disabilities. The author, however, does not encourage any type of labelling of this population.

Note on chapter 3: Some information focusing on the use of Photovoice in this chapter is part of a published article, reproduced with kind permission from the publisher '© Emerald Publishing'.

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Dedication

I dedicate this thesis to my mom Rani Tajuria and dad Tara Chand
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Chapter One: Introduction

“The grief, suffering and loneliness of adults with learning disabilities who have been bereaved still largely goes unnoticed, and may lead to behaviour which can cause further pain, difficulties and tensions not only for the individual concerned, but for families, workers, and the wider society around them” (Blackman, 2003, p.1).

This chapter sets out to define and explain the research focus of this thesis; namely loss, grief, mourning and bereavement for AWLD (adults with learning disabilities) and to introduce the range of resources and interventions available to support them. The chapter first outlines the types and causes/nature of learning disabilities and presents a brief history of care before considering the understandings of death, models of grief and bereavement, and therapeutic interventions relevant in this particular context. The chapter also considers the types of barriers AWLD face in accessing support services. AWLD were actively involved in this research by using creative, inclusive methods. Thus, the chapter concludes with a discussion of the involvement of AWLD in research on sensitive topics such as bereavement.

1.1 Learning disabilities

Defining learning disabilities is an extensive task as it has been variously described in very different terms by many scholars and organisations over time. The language used to describe, and address people is very important, as explained by Blackman (2003, p.20), “...favoured labels become outdated faster and faster, and often end up as words used to insult or hurt, as a process

of euphemism”. Terms like ‘vagabond’, ‘idiot’, ‘mentally subnormal’, ‘imbecile’ and ‘feeble-minded’ are examples of terminology originally used to describe AWLD following the establishment of the Mental Deficiency Act 1913 (Grant, Ramcharan, Flynn and Richardson, 2005). There have been large changes in describing this population since the late 19th and early 20th century after terms such as ‘learning disabilities/difficulties’ and ‘intellectual difficulties’ replaced the older terminologies mentioned above. The new terminologies considered to be less offensive were proposed for the inclusion of AWLD in society; however, they may change in the future if some other, more suitable terms are discovered (Taylor, 2007).

For the purpose of this thesis, a definition of learning disabilities provided by the Department of Health (DH) is used:

- “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” (DH 2001, p.14).

This definition was selected because it highlights the multifaceted and variable nature of learning disabilities and its previous version has been used in the United Kingdom (UK) since 1992 after being introduced by the DH. Outside of the UK, (e.g. in America, Canada and Australia), ‘mental retardation’ and ‘intellectual disabilities’ are the terms still commonly used. While the latter term ‘intellectual disabilities’ is widely used in many circles of academia and other services, the term ‘learning disabilities’ is a frequently used term beyond the

scope of academia, and is often used by those who suffer with such disabilities and their family members. However, AWLD themselves do not like to be labelled as any differentiating terminology.

There was lack of clarity in differentiating between people with mental illness and those with learning disabilities because of a lack of knowledge between the two until 1959, when the distinction was made clear in the Mental Health Act (1959). Although the National Health Service (NHS) had built mental asylums since 1946, AWLD and adults with mental illnesses were treated in much the same way. A series of scandals in the 1960s including Ely Hospital (Report on Ely hospital, 1969) revealed the ill treatment of patients and pilfering by staff, an indifference to complaints, lack of medical care, and medications used to sedate residents. Reporting on such scandals led the government to produce a White Paper in 1971, called 'Better Services for the Mentally Handicapped'. This paper recognised the need for AWLD to live as normal a life as was feasibly possible. This led to efforts to bring patients from 'mental handicap hospitals' into community care and also to recognise that their needs were separate from those of people with mental illnesses. The White Paper by the Department of Health and Social Security (DHSS, 1971) used terminology like 'home' to convey the importance of a sense of stability for residents. It acknowledged the importance of sustaining long-lasting personal relationships for AWLD and encouraged social workers to work with individuals as well as families to promote familiar links with the individual with learning disabilities (Mansell, 1997). A more recent White Paper, published in March 2001 by the Department of Health (Valuing People, 2001), can be summarised as taking a life-long approach towards AWLD based on four key principles: civil

rights, independence, choice and inclusion. This legislation recognised the rights of vulnerable people and acknowledged that the rights were essential in providing support to AWLD across a diverse range of issues, including bereavement.

The idea of 'normalisation' (Bank-Mikkelsen, 1969; Nirje, 1969; Wolfensberger, Nirje, Olshansky, Perske and Roos, 1972; Grunewald, 1977; Juul and Linton, 1978; O'Brien and Tyne, 1981) also changed people's viewpoints to a large extent and a number of versions of the concepts of normalisation have been proposed from 1960 onwards. The concept of normalisation is based fundamentally on human rights and can be defined as the formation of ordinary living circumstances as much as possible for AWLD (Bank-Mikkelsen, 1969). The basic ideas and aims of the principles of normalisation advocated community-based support for AWLD whilst moving away from institutionalisation. However, one of the most apparent obstacles in achieving this has been the attitude of those in the 'community' towards AWLD. Thus, Wolfensberger et al., (1972), introduced the concept of social role valorisation by recommending the formation of social roles for AWLD in order to improve their status and change the traditional negative attitudes towards them.

Further to social role valorisation, O'Brien (1987), in the context of services, suggested that AWLD should be respected and involved more in local societies; their choices should be reinforced while providing support for them to obtain skills. The NHS and Community Care Act (1990) advocated a massive change from the way services had been provided to AWLD in the past. In this Act, emphasis was given to home care, day care and respite care to help people live in their own homes wherever possible. More recently, the concepts

of normalisation and social role valorisation have been developed through the inclusion movement that involves AWLD and their supporters as crucial people in helping them (Atherton and Crickmore, 2011).

Such changes in definitions, terminologies and approaches to service provision and support are positive steps towards the recognition of the needs of AWLD. However, consideration still needs to be given to the understanding of the world of 'learning disabilities', the inclusion of this population in society and working on the stigmatisation they experience.

1.1.1 The Causation and measures of learning disabilities

For many people diagnosed with learning disabilities, the cause remains unknown (Holland, 2011) However, it is known that the following factors may play a role (Grant, Ramcharan, Flynn and Richardson, 2010):

- Heredity factors – Certain genes from parents can affect brain development and can lead to learning disability. For example, Down syndrome.
- Problems during pregnancy and birth – An illness or injury to the mother or child during or before birth, or certain drugs or alcohol used by the mother during pregnancy, may cause learning disability. For example, foetal alcohol syndrome, a premature birth, lack of oxygen provided to the child, prolonged labour, human immunodeficiency virus (HIV) infection are likely to lead to learning disabilities.

- Problems after birth – Head injuries, exposure to toxins, serious illness, poor nutrition and other environmental factors can also cause learning disabilities (Grant, et al., 2010; Atherton and Crickmore, 2011).

A learning disability (LD) is typically measured using tests of Intelligence Quotient (IQ) which are then used to classify people based on the International classification of diseases (ICD- 10) as follows:

- Mild LD = IQ level 50-69
- Moderate LD = IQ level 35-49
- Severe LD = IQ level 20-34
- Profound LD = IQ level < 20 (Grant et al., 2010)

However, the role of IQ in defining a learning disability has been criticised in academic literature as it can provide only a general indication of someone's intellectual capacity and conveys no information about how a person functions in daily life. IQ testing may suggest how someone might cope with their emotions; however, diverse individual and contextual factors, other than IQ, could lead to unique responses to experiences such as bereavement (Grey, 2010). IQ testing can generate negativity around AWLD and lead to failure on the part of families and services to encourage greater independence (Siegel, 1989; Rispen, Yperen and Duijn, 1991). In spite of this, the use of IQ testing persists in establishing eligibility for specialist learning disability services in the UK.

1.2 Research background and rationale

Loss is inevitable, it has been defined by Read (2014, p29) "...as a sense of being deprived or being without and as such can be expected or unexpected". Grief has been summed up by Engel (1961, p.18), as "...the characteristic response to the loss of a valued object, be it a loved person, a cherished possession, a job, status, home, country, an ideal, a part of the body etc". Bereavement has been defined as "...the period of mourning and grief that follows the death of a loved one" (Travers, Ali and Kolkiewicz, 2013, p.223). Thus, loss is a universal phenomenon, as everyone loses something at some point in their life, even if only a small thing. However, bereavement surely is not a universal phenomenon and not everyone experiences a loved one dying, as some people don't even have 'loved ones'. Mourning can be defined as "the social expression or acts expressive of grief that are shaped by the practices of a given society or cultural group" (Stroebe, Schut, Van Den Bout and Terheggen, 2001, p.6). Such definitions help portray an understanding of the grief process that has long been recognised for people without learning disabilities. However, it is argued that AWLD who are not told, for example, that a relative has died may not experience loss or learn how to cope with it effectively in the same way as someone who is well informed of loss throughout their lives. They may also lack precise understanding of the emotions they are experiencing, which are sometimes described as suffering a loss, going through a process of grief, or bereavement.

Limited information is available about what AWLD understand about death and bereavement and their concepts of death (McEvoy, 1989; Harper and Wadsworth, 1993). Paternalistic attitudes, negative supposition and

stereotypical expectations from AWLD are common and often begin in infancy (Lavin, 2002). Children who have grown up with learning disabilities are often perceived as children acting as adults for their whole lives (Cooper, 1997), which often results in denied access to mourning rituals, even though they are chronologically at an age to participate in such rituals (Lavin, 2002).

Historically, it has been assumed that AWLD could not become attached to anything emotionally and subsequently have been perceived as being unable to grieve (Oswin, 1981). According to carers and professionals, AWLD were thought not to "...grieve or respond to death, largely due to lack of cognition or their perceived understanding of the concept of loss, death or dying" (Read, 2005: p.33). However, AWLD can and do experience the full range of reactions such as tears, anger, disturbed sleep, depression, and disbelief, responses that are in keeping with the literature on reactions in the general population (Oswin, 1991). Some AWLD possess some understanding of the effect of death but ageing and the normal life cycle is thought to be poorly understood by them, predominantly in relation to themselves (McEvoy, 1989). This lack of understanding of life course perspective in AWLD is owing to absence of normative life of an AWLD. Life course perspective can be defined as a way to understand the relationship between different stages of life and time. It focuses on the changes in people's life from birth to death due to life events, changes in relationships and family roles (Hutchinson, 2008; Chambers, Allan, Phillipson and Ray, 2009).

Knowledge about the experiences of loss in the lives of AWLD is described as very important by Read (2000) because knowing the significance of losses can be useful in the provision of support to cope with them. Literature

related to effective approaches to support AWLD at the time of loss is minimal in comparison to the general literature, and research on this topic can add valuable information to help this particular group in any support setting. There has been little empirical evidence available with regards to support for bereaved AWLD until the landmark work by Emerson in the late 1970s and early 1980s when Oswin (1981) began to challenge misconceptions about grief and mourning among this population.

Emerson (1977) described the inequality in mental-health care of bereaved adults with and without learning disabilities. She further highlighted the importance of focussing on how the bereavement issue is handled in the lives of AWLD, as the loss may not have been considered as significant by those who work with AWLD and thus, they may not have received help with their expression of loss. Likewise, bereaved AWLD may not have been given appropriate emotional support and adequate time to grieve. It is important to draw attention to Oswin's (1981) work here because whilst it commenced over 30 years ago and noted how parents and carers of bereaved AWLD should use a proactive approach, her 73 recommendations in connection with bereaved AWLD remain relevant today. These recommendations can be summarised as:

1. Learning and training opportunities available for all those working with bereaved AWLD can be helpful in order to answer any queries related to bereavement that they may have.
2. Preconceived ideas, such as a lack of understanding of death in AWLD, should not be used to hide the bad news or tell lies.

3. Bereaved AWLD must not be excluded from attending funerals under any circumstances. Instead, appropriate support should be provided to help them to attend the funerals.
4. Multiple losses need to be acknowledged and listened to, even if the person has limited vocabulary to speak.
5. Bereaved AWLD should be supported and encouraged to remember the deceased and allowed to make decisions about the material possessions after the death rituals.
6. Everyone working with bereaved AWLD should work in partnership and allow sufficient time for AWLD to grieve before taking decisions such as moving away from their residence and no assessments should be made within 12 months following a death.
7. Bereavement in long stay hospitals should be communicated to all those who knew the deceased and involve them if they wish to get involved.
8. Any loss other than bereavement, like the death of a pet or moving house, can be significant for AWLD. These losses should also be recognised, and individuals should be appropriately supported.
9. Professionals should remember that the bereavement needs of every individual are different, as will be their experience of bereavement; thus, assumptions should be avoided regarding the coping mechanisms used by each individual (Oswin,1991).

Oswin's work, summarised above, remains important even today, as most research or non-research-based work still abides by her recommendations and many of them are unmet even after more than 30 years.

Despite having rich and diverse dreams about the deceased (Turner and Graffam, 1987), AWLD may often be reluctant to talk about bereavement for a host of reasons, such as limited or no language for complex communication to express feelings (McEvoy, 1989). There is ample evidence to demonstrate that the death of a family member can create a need for crisis intervention and, furthermore, cause complex grief symptoms (Kloeppel and Hollins, 1989; Emerson, 1977; Bonell-Pascual, Huline-Dickens, Hollins, Esterhuyzen, Sedgwick, Abdelnoor and Hubert, 1999; MacHale and Carey, 2002; Dodd, Dowling and Hollins, 2005). AWLD are more likely to experience multiple or successive losses (Elliott, 1995; Read and Elliott, 2007), some of which might necessitate an urgent move to respite care. For example, the death of a main carer is difficult in itself, but for AWLD this can lead to additional transitional losses, as the person may need to move into a respite care initially (Hubert and Hollins, 2000), followed by other more permanent residences. In such situations, numerous hidden losses may follow the death of a parent (or primary carer), owing to a lack of experience of grief or rituals after death and sometimes not being made aware of the death for very long (Cathcart, 1995), possibly leading to delayed and/or disenfranchised grief (Doka, 1989, 2002).

The phrase 'disenfranchised grief' is used to describe grief that is not recognized by society owing to either unacknowledged loss or an unrecognised legitimate cause of grief (Doka, 1989, 2002). Different contexts such as illegitimate relationships, assumptions about a person's ability to grieve,

paternalistic attitudes preventing people from grieving, and the circumstances of loss can all lead to disenfranchised grief (Doka, 2002). As discussed earlier (p8) many AWLD act in behaviours as younger than their chronological age. This might influence how people respond or expect people to behave so if a 50-year-old acts like a 10-year-old that might influence how he might go to funeral. Thus, adding more reasons as to why disenfranchised grief is more likely to occur. Many bereaved AWLD do not have the opportunities to access the help and support they require. When these losses go unrecognised, the original grief is compounded, and the person is more likely to have difficulties associated with their grief (Blackman 2003; 2008). As research suggests multiple losses and not knowing about losses can hinder the coping process after loss, time to prepare for the approaching loss can be useful in supporting people to come to terms with loss (Kloeppel and Hollins 1989; Bonell-Pascual et al. 1999; Read, 2000; MacHale and Carey 2002). This can be done by honest and clear communication with bereaved AWLD about their loss by family or professional carers in supporting roles (Emerson, 1977; Oswin 1991).

Bereavement is essentially a time of disruption and emotional stress and for individuals with learning disabilities; a limited understanding of the concept of death may exacerbate this distress (McEvoy, MacHale, and Tierney, 2012). The impact of bereavement depends on the intensity of the loss experience, the relationship with the deceased, and the number of adults affected (Stroebe, Stroebe and Hansson, 1993; Read, 2005). The closer the relationship, the greater the potential for multiple losses (Wayment and Vierthaler, 2002) and an insecure relationship may lead to more difficult grief reactions (Raphael, 1983).

Involvement in bereavement rituals (such as visiting the Chapel of Rest to say goodbye to the deceased) is often difficult, but is fundamentally crucial, according to Doka's (1989) model. Rituals can cause distress to a bereaved person with learning disabilities if there is no information provided beforehand about what to expect, but this has to be weighed up against the importance of saying a significant 'goodbye'. People without learning disabilities usually learn about bereavement through life experiences but AWLD are usually protected from these experiences throughout their lives. They need to be taught specifically about bereavement, preferably in anticipation of any loss likely to be experienced (Lavin, 2002).

There is a higher risk of poor mental health among AWLD than among adults in the general population (Deb, Mathews, Holt and Bouras, 2001) owing to complex physical, psychological and social factors. This can lead to the occurrence of common mental health difficulties following loss, including anxiety and depression (BILD, 2014). This information is relevant to the current research because the mental health of AWLD is often affected and gets worse owing to the vulnerability caused by life events like loss and bereavement, which sooner or later makes it more difficult to cope with their impact (Linehan, 1993). The psychological needs of bereaved AWLD were largely ignored in the past (Priest and Gibbs, 2004) but more recently it has been recognised that AWLD experience mental health complications in the same manner as the rest of the human population, but they differ in their manifestation (Priest, 2014).

In summary, there have been changes in attitudes towards the loss and bereavement experienced by AWLD, as most scholars now agree that it is neither beneficial, nor healthy, nor respectful to hide information about death

from AWLD (Foundation for People with Learning Disabilities, n.d). Historically, the research exploring this issue excluded AWLD from participating and expressing their views on important, sensitive topics such as death and its impact (Tuffrey-Wijne, Bernal, Butler, Hollins and Curfs, 2007). Against the backdrop of increasing awareness that loss and bereavement affect AWLD, too, there is still a huge absence of views from bereaved AWLD. Subsequently, there is a need to explore the voices of AWLD and how they are supported after loss as the voices and support remain crucial. This study was therefore planned to address this gap in scholarship and consequently, this is why a research project such as the current one is so important, because it will provide the empirical evidence that societies require in order to learn what is the best form of support that AWLD find useful to cope with their grief and how that can be provided. The crucial areas, such as how people grieve generally also focussing on AWLD, how they are supported and what stops them from accessing support are now discussed, as they act as the foundation for the current research.

1.3 Models of grief and bereavement

Several stage models of grief have been proposed by a number of scholars, such as Kübler-Ross (1969), Parkes (1972), and Bowlby (1980). Grief responses such as denial, anger, bargaining, depression, acceptance, numbness, and cognitive restructuring are recognized by most of the stage models (Bowlby, 1961; Parkes, 1972; Stroebe and Schut, 1995; 1996 and Klass, Silverman and Nickman, 1996). These stages of grief are provided to describe bereaved adults generally and not specifically for AWLD; however, AWLD can

also benefit from knowing and understanding these models to cope with grief. An understanding of these stages of grief can also help those who support bereaved AWLD to be better equipped in helping them to cope with their loss.

Worden (1982) focussed on grief as a process rather than a series of stages. This model is referred to as Worden's tasks of mourning and is explained as four overlapping tasks. These tasks involve: accepting the reality of the loss; working through to the pain of grief; adjusting to an environment in which the deceased is missing; and finding an enduring connection with the deceased in the midst of embarking on a new life. Worden highlights that these tasks are not stages and do not need to be addressed in the same sequence; instead, people can revisit the tasks when needed.

More recently, Continuing Bonds (Klass et al., 1996) is a proposed model, suggesting that it is important to maintain an ongoing relationship with the deceased in addition to living in current relationships. In addition, the Dual Process model of grief (Stroebe and Schut, 1999) recognised the importance of expressing and controlling feelings of loss. These are complementary approaches that allow for variations in the context in which grief occurs. The Continuing Bonds model tests the main assumption that grief is resolved through breaking bonds with the deceased (Davies, 2001). It recognises that attachment to the deceased person does not come to an end after the loss; instead, the bond changes and continues. The Dual Process model (Stroebe and Schutt, 1999) explains the importance of the bereaved person achieving a balance between expressions of grief and adjusting to a new reality. Stroebe and Shut (1995) named these two actions as 'loss orientation' (ruminating, yearning or using reminders of the bereaved) and 'restoration orientation'

(making lifestyle adjustments in the deceased's absence). The crucial aspect of this model is the way a bereaved person oscillates between these two distinct orientations as their grief work progresses. It is important to understand that there is a need for both negative and positive thought processes within loss and restoration; for example, expressing emotions by crying and then coming back into one's own self and doing ordinary things.

However, a review of the literature by Wortman and Silver (1989) suggested that stage models of grief were not always supported by available empirical evidence. Owing to the rigidity in the stages of grief models and the limited empirical evidence behind them, it makes them more difficult to generalise and use in the field of learning disabilities. This is because even though bereaved AWLD would have some pattern to their grieving process, the pattern will be unique to each individual in itself and in comparison, to others. Nevertheless, the Continuing Bonds and Dual Process models of grief both focus on maintaining relationships with the deceased, making them potentially useful as a framework to support bereaved AWLD. As each individual with or without a learning disability is different and may use their own methods to cope with grief after a loss, the flexibility of revisiting any task when needed suggests the tasks of mourning (Worden, 1982) as suitable for some to cope. Therefore, both these models can be used practically within person-centred approaches to support AWLD in coping with their grief.

There is a lack of information around loss and bereavement in the context of learning disabilities; however, there is no information explicitly suggesting that AWLD do not understand or experience loss. Seminal papers by Oswin (1981) and Emerson (1977) make it clear that AWLD experience loss

in the same way as those without learning disabilities, but that this fact is rarely recognised. This has raised the question of what type of support is offered to AWLD to cope with loss. The range of resources available to support bereaved AWLD at present are now introduced.

1.4 Resources and interventions to support bereaved AWLD

There has been increasing recognition that AWLD cannot be totally protected against loss and its impact, and that there is a need to understand that they require opportunities to grieve in their own way (Blackman 2003). Considerable amounts of help and support may be required by AWLD experiencing grief. Some AWLD may have support from family, friends or experts in support services, but others may not be aware of, or lack the ability to gain, support (Read, 2005). Whilst the recognition of bereavement support needs for AWLD has improved, research stating the types of support needed by AWLD after bereavement and what is most useful for them to cope is still lacking (Read and Todd, 2009). Therefore, to understand its effectiveness, it is important to be familiar with the types of therapeutic support available for bereaved AWLD.

Historically, support through talking therapies (e.g. counselling) was not considered suitable for AWLD for many reasons, for instance limited cognitive ability (Blackman, 2003). This view has now altered somewhat in response to the acceptance that an understanding of complex issues is not wholly reliant on IQ, and generic bereavement counselling services have been successfully adapted to meet the needs of AWLD (Read, 2001). Additionally, limited

empirical work in the field of learning disabilities has suggested that AWLD are able to experience emotions; and while they may have more psychopathology than people without learning disabilities, there is no evidence that they cannot engage and benefit from therapeutic interventions such as counselling or psychotherapy (Prout and Strohmer, 1991, 1998; Sevin and Matson, 1994). Prout and Strohmer (1998) further stressed that the support work offered or provided to AWLD should be similar to that for someone without learning disabilities. However, Conboy-Hill (1992) suggested that support offered to the bereaved AWLD needs to be based on the differences in behaviours exhibited by bereaved adults with and without learning disabilities.

Some AWLD are capable of engaging with psychological therapies and such therapies can be beneficial to relieve their distress (Willner, 2005). However, there is inadequate empirical evidence available to support this, particularly in relation to grief, loss and bereavement work. Professional carers or therapists supporting AWLD who are grieving must have the appropriate assessment expertise, skills, knowledge and the opportunity to develop creative approaches to facilitate grief work in an appropriate manner (Read, 1999; Read and Elliot, 2007). Psychotherapeutic interventions can be effective with AWLD to a reasonable level; hence they should be considered more frequently to see more significant results (Prout and Drabik 2003). Similarly, bereavement counselling that is accessible to bereaved AWLD is positive and valued (Gilrane-McGarry and Taggart 2007). Since psychotherapeutic/talking therapies are becoming more widely used, there is an increase in the need for research that critically explores the situations in the lives of AWLD, whether these therapies are productive for AWLD or not (Willner, 2005).

Resources available to support AWLD after bereavement include: general and specific bereavement counselling; support groups; crisis teams; and end of life care education (Elliot, 1995; Read, 1996; Botsford, 2000). Such support is often available through bereavement support groups and many other social support organisations to varying degrees. Life story work approaches (involving a review of a person's past life to produce their biography) can be used to aid counselling at the time when support is most needed (Hussain and Raczka, 1997; Botsford, 2000; Hollins, Dowling, Blackman and Brighton, 2003). Similarly, memory boxes created using a range of mementos related to the deceased person (Young and Garrard, 2015) can aid counselling and support. On the recommendation of the National Health Service (NHS) UK, interventions such as cognitive behavioural therapy (CBT), family therapy and psychodynamic therapies have also been developed for AWLD (Parry, 1993; Willner, 2005) and are advocated in the contemporary National Institute for Health and Care Excellence guidelines (NICE, 2016).

Read (1999) identified the importance of creativity in the way that counsellors support AWLD; for example, using family trees, artwork, life story work, pictorial books, drama and poetry, but these approaches have not been empirically explored or tested. In a case study presented by Read (1999), a young woman with learning disabilities wrote a poem followed by life story work to tell the story of the loss of her father. This creative method empowered her to tell her story in a more effective way. Although poetry may not be useful for someone who has severe communication difficulties, it can be effectively adapted to suit people with reasonable cognitive abilities. Different resources and procedures for AWLD to provide support after bereavement have been

identified. However, it is important to highlight if these are accessible to AWLD or not, and discussed now.

1.5 Barriers to accessing resources and interventions

Read (2000) provides a qualitative analysis of a bereavement counselling programme delivered over twelve months. The programme included counselling services to help people to deal with losses of all types. Action research was used in the development of this program and focus groups were used with the bereavement counsellors. Read highlighted that “there was a perceived ‘gap’ in the bereavement counselling service, but the professionals involved did not know how, or in what way, the service needed to be adapted in order to accommodate this [AWLD] client group” (p.22). In this research, she also described the therapeutic preferences and challenges counsellors faced while working with AWLD. For example, counsellors focused on empowering their clients through the use of interventions such as art, stories, memory work, and openness and honesty during the counselling period. However, the counsellors faced challenges such as a lack of guidelines and resources, feeling restricted on the number of sessions, evaluation of any support, issues of confidentiality and ending support when working with this population.

A recommendation by Read (2000) based on these challenges faced by counsellors was to design evaluation forms in clear language with accompanying pictures. She also stated that counsellors working with bereaved AWLD may witness the profound sadness exhibited by the AWLD, but often cannot fully understand it. Generic bereavement counselling agencies are not essentially prepared to accept referrals of AWLD, which makes access to these

agencies by AWLD difficult (Read, 2003). One of the barriers in accessing counselling therapies has been overcome by a key action point in the UK government's White Paper 'Valuing People' (2001), according to which all AWLD are to be registered with General Practitioners (GPs). Thus, referrals to counselling services could also be made by the GP services. Unfortunately, some of the barriers, i.e. lack of training to work with AWLD and preconceived ideas regarding AWLD being unable to appropriately access talking therapies, still need to be explored in depth before they can be understood and overcome (Blackman, 2003).

The participation of AWLD in research is one way of finding out their understanding of sensitive topics like death and exploring their knowledge about the support available for them. This is now briefly explained in section 1.6.

1.6 Involving AWLD in research on sensitive topics

Participation in research by AWLD can help them to learn innovative skills, contribute their views on a particular issue and understand the results of research (Heller Pederson and Miller, 1996). In the past, AWLD have only been the passive subjects of research projects, as opposed to active participants (Kiernan, 1999; Walmsley, 2001; Northway, 2010). The evidence relied on the health and social care practitioners or carers, which may not accurately reflect the views of AWLD themselves and which may be misinterpreted. Their involvement as active participants in research has increased in the past three decades, which has contributed valuable information in the fields of health, bereavement and advocacy (March, Steingold, Justice and Mitchell et al., 1997;

Kiernan, 1999; Chappell, 2000; Knox, Mok and Parmenter, 2000; Walmsley, 2004; DH, 2006). AWLD can now be seen to be involved in research, participating actively where research is done with them and not on them (Nind, 2008). However, the extent of the involvement of AWLD can still be improved, especially in research about their experiences of bereavement.

Researching sensitive topics such as loss is very important as it 'addresses some of society's most pressing social issues and policy questions' (Sieber and Stanley, 1988, p.6); however, it has been argued that distress can also be caused owing to the involvement of AWLD in research (McCarthy, 1998). Extensive planning is required to involve AWLD to anticipate and tackle any potential distress that may be caused during their participation in research. AWLD have been successfully involved in research on sensitive topics like bereavement contributing to group work and workshops to explore loss (e.g. Read, Papakosta-Harvey and Bower, 2000; 2004; Boyden, Freeman and Offen, 2010). Their participation in these projects has added valuable information relating to personal experiences as participants were actively engaged in different stages of workshops to explore loss (Read et al., 2004).

It is very important that AWLD who are going to be participants in any research have the project explained clearly, and that their understanding and informed consent is also gained. To do this, adaptations are often required to the traditional ways of involving people in research (Cameron and Murphy, 2006). Examples of such adaptations to the information giving and informed consent procedures are explained in detail in the context of this research in chapter 3. Although the participation of AWLD has improved generally, they are

often not involved after the completion of the research, as results are often presented in academic literature in ways that make it difficult for AWLD to access (Gilbert, 2004). Dissemination of the results to participating AWLD in clear information has been planned following the completion of the current research.

1.7 Conclusion and structure of thesis

Chapter one has outlined learning disabilities in the context of loss and bereavement, supported by grief work with bereaved AWLD. Different terminologies used to address the AWLD and the brief history of this population has been provided. The rationale behind the current research, based on the therapeutic interventions available to support bereaved AWLD and the barriers to access the supports, was defined. Inclusive research around loss, bereavement and AWLD was also briefly introduced.

Chapter two presents a literature review on research around bereaved AWLD, mainly focussing on research exploring the loss, bereavement and support experiences of AWLD coping with grief.

Chapter three begins with an introduction to creative approaches used to involve AWLD in research. Inclusive research with information on Photovoice with AWLD from previous research is described, followed by a description of the adaptations made to the technique for the current research with details of the preliminary Photovoice workshop organised for AWLD. The chapter then presents the research design and methodology, including participant groups,

and methods and procedures for data collection. This chapter also highlights the ethical issues of involving human participants, with a shown focus on AWLD, and how these were addressed in the current research. Reflections from data collection procedures are outlined in this chapter to maintain the continuity of the chapter.

Chapter four describes the data management and data analysis process, highlighting the use of thematic analysis. Adaptations to thematic analysis in order to include analysis of the photographs taken by participants are also described.

Chapter five introduces the findings from all participant groups. This chapter is divided into four sections namely: 5.1 (introducing the findings from bereaved AWLD, supported with direct quotations and photographs taken by the participants); 5.2; 5.3; and 5.4 introducing the findings from participant advocates, professional carers, and family carers respectively.

Chapter six discusses and integrates the main themes from all four participant groups that emerged after comparing the findings from all the participant groups. The final themes are compared and considered in the light of the literature reviewed. This chapter concludes with a summary of findings, highlighting the contribution to new knowledge and innovative methodology.

Conducting research with bereaved AWLD is challenging, nevertheless it is possible, and challenges faced during the research procedures are explained in chapter seven. It concludes with consideration of the strengths and limitations of the current study and recommendations for future research.

Chapter Two: Literature review

Although the literature around loss and bereavement continues to expand, the understanding is limited in relation to support after loss for AWLD. This chapter critically explores the existing evidence base in relation to support after bereavement for AWLD. In particular, it examines how creative approaches are used with bereaved AWLD, and how they can be engaged in talking about bereavement. This chapter presents the key findings of published literature in relation to loss and bereavement experiences, focussing on the support that is available for AWLD, and further examines the challenges people face in accessing these resources. This chapter concludes by making recommendations for more research based on the reviewed literature.

The current literature review was conducted to become familiar with the major strengths and weaknesses in literature that may also arise in the current research. This has further helped to plan the research questions and strategy. The literature review has helped to identify the research methods, participants and procedures for data collection. Although the current research used a creative method to engage AWLD that has not been used before in this context, the review has undoubtedly helped overall to shape the way this research has been undertaken.

2.1 Literature search strategy

A literature review was conducted to explain and describe the current research-based evidence base around bereavement and learning disabilities. Literature was searched in order to find out about loss, bereavement and

support experiences of bereaved AWLD to cope with grief. The following databases were used to identify relevant literature:

- MEDLINE
- PsycINFO- EBSCO
- CINAHL Plus- EBSCO
- Google Scholar
- Hand searching

These databases and approaches to data searching were adopted because of their relevance to the current research area. Table 2.1 describes the search terms and combinations used for data searching.

Table 2.1: Search terms used

Help Or Support Or Intervention Or Creative	And	Learning disab* Or Mental retardation Or Intellectual disab* Or Developmental delay Or Developmental disab*	And	Loss Or Grief Or Grieve* Or Death Or Bereave*
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*use of the truncation function.

The inclusion criteria for the literature search consisted of studies that focussed on bereaved AWLD and addressed support used/provided to cope with the loss. Limiters used for selecting literature from online databases were:

- Scholarly and peer reviewed journals.
- Reports, guidelines or policy papers.
- English language.
- Research studies involving only AWLD (18 years and over).
- References available from the year 1980 and onwards. However, some older seminal papers were also accessed as they are considered as landmarks in the history of learning disabilities.

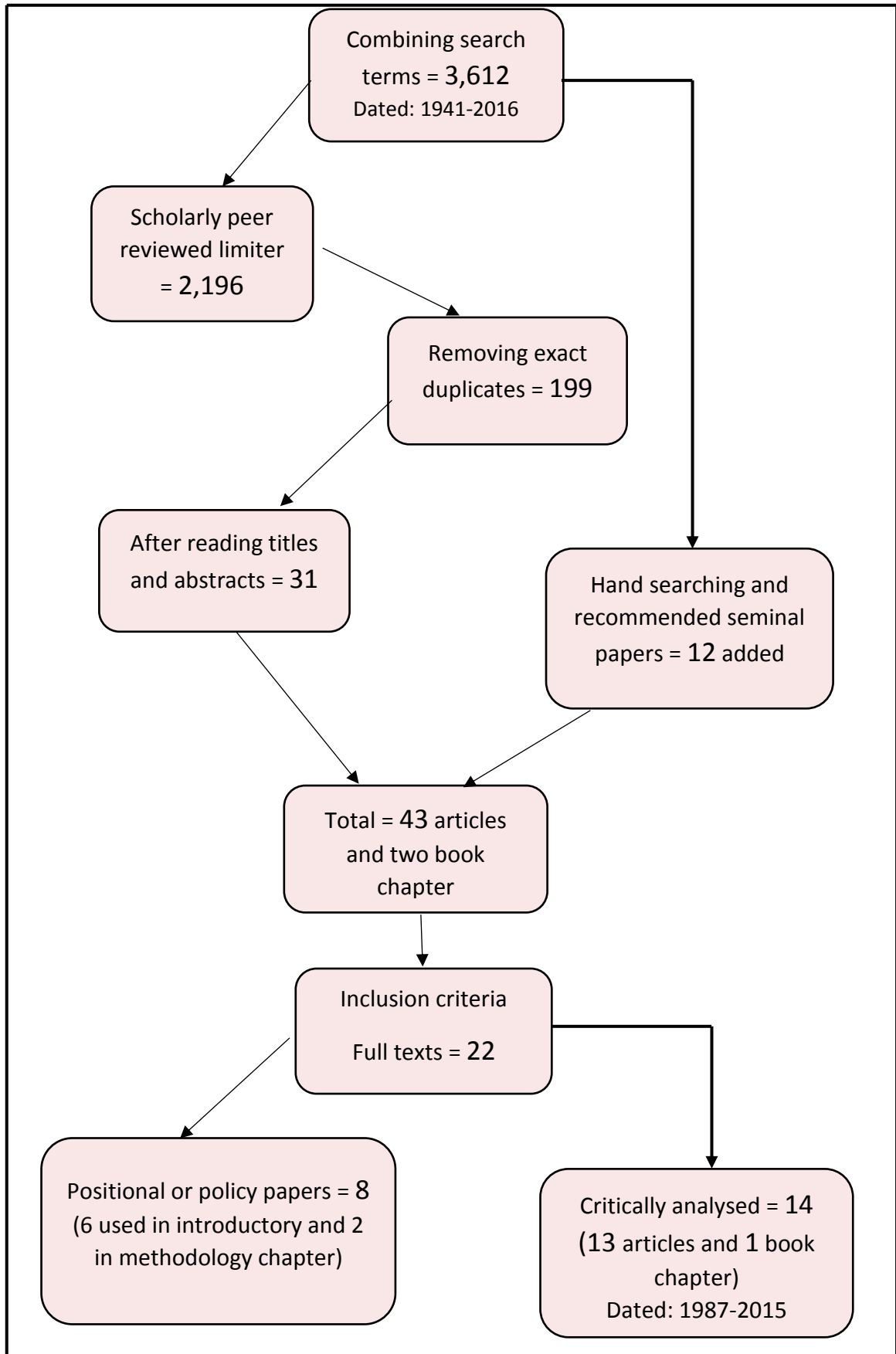
2.2 Search results

The initial search combining all the search terms detailed in figure 2.1 (p, 29) resulted in 3,612 papers dating from the years 1941 to 2016. However, after applying the scholarly peer reviewed limiter, this was reduced to 2,196 articles. Further application of all other limiters and removing exact duplicates resulted in 199 articles. The titles and abstracts of all 199 articles were studied for their specific link to the support available for AWLD following loss and bereavement, which led to a further removal of 168 articles, as they did not focus on loss, bereavement and support. Articles were removed if they focussed on issues such as general social behaviours and assessments, disorders within learning disabilities (autism, cerebral palsy, dementia), lifestyles affecting physical

health, issues of caregivers, aspirations, forensic evaluation, cultural groups and phobias. The remaining 31 articles were shortlisted as they focussed on loss, bereavement, coping, counselling, palliative care, attitudes to death and death rites. Results of the literature search revealed that some very important references that have been landmarks in the field of learning disabilities were missing. Hence, hand searching was done, and some historical literature was accessed from the supervisor, which added 12 more articles, making a total of 43 articles as well as two book chapters.

All 43 articles were read to see if they answered the literature search question. After applying the inclusion criteria to the full texts, 20 articles and two book chapters were retained for detailed review, out of which six were identified as more relevant for the introductory chapter and two for the methodology chapter as they were positional or policy papers and were not based on empirical research. The remaining 13 articles and one book chapter were critically analysed using headings from the Critical Appraisal Skills Programme Qualitative Research Checklist, (CASP tool, 2013). Out of these 14 pieces of literature, one study by Young and Gerrard (2015) was included owing to its uniqueness and to demonstrate that creative interventions can help people even with profound learning disabilities to cope with loss.

Figure 2.1: Literature search strategy and results



2.3 Description of papers

A brief overview of the literature reviewed is presented chronologically in Appendix A and critically analysed in this section, followed by the critical discussion. The engagement of AWLD in talking about their loss experiences has previously been lacking in the literature; however, four research papers and one book chapter in this review were conducted after 2007 and do include the voices of bereaved AWLD, namely studies conducted by Gilrane-McGarry and Taggart (2007); Borsay, Halsey and Critoph (2013); Forrester-Jones (2013); and Read and Carr (2014). The studies are now presented to illustrate the support that is considered beneficial for bereaved AWLDs.

Kitching (1987) discussed a case study of a woman with learning disabilities who was assumed to be coping after receiving the news of her mother's death. As she was not informed of, or involved in, the funeral, she faced delayed grief and displayed behaviours including anxiety, aggression and crying. She was helped to cope with her grief by a psychologist using guided mourning that included treasured objects from her home and applying art and drama to encourage the expression of latent feelings and emotions. She also visited the hospital where her mum died, followed by a visit to the grave. These activities used to facilitate the grief expressions were advantageous for this bereaved woman and helped her to deal with the delayed grief. The lack of similar literature since Kitching's research conducted three decades ago reflects that even today, such interventions are rarely available, or AWLD are not aware of them, or perhaps they are just not reported.

Kennedy's paper (1989), while not based on empirical research, also provides important information about how creative approaches such as life books, 'compare and contrast sets' (containing photos of people dead and alive), non-exclusionary time out (where something is withdrawn from the bereaved person displaying negative behaviour to reinforce positive behaviour) and formal diaries can be beneficial to help AWLD in coping with bereavement. These approaches are specifically highlighted as being useful because they were used by a community nurse as part of his work with AWLD. However, withdrawing someone from things such as favourite music or videos is negative practice as used in Kennedy's paper and creates ethical tension. Although limited, the types of case studies presented above demonstrated that AWLD can understand and cope in a better way if suitable support is provided.

Hollins and Esterhuyzen (1997) provide the first systematic study on reactions to bereavement with bereaved AWLD compared with a non-bereaved control group of AWLD. A semi-structured bereavement questionnaire; the Life Events Checklist (Stack, Haldipur and Thompson, 1987); the Aberrant Behaviour Checklist (ABC) and Informant based Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Matson, 1988) were used to assess psychopathology related to the grieving process of AWLD with sample sizes of 50 bereaved AWLD and 50 non-bereaved AWLD. Higher scores of anxiety or adjustment disorder in 21 bereaved AWLD were found compared to the control group, reflecting the adverse effect of bereavement on mental health. As this research could not distinguish the effects of bereavement from associated life events, it can be suggested that reporting additional information to find out what

the life events were, and if they were owing to the bereavement or led to the bereavement, would have enhanced this study. A follow up to Hollins and Esterhuyzen's (1997) study was conducted by Bonell-Pascual, Huline-Dickens, Holiins, Esterhuyzen, Sedgwick, Abdelnor and Hubert (1999) with 41 out of 50 bereaved AWLD from the original sample, but not matched with a non-bereaved group of AWLD. The results after using PIMRA again on the 21 participants suggested there was a slight reduction in anxiety and adjustment disorder in 18 participants and the scores of the remaining participants reflected delayed grief reactions. From the data collected from interviews with carers, this research also highlights the lack of planning in services provided to bereaved AWLD, the high frequency of change in residence that bereaved AWLD go through, that bereavement reactions are similar, but differ in expression and are more long-lasting and that family and carers' input is required to make AWLD understand death and grieve like others.

Read's (2001) study introduces a bereavement support service for AWLD that was developed and facilitated using an action research framework. It concentrates on data collected for evaluation of the bereavement service over the period of one year using statistical information from pre-and post-counselling evaluation forms completed by the bereavement counsellors and focus groups with counsellors. The key findings included similarities between bereaved AWLD and those without learning disabilities in relation to bereavement counselling and what was valued or disliked by the counselling staff, such as helping to empower the clients and ending the sessions. The study further informed the use of creative approaches such as memory books

and life story books to explore the experiences of loss amongst AWLD. Challenges faced by the bereavement counsellors were also highlighted as feelings of vulnerability, dealing with the end of support sessions and a lack of resources in providing bereavement counselling. This research contributed to knowledge for staff at the bereavement organisation to increase their expertise in supporting the bereaved AWLD as well as others working in the same field.

Raji, Hollins and Drinnan (2003) examined the views of funerals directors about the involvement of bereaved AWLD in the context of the funeral rites of local religious and cultural practices. Data was collected from six funeral directors and three representatives of different religious groups using semi-structured interviews. Key findings showed that AWLD face social exclusion in funerals; there was very little direct contact by funeral directors with bereaved AWLD and there was a lack of awareness of the support needs of AWLD who may be particularly vulnerable following a bereavement. Based on the data collected, a leaflet was designed containing information about the support available at the time of the funeral and the justification for including people with intellectual disabilities in funerals. It was intended to be distributed to funeral directors and religious leaders.

The study conducted by Clements, Focht-New and Faulkner (2004) presents three case studies to illustrate the grieving processes of AWLD. This article argues that AWLD may not grieve in the same way as the general population; however, awareness of their grief reactions can be useful to inform the process for assessment by professionals, as otherwise the grief can go

unrecognised. Two of the case study participants reflected that they did not receive enough information after their losses, leading to a lack of normal grief responses. Although the third case study participant was informed, he avoided expressing the painful feelings of grief in initial therapy sessions. A range of losses and the importance of communicating the loss to the bereaved AWLD followed by support to help with coping were described through the medium of the three case studies. An assessment of needs to plan suitable interventions was identified as important; however, as all the cases were at different stages of grief and one was a child, it is difficult to draw meaningful generalisations from the findings.

McEvoy and Smith (2005) investigated the attitudes of relatives of bereaved AWLD, addressing their grieving process, understanding of death concepts and support after bereavement. This study used questionnaires to collect data from 38 relatives and carers of AWLD. This data revealed that most of the AWLD had been through bereavement and reported common reactions to loss, such as sadness. Although most participants perceived that their relative with learning disabilities did not understand death, they still supported the idea of death education and early support.

A study by Dowling, Hubert, White and Hollins (2006) tested the hypothesis that traditional counselling and support provided by counsellors was less beneficial for AWLD in relation to mental health, behaviour and overall quality of life, compared to explicit integrated support provided by carers. A randomized controlled trial (RCT) was conducted with 31 participant AWLD,

where one group of 11 received integrated support using activities related to the loss and the other 20 received traditional counselling. For the integrated intervention, the carers (including family and professional carers) were provided with two days of training to familiarise them with grief work. This focussed on loss and restoration, based on the theoretical Dual Process bereavement model developed by Stroebe and Schut (1999). A separate two days of training was provided to the bereavement counsellors (owing to their lack of experience of working with bereaved AWLD), concentrating on the variations required in generic counselling with the bereaved AWLD. The traditional counselling group received tailored communication strategies based on individual needs including creative activities like drawing books, photographs, books beyond words, life story books and memory boxes. Photographs and visits to graves were used with the group receiving integrated intervention in addition to the normal care routines from carers. The findings of this study showed a reduction in aberrant behaviour displayed by the group receiving traditional counselling (23.1 SD before intervention and 15.7 SD after intervention) and further suggested that bereavement counselling with adaptations followed by bereavement counsellors in this field can be useful. However, scores from the group receiving integrated support were not much improved (23.2 SD before intervention and 22.8 SD after intervention). The hypothesis that the integrated, specific, approach would be more effective than generic counselling in improving mental health, reducing challenging behaviours and improving quality of life was proved wrong, as bereavement counselling was found to be more useful.

Gilrane-McGarry and Taggart (2007) examined how bereaved AWLD perceived the support provided by front-line care staff (who works directly with the client) before, during and after bereavement. This study used semi-structured interviews with 11 bereaved AWLD and found that practical support given to people before and at the time of death by the front-line staff was positive and included involvement of AWLD in knowing about the anticipated death, attending rituals and receiving support after the loss of their home. Support provided by the residential staff used photographs as a medium and activities such as family tree work, primarily. In addition, the staff practiced some basic counselling by engaging the clients to talk about their loss and helping them to release their emotions. Three participants in this research were referred for bereavement counselling support where creative approaches such as art therapy were used, and this was overall found to be useful by the clients. However, the participants felt that there was a lack of appropriate frequency and continuity of the sessions.

An approach by Borsay, Halsey and Critoph (2013) involved the participation of four bereaved AWLD in developing, facilitating and evaluating a bereavement group for eight weeks. This was based on work done by Boyden et al. (2010) with adaptations such as more focus on coping with the loss. AWLD participants explored, shared and discussed their bereavement experiences to learn coping strategies through different activities such as learning about death by viewing a video, sharing experiences of loss, recollections and strategies used to deal with loss. Owing to the unavailability of a bereavement-specific scale for AWLD general, questionnaires such as

Psychology service generic outcome measure, Clinical outcomes in routine evaluation – Learning disability (CORE-LD) (Marshall and Willoughby-Booth 2007) and Glasgow depression scale (GDS) (Cuthill, Espie and Cooper., 2003) were used in this study for data collection. Feedback responses from AWLD about the liked/disliked activities during participation in group activities are useful for planning such kind of research.

Forrester-Jones (2013) investigated the views of people with and without learning disabilities about sensitive topics such as funerals, as well as the opinions of practitioners in this field. This paper discusses the arrangements carried out by learning disability services in organizing funerals of the service users with learning disabilities and how they offer them support in decision making with regard to the choices for funerals. This study used mixed methods for data collection including unstructured questionnaires designed after interviewing 38 learning disability service managers and focus groups with 15 AWLD and 10 adults without learning disabilities. One key finding of this research was that all AWLD wanted to talk about funerals, conflicting with preconceived ideas that they would not like to talk about such matters. This finding also highlighted the viewpoints of managers, reflecting misconceptions about who is responsible for arranging funerals, the lack of guidelines about funerals associated with AWLD, and the lack of evidence on communicating information about death to AWLD. This study further suggests that bereaved AWLD are sometimes restricted by families from talking about death and participating in funerals. Although the focus group might have done justice to

the data collection given the sensitivity of the topic, individual interviews may have been more suitable to be used with AWLD.

Read and Carr (2014) highlight the lived experience of living with loss shared by an AWLD who also co-authored the chapter. Mary (case study participant) identified the challenges AWLD may face after loss and bereavement, such as loneliness, and how these lead to difficulties in coping with bereavement. She found bereavement counselling, visits from family and friends, and talking to others who had similar experiences as useful in coping with grief after the death of her mother. This chapter further explains the importance of talking about loss, as illustrated by Mary, who was happy to share her story of the loss of her mother whenever she had the opportunity. It also highlights the role of spirituality in coping; the importance of pet therapy; and also, compassionate care from experts in this field. This chapter is the only one of its kind where an AWLD highlights important viewpoints that can be overlooked when not taken directly from the bereaved AWLD.

More recent research by Young and Garrad (2015) cited the use of memory box work to support a bereaved young woman with profound learning disabilities. This study adopted a qualitative approach within a case study design when coping with grief. By video recording the process, the study demonstrates the use of creativity while working with people with limited communication. However, with this type of recording process there are ethical issues that can potentially be raised. For example, there was no information on whether the consent of the woman with profound learning disabilities was given

for videoing, even though consent from her parent and carers was described. This was the only study included in this review that was conducted with an individual with profound learning disabilities. This study demonstrated that creative approaches such as the successful use of a memory box can be used to allow research involvement, even when the adult has limited verbal communication. The way this case study was conducted can be useful for other populations of bereaved AWLD who lack verbal language.

2.3.1 Research designs and methodology in the literature reviewed

Most of the research papers were exploratory in nature, often using qualitative methods for data collection. Five articles (including one book chapter) used case studies (Kitching, 1987; Kennedy, 1989; Clements et al. 2004; Read and Carr, 2014; Young and Garrard, 2015). In the remaining nine studies, three used qualitative methods (Raji et al., 2003; Gilrane-McGarry and Taggart, 2007; Forrester-Jones, 2013), three used quantitative methods (Hollins and Esterhuyzen, 1997; Bonell-Pascual et. al., 1999; McEvoy and Smith, 2005), two studies used mixed methods (Dowling et. al., 2006 and Borsay et al., 2013) with one of these using group work (Borsay et al., 2013) and one used an action research approach (Read, 2001). Data collection across all of the articles and book chapters reviewed was conducted in a way that addressed the research issue, but there were shortcomings in some data collection procedures. For example, three articles used single case studies for data collection (Kitching, 1987; Kennedy, 1989; Young and Garrard, 2015). Interventions such as guided mourning, making memory boxes and keeping

formal diaries, reported in these papers, were found useful. However, every bereavement experience is unique and the views of AWLD were missing on the support they received. It would have been interesting to see, for example, if more participants had similar experiences when using similar interventions.

Information presented in the book chapter by Read and Carr (2014) has the major strength of including the voice of an AWLD herself talking about her experience of bereavement in its entirety. Thus, even though the input was only from one AWLD, it provided in-depth information that is helpful for everyone providing support. It was recommended that involvement of bereaved AWLD in the research by McEvoy and Smith (2005) and Raji et al., (2003) to examine the concept of death in AWLD and participation in funerals respectively could have added a different viewpoint to findings by involving AWLD. It is understandable to conduct research involving large samples using quantitative methods; however, it is not possible to measure the experiences of loss and bereavement in numbers by using quantitative methods only, as argued by Hollins and Esterhuyzen (1997), Bonell-Pascual et. al., (1999) and McEvoy and Smith (2005). The use of mixed methods for data collection by Dowling et. al. (2006), including semi-structured interviews and observations for qualitative data, was a key strength of the research. Support to cope with bereavement using group work explained by Borsay et al. (2013) included the voices of AWLD who were able to give feedback about what they found useful or not useful during the group work. For example, watching the video to learn about death was not found helpful by some of the participants.

2.3.2 Methods used for data analysis in the literature reviewed

Thematic analysis was used in one study (Gilrane-McGarry and Taggart, 2007); three separate articles used a combination of: thematic and descriptive analysis (Borsey et al., 2012); thematic and grounded theory (Forrester-Jones, 2013); and discourse analysis (Young and Garrard, 2015). Grounded theory for qualitative data and Statistical Package for the Social Sciences (SPSS) for quantitative data were used in the study by Dowling et al., (2006). In addition, comparisons were drawn between Aberrant Behaviour Checklist–Community (ABC-C, Aman, Singh, Stewart and Field, 1995) and the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD, Wing, Beevor, Curtis, Park, Hadden and Burns, 1998) by using the Wilcoxon signed Rank Test. Furthermore, t-tests were used to check the magnitude of changes before and after interventions. Data collected from AWLD and their matched group of non-bereaved AWLD in the first systematic study done by Hollins and Esterhuyzen (1997) was analysed by using statistical tests that involved matching peculiar ratios and using McNemar’s chi squared corrected test for binary data that is used with matching nominal data. Information from the carers was analysed using Fisher’s exact two-tailed test, which is useful to compare the findings.

The study conducted by Bonell-Pascual et al., (1999) used McNemar’s test for change (Siegal and Castellan, 1988) to assess if there were any changes in PIMRA scores and Wilcoxon matched-pairs signed-ranks test (Siegal and Castellan, 1988). Read (2001) analysed the data from the focus

groups using thematic analysis and as part of this action research project, produced and published a manual for counselling staff to help with the challenges and increase expertise while supporting bereaved AWLD. Three studies (Kitching 1987; Kennedy, 1989 and Clements et al., 2004) used case study methods and the remaining two by Raji et al., (2003) and McEvoy and Smith (2005) have not provided information on how the data was analysed.

Critical appraisal of literature reviewed on loss, bereavement and support available for bereaved AWLD illustrates that it was often originally studied owing to behaviours that may have changed following bereavement in the life of an AWLD. Most commonly, research in this field includes observations of AWLD, case studies on AWLD owing to challenging behaviours, use of different types of psychological examinations and perceptions of carers, staff and professionals working in this field. These were the limitations in the traditional research literature, as the viewpoints, thoughts and feelings of the bereaved AWLD were missing. It has only been in the last decade that AWLD have become routinely involved in presenting their viewpoints by participating in interviews and focus groups on sensitive issues like bereavement.

2.3.3 Analysis and synthesis of literature in themes

The information in the literature provided many similarities as well as differences in the ways in which the research was conducted and in its findings. To summarise the key points from the literature reviewed, the main findings are discussed under the following headings:

- Concepts of death in bereaved AWLD
- Multiple losses and disenfranchised grief
- Expressions and Communication reflecting the impact of bereavement
- Anticipated death and participation in funerals
- Support after loss, use of creativity and barriers to support for AWLD

2.3.3.1 Concepts of death in bereaved AWLD

As described by Oswin (1981; 1991), some AWLD do possess the understanding of loss and the irreversibility of death but their reaction can be different from that of the general population (Hollins and Esterhuyzen, 1997; Bonell Pascual et al., 1999; Read, 2001). This understanding was given approval by most of the participating AWLD in research by Gilrane-McGarry and Taggart (2007), and in the story of Mary (Read and Carr, 2014). Knowing of the loss but grieving in a different way from the general population and lacking the ability to grasp the inevitability of death in some AWLD does not mean that AWLD should be denied any opportunity to have an understanding of loss (Kitching, 1987). Knowledge of death in AWLD is underestimated by carers (McEvoy and Smith, 2005) and a better understanding was shown by Young and Garrard (2015) through a case study in which the participant used to call out the name of the deceased person. Additionally, the case study participant demonstrated an understanding of death (even though the difficult news was not given to her) in feeling anxious and through angry behaviour. However, instead of providing support, staff and carers often exclude individuals from the grieving process owing to misconceptions, for instance that AWLD cannot understand, which can have a complex emotional impact (Hollins and Esterhuyzen, 1997).

More research that disseminates results such as AWLD do understand loss and bereavement are now required. Indeed, this is especially the case because the experiences of loss and bereavement are complicated in the lives of AWLD compared to those without learning disabilities because AWLD are more likely to undergo multiple losses that are not commonly recognised.

2.3.3.2 Multiple losses and disenfranchised grief

Having a learning disability itself was described as a loss from childhood by Clements et. al. (2004), as the individual faced a loss of positive self-image owing to a growing understanding of their disability and realising that their development was not like that of others. A range of losses other than bereavement were identified by Kennedy (1989) and Borsay et al. (2013), including broken relationships, separation and divorce, miscarriage, abortion, amputation, and loss of employment. Additionally, reduced privacy and changes of staff members are losses for AWLD living in residential homes (Clements et. al., 2004). For an AWLD, bereavement does not end with just the loss of people; it often leads to the loss of home, a familiar environment and social networks (Gilrane-McGarry and Taggart, 2007). Losses followed by one loss are named multiple losses and the case study by Kitching (1987) is a significant example of multiple losses from older literature. The study detailed how the participant was moved to hospital as a crisis intervention owing to the illness of her mother. This move further caused an immense number of losses in her life, such as the loss of her home; her mother, who was alive at the time of the move; relationships with family members; independence, as she was never asked for her choice; and the right to know the truth about the death and funeral

of her mother. Multiple losses in the lives of AWLD can be easily neglected by the care-giving family/staff.

Difficulty in accepting and experiencing grief owing to incorrect or no information about losses and funerals often leads to delayed grief (Kitching, 1987) and morbid grief (Clements et. al., 2004). In the social context, the grief becomes disenfranchised when either the relationship or loss or the griever is not recognised (Doka, 1989). AWLD are more likely to face disenfranchised grief because they were (and often are) believed to be incapable of understanding and grieving after a loss (Hollins and Esterhuyzen, 1997). Delayed or “Morbid grief is the irresolution of feelings about a loss so that the person remains “stuck” at a particular stage of the mourning process” (Kitching 1987, p. 61) and often requires therapy to cope. As further explained by Kitching (1987), when an AWLD is moved from a residence after bereavement and displays challenging behaviour in the new setting, it can be easily overlooked by the staff, who are unaware of the situation and its potential impact on the bereaved AWLD. For example, in Mary’s story (Read and Carr, 2014), she came to know of her stepfather’s death after a long delay and expressed this in behaviour like running away from school. Delayed grief reactions such as the one shown by Mary may not have been understood as grief responses (Clements et al., 2004). In such situations when the reactions to loss are expressed in a different way by AWLD than the general population, they are not recognised and AWLD often face disenfranchised grief.

Communication has been suggested as crucial in coping with bereavement by Read (2001), and it is equally important to have capability and readiness among people working with AWLD to explain, answer and confirm

that their responses are heard and understood (Read and Carr, 2014). Different expressions used by AWLD to express the understanding of their loss and the communications discussed in the literature are now presented.

2.3.3.3 Expressions and Communication effecting bereavement

It has been explained by many experts that bereaved AWLD can experience similar emotions as someone without learning disabilities (Harper and Wadsworth, 1993; Oswin 1981; 1985; Strachan, 1981). Table 2.2 details different expressions of grief by AWLD after a loss, according to authors of the literature reviewed.

Table 2.2: Expressions of grief

Author	Expressions by AWLD
Kitching (1987)	Anxiety, aggressive outburst, crying
Kennedy, 1989	Aggressive behaviour
Hollins and Esterhuyzen, 1997	Behaviour disturbances
Bonell-Pascual et al., 1999	Behaviour disturbances
Read, 2001	Profound sadness
Raji et al., 2003	Emotional difficulties
Clements et al., 2004	Withdrawn, introspective, lonely
McEvoy and Smith, 2005	Sadness, depression, feelings of loss, anger, loneliness, fretful, talking/not talking about deceased, denial, weight loss, confused, afraid of own death
Dowling et al., 2006	Sadness, anger
Read and Carr, 2014	Crying
Young and Garrard, 2015	Distressed

Table (2.2) summarises 26 expressions of grief in total under 15 different categories used by bereaved AWLD in the literature reviewed. These expressions are common to the general population, however the way they are dealt with and amount of time they are displayed is certainly different in AWLD.

Disagreement and aggression towards loss initially, followed by role play of a caring deceased was sometimes used by bereaved AWLD to show the effect of bereavement (Clements et. al., 2004). This is because poor or no understanding of loss in bereaved AWLD can lead to emotional difficulties or abnormal grief reactions (Raji et al., 2003). Changes in staff and the support provided can create anxiety in people and add to a 'loss of power and control of the individual's decision-making process' (Clements et. al., 2004, p. 805). In one example, Mary's case study, she started smoking after the loss of her mother and mentioned that she eventually stopped (Read and Carr, 2014). This example is useful here because it reflects how an AWLD can develop unhealthy habits like smoking and after getting appropriate support can be helped to stop them. Lack of support has revealed frequent aberrant behaviour issues and an increase in psychopathology (Hollins and Esterhuyzen, 1997). Examples of behavioural issues owing to a lack of communication and support with the AWLD reflect the importance of communication related to loss and bereavement, which will be explained now.

According to the participants in the study by Forrester-Jones (2013), the topic of death was discussed casually at the time of death with AWLD. In the same research, deaths were disclosed by key workers, counsellors or senior managers in some cases; in others they were hidden, as either there were no clear policies or staff were not aware of them. Owing an absence of communication from the carers with the two case study participants about the significant losses in the form of family members' deaths and funerals, there was a change in the behaviours of bereaved people, revealing heightened aggression and distress (Kennedy, 1989; Kitching, 1987). Sometimes, when the

news of death is not communicated properly, the bereaved AWLD can develop the fear of their own death, as demonstrated by research done by Clements et al., (2004). Gilrane-Mcgarra and Taggart (2007) argued in their study that staff may think that AWLD are coping well with the loss on occasions where the AWLD do not feel able to communicate with the staff about their loss. Further, in the study by Hollins and Esterhuyzen (1997), 70% of the participant carers actually did not understand the challenging behaviours as grief expression. These examples highlight how communication plays an important role for bereaved AWLD and impacts on how the news of death is communicated.

According to Mary (Read and Carr, 2014), she was not informed of bereavements when she was young, and neither was she involved in funerals owing to the paternalistic attitude of her family. The importance of communication can be understood here, as being informed about where her relatives were buried was, for Mary (Read and Carr, 2014), important for her to know so that she could visit the place. In another case, although the participant was informed and involved in her brother's death and funeral, the symptoms of delayed grief were shown long after the death (Young and Garrard, 2015). As well as it being important to give the news of a death to AWLD (Hollins and Esterhuyzen, 1997; Forrester-Jones, 2013), additionally it is helpful to use the right words. As explained by Raji et al., (2003, p44) "...they need concrete explanations to help them understand abstract concepts such as death. Being told 'Mum has died' or 'Mum has gone to heaven' is confusing because these words can be misunderstood".

Terms such as 'gone to heaven' or 'gone away' used to inform of a death are euphemisms. The use of euphemisms was also briefly discussed by

Dowling et al., (2006), where one participant was told that her father is 'lost' but the meaning of 'lost' was not further explained. She never grieved for her deceased father and kept thinking that her father was sad and that was why he was not coming home. This was possible because for an AWLD, 'lost' could simply mean something that can be found someday if the specific use of the term is not explained. However, the same person coped with the loss of her mother's death very well as it was communicated properly. Communication using the appropriate language and right words and the use of creative tools according to individual needs have been suggested as useful (Read, 2001; Dowling et al., 2006).

Lack of communication around loss and bereavement may leave an AWLD in a state where he may not trust family or carers. However, improvements in relationships between carers and AWLD, in addition to improvements in behaviour, were seen when the case study participant was informed while making a memory box in a study by Young and Garrard (2015). Similar positive behaviours were noticed in the case study by Kitching, (1987) when the case study participant learnt about loss through stages of guided mourning. As clear communication has been suggested as beneficial for bereaved AWLD in understanding and coping with grief in a better way, anticipated death and providing support during funerals are also crucial aspects highlighted in the literature and discussed now.

2.3.3.4 Anticipated deaths and participation in funerals

Talking to AWLD on topics such as anticipated deaths and participation in funerals is considered very useful and hiding the truth can lead to an inability to mourn (Kitching, 1987; Hollins and Esterhuyzen, 1997). Although anticipated losses are believed to be less difficult to cope with, for AWLD even anticipated losses come as a shock as they are usually not part of the preceding months before a death when compared to the other family members. To prepare for anticipated loss, death must be discussed generally in day care services, minimising preconceived ideas (Kennedy, 1989). Even after three decades there has not been much difference in research and practice, as reported by Gilrane-McGarry and Taggart, (2007); while most AWLD were informed of anticipated death by family, the majority were not present at the time of death and this decision was taken by other family members. In the study by Hollins and Esterhuyzen (1997), participants were not supported to take part in events related to anticipated grief or after loss in order to avoid distressing them and creating problems for parents and carers. Limited knowledge of the effects of involving people in bereavement rituals, and the inconvenience of organising visits, were also used as reasons for not involving AWLD in funerals and other rituals in the same research. In contrast, the findings of Forrester-Jones (2013) recognised that all study participants identified the funerals as an important opportunity to access social support rather than an upsetting event. AWLD in this research wanted to 'carry the coffin', 'carry the flowers' and 'cheer up people', which reflects their understanding of loss and the significance of funerals (Forrester-Jones, 2013).

Forrester-Jones (2013) found that AWLD were not permitted to attend funerals even though they wanted to, which was because they were not informed of the death, there was a lack of transport, and out of fear of their behaviour at funerals. In the same context, some of the unacceptable behaviours that can lead to negative suppositions and the exclusion of bereaved AWLD from funerals were situations like AWLD lighting cigarettes from the burning candle during funeral mass; difficulty in understanding the place of the memorial stone; and climbing the walls of the cemetery. Their findings were shared by the funeral directors who participated in the study by Raji et al. (2003). Such unacceptable behaviours, together with taboo issues and stigma related to learning disabilities, were also considered reasons for not involving them in funerals. However, the same study suggested that participation in funerals can help bereaved AWLD to cope with loss with others grieving and confirming the realities of loss (Raaji and Hollins, 2003). It is evident that although many AWLD do understand loss, the communications around loss are missing from their lives, leading to disenfranchised grief. The next essential step is to understand what support is available to the AWLD to enable them to cope with the effects of bereavement (Raji et al., 2003). Different types of interventions used to support bereaved AWLD are now described in the context of the literature included in this review.

2.3.3.5 Support, creativity and barriers to support for AWLD

Prout and Stromer (1998) suggested that AWLD should be treated the same as a person without learning disabilities; however, the techniques to provide support should be given careful consideration and importance.

Comparable information was suggested by Kitching (1987) that AWLD can grieve and have the right to grieve but they need some extra support in doing this. According to Mary, having a bereavement counsellor, meeting family friends and people in day care service had helped her to cope with loss (Read and Carr, 2014). This was the only case study where an AWLD expressed that support from family, friends and advocates helped them to cope. This was from a single participant; hence the finding cannot be generalised; however, it can still be argued that completely missing the voice of bereaved AWLD in research would mean missing the important insight AWLD can offer on the support they receive. The use of fundamental methods, such as bereavement counselling, can help to involve participants actively (Read, 2001).

Some additional interventions that were used to support AWLD were visits to the hospital where the person is dying (Kitching, 1987) and to the gravesite (Kitching, 1987; Kennedy, 1989). These interventions can help AWLD to accept the reality of death and cope with loss. Further, Gilrane-McGarry and Taggart (2007) highlight how religious practices like attending mass and saying prayers were also found to be useful by some participants. Interventions used by Clements et al., (2004) included helping James (case study participant) understand the medical reason behind the death of his grandfather and that he was not going to die of the same illness. Additionally, Sabrina (another case study participant) was supported by reading a book together with a carer, which helped her to express her feelings and helped her to cope. None of the case studies by Clements et al., (2004) had details of activities undertaken with the support offered. For example, it would have been helpful to find out if James

was helped to understand just by talking and further information on which resources on loss and grief helped Sabrina to engage in the grief work.

Bereavement counselling, although limited in availability, has been considered helpful in coping with loss by Dowling et. al., (2006). Dowling et. al., (2006) compared the effectiveness of two therapeutic interventions (specific bereavement counselling with 25 participants and generic integrated interventions with 11 participants) as part of a randomized controlled trial. On the basis of ABC-C and HoNoS-LD tests before and after intervention, bereavement counselling was found more useful than the integrated interventions. The integrated interventions were not found to be very practical owing to lack of time; limited contact among support providers and receivers; new staff members; a lack of commitment from staff to offer extra support if needed; and staff's own bereavements. Whilst two days training was given to staff providing bereavement counselling, as well as integrated interventions, specific bereavement counselling was found to be more useful. Staff backgrounds could be one reason for this finding because bereavement counselling staff, even though they had not worked with AWLD, still may have more knowledge of bereavement support. The findings of Gilrane-McGarry and Taggart's (2007) are comparable to the findings of Dowling et al., (2006), as bereavement counselling support from bereavement counsellors was found to be valuable however, the low frequency of support was a concern. On a separate note, participant carers were not sure whether counselling could help AWLD to cope with loss and half of the participants thought medication was a suitable form of intervention after bereavement (McEvoy and Smith 2005).

Bonell-Pascual et. al., (1999) found that only 10 out of 41 participants had received bereavement support, including information about attending funerals, help to talk about loss, involving family and friends at the time of loss, visits to the grave, counselling, art therapy and access to a bereavement skills group. Out of the 10, six participants who received support after bereavement showed improvement in the Aberrant Behaviour Checklist (ABC). The scores of participants were measured using Wilcoxon matched pairs signed-ranks test. In contrast, their mental health and behaviour were not improved after bereaved AWLD were left for seven years without any bereavement-specific therapeutic interventions.

Creativity in any support has been apparently universally useful, as evidenced in the work by Kitching (1987), in which guided mourning was used to help the participant who was bereaved from the mother's loss and had been displaying anxiety and aggressive behaviours. Guided mourning uses a person-centred approach and in this particular case, treasured objects from home were added in the sessions with art and drama. In similar research by Kennedy (1989), creativity by using life story work, comparing and contrasting sets of photographs (including an ordinary photograph album with photos of living and dead people in it) and a formal diary (an ordinary diary with details of all the major events in the client's daily life) were used to address the behavioural issues displayed by Tom (case study participant).

The use of reminders of loss and talking about loss (Read and Carr, 2014) during the grieving process helps maintain healthy continuing bonds to the deceased (Klass et al., 1996). These reminders consisted of photos and life story works (Gilrane-McGarry and Taggart, 2007). This was evident in another

case study where Claire benefitted when involved in the making of a memory box that helped her to grieve and at the same time remember the happy memories spent with her deceased brother. It eventually helped her to understand his death and cope (Young and Garrard, 2015). In Borsay et. al., (2013), a bereavement group was used for a period of eight weeks with four bereaved AWLD where they discussed what helped them to cope. During these sessions, a video about 'coping with death' was shown, they took part in craft activities, role play was used in group activities, and relaxation CDs were used at home. In contrast, according to Hollins and Esterhuyzen, (1997) the propensity to minimise the exposure of bereaved AWLD to the mementos of the lost person was practised, saving them from the loss experience. Having highlighted the support needs and availability of support, the barriers to accessing this support are now discussed.

It is important to identify barriers to support because they are relevant to making recommendations for bereaved ALWD. A lack of knowledge in the family and professional carers on how to support the bereaved AWLD efficiently was a significant barrier (McEvoy and Smith, 2005). A further barrier is the lack of available support for staff to offer appropriate help. According to one of the managers in a study by Forrester-Jones (2013), bereavement support for care staff was available from outside sources and supervision but not everyone was aware of it. Similarly, staff providing integrated interventions did not access supervision (Dowling et al., 2006). Barriers in providing support identified by Read (2001, p.26), are "...vulnerability and uncertainty of the bereavement counsellor; the lack of concrete resources; and the difficulties of the specifics of counselling; such as dealing with endings effectively". Other barriers outlined by

Dowling et al., (2006) are limited numbers and less experienced staff in care homes to support bereaved AWLD.

Furthermore, experiences of the loss by carers also act as barriers to support (Dowling et. al., 2006), which leads to uncertainty about how to deal with the consequences of how AWLD feel. For example, if the bereaved person did not understand and became very upset, this became a barrier to telling the truth about the loss to AWLD. This is mainly owing to pre-conceived ideas towards AWLD, including their supposed lack of understanding of loss. Based on the literature, it can be summarised that lack of communication with bereaved AWLD plays an important role for AWLD in coping with loss. Additionally, as suggested by Gilrane-McGarry and Taggart (2007), the lack of collaboration among all those supporting an AWLD, such as the bereavement counsellors, staff at day service and other stakeholders also acts as barriers to support and coping with loss. This further reflects that the consistency of support is fundamentally important. However, these barriers are now slowly shifting over time, as reflected in this review. Although minimal, the voices of AWLD are included in recent research studies.

2.4 Conclusion

In summary, the literature suggests that AWLD experience loss and bereavement; however, their grief reactions may not be the same as the general population. This is owing to the accompanying challenges of multiple losses, lack of communication by others about death, and a lack of involvement

of AWLD in funerals and other rituals. Throughout our lives we become aware of the idea of loss and bereavement but that was missing in the literature around learning disabilities. Life course perspective is reflected as reactive and not proactive in the studies reviewed. The idea of life course development perspective is not really presented with AWLD certainly in terms of loss and bereavement.

Despite a significant increase in the amount of literature in this area, gaps are present in directly involving AWLD in research. Research examining the support available at the time of loss for AWLD and the voice of AWLD on what they believe is helpful in coping with loss is even more limited. There is a need for further empirical research to identify more specifically the needs of bereaved AWLD and the interventions and resources that are most helpful to support them. Strengths such as in-depth information using qualitative research designs and weakness such as lack of creative methodologies that involve AWLD in research to talk about sensitive topics like loss are outlined for the current research. In order to focus on the inclusion of AWLD in research, the current study intends to explore the experiences of loss, bereavement and support using creative methods. An innovative method called Photovoice that has not been used previously with AWLD in the context of loss and bereavement was used in the current research. Owing to the limited evidence base on this methodology used in this context, general Photovoice literature was investigated to understand its scope in the current research and presented in chapter 3, Research design that introduces the justification and preparation for the methodology, focussing on Photovoice followed by other methods and procedures.

Chapter Three: Research design

3.1 Introduction

The aims of qualitative research, as explained by Elliott, Fischer and Rennie (1999), are:

...to understand and represent the experiences and actions of people as they encounter, engage, and live through situations. In qualitative research, the researcher attempts to develop understandings of the phenomena under study, based as much as possible on the perspective of those being studied (Elliot, et al., 1999, p.216).

Owing to their exploratory and flexible nature, qualitative research methods enable the researcher to gather information on sensitive topics that are under-researched (Liamputtong and Ezzy, 2005). Furthermore, they play a vital role in recognising and comprehending the constructions of realities of people's worlds, particularly in relation to a vulnerable population (Clarke and Braun, 2013). Following the researcher's familiarisation with the theoretical position of research in the area of loss and learning disabilities, an exploratory design (used when there is a limited evidence base to draw on) was considered the most suitable for this research in order to address the study aims.

3.2 Inclusive research: choosing a methodology

A research project involving AWLD in active roles is a form of inclusive research (Walmsley 2001). There is a lack of any research involving bereaved AWLD to explore the loss, bereavement and support experiences (realised during the literature review chapter, 2). The current research selected Photovoice as part of the methodology to engage AWLD and use it as a tool to support the communication from AWLD around their experiences of loss. This chapter aims to provide a selective overview of the literature (and not a critical review of the papers) using creative methods in research, namely Photovoice. Another reason for not undertaking a critical appraisal was the focus on the discussions and limitations of using Photovoice in research and to demonstrate the potential of using Photovoice with bereaved AWLD in research. The research studies discussed in this chapter were identified by electronic resources (using terms such as Photovoice, learning disabilities, loss bereavement, and support) and searching for resources by hand. Papers were included on the basis that they informed of how Photovoice as a methodological technique originated and its use with AWLD. The theoretical knowledge is presented, followed by its use in this research to demonstrate inclusivity.

3.2.1 Photovoice: theory and practice

The use of photography in research has been documented as a creative technique in traditional literature that helps trigger participant memories and reduces fatigue, as well as reducing repetition and misunderstandings between the researcher and participant (Collier, 1957). Owing to these benefits, studies

involving AWLD have begun to incorporate creative methodologies, integrating approaches such as art and photography (Aldridge, 2007; Welsby and Horsfall, 2011; Povee, Bishop and Roberts, 2014). Researchers recently began to use photographs as a creative research method in order to facilitate dialogue with participants through which the meaning of the images taken was constructed (Lal, Jarus and Suto, 2012). Lal et al., (2012) highlight a number of approaches that have incorporated photography as a central component of the research process. These include auto photography, where participants are given a camera and asked to take photographs of important items from their environment (Aitken and Wingate, 1993; Noland, 2006); participant photographic research, focussing especially on photographs taken by participants (Aldridge, 2007); hermeneutic photography, which uses photographs as tools in the course of constructing meanings of life experiences (Hagedorn, 1994); photograph albums, used in open-ended interviewing (Swain, Heyman and Gillman et al., 1998); and Photovoice (Wang and Burris, 1997).

Photovoice is a method that is founded on what is discovered when "...people create their own visual images by taking their own photographs of their reality to be used for reflection and action" (Jurkowski, 2008, p.3). More specifically, it is community-orientated, as groups of people can use the process of photographic techniques to enhance, identify, and represent their community (Mizock, Russinova and Shani, 2014; Sutton-Brown, 2014). It combines photography with group work (Lal et al., 2012; Wang, 1999) or individual interviews (Jurkowski and Paul-Ward, 2007) to provide people with the opportunity to record and reflect on their life experiences. Therefore, its

theoretical root is as “a participatory research strategy commonly implemented in health research as a mechanism for personal and community change.” (Kuratani and Lai, 2011, p.1).

Photovoice originated in the work of Wang and Burris in the early 1990s. The first documented case study of Photovoice, which was initially introduced as a photo novella by Wang and Burris (1994) in their project with women from a rural village in China, was ‘The Ford Foundation-supported Women’s Reproductive Health and Development Program in Yunnan, China’. Wang, Burris and Ping (1996) then used Photovoice as part of a policy strategy concerning the health status of the women. In this case, the technique was used to provide a platform for the women’s voices and to empower them in a community where many women had no access to education, no rights in decision-making and no investment in their futures (Wang et al., 1996). This highlights the importance of Photovoice as a grassroots method to advocate political change and emphasises the fact that this technique could be used with marginalized groups to document and represent the strengths and concerns from their perspectives and their experiences using a specific photographic technique (Wang, 1999).

Kuratani and Lai (2011, p 1) state that Photovoice is based on “...three theoretical frameworks: empowerment education, feminist theory and documentary photography”. The empowerment education theory is based on Freire’s (1970) approach, which first adopts data collection, followed by taking photographs that represent the concerns of those taking the photos and concludes with facilitated discussions on the meanings of the photographs (Kurartani and Lai, 2011). Freire (1970) provided the participants with visual

images to encourage political and social discussion, and these were further distinguished as helpful to give judgements about the communities. The second framework based on feminist theory aimed to change beliefs in order to identify and appreciate women's roles as researchers, advocates and participants (Wang et al., 1996). The third and final framework in Photovoice uses a documentary photographic approach as a channel for expression. However, in contrast with documentary photography, the camera is placed in the hands of the people who experience some form of marginalisation in social reality (Wang and Burris, 1997).

The use of photographs provides vulnerable populations (such as AWLD) with the means of bringing the themes and their perspectives to light. As they are part of their communities, they can present information using photographs more creatively, and sometimes in a better way than experts in the fields of photography (Wang and Burris, 1994). The theoretical frameworks that inform the understanding of Photovoice also shape the benefits of using the method to achieve three main goals: "(1) to enable people to record and reflect their community's strengths and concerns, (2) to promote critical dialogue and knowledge about important community issues through large and small group discussion of photographs, and (3) to reach policymakers and others who can be mobilized for change" (Wang, 2003, p.179). As a theoretical model, Photovoice creates evidence and encourages participation on a platform to share skills and knowledge (Wang, 2003).

Wang (2003) describes how Photovoice is used to promote action for social change by reaching out to those who influence or make policy. This may expose the methodology to criticism if the social action associated with

Photovoice is not implemented and communities are left experiencing the same issues. However, facilitated discussions following Photovoice as a research method, as presented in the current research, emphasize the importance of collective knowledge in drawing attention to both the personal and socio-political concerns of a community (Wallerstein and Bernstein, 1988), leading to increased morale and empowerment. Wang, Yi, Tao and Carovano (1998) drew attention to the potential advantages of Photovoice by referring to the participants of the Yunnan Women's Reproductive Health and Development Program. The potential advantages suggested are: innovations in a community enhancing self-esteem and recognizing others as individuals, which eventually improves peer status and their own concept of humanity. Wang et al., (1998, p.83) also noted the advantage to participants with less power to "...participate in representing and enhancing one's community through a vivid and specific way of taking pictures and telling stories", which ultimately underpins the theoretical foundation of Photovoice.

3.2.2 Photovoice as an inclusive research method for AWLD

Photovoice is used 'as a means of accessing other people's worlds and making those worlds accessible to others' (Booth and Booth, 2003, p.431) and, as previously identified, has a history outside of learning disability studies. The rationale behind the method of Photovoice involves giving people cameras and using the photographs they take to amplify their place in the world (Booth and Booth, 2003). By putting those who take the photos in charge of how they represent themselves and how they depict their situation, this process

challenges the politics of illustration (Booth and Booth, 2003). This is achieved by shifting control from “...powerful to the powerless, the expert to the lay-person, the professional to the client, the bureaucrat to the citizen, the observer to the observed” (Booth and Booth, 2003, p.432).

Photovoice offers a way of looking at situations with the same point of view as the person who has taken the photograph (Booth and Booth, 2003). What this reveals about Photovoice is that it is more than a data collection method because it has a social and political agenda. This active social element is reflected in its use for research in public health (Strack, Magill and McDonagh, 2004; Wang and Pies, 2004); research in art and design (Stanley, 2003); to discover immigration experiences (Streng, Rhodes, Ayala, Eng, Arceo, and Phipps 2004); and raising awareness of health discrepancies with AWLD (Jurkowski and Paul-ward, 2007) among people from a Latin-American background; with homeless and marginally housed women (Killion, 1998); and people with mental health issues (Bowers, 1999).

In research involving mothers with learning disabilities conducted by Booth and Booth (2003), Photovoice was used as a supportive education project. In their research, Photovoice was considered as a way to understand the lives of participant mothers in the way the mothers see themselves and empowering them with a sense of unity in identifying the group concerns. The findings in the form of photographs in this study clearly demonstrated that mothers with learning disabilities value family, home, and friends as they may be valued by many in general population. This study lists many practical and ethical difficulties in relation to how long it took for the research to be conducted, as well as the approach of how to motivate the group discussion

dimension. Although the photographs proved to be extremely revealing and powerful forms of data, nevertheless, they also revealed ethical challenges around image ownership and how the images could be shared more widely.

Cocks and Cockram (1995) and Jurkowski (2008) note that the use of participatory methods with AWLD, though not widespread, have been implemented successfully. Aldridge (2007) describes the use of participatory photographic research methods with AWLD to elicit the lived experiences of vulnerable people involved in a social and therapeutic horticulture project. In Aldridge's research, the need for an alternative to semi-structured or open interviews arose because, in the case of participants with learning disabilities, letting them do more of the talking (a tenet of good social research) proved problematic. Research studies including Photovoice add in-depth information, undoubtedly; however, as suggested by Prosser (1998), difficulties in the analysis of visual data may restrict its use in research.

Based on a year-long study conducted to recognize the beliefs, needs and interests associated with health advancement using Photovoice with AWLD, Jurkowski (2008) concluded that, "...Photovoice enables a sense of ownership among [AWLD] in the research process while providing researchers with insights into the perspectives of [AWLD]" (p.9). Hence participation of bereaved AWLD in research could be enhanced with the feeling of ownership towards their contribution. Photovoice has also been recently used successfully with people with profound and multiple learning disabilities by Cluley (2017), where participants were involved in the study and asked to take photographs of their daily life with carers' support. It can thus be pronounced as accessible for all AWLD, regardless of difference in their cognitive ability (Cluley, 2017). The

approach, as further argued by Aldridge (2007), allows for there to be a focus on the capacity rather than incapacity of the respondents, enabling them to show rather than tell of their experiences while contributing to the research.

Many of the photographs speak for themselves as much as needing to be interpreted; however, Aldridge (2007) suggests that by taking a photograph as a form of visual expression, the researcher's interpretation of the photograph and the participant's interpretation of the image may be very different. Therefore, it is important that the researcher and participant engage in discussion about the photographs that have been taken. In this way, photographs can help AWLD to speak or participate actively because whenever they look at the image they have chosen to capture, they have a story to tell and share the meaning behind it. The intention of taking photographs as a research method used by Aldridge (2007) encouraged participation and elicitation. During such practice, respondents take photographs of aspects of life that they have particularly enjoyed, followed by the content analysis of the photographs undertaken by the researcher. In the elicitation part, participants then choose their favourite photographs and explain their choices.

Providing AWLD with a camera gives them the freedom to take photographs of their own choice and is an inclusive research method, as it both empowers and enables them to participate more actively in the research. Inclusive research is not performed on marginalised people but done with, by and for them (Walmsley, 2004; Nind, 2014; Nind, and Vinha, 2014). Photovoice has already been suggested as a pioneering research method that is useful with sighted AWLD (Booth and Booth, 2003). This is conducive to research in the field of disabilities, as the articulated word can be problematic for those who

prefer to use alternative forms of communication (Rojas and Sanahuja, 2011). Photovoice, therefore, could help adults with limited verbal communication skills to participate actively by adding a visual component to any discussions. For example, if an AWLD is unable to express in words the daily routine that helps him or her to cope with the loss, then multiple photographs of doing different activities can reflect that.

The emphasis on Photovoice offering an accessible technique to describe different realities or viewpoints is particularly important as it educates and raises awareness of significant public and universal issues (Sutton-Brown, 2014). This aligns with Rojas and Sanahuja's (2011) call for broader participatory research approaches beyond traditional surveys or interviews to include visual methods for AWLD. The successful use of Photovoice in a range of research projects involving the general population, AWLD and people with profound and multiple disabilities suggests that it can be useful in engaging bereaved AWLD, too, in research with subsequent adaptations and flexibility (Tajuria, Read and Priest, 2017). Photovoice also fits well in the context of the current research as it is premeditated to provide in-depth knowledge on the research topic to AWLD by bereaved AWLD and hopefully could influence their lives in a unique way (Nind and Vinha, 2012; Nind, 2014).

Photovoice was explicitly selected as a tool to facilitate the engagement of bereaved AWLD in this research in order to share their experiences of loss and support. As the use of Photovoice with bereaved AWLD was not found in the literature, the use of Photovoice with AWLD outside bereavement was discussed in section 3.2.1 and 3.2.2 (from p59). Owing to this lack of literature on the use of Photovoice explicitly with bereaved AWLD, the current research

used adaptations to this method to add information to this scholarly gap by analysing how Photovoice helps bereaved AWLD to engage in research and share their experiences on this sensitive topic.

For this study, participants took their own photographs and talked about them. While the researcher could have taken the photographs for the participants or arranged for someone else to do this, the practice of the participants taking their own photographs ensures that they are actively participating and adding a visual component to the discussions, rather than verbal communication, which may be limited for some of the participants. This study specifically focuses on bereaved AWLD because death is a very sensitive topic and if creative methods are used to discuss such topics, it can fundamentally add useful views from someone with a learning disability and can be useful for this population, as well as for people working with them.

3.2.3 Rationale and aims for using a preparatory workshop

Clearly, a creative method such as Photovoice to facilitate the engagement of AWLD in research as an additional procedure along with traditional methods is beneficial. As suggested by Wang (1998), a Photovoice workshop was considered essential at the beginning of the project to ensure that the participants were introduced to the concept of Photovoice and how it was going to be used in the research project exploring experiences of loss, bereavement and support (Tajuria et al., 2017). An additional reason behind the Photovoice workshop was the possibility that AWLD may not have used a digital camera before. Hence, a group workshop was believed to be a

comfortable platform to give elementary training to use a camera (Tajuria et al., 2017). The aims of the Photovoice workshop for bereaved AWLD were:

- to assess their needs for using a camera, to provide technical information, and to provide training on ethically safe photography
- to promote understanding of the use of a camera by answering questions and enabling the participants to explore and use their cameras with support during the workshop (Tajuria et al., 2017).

The practical organisation describing the groundwork, implementation and results of the Photovoice workshop involving bereaved AWLD are now explained.

3.2.4 Developing a Photovoice workshop to engage with AWLD

Participant Information Sheets (p76) explaining the research project and consent forms (p77) for participation in the research, use of quotes and use of photographs were discussed with two AWLD who were invited as consultants (details of consultation and designing of documents described in this chapter from page 76 onwards). Additionally, the following documents were designed for use during the workshop and as an aid memoire for the AWLD to take home:

1. Information sheets for using the camera (Figure 3.4, p93)
2. Instruction sheet to take photos (Figure 3.5, p95)
3. Four important steps of photography (Figure 3.6, p96)
4. Ethical issues explained: checklist (Figure 3.7, p98)

A flexible written workshop plan was prepared to ensure the facilitator kept on track (Appendix C). To avoid any mix-up on the day, as described in Tajuria et al., (2017) every participant was allocated an identification number beforehand and the same number was used:

- on the camera and its components, such as memory cards, batteries, and battery chargers
- on folders with pictorial information sheets to take home, prepaid envelopes to post memory cards back
- on the folder created on a laptop to organise and store information and photos during the workshop and the rest of the activities in the research

3.1.5 Conclusion

This section of chapter three has discussed the foundation for selecting Photovoice as part of the methodology for the current research. Creative methodologies such as Photovoice in research are time-consuming and cost-intensive when compared to traditional research methods; however, they are vital with clear information to engage a potentially vulnerable population such as bereaved AWLD.

3.3 Study aims

There is growing recognition that AWLD grieve and respond to loss (Willner, 2005). They, like all bereaved people, require individually tailored support. Hence, there is a pressing need, as identified in the literature review in chapter 2, to explore the most effective interventions and tools to help this specific population at this sensitive time and to explore the situations in their lives where therapeutic support may be most effective (Willner, 2005). Against a developing backdrop of bereavement support for AWLD, this study aimed to:

- Identify the tools and interventions used to support bereaved AWLD.
- Critically explore which tools and interventions work best with AWLD to cope with loss and bereavement.
- Implement and evaluate the use of Photovoice as a research tool with bereaved AWLD.

3.4 Research participant groups

To accomplish the above aims, evidence was gathered by ascertaining the views from four participant groups:

1. AWLD who have experienced loss or bereavement (in the time frame of 2-8 years)
2. Advocates (with experience of providing support to AWLD to find information and discuss the choices available in any area; help people to speak up by supporting their needs during meetings such as consultations with health services)

3. Professional carers supporting AWLD who have experienced loss or bereavement.
4. Family carers who have supported a bereaved family member who is an AWLD.

3.5 Research questions

- What types of support are available for AWLD at the time of loss?
- What are the experiences of the range of support received? How often? How long? How do people access the support services? What have been the challenges in accessing the support?
- What is the loss and bereavement profile of AWLD who access support services?
- What is the role of advocates and professional and family carers in providing support?
- How are staff, carers and advocates prepared to support AWLD during loss and bereavement?

3.6 Ethical approval

All research involving human participants has to undergo independent ethical scrutiny, including a research ethics review panel, owing to the potential risks to those who are involved (The British Psychological Society; the BPS, 2014). This research also followed the procedure and was approved by the

University Research Ethics review panel in April 2015. (see Appendix D for Ethical Approval letter).

3.7 Research site

A number of locally based services were initially considered from the perspective of a successful recruitment site in addressing the research questions (e.g. Cruise counselling services; the local adult and children's hospices; a bereavement charitable organisation; and an advocacy organisation). These services provide different types of support to adults with and without disabilities, children and families, including bereavement support.

Initially, a bereavement organisation was selected and approached to participate in this research. However, after spending a considerable amount of time at the organisation, it was found that it was unable to fulfil the research criteria. This led the researcher to contact the second organisation that agreed to participate. 'Reach' is part of Asist, which is an established, local, self-advocacy organisation providing specialist independent one to one and group advocacy support to AWLD and people with physical disabilities and mental health issues. Reach specifically supports AWLD to have a voice and make informed decisions for their own lives. Subsequently, the researcher was able to access and recruit participants from this organisation, which became the research site.

It became known that the research site had a committee called 'Parliament' for AWLD that organises meetings once a month at different locations

accessible to AWLD. The research site uses the term 'Parliament' to include AWLD in performing the following activities:

- Arranging meetings and events for AWLD to speak up together for themselves and share opinions as part of group advocacy.
- Encouraging staff at the research site to work in partnership with local councils, health services, universities and voluntary organisations in order to find the services available for AWLD. Further to collecting information from these organisations, the Asist organisation produces resources and provides training to use those resources.
- Developing resources such as posters, leaflets, fact sheets, information guides, presentations and reports using clear information for the use of people with disabilities, policy makers and the general public.
- Involving AWLD and making them feel included in the process of making any changes in their lives.

Members of the supervisory team and the researcher approached this organisation and provided them with an overview of the proposed research project. Positive feedback was received, as this organisation was open to conducting and supporting research studies. To understand the research site and how it works, a two-week period of observation and familiarisation was arranged, followed by twice-weekly attendance at the site until participants were recruited. Then, the researcher organised desk space at the site in the anticipation of working within the research site to explore it in greater depth.

The space was used once a week during the interview period and additionally when required by participants or the researcher.

3.7.1 Rapport building

The time spent at the research site turned out to be very useful in building rapport with the AWLD, as some of them were Parliament members and others attended the meetings to share ideas on different topics. This also gave the researcher the chance to understand the needs of AWLD while they were involved in a group activity or asked to give a viewpoint on something. For example, it was recognised that stopping someone from talking can be as difficult as encouraging them to talk. In another example, the researcher realised that if an AWLD is very sensitive and has some underlying issues, then there is a need to consider carefully the topics chosen for group discussions. For example, one lady became very upset after group members initiated a talk about keeping fit because she was bullied many times for being overweight. During opportunities of shadowing the staff members working directly with AWLD, the researcher learned appropriate communication etiquette when working with AWLD, such as: shaking hands is not always welcomed and AWLD like to know who is accompanying their advocate, reflecting the need for clear information. The researcher also learnt about the importance of adopting a person-centred approach without being judgemental during the group meetings, such as the Parliament meetings organised by the research site.

Working from the research site also helped the researcher to become a familiar face for other participant groups such as advocates, professional carers and family carers who sometimes accompanied the AWLD to the research site.

3.8 Participation information sheets

Based on the recommendations of the Department of Health (DH, 2001; 2005), the chief principles considered in the current research were maintaining the dignity, rights and safety of all participants and primarily focussing on the bereaved AWLD. In order to achieve this principle, it was vital that the research project was explained clearly and that participant information sheets could work as aide memoire for AWLD. Detailed participant information sheets for the bereaved AWLD (see Appendix E) were designed in easy-to-read information using Photosymbols© (a unique photo library for everyone making Easy Read information), under the guidance of experts working with bereaved AWLD (e.g. supervisory team and staff at the research site). Participant information sheets were developed that aimed to explain the research process to the participants, information such as what was the research about (e.g. using photos showing AWLD involved in group work, photo illustrating bereavement); who was involved in this research (using real photos of the supervisory team and research site); activities in which they were going to be involved (using photos showing cameras to be used in Photovoice and tape recorder for interviews); and how confidentiality and anonymity will be maintained (using photos reflecting that no one will know who said what).

Although the potential participant AWLD were connected to the research site and were aware of Photosymbols©, nonetheless the use of self-explanatory pictures and bold simple sentences in participant information sheets (see Appendix E) and consent forms (see Appendix F) were thoughtfully considered to maximise the engagement and contribution of participants in this research.

Even though the Photosymbol© images aimed to make the participant information sheets as self-explanatory as possible, it was noted that every image was open to different interpretations, even if it was something as apparently 'concrete' as a picture of a grave. For example, on the participant information sheets there is a symbol of a grave and a man sitting next to it; such an image can be interpreted as a person grieving or the person waiting for the deceased, or identified as that person being alone, etc., if not explained by someone beforehand. An explanation of the project to the staff members at the research site was considered important, as they knew the potential participants well and were able to repeat explanations of their involvement in this research if needed in the research invitation.

3.9 Informed consent

Risks in the field of consent and confidentiality are complicated in research studies involving people; these risks may become even more complex with the use of photographic methods (Aldridge, 2007). The logistical structure in an individual's setting and others controlling the decision-making process can affect the consent procedures (Jenkinson, 1993). The General Medical Council (GMC, 2013) defined informed consent as a process by which an individual can choose to undergo a treatment or participate in research provided all the information needed to make a choice or decision is provided in a timely and explicit manner. Gaining informed consent from potentially vulnerable groups (including children, AWLD, offenders, people from ethnic minority groups, and those who have a poor understanding of English language) requires careful

planning to avoid misunderstanding (Royal College of Nursing, RCN 2009). Consent procedures for research studies involving sensitive and personal topics with vulnerable populations are particularly important (Renzetti and Lee, 1993); for example, being asked about sexual feelings, loss or bereavement, which has also been the case in the current research (McCarthy, 1998).

Because of the sensitive nature of this research, and the potential vulnerability of the participant population, informed consent procedures were followed, given their effectiveness to support participants who may struggle with memory and recall (Beaver, Luker, and Woods, 1999). In the light of information obtained from previous research on the principles of informed consent used with the general population (Nolan-Haley, 1998), a similar approach was adapted for the current research. This included: detailed information being provided before taking consent; assurance that continued participation is voluntary; and ensuring that informed consent is given after understanding the risks and benefits of involvement in the current research.

In order for research to be conducted ethically, participants are provided with a written information letter about what is expected from them and a consent form to read and sign. However, the ethics committee could argue that it would be inappropriate for those who have a poor understanding of written English to read and sign a traditional consent form (Dye, Hare and Hendy, 2007).

Traditional consent forms were adapted (Appendix F) with less text and more images to illustrate for what consent was being asked, such as a picture of a camera to consent to taking and sharing photographs; a photograph of a

model from Photosymbol© library to confirm that confidentiality will be maintained from the research team, etc. Risks of involvement, such as the risks of photographs being recognised by someone reading the thesis or other publication, were explained before taking consent. Verbal consent and separate written consent forms were used for the use of photographs (Appendix L) and quotes (Appendix M) with information that the photographs remain their property and would not be used without authorisation (Tajuria, et al., 2017). Participant AWLD were made aware that they needed to ask for permission before taking a photograph with people's faces in them as the photographs may be used in the thesis. Although the traditional consent forms were adapted to an extent where they were deemed easy to understand by AWLD, nevertheless more measures were followed to check the informed consent. For example, one measure was to refer to the UK Mental Capacity Act (2005), acknowledging that AWLD also have the ability to make decisions and they should be helped and facilitated to make decisions whenever needed and possible. Following this, it was explained to all AWLD what was written in the consent forms before and during research activities and understanding was checked. Furthermore, to check informed consent, each participant was contacted by phone a day before, on the day of interview and before starting any activity, such as participation in the Photovoice workshop and interview, to check if they still wanted to continue. Also, observations of non-verbal responses such as body language, tiredness, discomfort, facial expressions and eye contact were also carefully observed (Cameron and Murphy, 2006). On the identification of such non-verbal expressions, discussions with the participant were considered necessary to check their informed consent.

General participant information sheets (see Appendix G), consent forms for participation in research (Appendix H) and consent forms for use of the quotes (Appendix R) for Advocates, professional carers and the family carers were also prepared with details of the project. These documents explained the aims behind the research, the expectations from the participants during their participation in this research and the approximate amount of time that would be used in research participation.

3.10 The Consultation process

Research methods are expected to be more effective with the involvement of AWLD as advisors (Ward and Simons 1998). Hence, as described by Tajuria, et al., (2017), two bereaved AWLD were invited as consultants (members of the parliament at the research site) and the project was explained to them using the participant information sheets (Appendix E) prior to the recruitment of participant AWLD. This was useful, as both consultants identified their likes and dislikes about the project. For example, one consultant liked the idea of taking photographs, while the other was worried about the use of her own photographs. They were able to take the participant information sheets away with them and feedback over the phone was encouraged. This exercise gave the researcher confidence to use the documents with other participants. After consultations and some minor changes to the participant information sheets, the recruitment process was initiated and is explained as follows.

3.11 Research participant recruitment

3.11.1 Participant group 1: Bereaved AWLD

For this research, participants from four different groups were recruited (participant group names on p72) including group one: Bereaved AWLD; firstly, to obtain direct information from them, as this research was about their experiences; and secondly, the researcher believes in the quote suggested by an activist working for the rights of AWLD "...nothing about us, without us..." (Harrison, Johnson, Hiller and Strong, 2001, p.69).

An accessible invitation leaflet was designed in clear information using images in conjunction with members of the advocacy organisation (see Appendix I). This invitation leaflet briefly included that this 'finding out work' (used instead of the word 'research' as it is a complex term and can be difficult for some AWLD to understand) is about the experiences of support when someone in their lives had died. A photograph of the researcher and one advocacy staff member (with her agreement) with clearly written contact details were also used on the leaflet. Potential participants had the choice to contact the advocacy organisation or the researcher by phone, email or in person when they were at the research site. All bereaved AWLD in this study were provided with the invitation letter by the advocacy staff during the research site's 'Parliament' meeting, at which some members of the Parliament and other attendees were present. This invitation leaflet was also displayed on the notice board of the research site. Participants had a choice to decide on the day of receiving the invitation or within the following 2-3 days if they needed to discuss the research at home before committing. However, none of the bereaved

AWLD contacted the researcher or the research site to show interest in participating in the project; hence, after waiting for three days, a purposive sampling approach was considered appropriate from which to draw the sample. As per this technique, “particular settings, persons, or events are deliberately selected for the important information they can provide that cannot be gotten as well from other choices” (Maxwell, 1997, p.87). Inclusion and exclusion criteria to involve bereaved AWLD in this research are described in Table 3.1.

Table 3.1: Inclusion and exclusion criteria for AWLD

AWLD	
Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Aged eighteen years or older. • Mild to moderate learning disabilities • Have capacity to consent. • Faced bereavement • Used the research site at some point after loss. • Time since at least one bereavement 2-8 years 	<ul style="list-style-type: none"> • Bereaved for less than 2 years • Bereaved more than 8 years ago.

To avoid any element of coercion with the involvement of bereaved AWLD in this research, the staff members of the advocacy organisation acted as gatekeepers initially, contacting 16 potential participants who were bereaved AWLD and met the inclusion criteria (Table 3.1). A list with the contact details of 11 interested potential participants was given to the researcher by the advocacy staff. The researcher briefly explained the study over the telephone and oral consent was obtained from all 11 participants. Detailed participant information

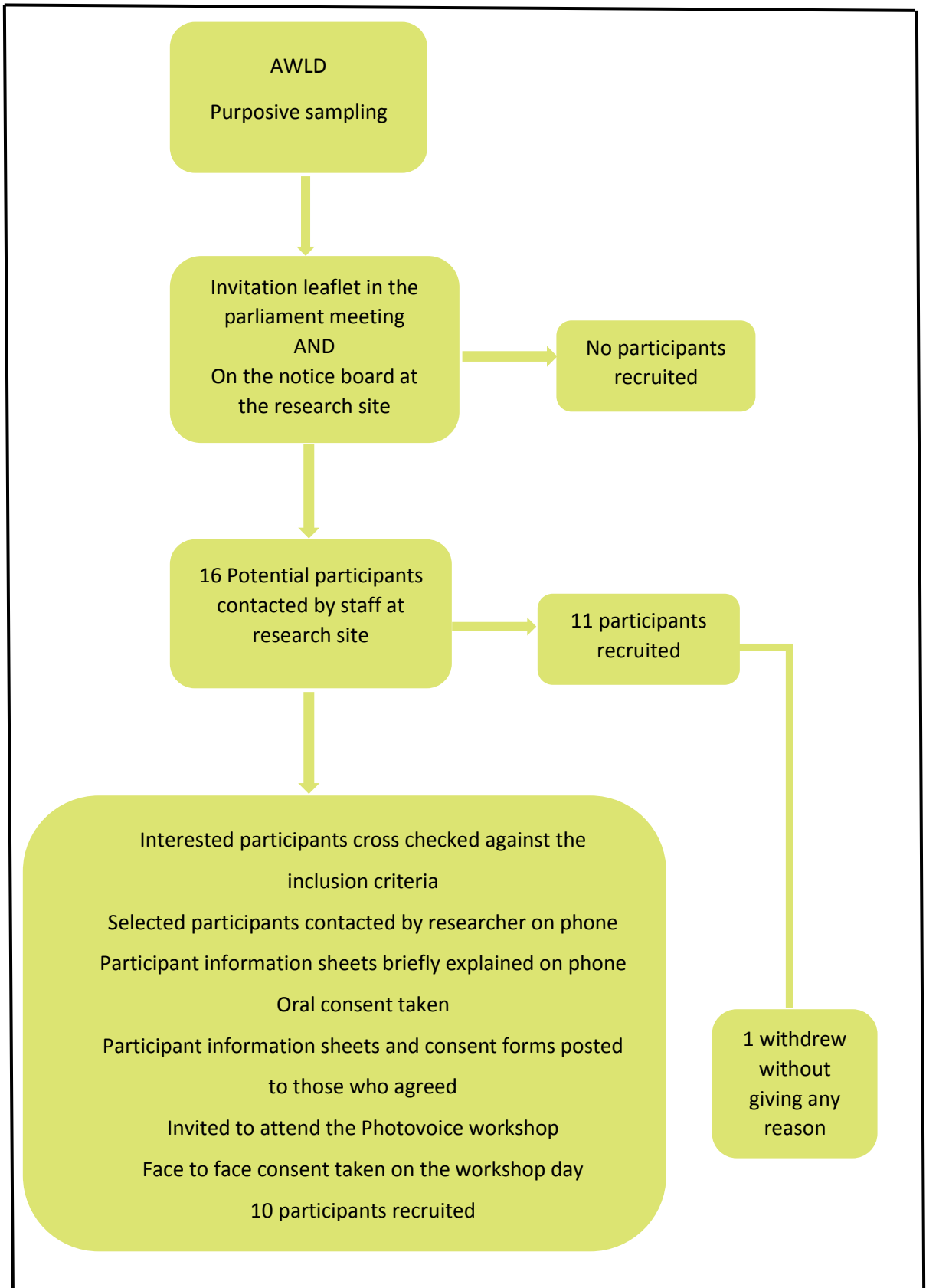
sheets (Appendix E), consent forms (Appendix F) and invitation to attend the Photovoice workshop (Appendix B) were then posted to participants. All participants were contacted after two days to check if they had received the information sheets and if they had any questions to ask. No questions were asked over the phone by the participants. Consent was confirmed again over the phone and subsequently face-to-face and in writing.

The researcher relied on information from the research site about participants in relation to age, level of learning disability and capacity for consent. Moreover, the UK Mental Capacity Act (2005) confirms that anyone aged 16 or over is legally able to make decisions for themselves unless there is evidence of a lack of capacity. A time frame of 2-8 years since bereavement was set as an inclusion criterion for AWLD to participate in this research in view of the multiple losses which AWLD may go through after a bereavement, as highlighted in the literature review. A minimum of two years since bereavement was selected on the basis of previous research suggesting that the usual symptoms of psychopathology and grief may not have reached resolution even after two years since the bereavement (Hollins and Esterhuyzen, 1997) and that the sense of continuous loss can be present even 6-8 years following bereavement (Bonell-Pascual et al., 1999). Case study participants in the work by Kitching (1987), Clements et al. (2004) and Borsay et al. (2013) also provided evidence of signs of grief being displayed between 10 months and 3 years post-bereavement. A maximum of eight years since at least one bereavement was chosen in case the AWLD fail to recall what happened more than eight years ago; however, the maximum number of years could be flexible if the accurate year of bereavement was not known/remembered. This range

was also selected in anticipation that AWLD would have accessed (if desired and available) some type of support after bereavement and multiple losses. So, the people who have met the criteria were of different ages and had faced loss and bereavement at different age in their lives. This reflects the concept of life course approach particularly with regards to bereavement because the participants were of different ages when they were exposed to bereavement and not at a particular age.

The process of recruitment of Group 1 (bereaved AWLD) is shown in Figure 3.1 p85.

Figure 3.1: Process of recruitment Group One



Details of the recruitment of participant group 2 (advocates); group 3 (professional carers); and group 4 (family carers) are now provided, preceded by the inclusion criteria for each group in Table 3.2.

Table 3.2: Inclusion and exclusion criteria for Group 2, 3 and 4

Inclusion criteria		
Group 2: Advocates	Group3: Professional carers	Group4: Family carers
<ul style="list-style-type: none"> • Based at the research site • Experience of working with bereaved AWLD 	<ul style="list-style-type: none"> • Experience of supporting bereaved AWLD (day care service) 	<ul style="list-style-type: none"> • Have provided support for a bereaved family member AWLD after loss

3.11.2 Participant group 2: Advocates

Since the advocacy staff at the research site work closely with AWLD on a wide range of issues, it was essential to understand their viewpoint on the support available to bereaved AWLD after bereavement. A leaflet (see Appendix J) advertising the research and inviting advocates to participate was designed and with the help of staff from the research site, copies were displayed. Initially, only two advocates contacted the researcher to enquire about the research, which was followed by four more advocates enquiring whether their limited experience with working with bereaved AWLD was going to be useful or not. However, none of them agreed to take part. A purposive sampling technique was then used to recruit the advocates and the invitation

leaflets were distributed to potential participants. An email was also sent by the advocacy staff member acting as the gatekeeper (who was not part of the research) with participant information sheets and encouraging advocates to participate if they wanted to, regardless of the amount of experience/knowledge they had working in this field. Eight advocates were finally recruited from the research site with a varied amount of experience of working with AWLD in a range of areas, including loss.

3.11.3 Participant group 3: Professional carers

3.11.4 Participant group 4: Family carers

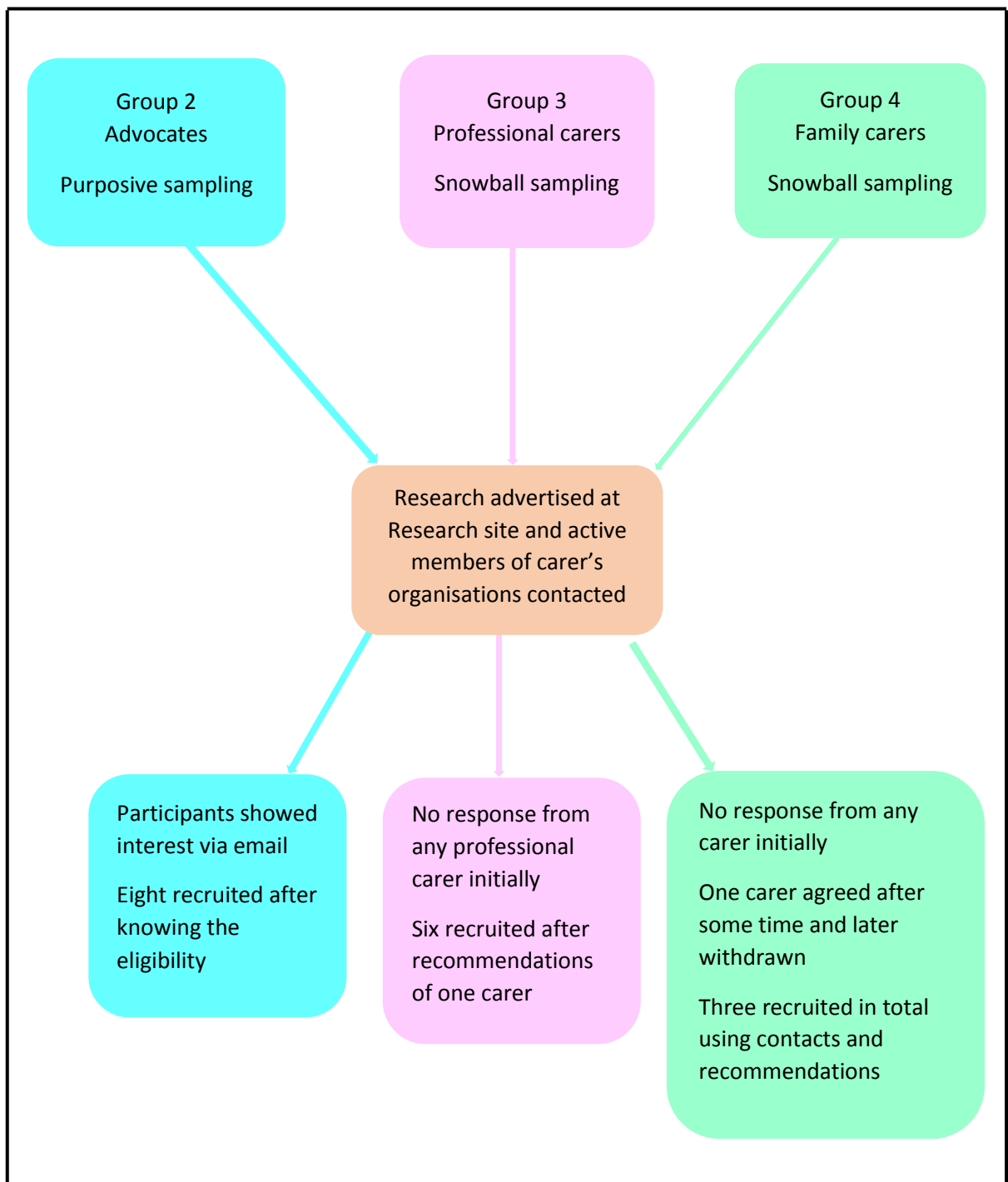
Literature revealed that AWLD do spend a considerable amount of time with professional carers after bereavement with/without choice of home or day care services; hence, the views of professional carers were essential to understanding their role in supporting AWLD at this difficult time. Family carers also play an important role in supporting bereaved AWLD and their viewpoints were also considered. To encourage their participation, copies of the leaflets (Appendix J) used to advertise the research for the advocates were also used to advertise the research for the professional carers and the family carers. The leaflets were given to one member (who agreed to participate and advertise the research at desired locations) of a carers' association working with day care services and the family carer groups. No interest was shown by any individual belonging to the two groups and the researcher waited for three weeks, occasionally checking with the agreed potential participant.

After three weeks one professional carer from a day care service assisting one AWLD at the research site showed interest in participation and

one family carer was contacted using the supervisors' contacts. At this point, a snowball technique was considered appropriate to recruit further potential participants. Following the ideas of Biernacki and Waldorf (1981), snowball sampling is "well suited for a number of research purposes and is particularly applicable when the focus of study is on a sensitive issue, possibly concerning a relatively private matter and thus requires the knowledge of insiders to locate people for the study" (p 141). This was with the case in this research study, too, as the experience of bereavement by AWLD is still considered as taboo by many in contemporary society. This method has been extensively used in qualitative research and involves recommendations made by people who know other people who have characteristics relevant to the research (Biernacki and Waldorf, 1981).

One day care service used by AWLD was contacted on the recommendation of the interested professional carer. With the help of the manager of the day care service, six professional carers were recruited who met the inclusion criteria of having experience of providing support to bereaved AWLD in their job roles. On the referral of one family carer, a total of three family carers were recruited and owing to the time limits of the process, no further recruitment was carried out. All of the participants in these two groups were then e-mailed the Participant Information Sheets for detailed information about the research. The recruitment process of participants from Group 2, 3 and 4 is shown in Figure 3.2 p89.

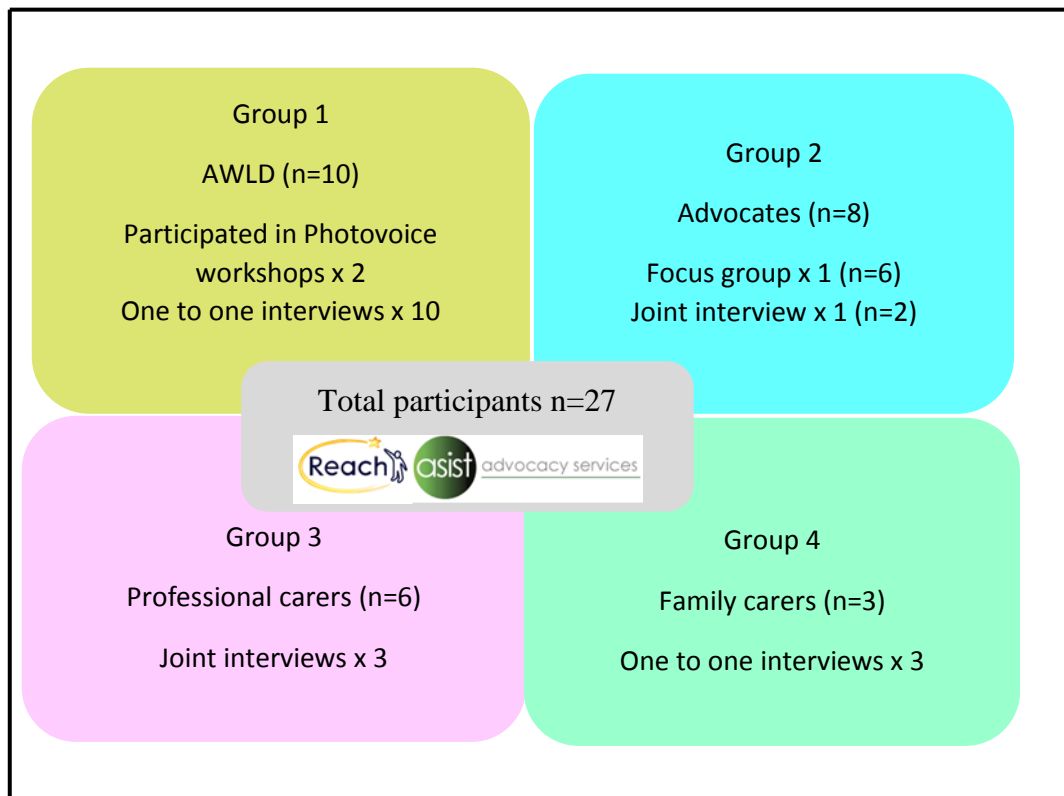
Figure 3.2: Process of recruitment Group 2, 3 and 4



As this is a qualitative study, the sample size was flexible, and it was hoped that up to 30 participants would be recruited in total. However, 27 participants took

part in this research: AWLD (n=10); advocates (n=8), professional carers (n=6); family carers (n=3). Figure 3.3 summarises the number of participants in each group and the methods used for data collection.

Figure 3.3: Summary of all Participants and methods of data collection



3.12 Data Collection Approaches

3.12.1 Group 1: AWLD

All bereaved AWLD (n=10) were invited to participate in the Photovoice workshop followed by semi-structured interviews. The introductory Photovoice workshop (details of rationale and groundwork in section 3.2.3 and 3.2.4 p68-

71) was organised and participants were initially informed by contacting them over the phone and simultaneously sending information sheets.

3.12.1.1 Delivering the Photovoice workshop

For the comfort of participants, the workshop was held at the advocacy organisation (research site) because it was a familiar and easy to access venue. While 10 bereaved AWLD were invited, only five attended the introductory workshop. To support the participants, two supervisors and two advocacy staff members also attended together with the researcher. For the remaining five participants who could not make it owing to a number of practical and personal reasons, a further, similar workshop was rescheduled.

Owing to the health and safety needs of participants, it was decided that participants would not be invited to step out of the room to take photographs. Various items such as ornaments and books were scattered around the room itself for participants to practise using the camera and to promote the discussion. Simple ground rules were agreed with the participants by adopting traffic light cue cards (using red, amber and green colors) because the participants were aware of them through their participation in other activities at the research site. A red card was used to stop someone from talking too much and to ask a question; a green card to show approval; and an amber card to show disagreement if asked. The researcher, supervisors and the advocacy staff introduced themselves, followed by an explanation of the research using the participant information sheets. Understanding of the project and informed consent was checked by giving participants opportunities to raise questions for clarity prior to signing the consent forms.

To introduce themselves, participants had previously been given the choice to bring a photograph from home; two had brought photographs of their deceased family members and one of his pet. All participants introduced themselves, irrespective of having a photograph with them to share with the group.

A clear information sheet using images of the camera and its different components such as the battery, memory card, USB card reader, charger, and on/off button highlighted with a red sticker was prepared (shown briefly in Figure 3.4 p93, complete information sheet Appendix K). This information sheet also explained how to use the camera with images, showing the button to press while capturing a photo (highlighted with a green sticker); images showing how to insert batteries and memory card; how to charge the batteries; and which part to post. This information was prepared as an accessible resource to take home for reference if needed by the workshop participants.

Figure 3.4: Information sheet for using the camera





<p>Camera image</p> 	<p>Battery</p> 
<p>Image showing how to insert battery in charger</p> 	<p>Image showing to how to insert memory card</p> 
<p>Please post these</p> 	

The researcher explained the different parts of the camera and their functions; each participant was then given their own camera to explore and practise its operation. Even though three participants had used their mobile

phones or iPads to capture photographs on previous occasions, all participants required support and training to use the camera. This included training around very basic issues such as how to switch on and off and replace batteries.

Treasure hunt activity: To establish any specific needs and to recognise individual abilities, all participants were invited to stroll around the room chosen for this workshop, to look through the windows and to take photographs of something suggesting a colour or shape of their choice. To encourage understanding and recall of the instructions, the same information was provided on a written instruction sheet with images (Figure 3.5 p95).

Figure 3.5: Instruction sheet to take photos

1. It can be your favourite colour.	
2. A shape like round, square, rectangle etc.	
3. It can be something you think nobody has noticed.	
4. It can be of you.	

A practical stepwise checklist was created and explained to participants using images to outline the expected quality of photographs. (Figure 3.6 p96). The checklist included the four components (4 F's) considered very important for photography, namely frame, focus, follow through and flash (Photovoice, 2014).

Figure 3.6: Four important steps of photography



The participants were given 15-20 minutes to practise using their camera on their own, supported throughout, followed by discussion of the photographs with the rest of the group.

Viewing and discussing the photographs: All participants enthusiastically captured photographs of the objects scattered in the room and through the windows, such as car parks, roads and buildings. The photographs were then transferred from the memory cards and saved onto the laptop

against each participant's exclusive identity number. The photographs were then randomly shown on the projector as a simulating exercise and participants were asked to identify their own photographs. Participants could identify most of their photographs, reflecting their engagement in the activity. Participants were encouraged to say a few words about the quality of the photographs they had taken. It was interesting to observe their positive feedback, as they expressed their views by using words such as 'not worked for blurred photos'; 'too shiny where the flash had brightened the photo'.

To help participants understand what was wrong with the composition of their photographs, the researcher made a list of the perceived needs of each participant. These needs were: how to insert the battery and memory card (for two participants), how to frame and focus before pressing the button to capture a photograph, the importance of waiting for a few seconds before moving the camera, and the appropriate use of flash (for all participants, Figure 3.6 p96). Based on these individual needs, each participant was provided with one-to-one support from the researcher and staff members to further practise using the camera. Although a clear information sheet using images was prepared beforehand to explain the ethical issues involved in taking photographs (Figure 3.7 p98), viewing the photographs as a group initiated a meaningful and useful discussion on these ethical issues.

Figure 3.7: Ethical issues explained

You do need to ask for permission if you are taking photograph of:

1. A stranger
2. A family member
3. A Friend
4. Any person



You do not need to ask for permission before taking a photograph of:

1. A Tree
2. A building
3. A place
4. An object
5. An animal



For example, a participant took photographs of the researcher without asking permission, and thus provided a practical illustration to initiate a discussion on ethical photography. The importance of gaining permission to take photographs was explained with the help of the information sheet (Figure 3.7). Aldridge (2007) explains that photographic methods pose challenges to researchers, predominantly in relation to consent and confidentiality. Verbal and written consent for the use of photographs in this research were obtained separately from participants and explanations were given about the importance of asking permission from others before taking their photographs (Appendix L).

Participants were informed that the photographs were their personal property and would never be used against their wishes. Some photographs captured by participants during their time practicing how to use the camera in the workshop are illustrated below (Figure 3.8). Photographs taken were not limited to the objects scattered around the room, but included things such as bereavement cards from home, their own and other participants' photographs, and information sheets.

Figure 3.8: Examples of photographs taken during the workshop by participants



Photographs taken by participant AWLD during the workshop mainly consisted of objects in the room, through the windows and themselves (Figure 3.8 p99).

Consolidation: Before ending the workshop, all participants were provided with their own numbered cameras with its components; all the information sheets to use as an aid to recall if needed; and a prepaid addressed envelope. In a quick recap, participants were reminded of the aims of the research project, use of the camera, and the time they would be given to take photos related to their experiences of loss, bereavement and support (2-3 weeks). All participants were again reminded of the next stage of the research that required their participation in a one-to-one interview to discuss the photographs taken during the allotted time period. Participants were reminded that the camera was for them to use and keep, but that the memory cards should be posted back.

Three of the participants enquired about some particular photos they wanted to take; for example, Scott wanted to take a photograph of the church where he (Scott) used to go with his deceased father; Rose wanted to bring a photograph of her deceased father from an old photo album; and Charles wanted to take a photograph of a pub where he used to go with his deceased grandparents. These rapid ideas reflected the initial interests the participants had already begun to take in the research activity and their ideas were much-admired. However, directions on the content of photographs were not provided in order that participants would use their own recollections and imagination in relation to the topic. The contact details of the researcher were highlighted, and participants were also shown the list of people on the consent forms to contact,

should they need support or have a complaint. All participants and staff members had a shared lunch before leaving.

Participant AWLD were asked to give some feedback about the workshop before leaving; the responses were recorded with consent and transcribed and included, for example:

“this is easy for me...”, “...I am used to this type of work...” Jack, Participant 5

“I know what photos I am going to get, you know, only if I can get around with this camera...”, “I have never used one of these...” Charles, Participant 2

3.12.1.2 Reflections on the workshop

Owing to the specific needs and potential vulnerability of AWLD participating in this research, it was crucial to do the groundwork before the Photovoice workshop in order to ensure each step was easy for the participants to understand. It was established, as expected, that most of the participants (seven out of ten) had not used a digital camera before the workshop and none of them had owned a camera before in their lives. The principles of good practice that arose from the Photovoice workshop include (Tajuria et.al., 2017):

- Planning, preparation and flexibility are the basis for good outcomes. The whole workshop was conducted using a flexible approach to respond to individual issues.
- Having an accessible venue is crucial, and decisions about where and when to conduct the workshops are fundamentally important.
- Overt practical involvement and rehearsal promotes concrete understanding.

- Treating people as adults, making participants feel welcomed and listening is important to encourage a sense of belonging and active participation.
- Opportunities for creativity and practice were an important aspect. Objects were used in the room to make it more colourful and give people more ideas to take photos. This worked well.
- Sharing reflections and consolidating practical experiences are essential components of qualitative research. Following this workshop, the research team briefly reflected on what had worked well and identified tips for good future practice.

The aims of the Photovoice workshop (p68) were met, as all bereaved AWLD could use the camera to take photos for this research (seven used cameras straight after the workshop and three with some additional support). All participants subsequently took part in one-to-one interviews to discuss their photographs and all participants had a brief idea of ethical photography involving obtaining permission from people.

Photography can be used in research by involving participants to take photographs and then discussing the photographs with the participants to understand their viewpoints. Discussing the photographs with the bereaved is crucial because every loss experience is unique, and everyone has their own way of expressing it. If the photographs are not discussed with the photographer, then there is a possibility of misunderstanding and misinterpreting the photographs. Participation of bereaved AWLD in research like this can promote understanding of the needs and capabilities among those

working with them. Mirroring a research finding by Boxall and Ralph (2011), where the staff became interested in the research owing to the way it engaged with the participants, similarly in the current research, the professional carers appreciated the number of photographs taken by some of the participants. All advocates, professional carers and the family carers showed an interest in the contents of photographs taken by the participating bereaved AWLD after the project had finished.

In addition to the meaningful and enjoyable experience of participating in research, creative methods also strengthen the research by enriching its focus and proving more effective (Ward and Simons, 1998). For example, in the current research, data from interviews supported with photographs adds in-depth information. Involvement in Photovoice is an empowering experience as AWLD have the opportunity to learn a new skill for life (Povee et.al., 2014). This workshop successfully engaged participants who were invited to talk about their photographs and experiences of loss, bereavement and support.

3.12.1.3 Reminders

Four days after the Photovoice workshop. each participant was contacted to see how they were getting on with using the cameras and to book a date for an interview to discuss the photographs. Five participants did not mention facing any problems in using the camera while three participants stated that they had had some initial difficulties but improved with practice. One participant had problems with inserting the memory card; he was invited to the research site and supported by the researcher. Another participant did not give

any particular reason for not using the camera; she was supported at the day care service twice by the researcher to practise using her camera.

Figure 3.9: Postcard reminder



Ten days after the workshop, each participant was sent a postcard (Figure 3.9) to remind them about the project with brief information to check the status of using the camera and to remind them of the interview date. The researcher called each participant three days after posting the reminder postcard to check if they had received the postcard and if they needed any more support. At this stage, all participants informed the researcher of their use of the cameras and the photos they had already taken. Each participant appreciated the postcard sent as reminder.

While Booth and Booth (2003) and Jurkowski (2008) refer to the difficulty of getting participants to follow through with picture-taking assignments, even when given multiple prompts, in this study eight participants who attended the preparatory Photovoice workshops were able to use the cameras independently

at home and to post the memory cards back. The remaining two participants required extra support from the researcher and family to use the camera and post the memory card back. Charles had difficulty in taking the memory card out; hence, it was suggested that he bring the camera with him on the day of interview, when his photographs were printed at the same time. It was realised during the telephone conversations that David and Scott were worried that if they posted the memory cards, they might not be able to get them back. For their reassurance, the researcher met them at their homes before the interview, transferred the images to the laptop, and handed the memory card back afterwards. Only three participants required extra time to take photos (owing to holidays and difficulty with using the camera initially) whereas the rest of the participants finished taking photographs in the specified time.

Charles was worried about some commands like 'card not inserted' as he had inserted it upside down. This made him worry that he would not be able to use the camera. He was invited to the research site and was supported to practise using the camera. During the second workshop for the remaining five participants, Abbey struggled to hold the camera properly and take photographs. It was acknowledged that she needed more support to use the camera independently; she informed the researcher over the telephone that she had not been able to use the camera. The researcher then visited her in the day care service after gaining permission from staff; however, she did not bring the camera with her the first time. During the second meeting, she had remembered to bring the camera and practised using it with support.

All AWLD were made to feel valued by actions such as being sent postcards, phone calls to check everything was okay and acknowledgment that

each need was addressed (such as if they could not travel, then the researcher would go to their homes to support them). Although the researcher had to make extra efforts with planning, it meant that every care was taken to avoid any distress that participants may experience from participating in the Photovoice work.

3.12.1.4 Semi structured interviews

Owing to the sensitivity of the topic and the vulnerability of AWLD, semi-structured interviews facilitated by Photovoice were considered more appropriate than quantitative methods like questionnaires, surveys etc. (Bryman, 1988). This is also in line with the reasons given by Gray (2004, p. 214) for using the interview technique:

- There is a need to attain highly personalised data.
- There are opportunities required for probing.
- A good return rate is important.
- Respondents are not fluent in the native language of the country, or where they have difficulties with written language.

In the process of preparing for interviews, it was ensured that participants had clear information of the purpose behind the interviews, as suggested by Gilham (2000). This was achieved by using the participant information sheets and consent forms and this was checked at different stages of the research using process consent (see Beaver et al., 1999). A flexible interview guide was prepared to use on the interview day (Appendix N). The questions from the interview schedule were pre-set to be asked after

participants had selected 3-5 photographs that related to their support experience; this was believed to be useful as it would have been difficult to discuss all photographs in one interview. Such a selection of photographs during the interviews has been described as a photo-elicitation technique; a means to include photographs during the discussion with the participant (Collier and Collier, 1986; Loeffler, 2004; Aldridge, 2007). Furthermore, the benefit of using photographs was highlighted by Collier and Collier (1986) as the photographs "sharpen the memory and give the interview an immediate character of realistic reconstruction" (p 106)

Suitable interview dates were discussed with each participant via the telephone and a letter was designed using a similar format as previous documents, such as the participant information sheets and consent forms, to maintain consistency. The interview invitation letters (Appendix O) were labelled as 'meeting' letters, as it was suggested by the research site that AWLD prefer the term 'meeting' over interview. Letters for meetings were personalised with each participant's name, had clear information text with images/photos reminding them of the purpose of the meeting (to discuss experiences of loss using photographs), the place for the meeting (research site or day care service), the date, time and duration of the meeting, information on refreshments being provided, and contact details of the researcher and staff member from the research site. All the memory cards were finally received by the researcher via different routes (namely six via post; two collected from homes by the researcher; one collected from a Parliament meeting by the

researcher; and one brought on the day of interview itself). For the completion of such an activity, flexibility is important and was sustained.

Photographs were saved on an office password-protected computer belonging to the researcher, as well as printed by the researcher for the participants to take home after the interviews. Although all participants chose to participate in the interviews at the research site, two interviews were conducted at the day care service at short notice owing to staff shortages to accompany the participants to the research site. Before starting the interview, each participant was asked to select any three photographs that they believed reflected their experience of loss and subsequent support. The questions related to the chosen photographs were open-ended, such as: 'What is special about this picture?' or 'Tell me something about this picture'. In addition, if the participants' answers were not explicit through their description of the photographs, the following open questions were asked whenever appropriate from the interview schedule (Appendix N):

- What is your relationship with the deceased?
- Tell me about changes in how you live since bereavement?
- What helped you, during bereavement, to cope with the situation?

The interview schedule and photo-elicitation technique were both essential to keep the focus of the discussion on the photographs related to the topic, as some participants had taken more than 100 photos. Letting the participants choose again allowed the bereaved AWLD to remain in control of what they wanted to talk about.

3.12.2 Group 2: Advocates

Focus groups were used to gather information from advocates. They are defined as, "...in depth group interviews employing relatively homogenous groups to provide information around topics specified by the researchers" (Hughes and DuMont 1993, p. 776). Focus groups allow researchers to gather data from communication among group participants in a short time compared to other methods (Smithson, 2008). While eight advocates were invited to participate in the focus groups, only six could make it on the day and another session was organised for the remaining two (conceptualised here as a joint interview described on p111). Owing to the time limitations faced by advocates, the focus groups were considered appropriate methods for data collection.

The focus group discussion with the advocates was organised at the research site using a flexible guide, asking open-ended questions focussing on the following areas (Appendix P):

- Tell me about the types of loss that are experienced by AWLD.
- What types of therapeutic interventions are used locally and what types of support are offered at the research site?
- How might you describe the role of advocates/professionals/family carers in supporting an AWLD after loss?
- What types of training workshops are organised at the research site and what are their benefits around supporting bereaved AWLD?
- What works for AWLD in the bereavement support process?
- Which areas need improvement in providing support?

- What might be the barriers to access the services provided at the research site from their (advocates) point of view?

3.12.3 Group 3: professional carers

Although one focus group was proposed with the professional carers (n=6), owing to time constraints only two participants were free to participate in each focus group at the same time. Hence, three small focus groups were organised to involve all six participants on different days and at different times at the day care service. Two professional carers participated in each discussion with the researcher for half an hour; these interviews could be considered as joint interviews rather than focus groups. Joint interviewing is proposed as suitable by Morris (2001) and Radcliffe, Lowton and Morgan, (2013) to explore collective practices. This was true for the current research as the professional carers disclosed that they follow similar practices working with bereaved AWLD because they work for the same organisation.

3.12.4 Group 4: family carers

Time was a big issue for two of the family carers (n=3) mainly owing to caring roles at home for an AWLD family member and additional job commitments for one of the family carers. Coming to the research site was difficult for them; hence, two were visited in their homes and one at their place of work for one-to-one interviews. An interview schedule similar to the one used for the advocates and professional carers was used with the relevant changes in words used to address the participants and their roles (Appendix P).

3.13 Inclusivity

To promote inclusivity, special consideration was given to make appropriate arrangements at the research site to engage participant AWLD. Some of the participant AWLD were wheelchair users; they were given support in moving around the research site during their participation in the research. Two participants with learning disabilities could travel independently using public transport, whereas eight participants required the arrangement of a taxi on the activity days related to the research. Taxis were arranged, and fares were paid for the participants; appropriate transport (to AWLD) and refreshments were provided at the Photovoice workshop and during all the interviews and focus group discussions to all taking part. Some of the expenses including room hires, taxi fares and refreshments were reimbursed by the University. The cameras used for Photovoice by the participating AWLD were given to them to show gratitude for their participation and the cost of the cameras was met by the researcher.

3.13.1 Participant expectations

In some circumstances, as anticipated, the researcher had to go to support/collect camera memory cards from the homes of AWLD, which can lead to the risk of intrusion. Research has indicated that owing to a restricted social life, some AWLD may have fewer friends than those without learning disabilities; thus, the intrusiveness of a researcher can sometimes raise expectations of a continuing friendship (Booth and Booth, 1994; Tuffrey-Wijne, Bernal and Hollins, 2008). This was considered beforehand, and provisions were made whereby the researcher kept visits to participants' homes to a

minimum and only at the request of the participant. For her own health and safety, the researcher kept the supervisory team and the research site informed of details of the interviews, the location, and other data collection sessions. To ensure the researcher's safety, the relevant lone worker procedures were followed in accordance with Keele University Lone Working policy.

3.14 Confidentiality and anonymity

As explained by Giordano, O'Reilly, Taylor, and Dogra (2007), confidentiality is "...information that has been communicated in trust of confidence, such that disclosure would or could incur particular prejudice" (p. 264). In the current research, confidentiality was assured in the participant information sheets and maintained at each stage of participants' involvement. Anonymity has been demarcated from confidentiality as a technique used to measure and maintain confidentiality (Wiles, Crow, Heath, and Charles, 2008) and is commonly performed by using pseudonyms in the research study. Absolute anonymity during a qualitative research study cannot be entirely assured because this would mean no one knowing who said what during research participation (Polit and Hungler, 1999). However, that is not always possible while participating in some qualitative research methods, such as focus groups.

3.14.1 Application of confidentiality and anonymity in current research

Owing to the potential vulnerability of the participants with learning disabilities, they were assured of confidentiality and anonymity as far as

possible to protect them from potential psychological and social harm, such as distress. Owing to the topic of the research, it was anticipated that some participants may become disturbed whilst/after talking about their deceased family members. Therefore, participants were invited to bring someone to accompany them if they wished to; however, the confidentiality and anonymity risks were explained for such occasions. None of the participant AWLD chose to bring someone to the interview. To support a participant who might become distressed during the session, the contact details of a bereavement counsellor (a supervisor who is involved with the research site) was provided on the participant information sheets and each participant was verbally informed of how to contact them if required.

Thoughtful disclosure of the confidentiality procedure to be followed if any information was required to be disclosed during an emergency, for example if someone was in danger, was also explained. Detailed procedures for signposting the participants were discussed with the research site on such occasions and it was mutually agreed that the researcher would inform the research site straight away. Previous research has indicated that sometimes AWLD or other participants do want their identity to be revealed in data presentation (Wiles, et. al., 2008). During this research, the implications of revealing their identity were fully explained to participants, together with using a pseudonym. Measures taken in the research study to protect participants as far as possible were as follows:

For the Photovoice workshop: Although the principles of confidentiality and anonymity were followed carefully, it was not possible to always apply them fully, and in these circumstances, the participants were informed. For example,

participants attending the Photovoice workshop were made aware of the presence of other people and thus neither anonymity nor confidentiality could be fully guaranteed. As all participants knew each other, they were all well-versed that they should not share information about others outside the workshop/group.

For the focus groups: Participants were informed on the consent forms that the confidentiality and anonymity of what they discussed could not be assured owing to the presence of the other participants, and they were also informed that information shared in the focus group discussion should not be shared with anyone who was not the part of the group. Also, during the recording of the focus group discussions, participants were instructed to maintain the privacy and confidentiality of themselves and the people they talked about by not using any names.

For the interviews: Confidentiality of the participants was maintained by replacing the number assigned to every participant during the Photovoice workshop with pseudonyms, as participants were aware of some of the numbers that other participants were given. On some occasions, if sensitive information that was specific to a participant was shared and was easy to recognise by others, then some of the information was changed without losing the main context. For example, a distressing account shared by an AWLD about a male family member that was crucial to the research findings was reported as if it was said by a female.

During transcribing: Only the minimum required personal participant identifiers were collected and were removed as soon as all data was

transcribed. No identifying information was used with any data. From the beginning of this thesis pseudonyms are used for each participant and any person they mentioned in their interviews.

Published information (thesis, articles or reports): it was realised that some of the bereavement stories could be unique; hence, even if pseudonyms were used, the participants could still be identified. Although participants were informed of the risk of someone reading the thesis or any other publication, the researcher will avoid using such information in publications that could put the participants at any risk of being identified.

3.15 Conclusions

There are ethical issues in the field of learning disability in establishing whether participants can give consent to be involved in research. In this study, informed consent procedures with adaptations to assist the participants in understanding the nature of their participation were used throughout. Clear information was developed to ensure that the AWLD could clearly understand the research and ask questions where appropriate reflecting their engagement in the whole project. All participant AWLD attended the follow-up interviews in line with knowledge gained from the Photovoice workshop that explained the importance of discussing the photographs with the researcher afterwards. This suggests that the extensive preparation for Photovoice, combined with a flexible approach, was effective in engaging participants in this inclusive research, in line with Cluley (2017). Confidentiality and anonymity have been given special

consideration and described, as well as followed, at each step. Participants were also ensured of these and they were maintained as far as possible.

Chapter Four: Data management and analysis

4.1 Data management and storage

The interviews and focus group discussions were audio taped with consent gained from participants during the initial stages and before each interview/focus group discussion. The first interview from each group was transcribed before conducting further interviews, in order to adjust the questions if required. After completion of the data collection process from all participant groups (i.e. the photographs taken by participants; interview transcriptions; the focus group transcriptions), all of the data was saved onto a password-protected computer in a secure setting at Keele University. If needed at the research site (for short periods), data was stored either in a locked filing cabinet or password-protected computer. Only the researcher had access to data at the research site.

Participants were informed about the data storage policy in line with Keele University guidelines and were told that the data would be retained by the principal investigator for at least five years and then would be securely destroyed. No-one other than the lead researcher and supervisory team had access to any data. No one from the research site had access to any identifying information about the participants. Some staff members at the research site knew the participants but none knew who contributed what in any interview or focus group discussion. To transport data from the research site to the University office, a personal password-protected laptop was used, which was

never left unattended. Once saved securely on the University computer, all data was deleted from the portable laptop.

All of the digital recordings from AWLD and the majority of the others were transcribed by the researcher using Express Scribe© software (apart from one focus group with advocates, one joint interview with the professional carers and one interview with one of the family carers, which was done by UK transcription services). At the beginning of transcribing the first interview with Adam, it was realised that the participant was referring to the photographs he had captured. Hence, a brief note on the content of the photograph that the participant was talking about was included in the transcript. This helped to connect photographs with their corresponding interview. It was quickly established that transcribing the digital recordings from AWLD was both difficult and time consuming. Six of the participants had speech impediments and/or mispronounced some words; in such cases where the speech was not clear, slowing the audio was not useful. Although a significant amount of time was utilised in transcribing the data, it was considered essential in order to assure the AWLD participants of confidentiality and anonymity as far as possible; and also, to enable the researcher to be immersed in the data. During the process of transcribing, pseudonyms were used and all identifying data was carefully removed.

4.2 Data analysis

“Analysis I take to be a scientific procedure. What I do is creative. It doesn’t spring from the same part of the mind” (Pinter, n.d.)

Data analysis is an important step in carrying out any research and requires clear understanding and explanation by the researcher. It can be difficult to evaluate the research and can cause an obstruction for other researchers to follow up the research in the same area if the analysis process is not understood and explained properly by researchers (Attride-Stirling, 2001). This section, therefore, illustrates the detailed analysis process undertaken with the photographs and interview data.

In summary, the following data set was generated in this research project:

- 445* photographs printed that were taken by participants (AWLD, n=10)
- Interviews with (AWLD, n=10)
- Two focus groups with six and two participants respectively (advocates, n=6; n=2)
- Three short focus group/joint interviews with two participants in each (professional carers, n=6)
- Interviews with family carers (n=3)

*In total 508 photographs were taken by the participant AWLD, however absolute copies and photographs containing content that was difficult to see (63 photographs) were not printed.

4.2.1 Thematic analysis

Data analysis was achieved using a thematic analysis technique, defined by Braun and Clarke (2006, p.6), as, "... a method for identifying, analysing, and reporting patterns (themes) within data". In addition to organising and describing the data from the research in detail, thematic analysis also enables the researcher conducting qualitative research to communicate the findings with people using different methods (Boyatzis, 1998). Braun and Clarke (2006) have argued that, compared to methods such as narrative analysis or grounded theory, thematic analysis has been less recognised yet more frequently used and sometimes used with different names, such as recurring themes (Braun & Wilkinson, 2003). Thematic analysis is not pre-fixed to any existing theoretical framework, unlike methods such as grounded theory, IPA, discourse analysis, and narrative analysis. This could be argued as both its strength and weakness; for example, the researcher can use it flexibly, however the focus of analysis can be easily lost as there is no theoretical framework to follow for comparison.

The process of thematic analysis as suggested by Braun and Clarke (2006) was used and is explained in the following stages in the context of all participant groups; adaptations were made to the procedure to analyse interviews and photographs from AWLD, which are described in section 4.2.2, p123.

Stage 1: Familiarisation with the data

This involved reading and re-reading each transcript and listening to the digital recordings for clarification, as well as taking notes of all significant and relevant points (data extracts).

Stage 2: Producing initial codes

After familiarisation with the data and noting recurring points in relation to the research questions, initial codes were then produced from the data extracts by using different coloured highlighter pens against the relevant data extracts from the previous stage.

Stage 3: Identifying potential themes

After coding all of the data, the codes were organized, and a broader level of potential themes was identified. All codes were checked and collated into themes and then checked against the data extracts. A theme can be described as an important pattern to describe the data by answering the research questions (Braun and Clarke, 2006).

Stage 4: Revising the themes

The identified themes were refined by checking the supporting data and separating into sub-themes or collapsing the themes accordingly. An overview of themes and range of sub-themes is presented in chapter 5 before results from each group for example see Table 5.1.1,(p129) for themes from data collected from AWLD.

Stage 5: Naming and defining themes

Based on the content and matched data extracts, the refined themes were named, and the names defined.

Phase 6: Producing the report

The final themes from each participant group are described and presented with supporting quotations in chapter 5.

4.2.2 Analysing photographs and interviews from AWLD

Techniques to analyse visual data are poorly described in the literature, but are traditionally narrative or thematic analysis (Loeffler, 2004). More recently, Interpretative Phenomenological Analysis (IPA) has also been used by Ciolan and Manasia (2017). However, unlike the work by Ciolan and Manasia, thematic analysis was selected in the current study over IPA owing to its flexibility and suitability for data analysis from different sources. Undoubtedly, the use of visual approaches such as Photovoice for data collection can enhance the understanding of research (Burles and Thomas, 2014); however, the lack of a clear analytical data analysis procedure and the importance of photographs in the research have been recurring issues related to its use (Ciolan and Manasia, 2017). Visual methods, whilst being innovative and creative, are believed to be unique in the way they are carried out and analysed in research (Smith, Mountain and Hawkins, 2016). Hence, Pink (2001) suggested that analysis of visual data may perhaps be undertaken by adopting creative techniques instead of depending on a manual produced by others to carry out each stage of analysis. Additionally, procedural correctness has been suggested as vital with the use of visual methods even if there is no, "...right or wrong way to undertake qualitative visual research..." (Smith et al. 2016, p 711).

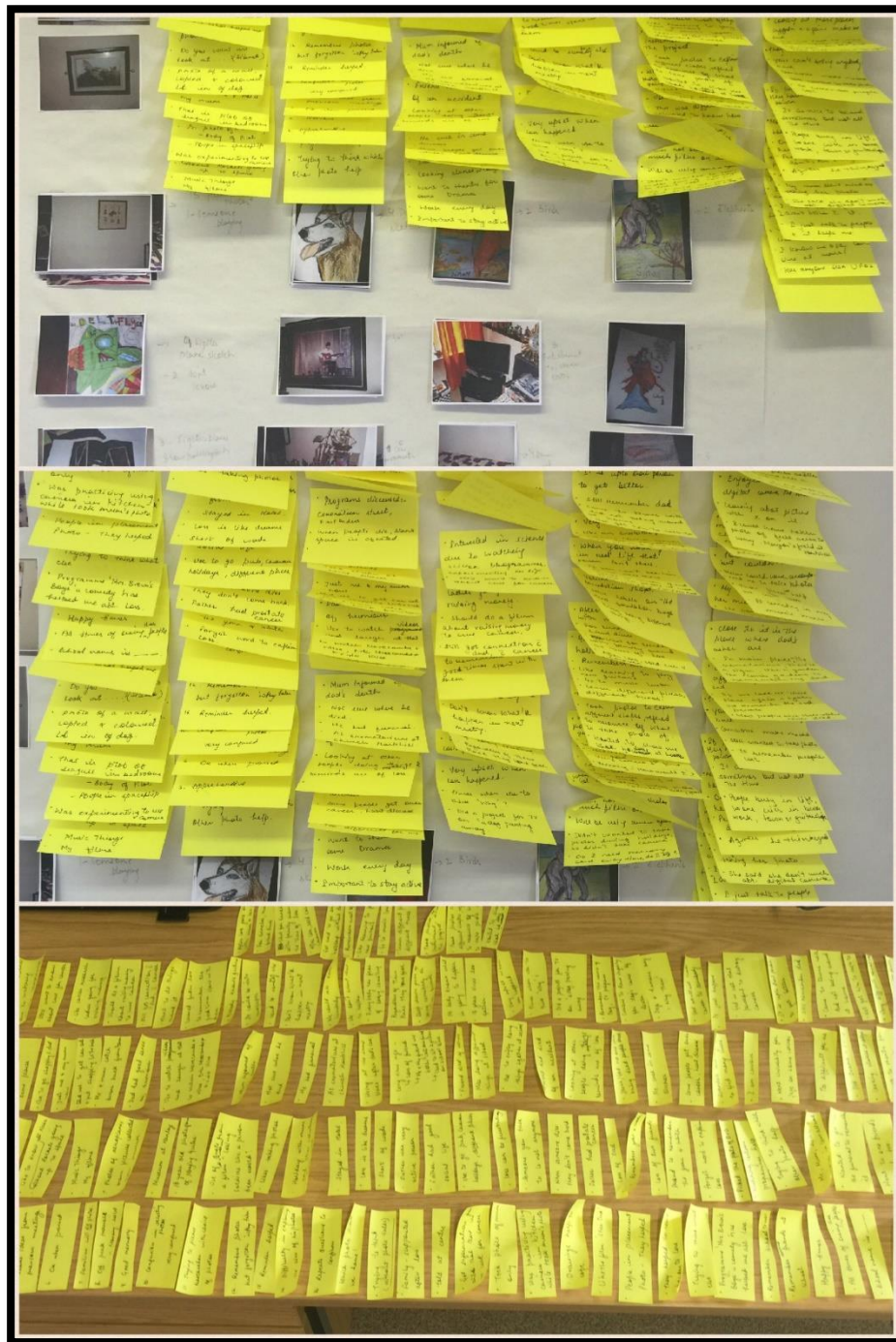
Following the suggestions of Ciolan and Manasia (2017), it was realised that the photographs were part of the data analysis because they were used to support and act as prompts for bereaved AWLD during their participation in the interviews. Photographs taken by the participants were not limited to illustrating the support source or the deceased; they were also about the participants' life before, during and after loss. To analyse the data produced from participant AWLD, work was done together with the transcripts and the photographs and the identified adaptations to the thematic analysis procedure, discussed as follows, were used for this data set:

- Owing to the inconsistent nature of data from AWLD, it was essential to keep the photographs and the transcripts together for data extraction for the process of finding themes. To be able to see all photographs during analysis, flipcharts were used to paste photographs and data extracts separately for each participant (see Appendix Q).
- All the photographs were printed thumbnail size 2x3" each to limit the space used on the flipcharts and grouped according to the content. The photographs selected by participants to talk about during interviews were glued on the top of the flipchart followed by other photographs. For example, all photographs with family members were put under one heading and photographs with friends or staff were put under separate headings for each participant (Appendix Q1-3).
- After reading and re-reading the interview transcripts, data extracts with information relevant to the research questions were written on post-it notes using different colours for each participant. Initial codes were generated based on noted recurring points relevant to answering the

research questions. The data extracts (including the direct quotes) were then combined according to the content and glued on the flipcharts in similar patterns (Appendix Q3-4).

- Once all the photographs and data extracts for each participant from the post-it notes were allocated, the flipcharts were then put on the walls to see and work on them further visually. More than 70 key points were noted by this stage; an image of one flipchart to give an idea of the flavour of the process is shown in Figure 4.1, p125. Each step followed in the analysis of photographs with interviews for all participants is shown in detail using images (Appendix Q4-9).
- Working headings/theme labels were given to key points in the data extracts from all participants that reflected similar patterns. Themes were then refined by checking the supporting information and separating them into main themes and sub-themes by collapsing the themes accordingly.
- Five final themes with a range of sub-themes were identified from the data set from AWLD, as shown on table 5.1.1, p128.

Figure 4.1: Sample Flipchart photo containing data from Scott



The findings from the data collected from participant AWLD, advocates, professional carers and family carers is now presented in chapter 5.

Chapter Five: Findings

In this chapter, findings from all participants (n=27) are integrated as the result of analysed interview transcripts, focus group transcripts, photographs and field notes. Findings from AWLD, advocates, professional carers and family carers are presented in sections 5.1, 5.2, 5.3 and 5.4 respectively. The conclusion of this chapter identifies the similarities and differences in viewpoints of the different participant groups; considers what new knowledge is contributed by this research in the field of loss, bereavement, support, AWLD and Photovoice as a methodology; followed by suggestions and recommendations based on all participant data. The findings will now be presented sequentially.

5.1 Introduction of findings from AWLD

“...Bereavement is a lot different for every person that is born in the world...what I am going to tell you if we had someone from another country like America or whoever was talking here, probably they would tell a different story...” (Scott, lines 1032-1037, T8).

Clearly loss has been identified by Scott as a unique experience for every individual in the world, including AWLD. There is a pressing need to understand the uniqueness of loss experienced by AWLD and provide support accordingly. As explained in chapter four (section 4.2.2), more than 70 key points were noted from data collected from participant AWLD. The four main themes with a range of sub themes derived from the data are presented in Table 5.1.1, (p128). The themes are principally based on participants’

recollections of their experiences of loss and further described with direct quotations from the interviews and the content of the photographs.

*Table 5.1.1: Themes across recollections of loss by *AWLD*

1. Experiences of loss	2. Difficult/bad news	3. Types of support	4. Continuing bonds
a) Types of losses <ul style="list-style-type: none"> • Primary (death, transition) • Secondary (home, time, freedom) 	a) Finding out <ul style="list-style-type: none"> • Day • Series of incidents • Date of loss 	a) Bereavement Support <ul style="list-style-type: none"> • Awareness • Attitude to bereavement counselling 	a) Interests (similar) <ul style="list-style-type: none"> • Feeling close to the deceased
b) Understanding loss <ul style="list-style-type: none"> • Death of people • Person-centered Metaphors 	b) Information after loss <ul style="list-style-type: none"> • Source • Funeral 	b) What helped <ul style="list-style-type: none"> • People • Keeping busy • Talking about loss • Rituals 	b) Reminiscence work <ul style="list-style-type: none"> • Deceased's personality'
c) Understanding the cause/place of loss <ul style="list-style-type: none"> • Sudden • Anticipatory 	c) Impact of difficult news <ul style="list-style-type: none"> • Changes in life • Faith/belief • Worries • More deaths • Own death 	c) Best help <ul style="list-style-type: none"> • Knowledge and information • Friends • Family • Keeping busy • Advocacy site 	
d) Feelings & expressions of loss <ul style="list-style-type: none"> • Physical • Emotional 	d) Long-term impact <ul style="list-style-type: none"> • Multiple losses • Positive impact 	d) Not helped <ul style="list-style-type: none"> • Non-involvement 	

*AWLD - Adults with learning disabilities

These themes are now explored individually.

5.1.1 Theme 1: Experiences of Loss

This theme describes the range of losses faced; definitions of understanding of loss produced by participants; the knowledge held by participants about the cause of death; feelings after loss; and how the participants expressed those feelings. Looking at the types of losses, 13 different categories were identified (four primary and nine secondary). Initial loss is identified as the primary loss and the loss that follows is referred to as secondary loss. Table 5.1.2 illustrates this range of losses.

Table 5.1.2: Types of loss

Participant	Primary loss	Secondary losses
Rose	Father (death)	Memory box made during counselling sessions Home temporarily Possessions related to father Freedom to see and talk to friends Personal Assistant (PA) Home permanently
Charles	Father (illness and death) Grandfather (death) Mother (alive but left) Cousin (death) Uncle (health)	Sister moving out of home temporarily Family activities (meals, jokes and stories) Music Fun activities with uncle Visiting pub with deceased family members Home
Adam	Brother (death) Father (biological; death)	Relationship with mum owing to her remarriage Freedom of speech Plants
Abbey		

	Father (Death) Mother (Death) Pet (death)	Time spent with parents
Jack	Father (death) Mother (illness and death) Grandparents (death) Great-grandparents (death) Sister (moving out and death) Uncle (death)	Home (twice) Sister (death followed by illness)
George	Father (death) Mother (death)	Contact with friend Visits by Social worker Home
Lisa	Mother (death) Father (illness and death)	Home
Scott	Two friends (death) Father (death)	Time spent with friends at school TV actor (death)
David	Grandfather (death) Grandmother (death)	Time spent with grandparents
Megan	Mother (illness and death) Father (illness and death) Sister (death) Aunt (death)	Own health Job

Theme 1, Sub-theme a: Types of loss

People: Primary losses included loss owing to the death of one or more family members for all the participants; additionally, illness and transition of family members also led to significant primary losses. People lost owing to death included: one parent (Scott, Charles, Adam, Rose; n=4) or both parents (Abbey, Jack, George, Lisa, Megan; n=5); grandparents (Charles, David; n=2); siblings

(Adam, Megan; n=2); friends and close family relatives (Jack, Megan Charles; n=3). Five participants brought old photographs of the deceased people they were they talking about to show to the researcher. For example, Rose and Scott brought their respective father's photograph; Charles brought his father's and grandfather's photograph; Megan brought different photographs of her parents, sister and aunt she had lost; and David brought separate photographs of his grandparents (Figure 5.1.1):

Figure 5.1.1. David's grandfather



“...I making coffee for my granddad... see the coffee there, that’s what I have done for him” (David, lines 118-122, T9).

Making a drink for a family member could be a great thing for an AWLD, as conveyed by David, who focussed on the coffee in his deceased grandfather's hand. David clearly expressed how AWLD build attachments with their family

members by doing small gestures. Other than the death of family/friends, death of TV actors was conveyed as a substantial loss. The media (TV) can be a powerful way of learning about loss, as illustrated by Scott:

“...when people watch television programmes like all the drama programmes...just realise Jack and Vera are not in the programme anymore, they have died in the programme.” (Scott, lines 498-501, T8).

Somebody dying in a TV programme can be a serious loss in the life of an AWLD, as reflected by Scott, who may have believed that the actors have died in real life, too. Disappearance of a TV actor thus could be useful for initiating conversations about death with AWLD; however, if not discussed thoroughly and sensitively, such discussions could easily be confused with a real death. Family members moving away from home with or without the participant's wishes was a significant loss for three AWLD, such as Megan's mother who was moved to a care home and Jack's sister who left home, followed by the death of both; in these cases, the move was equally as distressing as the death. Megan shared the following photograph while talking about her mum, when she (mum) was moved to the care home and neither Megan nor any of her siblings were allowed to stay with her (Figure 5.1.2):

Figure 5.1.2. Megan's family



“...we could have stopped there [care home], and I didn't know what to do with her...” (Megan,

lines 382-383, T10).

Losing the opportunity to look after her mother and not being able to spend more time with her in the care home was distressing for Megan before her mother's death. This clearly reflects that some AWLD may possess the same wishes, such as to spend time with a dying family member, as a person from the general population.

Pet: For Abbey, the loss of a pet was a significant loss and she brought the photograph of her pet's ashes (Figure 5.1.3):

Figure 5.1.3. Abbey's Pet's ashes



*“...his name is Jaz... that’s his
ashes...it was our dog”* (Abbey lines
322-346, T4).

At times, AWLD will refer to facts even in the context of a sensitive issue, such as the loss of a pet. The way Abbey lists the name of her dog, his ashes and her connection to her dog, reflecting her sense of ownership, displays the role of facts in her grieving thought processes.

Home: Secondary losses associated with the loss of parents or primary carers included the loss of a home. Five participants (Charles, Jack, Rose, George and Lisa) had lost their family homes after the death of their parents. Rose and Lisa said they were sent to day care services without their agreement. For three (Rose, Charles and George), however, the house move was positive, and Rose rationalises her second move as helpful in getting rid of the disturbing thoughts and visual images of her deceased father she was experiencing in her previous home. For George, he felt it was good to move somewhere different. The following quotations reflect why Rose, and Charles felt the need to move from their houses:

" weeks and months after or near his birthday or near the anniversary, sometimes I could see him lying there. I could see him. Now we are out of that house" (Rose, lines 142-144, T1).

"The reason I actually moved from where I was, was even when he was dead I kept imagining the telephone ringing and saying, 'Can you come up?' I had a dream one day that he had actually died at home and I wasn't there..." (Charles, lines 698-700, T2).

Expressing the move from one's own home to somewhere different/new as a positive thing reflects how difficult the grieving period would have been and that moving to a new house was a convenient choice. Evidence from these quotations shows that sometimes AWLD may weigh the difficulties of living with loss at the same place against living at a new place and choose the latter as an escape unknowingly. Even though on the interview day the house move was discussed as positive by three participants, it was a significant loss at the time

for all the participants.

Possessions: Rose had felt good after moving to a new house; however, in her move she lost her memory box and almost all the keepsakes of her father, which was a huge loss for her, as she said:

“My dad’s... my mum’s friend did a DVD with me with the photos when he was younger. That’s what annoys me, where is it gone ...” (Rose, lines 531-532, T1).

Talking about photographs and DVDs as a significant loss, Rose clearly presented how important such objects are for AWLD after a loss and how their loss can add extra stress. Possessions are certainly tangible reminders for AWLD, as they are, too, for many people in the general population.

Loss of support from external sources: The end of the visits made by a personal assistant (PA), carer and social worker was also a noteworthy loss for participants. George believed that his carer was a great support following his father’s death and there was no communication with regard to ending the visits from the carer’s side:

“I haven’t got one now. I don’t see her. I haven’t got one anymore...She’s moved, hasn’t she, somewhere?” (George, lines 739-747, T6).

Not seeing someone is a significant loss, as it was for George, who had no idea what had happened to his carer and this was all the more distressing as this was at a time when he had lost his parents and required support the most. This

indicates that AWLD often are not even informed before important changes that affect their lives.

Loss of relationship and the time spent with deceased: Loss owing to the death of one parent can lead to a change in or loss of relationship with the surviving parent. For example, following the death of Adam's father, his mother remarried, and Adam had felt like he was losing his relationship with his mother. This led him to feeling isolated owing to the loss of closeness he had previously shared with both of his parents. He talked about his mother's remarriage in the same context as the death of his father and brother:

*“only my brother and my dad, real dad and then my mum married
Josh...”* (Adam, line 50,T3).

AWLD are capable of differentiating between their relationships to different people in the family if they have the opportunity to do so. As Adam clarified, the one who died was his 'real father' but his mother and step-father are still alive. Sometimes, the difference in the closeness with the deceased is expressed in words and at other times it is reflected in body language, as was the case with Charles. While talking about a family photograph, Charles's attachment to his father was reflected through his body language as he was constantly looking at his father and his eyes became wet with tears. Charles introduced his deceased father in the same way as someone from the general population would introduce his or her family member. The following quotations from Charles (Figure 5.1.2 and 5.1.3, p137) demonstrate the bond that he had with his deceased family members:

Figure 5.1.2. Charles's family



“...Then the best one is my dad. He is my world...”

(Charles, line 290, T2).

The deceased person could still be considerably important to the AWLD, even after death. For example, for Charles, his father was still “my world.” The relation with the deceased is sometimes given more importance than the loss itself by AWLD.

Figure 5.1.3. Charles's grandfather



“that is my grandfather, he died of cancer, but I was very close to him”

(Charles, line 159, T2).

Talking about attachment with the deceased using clear sentences after losing a family member to a life-limiting condition could possibly develop into a greater sense of attachment over the years. This gives the impression that it was not just that he lost his grandfather, but also the closeness Charles shared with him. Loss owing to death or transition (moving out of the home) was associated with loss of time spent with family members by all participants. For example, for Charles, David, and Scott the death of their loved ones was also the cause of loss of family activities like having meals together, playing jokes, enjoying music, going to the pub, and going on holidays, as illustrated in the following quotations:

“...But we used to go around for Sunday dinner. That was a good one”.

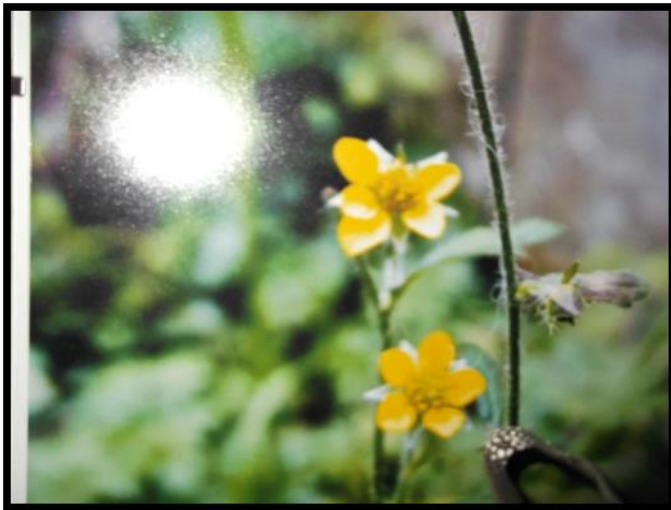
“The music in the family now has just disappeared because my dad used to play the organ...” (Charles, lines 513 and 452-453, T2).

“have a drink with them, with my nana and my granddad” (David, line 185, T9).

Clearly AWLD were projecting a bigger picture around what they had lost after the death of a family member. The importance of activities such as having meals/drink with the family was reflected by the distress AWLD expressed after losing them. Following the death of a person, the loss of relationships was substantial in the lives of all the participants. As nine participants were mainly talking about the loss of their parent/s and one (David) of his grandparents, all the participants reflected that the deceased person/s loved them the most and meant everything to them.

Other losses: Adam described a unique loss of some plants that he used to see in a valley where he used to go for walks with his father. He mentions that some of these grow in different places; however, they were lost from where he had the memories of seeing them. He had taken 20 photographs of these flowers from magazines, such as the one shown in Figure 5.1.6:

Figure 5.1.6. Adam's plants



“...well what that [loss] is, it is because the certain plants they got lost in the newfit valley” (Adam, lines 115-116, T3).

The disappearance of these plants was an ultimate loss for Adam, he goes on talking about these plants and their benefits during the interview. Megan had lost her job after her father's death, but she did not give the reason as to why; she had also experienced a period of ill-health after she lost her parents. However, she now feels that she is looking after herself. Two participants (Rose and Adam) believed that their parents were losing their health and talking about loss was making it worse. Hence, they refrained from talking about the deceased person in front of their family members. Eventually, this augmented the sense of another loss, that of the ability to speak freely. As described by

Adam, in light of his mother's illnesses, he was expected to say only things that were not going to cause distress to his mother; he was under pressure not to speak openly:

"I say to mum it's dad's birthday December 1st and she says oh yeah.

And [Josh, family member] says don't cause your mum stress ..."

(Adam, lines 274-275, T3).

AWLD are sometimes led by their non-learning disability family members to believe that talking about loss and death would make things worse, and this further complicates their emotions and their response to grief and bereavement. When there is no explanation to changes in lifestyle by the families, this creates additional stress, as expressed by Rose. Rose had lost the freedom to go out with friends since her father's death and she was disappointed. She complained about her lost freedom and gave a justification for having the freedom to go out with friends:

"...because me mum is not letting me go and meet my friends, see me other friends...That's what I need to learn, to stand on my two feet and be with my friends" (Rose, lines 182-183 and 479, T1).

Although loss is stressful, there are AWLD who understand that life does not stop, and they have the insight to live independently and prepare for any future losses. Clearly, participants faced a range of losses in their lives; some of these losses were connected whereas others were not connected to the death of a family member. The deaths of family members for all, a friend for one and a cousin for another were noteworthy losses. Additionally, the loss of a pet as a

primary loss, and many other secondary losses such as loss of home, possessions, health, job etc. were shared by participants, as listed in Table 5.1.2, p130.

Theme 1, Subtheme b: Understanding of loss

Understanding of loss was very focussed on death. Loss meant different things to each participant and was described using powerful analogies like 'blank canvas' and 'erased' by Scott. He discussed in different ways what loss meant to him; however, in every explanation, he tried to make loss less personal by referring to other people:

“...when those people are not there anymore it is like a blank space, isn't it? It is like erased...It is like an invisible person, like a blank canvas picture like these artists where they draw something, and nobody is there...it is a picture of somebody in the room and when you look again, the person is in the drawing, but when you look again, in real life, that person isn't there” (Scott, lines 501-502; 815-816 and 824-826, T8).

Loss means something different to every individual and describing it can be difficult for anyone. The participants in this research used some powerful analogies to describe what it meant to them. The use of analogies by Scott demonstrates how AWLD can very competently describe a sensitive topic by keeping it at a distance, as if they are talking about somebody else. For Charles, Adam and George loss meant death mainly and they used clear language to explain what loss meant to them, as illustrated by Charles:

“it is when somebody loses somebody, or loses a pet or something. It is something everybody gets used to but it hurts at the time” (Charles, lines 109-110, T2).

Like Scott, Charles explained the meaning of loss in the context of others, reflecting on loss more generally and how difficult it is for “everybody”. Loss for Abbey also meant death primarily and she pointed to her deceased mother’s photograph to explain what loss meant to her (Figure 5.1.7):

Figure 5.1.7. Abbey’s mother



“my mum” (Abbey, line 106, T4).

Although Abbey had experienced other losses and even discussed these during the interview, without being asked she described the loss of her mother out of all the losses she had experienced. Highlighting the image of something or someone could be an easy way of describing loss for an AWLD. Loss was also illustrated clearly by David with the help of photographs of his grandfather and grandmother (Figures 5.1.8 and 5.1.9 p143):

Figure 5.1.8 David's grandfather



“That is my granddad...He died” (David, lines 66 and 70, T9).

Figure 5.1.9 David's grandmother



I miss the caravan...yes, that's hers...it is still there, my Nanna isn't, my Nanna is gone, died” (David, lines 74 and 199-211, T9)

While talking about his deceased grandmother, David pointed towards the caravan in the background of the photograph (Figure 5.1.9). Although the caravan was still at the deceased grandparent's house, it was no longer

straightforward to access. With the loss of a family member, for an AWLD all ties with other things are easily disconnected.

Six AWLD demonstrated a varied understanding of loss, as illustrated by Scott where he shares his knowledge of the finality of loss by using analogies and metaphors when short of words. However, Abbey understood loss more simply through a photograph of her deceased mum or dog. The importance of photographs was reflected in participants' understanding of loss and in communication with the researcher. They helped the AWLD to connect with those who had died and sometimes, the content of the photographs worked as factual information to support understanding of loss.

Theme 1: Subtheme c: Understanding the cause and place of loss

Across the 10 participants, 29 losses owing to death were documented, out of which 23 were sudden and six were anticipatory losses. A distinct sense of loss was present in all the interview participants (n=10). Nine participants had some understanding of either the cause or place of death; however, only six (Charles, Adam, Jack, Lisa, Rose and David) knew what caused the death and where the person had died. George had received no information about how the loss occurred and three participants (Scott, Abbey and Megan) had information about the cause of only one loss, as they were talking about more than one death.

With regards to place of death, a hospice was reported by two participants (Jack and Megan); a hospital by four (Adam, Jack, Charles and Megan); at home by four (Abbey, Jack, Rose and Lisa), and in an elderly care home by one (David). George and Scott were unsure of the places where death occurred, and Charles was not sure of the place of one death. For the most participants, the deaths were caused by illnesses (eight participants); cancer for two participants (Scott and Megan); heart attacks for two (Rose and David); dementia for one (Jack) and unknown conditions for five (Charles, Adam, Abbey, Lisa and Megan). Seeing their family members' ill health meant that participants could anticipate losses, as further illustrated by Charles and Jack:

“...I saw him [father] in that state and thought, ‘You are not going to survive’. I said, ‘I am getting you into hospital. That was the day I took him into hospital...’” (Charles, lines 635-636, T2).

“...I knew that that was going to happen [father will die], as soon as we moved, but they [hospital staff] said, ‘No. You’re best going home, getting something to drink and eat, and then we’ll see in the morning, ring you...’” (Jack, lines 349-352, T5).

Although deaths were feared, trust in hospital services was nevertheless expressed as Charles and Jack talked about their ill family members. Visibly, AWLD can follow the normal procedures such as taking the ill to hospital and they could support their family at the difficult time of loss, which could in turn eventually help them to cope with their own grief. Thus, on occasions where the illness could have been used to inform an AWLD about the potential loss still, six participants came to know about the loss only after it had occurred. All

participants added some information about the causes of deaths; additionally, Scott and Adam mentioned difficult losses caused owing to an accident and suicide. In the period between knowing of the illness and death of his father, Adam learnt all the medical names of the diseases his father had suffered, but for his brother's death, he only shared the following statement about his death:

"...with an object and killed himself because he was under pressure"

(Adam, line 205, T3).

Talking about sudden death from suicide is difficult and it wasn't easy for Adam, as he expressed a deep sigh before explaining how his brother killed himself. The death of a sibling can be isolating, and this was shown in the long pause that Adam took after finishing his sentence. Similar pauses were taken by David while talking about the causes of death of his grandparents. The following quotations by David are about his grandfather and grandmother's death, both of whom died of heart attacks:

"He had a heart attack, you know, his heart, his heart in his tummy, It goes 'bang' gone...Old people house...In the bed lying down, the heart stopped, heart attack" (David, lines 138-139, 147 and 156 T9).

The response from David about his grandparents' death, although very simple, factual and clear, was remarkable to hear. Descriptions of how a person died remain with us forever and during the interviews, every so often it sounded like the AWLD were using learned phrases in their dialogue in addition to how they felt.

Sudden losses were faced more often than anticipatory losses by AWLD, were

usually caused the result of death, and had a more significant impact on the participants. Participants who had anticipatory losses were very supportive towards their family members during family members' illnesses. Also, they were clearly able to recall the cause and place of death and series of incidents with clear dialogue from people such as hospital staff. Hence, the period between the illness and death of a family member or someone known to an AWLD can be used to make it easier for them to cope with and understand the loss

Theme 1, Subtheme d: Feelings and expressions of loss

Different terms were used for both physical and emotional expressions of feelings, as participants were at different stages of the grieving process. The responses to expressed feelings were also noted in the body language. For example, Abbey became a little uncomfortable and lost interest in talking when asked how she felt after loss; she started looking at her watch, started coughing and said:

"Oh, I can't say now, my voice is going" (Abbey, line 508, T4).

Abbey's voice went very low as she started to talk about her feelings after loss. It was clear to see that she was engaging in deep self-expression, even after so many years. AWLD may not use the names of general feelings sometimes, but the distress caused at the time of loss cannot be hidden and it was particularly visible in Abbey. Scott also found it very difficult to name his own emotions; however, in general he did describe feelings as being frustrating, upsetting, and very difficult sometimes. Additionally, he suggested that sometimes people hide their feelings by not expressing them in public. But for his own feelings he used analogies to describe them, as illustrated in following quotations:

“...Most men keep it [feelings] all bottled up, don't they? Most people do...People let it out, the majority they don't. Am I right with that?”

(Scott, lines 1147-1149, T8).

“...it is like, what is that word called? I am trying to remember what Ray Johnson said in the film archive; about the Second World war losing those soldiers like a person's being erased or something, they are not there anymore” (Scott, lines 195-198, T8).

Again, Scott was referring to others while describing his emotions. It appeared he believed that ‘men’ are not supposed to express their sorrows openly. It was hard for him to find the right words to express the deep emotions and using terms such as ‘erased’ was as if he was putting an end to his thoughts and feeling about loss. Six participants had experienced more than one bereavement, and some ranged from between 5 and 15 years previously, yet they were able to give words like insecure, empty, upset, annoyed, angry, sad, unhappy etc. to express their feelings. The emotional reactions discussed by the participant AWLD matched with the literature, as highlighted in chapter 2 (Table 2.2: Expressions of grief, p46). For Jack and Charles, the deaths were profoundly described, as reflected in the following quotations:

“Well, now I have lost everything, I just feel empty inside...” (Jack, line 360, T5).

“Especially when it is your father...It is upsetting. It is annoying. You want to complain about things, but you can't at the time because you

are that annoyed you just want to break windows” (Charles, lines 114 and 118-120, T2).

Feelings after loss may not be the same in everyone, as each individual is unique, but all of the feelings are normal, and they are important in the process of grieving. Although the feelings that Charles expressed in his quote above were not pleasant, he had accepted them. This is an example of an AWLD provided with good examples of accepting and living with their feelings and not pushing them away.

In summary, all AWLD presented a range of losses and shared a very clear understanding of what loss meant to them personally. Losses were clearly known, and death was not always the only cause of a significant loss; separation was equally significant. In anticipatory losses, the time after finding out that someone was going to die and before death played an important role in how the loss was understood and the impact after the death, as echoed in the generic literature.

5.1.2 Theme 2: Difficult/bad news

Knowing about a loss/bereavement is always difficult but may not be bad, for example, moving to a new house may not be bad but is certainly difficult; hence, together with the usual phrase ‘bad news’, ‘difficult news’ is used. This theme discusses participants’ memories of the time when they were told the news of a death. This includes information such as where the participant was at

the time of death; who informed them; and how. Information related to funerals (including awareness, attendance and choice) is also presented.

Theme 2, Subtheme a: Finding out, day, series of incidents and date of loss

Seven participants had remembered all the incidents related to their loss exactly the way they had taken place. The following quotation from Rose shows how an AWLD remembers and expresses the difficult/bad news explicitly:

"...me and my mum went shopping and when we came back he was upstairs. My mum was parking the car and I shouted, "Dad!" and couldn't wake him up...I was panicking because my mum seeing him...It was good job that we did not have any eggs in because I dropped the shopping bags..." (Rose, lines 112-123, T1).

Rose not only describes finding out about the death; at the same time, she explains how she was aware of remaining considerate towards her mother so that she didn't get a shock from seeing her dead husband. These kinds of reactions to the news of death are not expected even in the general population and the fact that they were performed by an AWLD certainly reflects that all AWLD possess different abilities and they should not be put under one umbrella. An example of this difference in abilities is shown in the comparison between Rose and Charles's memories of certain details surrounding their loss. While Rose even remembered that she had not brought eggs on the day when her father died, it is possible Charles was a little confused at first about the

series of incidents of his father and grandfather's deaths. Nonetheless, he cleared up the confusion by separating the two in the middle of his talk. He remembered that he was with his granddad before his death and could confidently remember the date and time. As he shared the information, his body language and gestures appeared as if he was reliving the event:

"...when he died, I was actually there...I held his hand. He said, 'I love you. Give me a kiss'. Then he just closed his eyes. I was there when he died. I went into my dad and I said, 'Dad you had better prepare your mum. Prepare Nan. He has just passed away'. That was four minutes past two on the 12th September 1996. I will never forget it..." (Charles, lines 177-184, T2).

Experiencing the death of a family member in front of one's own eyes can be daunting, and it must have been traumatic for Charles. However, surprisingly, he was proud of being with his grandfather during his last moments. It may look as if AWLD are not understanding or paying attention to a situation, however experiencing a bereavement has been taken very seriously by all and described in detail in many cases. Jack had lost ten close relatives in less than 12 months. During the interview, he discussed three of those losses, including his father, who had died of a cardiac arrest. Jack said that he knew his father's condition was not good, but he still had to leave the hospital when told to by the staff. His quotation gives information on some of the incidents before the death of his father:

"We got dad out of the car, phoned an ambulance...Went back down with it, got some stuff, went up the hospital. Mum came with us, my

sister came with us...He'd died in the two minutes before we'd got through to him" (Jack, lines 339-349, T5).

Jack presented evidence of remaining patient, supportive and understanding when his father was being shifted to hospital as he talks about arranging for an ambulance and packing the things required in the hospital. Remembering the series of incidents, own behaviours and others' behaviours clearly reflects that loss and bereavement experiences stay with AWLD in the same way as they do with the general population. Lisa also discussed that her father died in hospital while she was at home and her mother died at home while she was around, too. Her father's last words were imprinted in her memory and she shared them very sadly:

"... he said, 'If anything happens to me, I want you to be the lady of the house" (Lisa, lines 242-243, T7).

Whether an AWLD is able to fulfil the last wish of their dying parent might not have been in their hands but the memories of that last wish remain important for them. As Lisa repeated her father's last words, she also conveyed a sense of honour at being with her father at the time of his death. George was not able to recall the time since his parents' death; neither did he know where they had died. Losing his home following the death of his parents appeared to have had more of an impact on him than any other losses. He remembers that after the difficult/bad news, he was looking for somewhere to live and shared in an angry tone:

"Looking for somewhere to live, wasn't I?" (George, line 319, T6).

Being with the dying parent was a proud moment for some of the AWLD. However, George had not been able to comment on any such situation as he was not with his parents when they died. All George knew was he had nowhere to live straight after the loss of his parents. Sometimes AWLD do not get time to understand and process the news of death and react to it because it is followed by another significant loss. Like George, Megan did not know anything about her mother's death as her mother was moved to a care home owing to illness. But she was aware of her father's condition (he died five years after her mother) and shared the moment when she went to see him for the last time:

"...Yes, they took us to see him before he passed away at [the hospice]. He leaned over to me and just managed to just twirl my hair around. He couldn't even talk properly" (Megan, lines 575-577, T10).

Receiving a chance to visit the dying family member in hospital/hospice is a big opportunity for AWLD to say their final goodbye and gather memories. This is evident because with death of a family member, AWLD also remember small gestures such as Megan's father's managing to "just twirl my hair around" was a special memory for her. Regardless of how much or how little the participants knew about the death of their family member, all participants shared some information. Five provided information with great clarity on the series of incidents that took place at the time of the loss or close to the loss, while others just made brief reference to those events. This confirms that AWLD are able to remember and share their experiences of death of a family member. Most people remember the details of difficult/bad news forever and this research reaffirmed this from the perspective of AWLD.

Theme 2, Subtheme b: Information after loss

Source: Charles, Jack, Lisa and Megan had very fresh memories of how the difficult/bad news was given to them and some (n=3) participants could even remember the exact words used. Participants often identified more than one loss and therefore the sources are more than the number of participants. Four participants (David, Adam, Scott and Abbey), were informed face-to-face by their relatives. Two participants (Lisa and Jack) were informed by relatives over the phone; whereas three participants (Charles, Jack and Megan) were informed by hospital staff over the phone. Neighbours informed one person (George); the newspaper was the source of difficult news for one (Jack); and the police informed one participant (Adam); he casually stated:

“The police department came up...They inform the family, yeah, that this has happened...you have to see for the ID purposes, so I did see the body” (Adam, lines 244-253, T3).

Adam, though, talked casually of his brother's death, but the discomfort in his voice and body language was visible. He shared factual information about the loss owing to his brother's attempted suicide in the form of a list, as the police might have done on the day. News of death owing to suicide remained a taboo and he tried to put an end to discussing it further. In other circumstances when the death was due to heart attack, David was informed by his parents of his grandparents' death; Megan's father was suffering from cancer and she was informed of his illness and death appropriately by the hospice staff. Parents and the hospice staff were projected as the moral source of information of death,

which differs markedly to how Megan was informed of her mother's death over the phone from the care home staff. Three participants (Rose, Abbey and Lisa, one loss each) had themselves discovered the death, which was confirmed by others; similarly, Charles was the first person to discover his grandfather's death and had informed others in a very calm manner. The following quotations illustrate the different ways in which difficult/bad news was given to participants, compared to what they had expected:

Lisa received information about her father's death from a sibling:

"I was standing up with the phone in my hand. He goes, 'Well, I've got something to tell you'...I want to tell you while you're standing up...That's when he said. He shouted it down the phone as loud as he could..." (Lisa, lines 449-452, T7).

On the contrary, Lisa had expected some time to sit and prepare herself before getting the news over the phone:

"...I said, 'Give me a chance to sit down.' He said, 'No'..." (Lisa, line 450, T7).

Charles describes the way he was told about his father's death as follows:

"I phoned up on the Wednesday afternoon and I said, can you tell [Mr name] that I am coming up this afternoon today?...They turned around on the telephone and they just said, 'Don't bother coming up Mr Charles. He is dead'" (Charles, lines 565-568, T2).

Charles had expected to be told in a very different way:

“...They should have said, ‘You need to come up and we need to speak to you face-to-face’. You don’t tell somebody that they are dead over the phone, especially when you are close to them...I thought that was really bad conduct” (Charles, lines 576-578 and 582, T2).

Jack was also informed of his father’s death over the phone:

“...They gave us those, you know, gave us 24 hours, 48 hours, whichever...we got a taxi at about ten to twelve, got back in the house. The phone rang, I answered it...” (Jack, lines 341-346, T5).

How Jack passed on the difficult/bad news reflects clearly how he had expected to be informed of his father’s death:

“...then I had to break it to them both. It wasn’t easy, but I managed to do it, and I’d got them, made a drink, and got them to sit down, and then did what I’d got to do” (Jack, lines 563-565, T5).

The way difficult/bad news was given to Lisa, Charles and Jack played an important role in the expressions of grief and their abilities to cope with it. While discussing the difficult/bad news given over the phone, participants were reliving their experience of loss. They demonstrated profound understanding of their needs and wishes during this difficult time.

Funeral (attended or not; informed choice, memories of funeral): The funeral was another key issue discussed by eight participants, whereas it was only casually discussed by George and disliked by Abbey. There were mixed views on attending or not attending the funeral services. Seven participants

(Scott, Adam, Jack, George, Lisa, David and Megan) had attended one or more funerals of a deceased family member or friend; however, Jack was not informed of one of the funerals. Apart from Abbey, all participants were aware of the process of cremation or burial and where their family member's ashes were kept or where they were buried. Although Abbey, Rose and Charles were given a choice to attend the funeral, only Abbey refused to attend. The other two participants took part in organising the funeral, for instance Charles paid for the funeral costs and Rose selected the writings for the gravestone and the burial place for the deceased; however, neither of them could attend the funeral as Charles had collapsed and Rose required appropriate medication and more support from her family.

Although Lisa became upset while talking about her deceased father during the interview, attending the ritual after death was certainly significant for her. She very proudly informed that she had helped to carry her father's coffin during the funeral. In contrast, Abbey justified her reason for not attending the funeral and her response was visible from her body language as she closed her eyes and showed disinterest in talking. For Scott, the funeral was a way of remembering the deceased, as further illustrated in quotations from Abbey and Scott:

“sad place.... No that's fine” (Abbey, line 294, T4).

“We went to the funeral at [cemetery name] Church... Yes, I wanted to go to remember it” (Scott, lines 607 and 624, T8).

There was lack of knowledge shown by Abbey on expressions of emotion after loss, as she didn't want to be sad by going to the funeral, which she believed

was a sad place. A person with or without learning disabilities might decide the same as Abbey if not explained the significance of attending the rituals after loss. However, attending the funeral was important for Scott as he believed that it was the appropriate time to remember the deceased. Such beliefs highlight a need for people who are in caring roles to understand the faiths and beliefs of bereaved AWLD and support them accordingly to involve them in rituals after loss. Rose is now aware of the significance of attending funerals, she still visits her father's grave and brought one photograph of putting flowers on it (Figure 5.1.31, p193). Rose described that her family did not push her enough to attend the funeral. Similarly, Charles shares a series of incidents from his grandfather and father's funerals respectively and explains how he was not able to attend the whole service:

"...I sorted it [funeral] out with my mum and sister but the one bit... my mum and sister went to see him in the coffin...My mum said but my mum didn't push me but I felt like I wanted to..." (Rose, lines 163-168,

T1).

"...When he [grandfather] died, the day of his funeral I couldn't even get out of the car. I collapsed because I was so close to him. I collapsed in the funeral car...I couldn't go to the burial. I went into Kirk [church] and as I came out of Kirk I collapsed" (Charles, lines 189-190 and 194, T2).

Rose and Charles had not attended the funerals, but they knew the importance of attending a funeral. Support from families and professionals in caring roles could help AWLD by making an extra effort to involve those AWLD in funerals who hold an understanding of their significance but temporarily do not want to

be part of a funeral. Differing from Rose and Charles, David had attended the funerals for both of his grandparents; for him, the events related to the funeral and the support and actions of family members towards him were very important and he could still remember and appreciate them. David and Megan also shared the 'bereavement cards' as happy memories from the funerals they had attended. While talking about them, David had a smile on his face and Megan became emotional as she had the bereavement cards with her during the interview, too (Figure 5.1.10, p160). The following quotation from David illustrates aptly his involvement in after-death rituals:

"...you know where the funeral is up the road, turn right there, my Nana thing [grave] there...And my granddad down the bottom and Nana on the top...We gave them flowers up, you know we buy some flowers and keep them on Nana thing...I got the book of them with picture of them two. Nana there and my granddad there...They got little thing [bereavement card] there, my mum read that..." (David, lines 276-286, 341-346 T9).

As most of the participant AWLD remembered the series of incidents before a loss and the way they received the difficult/bad news, they shared the experiences of attending the rituals in the same way. The whole process of visiting a grave of the deceased family member was important, beginning at the place to visit, followed by activities such as buying flowers. Such actions are generally taken casually but for bereaved AWLD, these rituals are important, and they share them proudly when they are part of them.

Figure 5.1.10. Megan's bereavement cards



“My sister got them for us...Off the undertaker” (Megan, lines 926 and 929, T10).

Bereavement cards, also known as memorial cards, were used as keepsakes by Megan, who always keeps them in her bag and appreciates that her sister bought them. Understanding, accepting and living with loss was reflected as the bereavement cards, although were the reminders of the deceased, were still loved by the bereaved AWLD.

Difficult/bad news was clearly more difficult for some of the participants when not given appropriately, yet AWLD can be a good source to inform others of difficult news if need be and this was clearly evident. Involvement in funerals or exclusion from funerals both left a striking impact; thus, the professionals, carers/families/friends need to explore the opportunities fully with the bereaved person themselves and then weigh one against the other.

Theme 2, Subtheme c: Impact of difficult news

Rose and Charles shared how they were affected for a very long time by their losses. Rose reported some physical effects of loss as she remembers having dry lips and anxiety, and was later diagnosed with depression. Rose disclosed

that she even distanced herself from her mother after her father's funeral. Charles, too, was affected severely by his losses; additionally, the way news was given to him had a deep impact on him and led towards an increase in his challenging behaviours and he ended up becoming an alcoholic. The following quotations from Rose and Charles further illustrate this impact:

"...that's why last year I had the depression from it. That's why I was having more spasms, having tablets for depression, that is why I broke my arm, falling over..." (Rose, lines 148-150, T1).

"Over the phone they told me that. I put the phone down and I ran and got a brick from the skip outside the pub. I ran down the road to put the doctor's window through. I was going to go and kill the doctor, his [father's] doctors...I ended up doing a pub-crawl of all the pubs in [names all places]. I got very, very drunk very, very quickly..." (Charles, lines 572-575 and 860-863, T2).

As Rose was devastated after her father's death, she clearly was aware of how the bereavement affected her physically. She was happy to take the medicine prescribed to her for depression, unaware of the side effects. Charles had turned to alcohol in anger after receiving the difficult/bad news and he found that alcohol was temporarily helping him by making him feel numb. AWLD need awareness about the effects of anti-depressant drugs and alcohol, and such information needs to be provided before any loss. At the time of a loss, the person may just want to get rid of sadness through any means, even if it is temporary. Clearly AWLD have immediate physical and long-term emotional effects on their lives after loss; the duration of such effects depends on the way

difficult news is given and the extent to which an individual AWLD is involved with and supported during their loss.

Changes in life: Loss changed most of the participants' lives significantly, mainly posing restrictions around activities that were done before the loss of parents (e.g. going on holidays). The changes in lives after loss in comparison to life before loss are shown in Table no 5.1.3, p163.

Table 5.1.3: Life before and after loss

Participants	Life before loss	Life after loss
Rose	Holidays Freedom	Restrictions on going out with friends No holidays Over-protective behaviour of mother
Charles	Used to look after father	Lives alone
Adam	Walking with father Learned about nature	No more walks now Health deteriorated Restrictions on going out
Abbey	Holidays with parents	No holidays Family games with siblings
Jack	Lived with family	Lives with wife only
George	Holidays with parents Did everything with parents Did everything in the garden	No holidays now Goes out to town with or without carer Neighbours do the gardening now
Lisa	Helping parents to cook Holidays with parents Family time in garden	Goes on holidays with husband now
Scott	Shopping with father Owned a car and caravan Holidays with father Watch funny videos with father	With mother, now uses public transport Does not own a car or caravan now Holidays with mum and her friends Goes away with work colleagues
David	Fun things with grandparents	Parents do everything now
Megan	Holidays with parents Playing bingo Shopping with parents Carnival with parents Visiting families with parents Baking with parents	Goes to day care centre No bingo Restrictions on holidays

In addition to changes in participation in activities such as going on holiday, shopping and having more freedom, not having the deceased parent to talk to was also highlighted as a significant change after loss, as Scott explained:

"...It is just me and my mum go shopping on a Saturday, my dad used to get the car out and put the shopping in the back. But just me and my mum caught buses back from the town...We haven't got him to talk to..." (Scott, lines 537-539 and 814, T8).

Scott shared in detail how his father's absence impacted his life. He was highlighting each void created in his daily routines owing to his father's death. While discussing the changes in life after loss, AWLD demonstrated the understanding of changes in relationships with other family and friends too.

Faith and beliefs affected by loss: David and Scott mentioned 'God' and 'heaven' in a calm way during the interview, however it was not clear if they were religious before the losses or turned to religion after they faced the loss, or even whether they understood the concepts. David believed that his grandparents were like fairies that came in the night and patted him while he was asleep. Although there was not much information on Scott's religious values, some references made to God suggested his belief that death is final. Views from both are illustrated in the following quotations:

"...they up in heaven now, nan and granddad are, in heaven them two are" (David, lines 459-460, T9).

“...one thing which we can’t do which God or Jesus, whoever it is, I know Jesus can’t bring dead people back, how they were before a disease or person...” (Scott, lines 658-659, T8).

Both David and Scott referred to their beliefs in ‘god’ and ‘heaven’. These terms might have been used as they were learned from others and they could be comforting while talking about loss. There is a possibility that the desire to be reunited with the deceased family members was making them reflect on and talk about signs of god and heaven.

Worries related to loss: Four participants (Rose, Charles, Megan and Adam) had fears of losing more family members. In addition, Charles and Adam feared their own death. Charles had developed the fears as he believed that an overdose and the wrong medication killed his father and cousin respectively. He also believed that the death of someone at a young age is more difficult to cope with. The following quotations illustrate Charles reflecting on his worries about losing more family members, and his worry about breaking down at the time of his cousin’s death. He also described his fear related to his own death and reflected his understanding of how the family of a deceased person suffers after loss:

“Losing family. My cousin [name] passed away...I went to her funeral...As they were talking about her...I was thinking, ‘I am going to pass out again’...With her being so young, she was 24, it is no age. It is not just my grandfather and my father I have lost, it is somebody that is 20 years younger than myself...It was just so hard” (Charles, lines 893-901, T2).

“...if my life is lost, my sister loses me. My nieces and nephews I won’t see get married. I won’t see our [name] when she gets a teaching degree ...” (Charles, lines 915-916, T2).

Death is not easy to accept for anyone, not even for an AWLD like Charles who understands that dying is inevitable. For Charles, death is unfair on people who die very young and the ones who grieve for them. He discussed that he fears for his own death and would want to spend his life with his extended family members around. Activities performed by Charles could be useful for anyone, such as spending time with loved ones, staying active and thinking positively. Adam had also developed a fear of losing his house since his father’s death and mother’s remarriage. The fear of his own death was evident as since his father died of multiple illnesses, he started learning about diseases and had started believing in a natural herbal remedy related to his good knowledge about plants and flowers:

“...My foot also hurts. One of the things is that I have a certain remedy (herb leaves). I have this every day...That is ‘fensia daisy’. I worried about if I get immobile and I can’t go and get them I sometimes won’t see 60” (Adam, lines 415-418, T3).

There was no evidence for Adam’s belief that consuming the particular plant leaves will help him to live longer. However, people can easily divert towards such beliefs and sometimes misconceptions after experiencing bereavement. On some occasions unknown losses that anybody could experience were also reported and further illustrated by Jack and Scott:

“...it still tears you up inside, and I just wonder what’s around the next corner” (Jack, line 375, T5).

“...We could all lose somebody...I think everybody has that fear of losing something and most people with learning difficulties; doesn’t matter if they are from Wales, England, Scotland or Ireland or America...I think everybody has got that fear, deep down they think they are going to lose somebody or lose a group of friends. We just don’t know what is going to happen” (Scott lines 777-786, T8).

Scott stated the wider picture of loss in the context of different places in England and further afield. He had developed a clear understanding of the finality of loss among AWLD around the world. Experiencing loss once or more does not mean that it won’t happen again for AWLD and similar thoughts could be seen in general population.

To summarise, in relation to difficult/bad news and its impact, all participants reflected upon the impact loss had had on their lives and mentioned that lifestyles were slightly better if at least one parent was alive and healthy. For example, for David, going on holiday was the same as when his parents were still alive; similarly, for Simon, his mother still organised holidays. For Adam, his mother was alive but very ill, hence she had no role in supporting any of Adam’s recreational activities; Abbey had similar circumstances to Adam, as she had lost both her parents. The number of losses faced also left a greater impact, as it did in Jack’s life, where rather than counting how many family members had died, he said that there was no one now left from his family.

Fear of the unknown and numerous losses in addition to their own death have built up in some of the participants, reflected in increased feelings of vulnerability. When AWLD don't talk about fears it can be difficult to understand if they really meant that or were just hiding their fears, as Scott had suggested that people do hide their feelings. Faith and beliefs are affected by loss and sometimes are as a result of fearing future losses.

Theme 2, Subtheme d: Long term impact

Multiple losses: Loss owing to one death for an AWLD is never isolated; it is always accompanied by multiple losses that often go unrecognised. All participant AWLD in this research had been through multiple losses, even though they started talking about just one or two losses caused by death. Only two illustrations of multiple loss experiences are illustrated here, although all other participants also had similar losses in their lives followed mainly by the death of a family member. For example, George faced the illness of his parents that eventually led to their death, causing him to lose his home, friends and neighbours, financial support, and his support worker; all of which left him to live alone. Another example of multiple losses that are sometimes not even recognised by the individual themselves was shown by Adam, who had lost his father, and some important memories of time spent with him were reflected in his photographs.

Positive impact: (Responsibilities/care towards family members): While all participants were affected by loss in a way that they were not doing the same things as before, some participants had experienced positive changes in their lives. Some had become more supportive and responsible family members. For

example, Jack explains what he said to his mother after his father's death to support his family:

"... You've got to accept it. You can't do anything else. It's not easy on me, I've got to take dad's role...I pulled mum and dad through, and they pulled me through. We all got together and helped one another" (Jack, lines 472-473 and 571-572, T5).

Jack demonstrates his ability to support his family maturely, even though the loss had impacted upon him the same as other family members. However, the way Jack consoled his upset mother and sister after the death of his father clearly shows that AWLD also need to be aware of normal grieving expressions used by others. AWLD discussed how they took the responsibility of family by putting their own emotions aside. Charles and Megan have become supportive of their siblings, as Megan explained that she helps her sisters with housework and shopping. Since his father's death, Adam also tried to help his mother and makes sure that she gets what she wants as she has mobility issues. As further illustrated by Charles and Adam:

"The favourite place that I am living at the moment is in [Town] because I am five minutes away from my sister. If she needs anything, I can take five minutes to walk up there" (Charles lines 710-712, T2).

"I have been getting sandwiches for mum, doing potatoes, raw salami, the new jersey ones and some cauliflower...mum can't go, she misses

that if she doesn't go, she won't get anything of these if we don't go"

(Adam, lines 80-83, T3).

The importance of living close to family after the bereavement was discussed by Charles, as he had moved to a house very close to his sister. He and Adam displayed the care and affection they had developed after the loss towards their family members and wanted to make sure that they could support them when needed. Sometimes people perform the behaviour that they expect from others and in the cases of bereavement in the lives of AWLD, it is their own need for love and care that they provide to others.

To summarise, loss clearly leaves everybody with deep wounds and the experiences of participant AWLD were no different. Some evidently go through multiple losses following one death. Appropriately breaking the news and involving AWLD in funeral rituals can be used as two crucial steps in reducing the impact of multiple losses.

5.1.3 Theme 3: Types of support

In this section, information about the awareness of external support (such as bereavement counselling and other external sources outside of the home environment) is presented. This is followed by a consideration of what support participants received and what they thought was the most useful support to help them to cope with their loss.

Theme 3, Subtheme a: Bereavement support

All participants were aware of local bereavement support services outside the home environment that can provide support after loss; however, the

researcher had to ask direct questions in order to check this awareness as seven participants did not spontaneously mention this. Only three (Rose, Megan, and Lisa) had mentioned such support without asking. Scott, Jack and Adam had not received bereavement support and did not express positive attitudes towards it. Charles had attended counselling sessions but still did not have very positive attitudes towards these at the time of the loss because he displayed violence and anger towards the therapist during an initial therapy session, for which he was later embarrassed. Charles believed he was not provided with bereavement support at the right time, as he was heartbroken and felt very angry as nothing was working for him:

“...The Bereavement Service. I had a couple of sessions there but it was too heart-breaking at the time. I was taking my anger out at the staff saying that the staff didn’t know what they were on about ...”

(Charles, lines 784-786, T2).

Charles demonstrated the insight that his behaviour towards the therapist was not appropriate during the bereavement counselling after his father’s death. However, the retrospective feelings he shared were typical of the general population, too, for anyone to feel and express. There was a lack of support provided to him in terms of understanding his needs and the right time to give him support. Scott did not provide any details of the bereavement counselling support; Adam had a firm view against bereavement counselling; and Jack compared himself with his wife who was going through the intervention and believed he did not require it for himself. The following quotations reflect their viewpoints further:

“I have heard about counselling...I didn't bother with counselling, I just talk to people and it helps” (Scott, lines 1190 and 1194, T8).

“Oh, no, no, I didn't need that counselling services, nothing needed”
(Adam, line 324, T3).

“...I said, I'll cope with it myself, sort of thing. I'll go my own way and, you know, because there's a lot of people that always say, 'Oh, you need counselling to get through something like that,' And then you find another way around...” (Jack, lines 443-446, T5).

Men are less likely to access psychotherapeutic support such as counselling compared to women, as they do not like to show their emotions (Winerman, 2005). The use of terms such as 'didn't bother', 'didn't need', 'find another way around' by Scott, Adam and Jack while talking about bereavement counselling exhibited to some extent that they were hiding their emotions and showing their strong personalities. Four female participants (Abbey, Rose, Megan and Lisa) had been through bereavement counselling and found it useful. Lisa and Rose enjoyed making memory boxes during the sessions because they were a tangible personal treasure for them to keep. The timing of bereavement support, however, did not feel appropriate to Rose, as it was straight after the loss of her father. The following quotations by Rose and Lisa show the extent to which the interventions were useful for both:

“...so they put me through the counselling service. It did help but not as much as now...that helped me a bit. And that would bring like the

memory box, they help me do the memory box...” (Rose, lines 256-257 and 262-263, T1).

“I had counselling over my dad. Then I had counselling over my mum...It's helped me a lot...We did a memory box...I did a memory book...” (Lisa, lines 578, 561 and 524, T7).

The process of making a memory box was found useful by Rose and Lisa during the bereavement support as it gives a platform to share the feelings of loss by using the objects that connect the grieving person to the deceased. Creating a memory box could be practiced more, as the process of making it and the end product both help the bereaved to remember the deceased. In addition, on a single instance, David found the support from the Vicar from the local church very helpful, particularly as he came to his home three times:

“...he told me about Nana and Granddad. He told me okay...and said don't cry...be brave...” (David lines 361-362 and 366, T9).

Learning of the death clearly from someone such as a Vicar made a permanent impression on David and he clearly remembers the conversations he had. Although comforting phrases such as, “don't cry, be brave” are commonly used with the bereaved, they may not be helpful in coping in the long term because sometimes people may feel comfort in crying and feeling weak. All participants appeared aware of the concept of bereavement counselling. Bereavement support was found useful by all four female participants whereas three male participants were less complementary towards bereavement counselling. Inappropriate timing of the provision of bereavement counselling was

suggested by two participants and George, who noted the lack of support after his losses. However, he was supported by a social worker to find a place to live.

Theme 3, Subtheme b: What helped

All sources of support other than bereavement counselling that helped AWLD to cope with loss are now presented. Photographs were found useful in many ways as communication tools; they were used as prompts for participants to recall things that were not easy to remember from the past.

People (Family and friends): Eight participants referred to photographs with people in them while talking about what helped them to cope with their loss, while Abbey did not have any photographs containing people who helped her to cope; George had not taken any photographs containing people. The main source of support for most participants was close family, including parents for two (Adam and David) and parents and siblings for three (Abbey, Megan and Charles); additionally, a partner for two (Jack and Lisa) and friends for four (Rose, David, Megan and Scott). Photographs of parents, siblings, friends and partners were brought and discussed by participants while talking about people who helped them to cope. The following quotations accompanying the photographs were shared by participants while talking about support sources.

Adam described the exceptional support he received from his mum, even though she has a speech disorder, and he refers to his mum in a photograph (Figure 5.1.11, p175). This was a very unique case of being supported without the use of words, and he clarified that we don't always need words to provide support in the following quote:

Figure 5.1.11. Adam's mother and stepfather



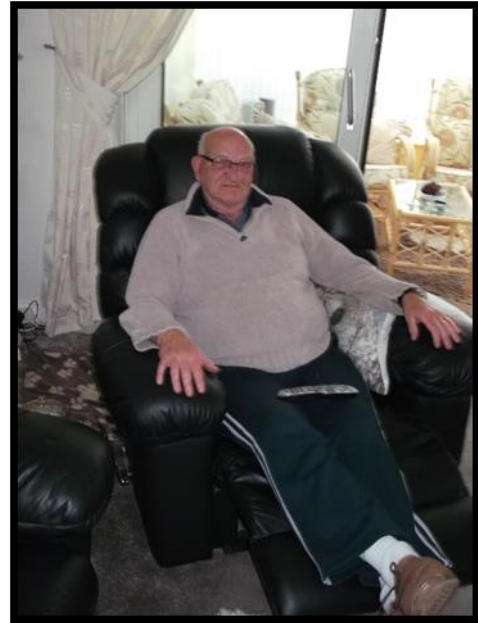
*“...ra... ra...ra.. ra....
because she can't say
words how we say
them...No sometimes not,
no, in that particular case,
no” (Adam, lines 356 and
396, T3).*

Adam used some of the words his mother used to communicate with him in the absence of clear verbatim. Consistent to the recommendation by Read and Carr (2014) it was visible that support after loss could come in different forms from different people. David was also supported by his parents after he lost his grandparents and he clearly remembers the conversations with his family and friends that helped him to cope. When he was talking about his mum and dad who have supported him, he kept referring to the photographs (Figures 5.1.12 and 5.1.13, p176) of them:

Figure 5.1.12. David's mother



Figure 5.1.13. David's father



"...in my bedroom, I am lying down and sad again, my mum comes up and says calm down, son, calm down...and my dad comes up, too, to calm me down" (David, lines 400-401 and 413, T9).

Some of the set dialogues used by people with the bereaved (such as 'calm down' 'don't cry') were found useful by David. However, as there is now plenty of literature discussing the right words and phrases to use with the bereaved in the general population, similar guidelines must be used with AWLD. Additionally, such information must be adapted according to the person-centred needs of AWLD. After parents, siblings were discussed as source of support as for Abbey, her brother had been a great support; additionally, physical affection by sleeping with her sister worked well when she was sad. For Charles, his sister has been very supportive through his bereavement and everyday life and

he still lives very close to her. To have family and positive thoughts about family helped Charles to cope with negative thoughts following bereavement. He shared the following photograph to reinforce what he meant (Figure 5.1.14):

Figure 5.1.14. Charles with sister



“My dad died, and I thought...Well, I have got nobody. There is nobody to live for. But then I realised, hang on a minute. My sister is up the road...I have got my sister to talk to if I get into that state” (Charles, lines 731-736, T2).

Charles was devastated after his father’s death and discussed how he fell into a drinking habit and became violent with his therapist. But in spite of these behaviours, he coped with loss and started living with positive thoughts owing to support from his sister/family. Family members could inspire an AWLD to live a good life while coping with grief, provided that they are aware of the truth behind the experienced losses. Megan’s siblings have also been very supportive after the death of her father and mother; while talking about who helped, she discussed almost all of her family members’ photographs to say that they have been supportive (Figures 5.1.15 and 5.1.16, p178):

Figure 5.1.15. Megan with siblings



Figure 5.1.16. Megan's sister



“...Yes, and my sister, [name], she supports us as well...”

(Megan, line 790, T10).

From Megan's discussion it was evident that elder siblings play an important role in supporting younger ones after the death of parents. AWLD were trying to bring the person to life in the interview, especially while talking about the ones who helped them to cope after loss. The details on how the support was channelled from family usually ended just with the information that the family members were there for them (AWLD). After siblings, spouses were discussed as supportive, as per Jack, whose wife has been a great support, even though she herself was going through bereavement (Figure 5.1.17, p179):

Figure 5.1.17. Jack with wife



“...when I lost dad and when I lost mum there was always somebody with me, and that was [wife name], and she pulled me through...”

(Jack, lines 441-442, T5).

AWLD remember everything clearly that is associated to their experience of loss. For example, how the person died, who informed them and who supported them. Jack appreciated that his wife was a great support for him. Sometimes a companion to cry or talk to or spend time socialising with can make the difference in the coping process. Hence, AWLD who usually are left alone after the significant losses in their lives may struggle more to cope with loss. Lisa had to face lots of criticism from her siblings after the loss of her parents owing to their (sibling's) negative attitude towards her learning disabilities; she sees her husband (Figure 5.1.18 p180) as her only remaining family support.

Figure 5.1.18. Lisa's Husband



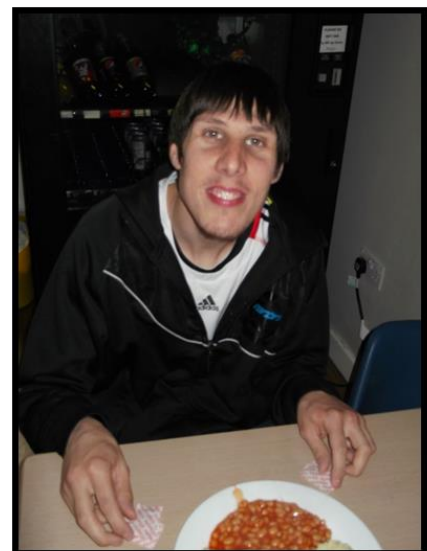
"He was there for me" (Lisa, line 189, T7).

Lisa believed having her husband by her side was the only family support she received. Having the spouse at the difficult time appears useful, regardless of any particular bereavement support knowledge. Other than family members, people who supported the participants to cope with loss in some ways were friends. David cheerfully shared photographs of his friends (Figures 5.1.19 and 5.1.20) and he was imitating his friends, who were smiling in the photographs:

Figure 5.1.19. David's friend



Figure 5.1.20. David's friend



“...they come over and talk to me”. “they say calm down a bit” (David, lines 564 and 572, T9).

Similar to other participants, for David, having friends around was a support at sad times. Merely talking about loss could help AWLD to express the emotions after loss and this was highlighted as useful by all of the participant AWLD on different occasions during the interviews. Talking to friends played a very important role in Rose’s life, as she trusts that her friends understand her and help to keep her mood up (Figure 5.1.21):

Figure 5.1.21. Rose with friend



“...now every so often, he just keeps texting saying am I alright and that keeps my moods up...I have got couple of good friends, three good friends who really know when I am low” (Rose, lines 323-325 and 333, T1).

Rose highlighted that having friends and using technology was keeping her close to her supportive friends. For AWLD who have a limited social circle, having someone who could just send a casual text message to check on their wellbeing could be an inordinate support that may not be valued to the same extent among the general population. Additionally, Scott believes that just being

part of a group of people at the place where he volunteers has been useful (Figure 5.1.22):

Figure 5.1.22. Scott in volunteers' calendar



“With being with the people in my placement, the [organisation name] Volunteers because they have helped us come to terms with loss” (Scott, lines 425-426, T8).

Echoing David and Rose, Scott also finds support in the form of different people at his work place as useful. To summarise, close family and friends played an important role in supporting most of the participants. This echoes the findings of research by Booth and Booth (2003), where mothers with learning disabilities took photographs of things important to them that were the same as they would be for the general population. Photographs of friends and family were used as prompts as well as evidence by participants to share their feelings.

Professional carers, advocacy staff, bereavement counsellors and their organisations: People in these categories have also played a significant role in providing support after loss. According to Rose, she was well supported by her personal assistant (PA) and brought a photograph (Figure 5.1.23, p183) to

illustrate the bond she shared with her PA. According to Rose, a bereaved person can better understand another person's loss.

Figure 5.1.23. Rose with PA



“I started having PA and that PA, at the same time she lost her dad, so she knows how it feels when it’s his birthday or when it’s Father’s Day ...”

(Rose, lines 212-213, T1).

Every bereavement is unique, and every individual experience bereavement and coping afterwards in their own way. However, two AWLD (Rose and Jack) gave an impression of their understanding that a person grieving at the same time understands others in a better way. Thus, sometimes making a brief reference to their own grief by a PA or a support worker can be helpful in gaining the trust of AWLD so that they can talk about their experiences freely. Megan felt that she was supported in different ways by the staff at the day care centre and an advocacy organisation. She proudly shared the place she was talking about with the photograph of the building (Figure 5.1.24 p184) along with the staff that supported her:

Figure 5.1.24. Megan’s day care centre



“Going to [day care centre] and being around the staff...Yes, and having things to do. If we want to talk to anybody, we’ve got the staff to talk to...” (Megan, lines 639 and 643-644, T10).

Figure 5.1.25. Megan with a staff member



“Yes, and here [research site]...Talking to them...When we’re at [day care centre], I text [advocacy staff] to see if I can talk to [advocacy staff member]” (Megan, lines 1297, T10).

Reference to useful support was made by Megan in the context of the day care service and the research site (advocacy organisation). Megan clarified that sometimes the opportunity to share her feelings with someone was available at the Advocacy organisation. Charles provided details about how his social

worker, advocacy staff and the bereavement counsellor (associated with the research site) helped him:

“... [bereavement support expert] helped me and [advocacy staff] helped me. She got me into doing more here [research site]...Just talking me down and being there to listen to my problems if I had got any problems.” (Charles, lines 765-766 and 856, T2).

For Charles, the bereavement expert staff member associated with the research site supported him to cope with loss by talking and listening. Staff supporting AWLD need to make sure that the problems an AWLD presents with may not be the actual problem sometimes.

To summarise undoubtedly, support at the time of loss was significantly valued by the participants; the most important source of support for most participants after family and friends seemed to be coming from the social workers, day care and advocacy staff, in conjunction with the bereavement counsellors associated with the advocacy organisation.

Keeping busy: Various routine activities were discussed as being very useful by seven participants, excluding Adam, Jack and George, who did not share much information on what they do in their daily lives. The participants were involved in activities including music, colouring/drawing, pottery, watching humorous programmes on TV, going for walks, activities such as baking/sewing/shopping at the day care centre and involvement in different advocacy projects at the research site. Socialising and using technology such

as an iPad was found to be helpful to keep busy and cope with loss for Lisa. Some of the participants brought photographs while doing various activities.

Charles very clearly explains that remaining idle after loss was not very helpful for him; instead, working at the research site and keeping busy helped:

“...when I wasn’t doing anything and everything seemed so bad, I just wanted to commit suicide myself...We did the toolkit. I was doing the parliament meetings and just coming in and talking to people...”

(Charles, lines 730-731 and 771-772, T2).

The time after loss was difficult for all participants, as it is for the general population; however, Charles strongly believed that not doing any work was damaging for him. A lack of awareness of normal grieving reactions was visible as well, owing to no guidance to cope with grief. As such, suicidal thoughts and drinking alcohol were displayed. According to Scott, who had different work experiences including volunteering every day, keeping busy was very good and he referred to a photograph (Figure 5.1.22, p182) of his work place to support his comment:

“...I think it is important that people stay active... if people didn’t do anything, they would probably get bored...If they are bored, I just think people wouldn’t be able to have relationships with people and like projects...” (Scott, lines 685, 689-690 and 694-695, T8).

Scott also mainly focussed on keeping himself busy with something to stay away from boredom that could lead to problems in relationships. This could be true for Scott and many other AWLD; however, the majority of the population

may not have such opportunities to work. Moreover, Rose found it very useful to be independent and while using the photograph to support this comment (Figure 5.1.26) she said:

Figure 5.1.26. Rose doing pottery



"...every Friday morning, I go to college with my friends. It's like a bit of relaxing and doing stuff on my own without mum or PA. I got the independence a bit..."

(Rose, lines 47-49, T1).

Keeping busy was also seen as an opportunity by Rose to have some freedom away from carers. The carers might have been a good source of support and loved by the bereaved AWLD but, still, AWLD look forward to some time to perhaps learn to live independently. Participating in different group activities had given Rose self-confidence and she enjoyed taking part in them (Figure 5.1.27, p188):

Figure 5.1.27. Rose participating in drama



“...I do drama and singing, and that group has got my confidence up...” (Rose, line 343-344, T1).

Some planned time to pursue hobbies/interests such as

participating in drama/singing could be beneficial for AWLD to learn about loss from others’ experiences; however, they are also useful for general improvement in quality of life. While pointing to a photograph taken of an old photograph (Figure 5.1.28) of himself in fancy dress and singing, David’s happiness was reflected in his body language and facial expressions, as he could not stop smiling:

Figure 5.1.28. David singing



“...I sing a song for my nana and granddad on my microphone. I sing songs for them two” (David, lines 387-388, T9).

Again, using hobbies, but in a different way, as David was singing for his deceased grandparents, was helpful for him to cope with grief. Apart from

attending activities like drama in conjunction with the day care centre, Abbey proudly shared that she helped her sister with household chores and said:

“I do knitting, like baby cardigans and I go shops to sell them...”

(Abbey, line 553, T4).

When an AWLD has a talent and passion for something, such as Abbey’s skill in knitting, bereavement support could be focussed in a way that their talent is creatively used in the support sessions or daily activities. Evidently, participants who had some options of keeping themselves busy were doing interesting activities outside their home environment. Seven participants were very pleased with the activities they were engaged with, and shared much information, supported by their photographs.

Talking about loss: Seven participants (Charles, Abbey, Jack, Rose, George, Scott and Megan) made reference to ‘talking about loss’, which they had found very useful. According to Charles, talking to someone and sharing his feelings can help him to cope with loss in a better way. On the day of the interview, after talking about loss, Charles compared it with other days when he talked to someone about his loss:

“...today I have a laugh. I have laughed. There is a tear in my eye talking about it but if you don’t talk about it, you won’t mind about it and then you won’t go crazy and do stupid things to yourself...” (Charles,

lines 911-913, T2).

Not being able to talk to anyone about their feelings after a loss was considered as the major reason behind the excessive drinking and suicidal thoughts by

Charles. Clearly, when given a chance, AWLD are capable of talking in depth about their experience of loss, provided the other person has good listening skills.

Additionally, talking to other friends and families was supported by David and shared in a photograph and its caption (Figure 5.1.29):

Figure 5.1.29. David's relative



“...my brother in law [name] comes to my house...he told me, he lost his dad...he lost his dad and got only his mum left...I calm him down [name] I did...make him a coffee and say [name] don't cry...” (David, lines 545-557, T9).

David felt supported by his friends when they talked to him after his losses and in the same way, David imitated this support for his brother in law, who experienced a loss. AWLD do watch how they are being treated/supported by others and they do not hesitate to provide the same support to others when needed. Megan explained how she felt supported by the staff at the advocacy organisation and how the activities involving speaking up during different events have helped her.

“Telling people how I feel now my mum and dad have passed away, and now we can remember them, so good times we had with them”

(Megan, lines 1134-1135, T10).

For Megan, sharing the feelings of loss after many years was a support strategy. It is clear evidence of coping well when an AWLD is able to reflect on old feelings and compare with the present day's feelings without getting disturbed. Interestingly, talking about loss was not cherished by Lisa, as she said it upsets her. However, at the end of the interview, she was very happy that she could talk to the researcher. Megan highlights that a talking opportunity at the right time is crucial in coping, as illustrated in the following quotation:

“...If we want to talk to anybody, we've got the staff to talk to. As I said, if we want to be on our own, we could just tell them and then they'll let us sit on our own. If we want to talk to them, they'll sit and talk to us in one of the rooms” (Megan, lines 643-646, T10).

Freedom in some form was discussed as valuable by Megan because she experiences freedom to talk/not talk in her own time. Undoubtedly, talking about loss was found to be useful in coping with the loss by most (nine) of the participants; however, talking at the right time and sometimes not talking at all was also pointed out as an important factor, demonstrating the need for a person-centred approach.

Rituals and loss itself as support: Remembering the deceased, looking at photographs, and missing the deceased had been useful for Scott, Rose and David respectively. Visits to the memorial garden, the crematorium and walking

to the church helped Charles, Rose and Lisa respectively to cope with their losses. For Rose, her last photograph (Figure 5.1.30) with her deceased father helped her as a form of therapy to cope with the grief. Additionally, another photograph (Figure 5.1.31, p193) used as evidence of her visit to the grave was used to show how rituals could be helpful in coping:

Figure 5.1.30. Rose with father



“This is two days before he died, my dad. This doesn’t upset me as much but my mum got one on the fridge to see if I was upset... Sometimes when I am feeling low I keep on looking at it.” (Rose, lines 64-67, T1).

Rose used the photograph of the deceased to represent the meaning of loss as well as the support to cope with grief. Sometimes people may put the photographs of the deceased away, but this could be disrespectful for AWLD because even though they may have learned the finality of loss, they like to talk through photographs as if the person is still alive. Thus, Rose had the photographs of her deceased father always close to her.

Figure 5.1.31: Rose at her father's grave



“...when I put flowers on my dad’s grave...” (Rose, line 376, T1).

Putting flowers on a grave holds a special sentimental value for the bereaved to show their love and pay tribute to the deceased. This practice has been discussed as equally essential as the funeral by Rose, which is why, after not being able to attend the funeral, when she put flowers for first time on her father’s grave she had the moment captured in a photograph. She might have visited the grave and put flowers many times now, but she found it very difficult to do it the first time. Although AWLD may feel tremendous sadness to visit the grave for the first time, this needs to be weighed against the release of emotions and the peace of mind it could bring. Visiting the memorial garden was useful for Charles and although there was no mention of his family in the photograph of the memorial garden (Figure 5.1.32, p194) he still wanted to share this picture:

Figure 5.1.32. Charles (memorial garden photograph)



“...This is just a memorial garden in Town...Where you can actually go and put flowers on benches and put a name on a bench if you need to” (Charles, lines 381-386, T2).

It is common practice to visit the cemetery where the family members are buried; however, Charles highlighted how visiting the local cemetery where none of his family members were buried was a supporting activity for him. Finding peace in any cemetery could also be the case when the bereaved start feeling that the deceased do not remain in the grave forever and it is the ritual that gives comfort and not a particular place. David and Scott also shared information on the rituals performed after death that were useful for them to cope with their losses. Scott described his family history, about the place where people were buried from his family, and he believed that the rituals were important to attend after the death. He also reflected upon conflicts in his emotions because he knew the importance of rituals but did not want to be sad as a result of doing them:

“...Up at the church, I am missing Nana and Grandad...up at the church and I am missing Nana and Granddad like that” (pulled face,

made a sad expression and crossed hands with eyes closed, as if in church) (David, lines 97-99, T9).

“...my mum goes to her mother’s grave and she pours water into the pot and put flowers in...I think that helps me as well... sometimes we go to the cemetery to look where my mum’s grave is. Around the corner of [name] cemetery it is like a little part, a little side where my dad’s ashes were put...to remember my dad...I think it would make me sad...The reason why people go there because it is to remember. If people don’t go there, they haven’t remembered that person” (Scott, lines 1088-1136, T8).

As is clear from the quotes from David and Scott, some AWLD have the concept that participating in the rituals such as visiting church or a gravesite is like paying tribute by remembering the deceased. There was also a sense of comfort in being able to participate in the accustomed routines of visiting the cemetery because these routines were an opportunity to express their own feelings. Generally, it is often believed that places and rituals related to death are upsetting for AWLD, but data from these participants indicates that even though they knew it would make them sad, they still liked to participate in activities such as visiting and putting flowers on graves. Hence, these activities should be encouraged by talking to AWLD and preparing them for what they could encounter and experience as a result of such participation.

Theme 3, Subtheme c: Best help

Participants have confirmed that they like to go back and think about the different stages they have been through after loss. As with the general population, they also reflected on the events in their lives even if those events were difficult ones. This is further illustrated in Scott's quotations where he was keen to learn and share knowledge about bereavement with the world:

"...a conference telling people about bereavement and telling them about everybody's loss is different like the rest of them in this country"

(Scott, lines 1030-1031, T8).

Suggestions such as sharing information about the uniqueness of loss and bereavement, although predominantly suggested for AWLD, from a wider perspective could be helpful for all to prevent the assumptions that might otherwise develop about the experiences of loss.

In summary, knowledge and information about death, funerals, and rituals after loss at different stages were the best forms of help for nine of the participants. Clearly, the support that was appreciated and found most beneficial by AWLD was in the form of exchanging knowledge and talking about loss (sometimes just talking and/listening to the bereaved), by activities such as involvement in the advocacy organisation and sharing the experiences of loss in different ways. Family and friends were seen as the best source of support among all the support coming from people.

Theme 3, subtheme d: Not helped

It was evident that not knowing the illness of a family member, such as in Jack's case, where he was not informed of his sister's illness, was not helpful. In the information shared by Rose, where although she was well-informed of loss, she still could not attend the funeral owing to health reasons, was also not cherished by her. Both intimated that missing the opportunity to see the dying family member or the ritual leaves a person with deeper issues than there would have been had they been allowed to take part. Six participants could name several things that were not helpful at the time of loss and beyond. Charles shared that bereavement counselling was not useful for him owing to his own behaviour. He attended bereavement support soon after his loss and admitted that he did not behave during the session:

"...But in a certain way I wasn't being fair to the bereavement counsellors. I wish I had been a bit more patient and a bit calmer when I was speaking to them than I was" (Charles, lines 841-843, T2).

The time straight after a bereavement is overwhelming and every individual would like to devote themselves to it in their own way to work on a personal coping strategy. This had not been possible in case of Charles because without understanding his needs and the causes behind challenging behaviours, he was referred to bereavement counselling straight after the death of his father. Sometimes even the correct support can be erroneous if the timing of delivery is not assessed. The behaviour of his brother-in-law towards Jack, where Jack was not allowed to see his sister before she died, had made it difficult for him to cope with the death of his sister, as he illustrates:

“Well, what didn’t help me is him just springing it on me, with my sister, and if he’d have let me go to the [hospice]. If he’d let me just go and see her, see my sister for the last time, it wouldn’t have cut me up so much” (Jack, lines 774-776, T5).

Missing the opportunity to visit his sister in the hospice before her death made Jack feel angry and dejected. Such visits may not seem to be helpful straight after loss, nor at the time of illness of a family member, but they are very advantageous to cope with loss in the long run when an individual reflects back on the time spent with the deceased. According to Rose, she couldn’t attend the full funeral and now regrets this:

“...I could have done it [attended funeral] but I think with the medication I am on now, I could have done it. With the right medication...” (Rose, lines 178-179, T1).

Rose had also missed the opportunity to attend the funeral of her father and had discussed reasons such as not being pushed by her family and the wrong medication being responsible for her absence. As the loss stays with the bereaved for their entire life, rituals like funerals need to be discussed with AWLD during all life events and not just at the time of loss. Because it may not be easy for a bereaved AWLD to understand the benefits of being involved in a ritual if told about it for the first time only after a loss.

To summarise, bereavement support needs and the timing of support must be assessed before beginning the therapy sessions. As reflected above, what did not help Jack and Rose was their lack of involvement in events before, during

and after death, clearly providing evidence that AWLD do like and need to be involved in events related to loss. None of the participants reported that they did not want to know about their loss, thus verifying that the best support was knowledge and information.

5.1.4 Theme 4: Continuing bonds

This theme demonstrated that the participants continue with the activities that maintain a bond with the deceased, for example holding on to the memories of time spent with the deceased and doing the same things to feel close to the deceased.

Theme 4, Subtheme a: Interests similar to deceased

Six participants shared that they felt close to the deceased while doing things that were connected to them; for example, Rose adored one of her father's favourite songs and even sang a few lines during the interview. Margaret felt close to her father by visiting his favourite place after his death and by keeping bereavement cards with her. Scott developed an interest in cancer as his father died of it and Adam continued linking his talk to his father's illnesses. According to George, his parents liked blossom trees and he shared a photograph (Figure 5.1.33, p200) of a blossom tree.

Figure 5.1.33. Blossom tree by George



"There is blossom on the trees, isn't it?...it reminds me of summer...They [parents] used to like trees and the blossom" (George, lines 124, 128 and 137, T6).

Bereaved AWLD also remember their deceased family members in very common things such as in blossom trees. Living in and being supported in the same environment as before loss could give opportunities to bereaved AWLD to feel close to the deceased. Keeping possessions such as the last present from her deceased father, holding a birthday celebration close to her father's burial place and playing his favourite song were some of the examples used by Rose to show her continuing bond with him:

"On my 40th, it felt like playing simply the best [song] and I started crying, I knew my dad was looking over me... Every time it comes on and I am thinking yeah, my dad is close to me" (Rose, lines 242 and 381-382, T1).

Although Rose understands the finality of death, she continued feeling the presence of her deceased father for a long time after his death. This feeling

could sometimes help the grieving person feel comfortable by believing that their deceased family member is watching them and protecting them. Lisa very emotionally explained that she liked to keep and use the same set of garden furniture that her parents had (Figure 5.1.34):

Figure 5.1.34. Lisa in garden



"I Just like sitting outside...I have always sat outside when I was young...we used to have that sort of furniture..." (Lisa, lines 144, 148 and 152, T7).

Keeping the possessions once owned by deceased parents and using them in the same way was a technique using by Lisa to feel close to her parents. At such points it demonstrates how the reminders of loss turn out to be the support to cope with loss and this was true for most of the participants in this research. David's grandmother used to love animals and he loved them, too; after his grandmother's death he looked after her dog and still does so, which he feels very happy about (Figure 5.1.35, p202):

Figure 5.1.35. David's dog



*"...I walk her dog for her"
(David, line 239, T9).*

Keeping the same pets as the grandparents, and also to have the ones discussed with grandparents was a joyful experience for David. He explained that he always wanted birds as pets when his granddad was alive and now, even after his granddad's death, he has lots of birds to look after (Figure 5.1.36):

Figure 5.1.36. David bird's photograph



*"Me dad buy them for me
because I will ask my Nana
and Granddad, he bought
the birds for me, my dad"
(David lines 483-484, T9).*

Family members' support in completing a wish of the bereaved AWLD was appreciated by David, as he was given the same pets he always wanted to

have before his grandparents died. However, there is another viewpoint to this because sometimes bereaved AWLD are given different objects and pets to distract from facing the difficult feelings of loss and this must be done in a thoughtful way.

Fulfilling the last wish of deceased: After the death of his father, Jack had accepted the responsibility of looking after his mother and sister, so he stayed with his mother until she was settled after the loss. Jack's mother's last wish was to see him getting married; Jack fulfilled this after her death:

“Well, the last thing my mum ever said is...She said, ‘I want you to meet somebody, and really get together, and get married,’ And I did” (Jack, lines 404-406, T5).

Jack had not displayed any spiritual feelings or beliefs during the interview towards the deceased family members but fulfilling the last wish was a sense of completing a task for his mother. This is quite common in the general population, in which beliefs associated with the completion of the last wish of the dying person are given a lot of importance.

To summarise, the participants shared similar interests as the deceased, which they either always had or developed with time after loss. Fulfilling the last wishes and remembering the personalities were also a symbol of continuing bonds that were discussed during the interviews.

Theme 4, Subtheme b: Reminiscence work

All participants had memories of time spent with the deceased, regardless of the time since the loss. Eight participants shared detailed lists of things they used to do with the deceased but two (George and Abbey) just summed up the

activities by saying they used to do everything. Adam, although sharing a lot of information relating to the loss of his father, did not share information about time spent with his brother. Common activities that were reported by participants performed with the deceased family members were everyday activities:

"Everything, go everywhere with them, on daytrips and everything"

(George line 157, T6).

Loss can be devastating for someone like George because when someone is used to doing everything with their parents and then after their death, the previous life, in a way, gets disconnected from the present owing to the amount of changes a loss brings. For Megan and Lisa, the recollections of time spent with their parents was also everything including going on holidays, living together, doing basic things and looking after them:

"Being there with them, looking after them, going out, help them to do their shopping" (Megan, lines 359-360, T10).

"I went food shopping with them...I have been everywhere and did things with my mum and dad" (Lisa, lines 92 and 87, T7).

The absence of the deceased family members was highly recognised in everyday life by participants. Responses reflected that the life before loss was the best life. Scott also shared numerous activities that he used to do while spending time with his father and most of all, he used to watch lots of TV programmes with his father. He still continues to do that and felt like he was

using the humorous programmes to distract him from difficult feelings of loss (Figure 5.1.37):

Figure 5.1.37. Scott's DVD



“We used to go touring. He [father] used to have touring caravan holidays...We used to all go shopping together...Like watching the videos...we would have a good laugh at that” (Scott, lines 519, 537 and 555-557, T8).

Most of the activities performed before the death of his father were no longer undertaken by Scott, but humour as support was continued to be used. Performing the same activity may not feel the same after a loss but certainly can bring some memories of time spent with the deceased. David and Charles also shared the memories they had of doing different activities with their deceased family members:

“She [Nana] used to cook some dinner...play cards...I take my Nana to the zoo to show animals...” (David, lines 294, 223 and 469, T9).

“We used to go for walks...Well, we went to the pub and had some whiskeys...” (Charles, lines 441 and 445, T2).

AWLD undoubtedly remember how their deceased family members influenced their lives, and how the lives were now changed after death. If the most appreciated activity that might have been started by the deceased with the AWLD was performed by someone else, then they may not have missed it as much. But the discontinuity after a loss makes the activities and time spent with the deceased more critical.

To summarise, while all participants were sharing their memories, they clearly demonstrated that reminiscence work was useful, and the participants liked to talk about the time spent with the deceased. Most of them had a lot of information to share that reaffirms the fact that AWLD like to talk about their experiences of loss in an appropriate environment. The researcher took extra care in order to make the participants feel valued and heard.

Lost person's personality: Some of the participants made reference to the personality of the deceased, sharing, for example, how they looked, what they did, and what they liked. Rose compared her own appearance to the deceased and Adam explained how he missed the chance of doing the same job as his father. For Scott, Charles and Megan, the likes of the deceased were very special; This is further illustrated by Rose and Adam:

"I'm a daddy's girl, I look like him, everybody says" (Rose, lines 152-153, T1).

"... I could have stepped in his shoes and became a union rep, because he was a union rep at one stage..." (Adam, lines 185-186, T3).

Half (n=5) of the participants described the nature of the deceased in a positive way, describing how their ambitions such as following the deceased's footsteps and doing the same job. These ambitions were although taken away after the loss, they were still remembered. The deceased person's likes and dislikes may have been of interest while they were alive, and they were a special topic to discuss during interview.

To summarise, the awareness showed by all AWLD in discussing their memories clearly demonstrated that they had experienced bereavement in their own ways and had constructed an understanding of loss, but required opportunities to also grieve in their own way and to talk about it. It was clearly visible that talking about the deceased was giving pleasure to all of the participants but may have been uncomfortable for some.

5.1.5 Conclusion

To summarise, the results from the interviews with AWLD demonstrated multiple losses experienced by the participants; however, they did not present their losses as multiple. Instead, they were talking about them as the effects of their main loss, which in most cases was the death of their parents or grandparents. Most participants had a very clear understanding of loss, and the associated feelings and worries. More than half of the losses, which were not communicated to participants properly at the time, had left the participants in a difficult situation for them to cope, compared to the losses that were communicated well. Families, friends and keeping busy were the most useful supports after loss, along with knowledge and the availability of relevant information. Time and again, nine of the participants clearly reinforced the fact

that the knowledge and information they had about the experience of loss was helpful.

The loss had indeed impacted upon every individual in different ways, such as going through multiple losses after the death of a family member, changes in daily routine activities, fear of more losses and many more effects, depending on their relationship to the deceased. Additionally, the loss of home and separation played a significant role in the overall impact. The participants reflected on the importance of connections and continuing bonds with the deceased as they remembered the deceased on special days, while visiting religious places and doing similar activities as the deceased. Most of them had accepted the loss and found their own ways to cope with it. Most of the participants used photographs and some used physical items related to the deceased reflecting their continuing bonds, for example bereavement cards. Photographs were found to be very useful to engage AWLD, especially while talking about the deceased person and provided in-depth information with photographs as supporting evidence.


As the main participants (AWLD) were recruited from an advocacy organisation, it was essential to incorporate the views of advocacy staff members in this research to understand their perspective of loss as experienced by AWLD. Advocates were the second participant group and the results from this group are presented in section 5.2, p209.

5.2 Introduction of findings from advocates

“...His mum died over the weekend and he was moved straight out of the family home then moved around all over the place, one placement after another after another because they didn’t - couldn’t identify somewhere permanent and everything he’d ever known was gone...” (Dolly, lines 724-727, T11).

Bereavement is indeed a stressful experience for AWLD and particularly so if the death is of the main family carer, leading the bereaved AWLD to experience multiple losses afterwards that are often not recognised. In this section, results from the data collected using one focus group with advocates (n=6) and one joint interview (n=2) with two advocates are presented. After analysing this data, four main themes with a range of sub themes were formed. All four themes are presented in Table 5.2.1, p210 and further described with direct quotations from the focus group discussions. Views of participant advocates on other groups of people working around AWLD are shown in different colours (Table 5.2.1, p210) for example, green text demonstrates the views of advocates about the family carers with regard to AWLD.

Table no 5.2.1: Themes from advocates (n=8) regarding bereaved AWLD

1) Perceptions of Advocates on losses to which *AWLD are exposed	2) Communication related to loss	3) Support	4) What could help
<p>a) Multiple losses:</p> <ul style="list-style-type: none"> ● Bereavement ● Transitional losses: separation; social life; belongings ● Children removed <p>Other significant losses:</p> <ul style="list-style-type: none"> ● Rights, confidence, hope 	<p>a) AWLD mainly not informed of:</p> <ul style="list-style-type: none"> ● Death or transition ● Illness or ritual ● Left to discover <p>b) Occasionally informed:</p> <ul style="list-style-type: none"> ● Family/professional carer ● Limited/Inconsistent ● Understanding not checked <p>c) Causes of non-involvement:</p> <ul style="list-style-type: none"> ● Preconceived ideas-AWLD do not exist ● Practicalities ● Convenience 	<p>a) What is available:</p> <ul style="list-style-type: none"> ● Bereavement organisation ● Community **LD nurse ● Advocacy ● Seldom family support <ul style="list-style-type: none"> ● Barriers in accessing support for AWLD: ● Limited time ● Lack of continuity ● Physical barriers ● Economic barriers 	<p>a) Communication:</p> <ul style="list-style-type: none"> ● Using person-centred approach <p>Procedure:</p> <ul style="list-style-type: none"> ● Positivity in the perceptions ● Proactive approaches <p>Activities:</p> <ul style="list-style-type: none"> ● Accessible information ● Routines are useful <p>People:</p> <ul style="list-style-type: none"> ● Role of Advocates (Referrals) ● Families by planning ahead 
<p>b) Reactions of loss:</p> <ul style="list-style-type: none"> ● Behaviour changes ● Learnt behaviours ● No obvious reaction ● Practical ● Based on expectations ● Drinking habit 	<p>d) Impact:</p> <ul style="list-style-type: none"> ● No knowledge ● Misinterpretation of behaviours ● Mental health issues ● Benefits of involvement ● Drinking habit 	<ul style="list-style-type: none"> ● Barriers for services: ● Economic barriers ● Lack of accessible resources for workers/nurses ● Lack of training ● Useful for advocates ● Regular supervision ● Peer support 	

Key for table *AWLD: Adults with learning disabilities **LD nurse: Learning disability nurse

Red
AWLD

Dark Green
Family Carers

Blue
All working with PWLD

Purple
Advocates

These themes are now explored individually

5.2.1 Theme 1: Perceptions of Advocates on losses experienced by AWLD

This theme explores the understanding that advocates (n=8) have regarding the losses faced by AWLD from their experience of working in this field. Advocates believed that AWLD go through significant losses in their lives, which may or may not be owing to bereavement such as loss caused by death, separation, social life, transitional losses, confidence, rights, health and hope.

Theme 1, Subtheme a: Multiple losses

All advocates believed that AWLD always go through 'multiple losses' and not just one loss. Loss owing to the death of a close family member meant loss of everything associated with that person, for example their family home, belongings, and time spent with the family. Advocates believed that although the range of basic losses were similar among AWLD to the general public, there were some differences, as illustrated by Erica and Nancy:

"...if somebody has got a learning disability and the loss of someone who was maybe a carer for them, things happen so rapidly. Whereas if we lose someone, we don't immediately move out of the house, throw all personal possessions away or have them packed away by somebody else and just have to get on with it..."

(Erica, lines 715-717, T11).

"...they have moved out of their own home and they are in a care home or whatever. They are not always given the opportunity to go home and get

the photos or what is important to them...somebody's house can just be sold from underneath them and all the stuff goes with it and it just goes in a house clearance. It is quite ruthless, really” (Nancy, lines 361-366, T12).

Here, Erica describes how the life of an AWLD changes rapidly after the death of a carer and, often, without any knowledge. Nancy highlights the severity with which AWLD can often be treated. As she says, the ‘ruthless’ nature of such treatment augments the losses experienced by AWLD even further. The difference in experience an AWLD faces after a loss compared to the general population is enormous because each loss leads to many more. Dolly shared a specific example to illustrate the series of multiple losses experienced by one AWLD who lost his mother:

“...His mum died over the weekend and he was moved straight out of the family home then moved around all over the place, one placement after another after another because they didn't - couldn't identify somewhere permanent and everything he'd ever known was gone...” (Dolly, lines 724-727, T11).

Dolly conveys the lack of sensitivity shown to AWLD after a loss where she remarks that ‘he was moved straight out of the family home’, which suggests that AWLD’s feelings and wishes in the immediate aftermath of bereavement weren’t considered. The AWLD in this case seems to be treated as a problem for the family, rather than as a grieving person. Indeed, as in Dolly’s example, where the AWLD experienced “one placement after another after another”, following the death of a family member who was the main carer, sometimes when AWLD are provided with carers or PAs (personal assistants), the carers

may change either owing to changes in the job role or closure of the care service. This leads to multiple losses that could go unrecognised, as demonstrated by Lucy and Nancy:

“...a loss could be that they had a carer like a PA or so for a long amount of time but then the PA gets another job, brilliant carer gets another job. So, although, perhaps to the member of the staff it is their job and they move on, it could be a huge loss to that person...” (Lucy, lines 38-41, T12).

“...when a lot of the day services were closed, and some people had been going to the day service for like 20 years; so, the staff there they knew so well and if they got any issues at all, the key workers or whatever who worked at that day service were like family to them...” (Nancy, lines 54-58, T12)

Lucy brought up the focus on the ‘brilliant’ carers who often get new job offers, which they may accept owing to their own circumstances, leading to a major sense of loss for the AWLD. In the same way, when the ‘day services’ close, as Nancy reported, it brings immediate change in whole staff team, including all the familiar faces to AWLD. It is miserable that care service or the carers who are supposed to offer support after a bereavement unknowingly become part of multiple losses for AWLD. Another substantial loss faced by AWLD was having their children removed by the social services without explanation. Owing to lack

of information, the AWLD parents remain hopeful of getting their children back, as illustrated by Cathy and Erica:

“...for parents with learning disabilities who’ve had children removed...for them it is a bereavement” (Cathy, lines 28-29, T11).

“...But so many parents are still so, so hopeful, they’re in no way really prepared for the fact that actually, the court is going to turn round...”

(Erica, lines 284-286, T11).

Once the children (of parents with learning disabilities) are forcefully removed without any explanation, it leads to the loss of hope that people hold onto until the final decision from the court. Whilst a bigger issue such as removing children from parents with learning disabilities are ignored, other issues such as sending bereaved AWLD to respite care without choice also go unnoticed. Erica describes how for the most part, AWLD are not given choices such as if they want to live in their home or go into respite care after loss:

“...if they’re not happy to move and stuff like that then often capacity is brought into this...and so decisions are made on their behalf” (Erica, lines 49-52, T11).

The choice to move house after the death of a family carer is made for AWLD. Decisions are forced on them and their lack of capacity for argument is used if there is a disagreement.

In summary AWLD undergo multiple losses and sometimes more significant losses are overlooked owing to a bereavement. Substantial losses are believed to take place owing to broken links with previous accommodations and fellow residents, lack of communication with AWLD and the stigma attached to the learning disability itself.

Theme 1, Subtheme b: Reactions to loss

Advocates believed that bereaved AWLD usually express their feelings of loss through changes in their behaviours, such as being withdrawn, distressed, aggressive, self-harming, tearful behaviours or by using alcohol/smoking, and less often by using words. If they do use words to express their feelings, then the words are normally very limited and learned from other people. Cathy believes that every AWLD reacts to the loss in his/her own way, hence making it difficult for carers to understand and running the risk of expressions of loss being overlooked for a long time. As she explains:

“...often, troublesome behaviours can start appearing and can continue for quite some years until somebody could perhaps be like, ‘well, is it because of this?’ And that might be quite a long way down the line before they actually feel that emotion or that loss properly” (Cathy, lines 567-569,

T11)

The irony of the situation of how the bereaved AWLD react to loss, as described by Cathy, is the way in which behaviour changes after loss that are sometimes not self-explanatory are overlooked. AWLD may remain in despair for ‘years’ until their reactions are recognised and addressed. However, there

was recognition of such behaviour sometimes by the advocates, as Erica shared an example of how an AWLD who she was supporting reacted to loss:

“...it didn’t come out in words, it came out in actions...his behaviours changed, he became very aggressive, he would run off, he was crying, he’d be all those sort of things...” (Erica, line 549-555, T11).

Erica discusses here another unique loss where an AWLD faced a completely broken relationship with his parents over money issues. Here he was not given a choice or involved in discussions with his parents to try to repair the relationship with them by sorting out his financial issues. This led him (AWLD) to express aggression in his behaviours. Other than aggression, many mixed expressions of loss from AWLD were explained with examples from all advocates and those examples were similar to the quotation by Gill, as she explained that sometimes a factual communication made it look as if there were no effects of loss:

“...[they] go into themselves and don’t talk and then in fact don’t talk about pretty much anything they, you know, find it very difficult to communicate and then there’s others that are quite direct and, as you say, tell you quite a lot, ‘This person’s dead, they’ve died, they’ve gone’ and so you hear about it quite a lot...” (Gill, lines 992-997, T11).

As Gill differentiates, for some bereaved AWLD it is difficult to talk about loss and others might just talk a lot in facts about loss. This could be because the AWLD are usually not involved in daily communications where they can learn about the appropriate language to talk about loss. Erica further shared an

example of the use of factual/learned behaviour by the bereaved daughter of her friend (the daughter has learning disabilities) to provide information to the visiting family friend:

Visiting friend to daughter: *“where is your mum [name]?”*

Response of daughter: *“She’s just sorting my dad out, it’s a bit sad about him, isn’t it?”* (Erica, lines 612-616, T11)

Communicating about loss to others using words such as ‘sorting my dad,’ as discussed by Erica, might not be thoughtful conduct, but it could be the only words some AWLD have heard and learnt. Other than some typical responses, the set phrases used commonly after loss by AWLD that are believed to be comforting by advocates were shared. These phrases are learnt from others and their meanings are not necessarily familiar to AWLD; some examples are provided by Dolly and Betsy:

“We can’t be sad all the time, can we?” (Dolly, line 666, T11).

“We all have to go one day” (Betsy, line 670, T11).

Set phrases used unknowingly by AWLD such as the two outlined by Dolly and Betsy in above quotations could be soothing and the expected form of dialogues from others without learning disabilities. Dolly and Betsy also believe that expectations of others play an important role in the use of certain responses by AWLD in expressing loss. It has been further assumed that professionals note the verbal response as evidence for the expressions of loss by AWLD:

“...they’ll say what they think people want to hear a lot of the time” (Dolly, line 689,T11).

“Professionals want to hear that because they think she’s come to terms with it” (Betsy, line 687, T11).

Here, Dolly and Betsy, revealed that AWLD are sometimes misunderstood by their carers owing to the use of certain terminologies because as soon as AWLD understand what pleases the carers, they start doing it. In this scenario, although AWLD may feel that they want to stay home and do nothing, in order to please the carer, they have to say something else that goes against their feelings or wishes.

To summarise, loss is expressed in behavioural reactions more commonly than using language and AWLD sometime use learnt phrases to talk about loss that they believe are expected from them. Advocates believed that no matter how a person with learning disabilities expresses grief, it is essential that their grief expressions are acknowledged in a similar way to those of someone without learning disabilities.

5.2.2 Theme 2: Communication related to loss

This theme provides information from the advocates on the communications with AWLD related to loss and bereavement, such as: if AWLD are informed or not informed of loss; how are they informed; the source of difficult news; causes of non-involvement of AWLD in bereavement and rituals; impact of loss; and lack of communication around loss.

Theme 2, Subtheme a: Not informed of loss

AWLD are not normally informed of the range of losses (potential or past), even if those who are in caring roles are aware of them. Gill described certain situations where decisions were taken by professionals and AWLD were not informed of bereavement, house move or illnesses (own/family member's):

“...people [families or specialists working with AWLD] making best interest decisions to not tell people [AWLD] about loss or the fact, actually, you're going for an operation where, you know, it might be a hysterectomy...”

(Gill, lines 394-400, T11).

According to the Mental Health Capacity Act (2005), the 'best interests' refer to any decision made on behalf of an adult lacking capacity must be in their best interests. However, Gill challenged not telling an AWLD on the basis of assumptions about their capacity to understand and make decisions, as this cannot be deemed to be in their 'best interest'. According to advocates, the decisions of not informing AWLD of a loss are also taken owing to the stigma attached to learning disabilities, Gill illustrates further:

“They don't even get told and then, actually, 'oh, yeah, so and so was buried two weeks ago'...” (Gill, lines 459-460, T11).

Whilst the news of death is delayed/not given to AWLD, the information about burial was also hidden. This takes away the opportunity from bereaved AWLD to comprehend the certainty of death and grieve with family. Lucy and Nancy added that sometimes, owing to the stigma associated with learning disabilities, the families decide to stay away from their family member with learning

disabilities and neither inform nor involve them in funerals and the subsequent bereavement matters, as illustrated by Lucy:

“...this man had got a learning disability; and I think he had been put into care at a very young age. And then I think it was his mum, when she passed away, they were thinking, oh, certain members of the family didn’t know about this child [who is now AWLD] that had been pushed off into care...” (Lucy, lines 931-935, T12).

Another scenario, as discussed by Lucy, was if an AWLD was admitted to a fulltime care home at very young age, extended family may not even know of that child’s existence. The child (now an AWLD) goes through repeated multiple losses of parents by separation at a young age and now, after death, had his/her opportunity to say a final goodbye or participate in rituals taken away. As shared by Lucy, loss is sometimes left for an adult with learning disabilities to discover him/herself. This is illustrated using other situations, like the one described by Gill:

“...particular hospitals like that, they don’t tell them [AWLD] that actually, they’re not returning home, they’re just going to take them to the care home and they’ll have to work it out themselves...” (Gill, lines 388-390, T11).

As Gill, previously informed, sometimes decisions are taken in the ‘best interest’ of AWLD and they might just go for major surgery without knowing. To add to the stress, when AWLD are discharged from hospital, they may not be informed that their house has also been taken away and there may/may not be any

definite place for them to go and live. These kinds of losses are no less of a bereavement; however, these go largely unnoticed.

To summarise, advocates explained clearly that AWLD are regularly not informed of loss, regardless of the relation the AWLD shared with the deceased. In addition to bereavement, the advocates emphasised other transitional losses, such as a forced change of residence at a time when it is needed the most. Moving house could be justified in the absence of anyone to look after an AWLD at their homes, however even this reason needs to be explained to the person. They shared further cases where this has been practised with the AWLD and the fact of difficulties in coping with loss in the long term was completely overlooked.

Theme 2, Subtheme b: Occasionally informed about loss

Advocates believe that family members and professional carers are believed to be the main source of information of loss, and that advocates have rarely been part of the process of informing an AWLD of a loss. They believed that although they are not trained for breaking difficult news, if the need arose they would be happy to do so. As Erica explained:

“...I’m the person who he knows the best and has been the most, sort of, continuous and consistent person in his life; they asked me to come in...Sometimes they’ve asked us to pass that information on and we’ve said that’s not appropriate but we will support at that point” (Erica, lines

357-363, T11).

Erica's comment reveals that AWLD might not have many 'continuous and consistent' people in their lives that could help to pass on very difficult news, such as of a death in family. In such circumstances it becomes the moral duty of those working with AWLD to remain truthful; however, all advocates recognised that incorrect/confusing information had been used by support workers and carers to communicate sensitive information with AWLD. Using two examples, Dolly illustrates how one AWLD was told a lie to get him out of his home and another one was not given an explanation of what the term 'heaven' meant:

"...I met him there as I always did to support him before his CPAs [care programme approach meetings] and a member of staff took me to one side and said, we had to lie to him to get him down here. But he's not going back, he's staying here now" (Dolly, lines 419-425, T11).

"...it very much makes a difference with what language is used as well to tell the person. I think that because one lady I'm thinking of, who was in her fifties and her mum had recently passed away, and she was told that her mum had gone to heaven...well, I want to go to heaven 'cos I want to still be with my mum..." (Dolly, lines 581-584, T11).

The practice of hiding the true reason behind shifting an AWLD to a care home with deception was condemned by advocates. At other times, phrases such as 'gone to heaven' were used, which may be comforting to those who know the meaning of 'heaven', but for AWLD, if any such term is used, the understanding must be checked straight away, as they might not know the meaning of words that are not used with them regularly. In such circumstances the rituals after

loss that are considered important by advocates for AWLD to grieve in the same way as they are for the general population are still not followed. It was further clarified that AWLD are usually not involved in rituals after a loss, as illustrated by Erica:

“...somebody’s got a learning disability, [it] doesn’t mean that they don’t want to go and pay their respects and to have their chance to mourn and sometimes to visit the grave makes it real...” (Erica, lines 474-476,T11)

Whilst there is a place and time for everyone to ‘pay their respects’ after a bereavement, AWLD are not even made aware of such occasions. There is a pressing need to weigh and understand the benefits of involving and the long-term consequences of excluding bereaved AWLD from news of a bereavement and/or ritual.

In summary, communication between bereaved AWLD and professionals has been considered to be very useful by the advocate participants; however, they have clearly reported a big gap in this area. AWLD usually are not informed of any loss owing to preconceived ideas held by professionals and families and on rare occasions if they are informed, then clear language is not always used. Decisions about informing AWLD of the loss are usually taken by professionals and people in caring roles without involving the bereaved adults.

Theme 2, Subtheme c: Causes of non-involvement

Erica talked about when sometimes people, especially elderly people, may see a family member with learning disabilities as being shameful or as possibly

causing a disturbance at events such as funerals, and hence tend not to involve them. In some scenarios, AWLD did not appear to exist as the families had separated them at a very young age owing to the disgrace or stigma attached to having a family member with learning disabilities. This is further clarified by Erica and Gill:

“...some people are of the old-fashioned view that people with a learning disability shouldn't really be seen. And like you say, the disruption that other people will perceive that the cause, but I do think, particularly with older generation families” (Erica, lines 509 -512, T11).

“...their [AWLD] family chose to never have any contact with them again, so these people [AWLD] don't know whether their mothers and fathers are alive or dead, if they've got brothers or sisters...They [AWLD] didn't exist in the family kind of dynamics at that point and they were cast out of society” (Gill, lines 518-523, T11).

Here, Erica and Gill discussed their views on how some families even in present times consider that people with mental illnesses and learning disabilities are the same. Thus, a lifelong loss of their identity surrounds AWLD as they are supposed not to 'be seen' and are 'cast out of society' sometimes. Not knowing about learning disabilities and the associated stigma primes people in societies to have negative assumptions (such as AWLD do not understand death), therefore not involving them in loss and bereavement experiences, as explained by Gill:

“...sometimes, professionals rightfully or wrongfully make assumptions...if you’ve got a learning disability, they’re assuming actually you don’t fully understand why somebody has passed away, or why your children are being taken from you...” (Gill, lines 148-152, T11).

Societies do make assumptions on the abilities of people in general, but in the case of AWLD the assumptions are sometimes baseless and without any evidence. The vicious cycle of assumptions is present around AWLD all the time, as it is believed that they ‘don’t fully understand’, so efforts to make them understand are not commonly practiced. Assumptions were evident in the over-protective behaviours of the parents towards their children with learning disabilities who have become adults and it can result from a lack of understanding about the abilities of an AWLD. Such behaviours play an important role in communication as Erica explained:

“...some parents very much have wrapped their children in cotton wool, which you can totally understand, try to protect them from the world and some of the unpleasant things that are out there but then that person has never really functioned in the outside world...” (Erica, lines 1263-1278, T11).

From Erica’s quotation it is apparent that parents who always wrap their children in ‘cotton wool’ need to get the balance between protecting their children (AWLD) from open threats but also need to provide them with the freedom and opportunity to explore the world around them. Assumptions on different level are followed by the potential for challenging behaviours exhibited at the time of loss or bereavement rituals that were also used as a reason not to

communicate with AWLD. Challenging behaviours are understood as difficult behaviours or socially unacceptable behaviours that are a challenge to people including professionals, carers and parents (Scope about disability, 2017). Gill describes further behaviours that are not appreciated:

“if you’re, like, learning disability or your presentation means that you shout or make a noise or things like that...it wouldn’t have been appropriate because it might have upset people [general grieving families] because they [AWLD] wouldn’t have sat, you know, quietly or respectfully...” (Gill, lines 493-497, T11).

During any ritual after a death, sometimes AWLD may ‘shout or make noise’ that in general people do not make. However, it is reasonable on the part of an AWLD because everyone has their own way to express their grief. Also, because AWLD usually are not involved in such rituals, they may not be able to recognise the differences between a bereavement ritual and another family gathering. Perceptibly, whoever informs or involves an AWLD in a ritual would be the person responsible for any offensive behaviours and support afterwards. In such situations, often the person responsible for informing the AWLD of loss weighs the potential reactions and difficulties of providing support, and then they usually decide not to inform them:

“...What if they [AWLD] say the wrong thing? And then what if the behaviours escalate if they find out about this [loss]? So, I would imagine on the same thought process with bereavement and loss, you know, it is just like, well, either we [person responsible to inform the AWLD] won’t tell them...” (Nancy, lines 206-210, T12).

Advocates argued that making assumptions about the difficulties of addressing the 'escalated behaviours' from AWLD after receiving difficult news sometimes does more damage to them than the difficult/bad news itself. Such practices confirm that the carers do not feel equipped to support AWLD in such situations. Another instance where sad news was hidden from an AWLD to avoid difficult reactions before his birthday; however, as Erica described, it is not good practice as short-term happiness could lead to prolonged distress:

"...they decided not to tell him [AWLD] till after his birthday, so he could have a good birthday, which was three weeks after the lady [foster mum] had passed away. And she'd already been buried..." (Erica, lines 465-468, T11).

On this one occasion, as discussed by Erica, the AWLD might have had his birthday in an environment without the sorrow of the news of his foster mother's death. However, there is no guarantee if the birthdays every year after the loss were also good because AWLD remember the difficult/bad news explicitly.

To summarise, clearly, AWLD were not informed of loss and not involved in rituals after death owing to preconceived ideas over lack of understanding in AWLD about loss and bereavement, which leads to continuous wrong assumptions. Additionally, advocates indicated some practicalities, such as a lack of trained staff responsible for not communicating loss to AWLD.

Theme 2, Subtheme d: Impact

It was evident from the information provided by the advocates that AWLD were not usually involved in the communications around loss and bereavement and

the far-reaching impact on the coping procedures in AWLD were discussed. As conveyed by Lucy, this can affect AWLD in different ways. For example, sometimes AWLD can be entirely unaware of their own death, as was the man in the following quote:

“...He said something about, ‘That’s a nice box. What’s in the box?’ And this was a coffin and you began to think, gosh, actually the understanding, at least at that stage, wasn’t there, really...” (Lucy, lines 821-827, T12).

A person not knowing what a ‘coffin’ is clearly demonstrates that the person has never been informed or involved in anything related to bereavement in their whole life. Such an example from Lucy elucidates the amount of stress AWLD may have to go through all their lives after learning about death through inappropriate communication methods. For example, for an AWLD who is unaware of death will be shocked to hear if he is going to die soon. Nancy demonstrated other impacts of loss and bereavement owing to a lack of communication, no time to grieve and no information on how to behave in the form of challenging behaviours. These are often misinterpreted and dealt with through medication:

“...then the behaviour escalated as a consequence of that difficult time. I am not confident that they would be treated in the same way...whether they would be medicated more rather than, well, it’ll pass. They’ll need time and support and then it’ll pass...” (Nancy, lines 135-140, T12).

After a significant loss when it is not communicated, and the person is not supported appropriately, often the behaviours are changed into more of a challenge for everybody to tackle. Here, Nancy explains that AWLD would not be 'treated' in the same way as others. Time may not be given to grieve with appropriate support to let the behaviours settle; instead, medication would be used to control the person. This could affect the mental health of AWLD according to Betsy and, additionally, can lead to alcohol abuse, as informed by Cathy:

"...Ended up quite poorly, he's now, he lives at [hospital name] which is a mental health unit but it's a very secure, very restrictive environment...because there was no support in place for him to deal with the emotional impact of losing his mum, who was his absolute world"

(Betsy, lines 189-193, T11).

"...the only ways he could do it was to go out and buy a litre bottle of vodka every day and drunk to the point where he's developed a psychosis and he's physically really unwell..." (Cathy, lines 664-670, T11).

As illustrated by Betsy and Cathy, there is a lack of contingency plans put in place by families/carers of AWLD for the period after a bereavement of someone who they consider as the 'absolute world'. This, in turn, causes the emotional downward spiral into self-abuse through alcoholism or ill-health from a lack of self-care. Apart from these, Dolly summarised the major impact as loss of trust owing to not telling the AWLD of the loss or bereavement and excluding them from rituals:

"It destroys people's trust as well" (Dolly, line 474, T11).

The long-term impact of loss does indeed break the 'trust' of AWLD with the families/carer and everybody around them and there exists the possibility of a situation in which a carer may be being honest but is not trusted because of what was done following a bereavement. On a positive note, Cathy provided evidence to show the positive long-term impact of learning and involving the AWLD in the bereavement and funeral. Even though the behaviours exhibited by the AWLD might not have been considered appropriate by some people, they were beneficial for the AWLD:

"...I went with him to the funeral and he just ran around the church screaming and screaming and screaming and he ran off. I managed to get him, we got back to where we were but a couple of weeks after, he was much calmer and I think because he'd been to the church, because he'd said his goodbyes in his way he was, erm, he was quite accepting" (Cathy, lines 501-507, T11).

Behaving in any way that is not generally acceptable during a funeral could be criticised by those who lack understanding of the unique ways of expressing grief. However, with agreement from bereaved AWLD, decisions need to be taken involving them [AWLD] in their 'best interest,' even if they end up 'running and screaming' around the church during a funeral. That could be their way of expressing the sorrow and could help them with coping in the future.

To summarise, the far-reaching impact of loss and not knowing about the loss sometimes depends on the relationship with the deceased. The death of the

main carer can make the AWLD feel like an orphan even if he/she has other family members. When loss is not communicated, it can make the AWLD feel deceived and can lead to challenging behaviours, mental health issues and alcohol addiction.

5.2.3 Theme 3: Support for bereaved AWLD

This theme highlights the views of advocates on the bereavement support available from different sources in the local area. Further, the perceptions of advocates on barriers for bereaved AWLD to access the support and the barriers for support services in providing the support are described. Finally, information on what has been found useful by the advocates in providing support is also presented.

Theme 3, Subtheme a: What is available

Advocates reported the general lack of support available for bereaved AWLD to cope with the loss. In terms of currently available services, family support, bereavement organisations, the community learning disability nurse and the advocacy organisations were known to the advocates. Advocates had fair knowledge of the services provided by the bereavement organisation, as illustrated by Cathy:

“It’s a counselling service around bereavement or loss...work with anybody but they have a project specifically for people with learning disabilities and they’ve actually got a project to support parents with learning disabilities who’ve had their children removed” (Cathy, lines 857 and 861-864, T11).

The role of advocacy staff in supporting bereaved AWLD usually involves signposting individuals to the right places after discussing the needs with the person. An advocate and his/her role, as described by Nancy and Lucy, is:

“...an independent person [advocate] where that person might be able to express that they are having difficulties with this; and then you would be in a position to signpost them to the relevant places” (Nancy, lines 555-558,

T12)

“...thinking about what support, perhaps, what they felt they might need but also making them aware of what support was out there. Because I suppose that is it, they might have no idea of what services are out there, so I suppose it is us looking at options for them and seeing if they want to explore those, really” (Lucy, lines 89-94, T12).

While discussing the role of advocates, Nancy and Lucy explained how advocacy organisations are the links between the AWLD and the different support channels. However, all the bereaved AWLD would not be able approach the advocacy services and may remain unaware of all the support available around them. Erica and Betsy described a person-centred approach that often began with rapport building when the issue was sensitive, as described by Betsy:

“...we go at different times, we, you know, go while they’re having dinner, we can sit with them. They will build a relationship and they will talk about other things...that person may not understand that that’s their loss until you kind of go down that route to explain...” (Betsy, lines 729-735, T11)

Bereavement support need to be person-centred, however, AWLD sometimes may take time to open up to discuss their needs, hence time used for rapport building could be beneficial. There were few positive things discussed about the support provided by the family to bereaved AWLD; however, Nancy had come across families that support their family member with learning disabilities as much as they could:

“...some people trying to do the right thing. I don't think it is malice at all”

(Nancy, lines 115-116, T12)

Following a bereavement, as Nancy suggests, some families are ‘trying do the right thing’, however, it can be argued if that right thing is often the right thing for the family, excluding the AWLD, rather than for the AWLD and their family included.

To summarise, a general lack of bereavement support available to AWLD was highlighted by the advocates. The only bereavement support service available in the local area was discussed as useful, however there was a lack of knowledge on the bereavement-focussed support offered by the organisation. Advocates presented themselves as a good source of support, which was true to some extent because once a person is referred to them they provide person-centred, one to one support.

Barriers for AWLD to access support Generally, the barriers to accessing bereavement support for AWLD are: limited time, limited services, lack of awareness, language, autonomy; and some physical and economic barriers. According to Gill, the initial responses to bereavement support by AWLD are often used as the deciding factors as to whether the support should be

continued. However, this is not considered good practice because the grieving person may not be able to engage at that time owing to their deep sorrow, yet he/she would not be offered the support again:

“...if they’re not engaged when it’s first happens, for example, ‘cos they’re not ready to talk about it...that they’re not offered that again. ‘Cos, well they had that choice and they didn’t like it and they didn’t engage, so it’s never offered again” (Gill, lines 887-890, T11).

Bereavement support may not be recognised until a significant period and once it is recognised, the support may not be available straight away. The irony of the situation for bereaved AWLD in such circumstances is the ending of therapeutic support for expressing grief in their own way that may look as if the AWLD is not benefitting from such support. AWLD then have to follow the procedure of referrals again and the long waiting lists can become an issue, as informed by Erica:

“more recently, I think it’s four to five weeks but it’s going to be massively oversubscribed, too...” (Erica, line 884-885, T11).

Here, Erica highlights the ‘oversubscribed’ support services for adults in the UK focussing on AWLD, caused in part by the UK’s adult social care crisis. This has a detrimental knock-on effect on areas such as care for bereaved AWLD. This is because more of the general public and AWLD are living longer, which increases their complex support needs as well as imposing financial pressure on care providers, whether these are publicly funded by the government or privately through family resources. These needs go unmet because of the cuts

in the financial support to social care services (Forster, 2017). Advocates informed sometimes, if the AWLD was ready for the bereavement support and even when they had been referred, they came up against economic barriers. Because of the closure of support services and changes in staff providing support, they may not be able to receive support, as briefly noted by Erica:

“...with the cuts and things, actually, professionals withdraw very quickly, so when the person is ready for that, there isn’t the professionals involved...” (Erica, lines 909-912, T11).

Personal finances are a major issue for AWLD in the process of accessing support services, leading to a lack of continuity in support, as described by Cathy and Nancy:

“...0800 numbers, people were getting charged and, you know, and sometimes £2.50 to get into town on the bus – you haven’t got £2.50, you either go and do your counselling session or have nothing to eat...”
(Cathy, lines 944-948, T11).

“...People wouldn’t necessarily recognise because the staff might have changed by that point. They might have moved home by that point, you know, so that continuity I think, especially if they can’t say, I’m feeling upset because of this...” (Nancy, lines 427-431, T12).

For bereaved AWLD, ‘continuity’ of care is fundamentally essential, especially when they experience a significant loss/bereavement and have been through multiple losses after that. They may already be finding it difficult to cope and on top of this, if the carers also keep changing, this adds additional loss and

stress. Another barrier discussed was the means of communication, especially language and vocabulary. They also make it difficult for AWLD to access the support because sometimes the services are not specialised in providing support in an appropriate language, as illustrated by Betsy:

“...you’ve always got the language barriers as well. If English isn’t somebody’s first language, then you’ve got all of what’s been discussed plus that, and services just don’t cater for that sort of thing. Well, they don’t cater for people who use braille, sign language, things like that, so people just give up” (Betsy, lines 959-962, T11).

The lack of access to support goes beyond financial or familial restraints but is actually a critical failure to recognise other forms of communication for AWLD, who may also have a hearing/sight disability. Further, the physical needs of AWLD, for example to use public transport independently, put the decision in the hands of others, as explained by Cathy:

“...so many times where people might have a mental health need or a physical health need, which actually means that they cannot jump on a bus and go up to town and walk from one side of town to the other to access that kind of thing” (Cathy, lines 896-899, T11)

Difficulty in accessing support services owing to physical needs are largely affected by funding cuts, whereby a carer may not be able to accompany the AWLD to a support service and they lack the confidence to travel alone because of being over-protected by their family. Another barrier to independent living was criticised by all advocates for creating gaps for bereaved AWLD who

require their needs to be fulfilled. Further, as illustrated by Nancy, moving out of community homes and the familiar environment severs their connection with the world, leading to a lack of awareness:

“...now, because people live independently in the community more so with whoever the agency sends that day or, you know, there is some reliable staff support. And they haven’t necessarily got that network anymore that they probably wouldn’t even know about it” (Nancy, lines 632-635, T12).

Nancy believes that when AWLD live independently, their network of ‘reliable support’ is disconnected. This is true to a large extent because while living independently, the needs of AWLD go unnoticed, given the funding issues and staff shortages. If an AWLD makes the choice of living independently, they need appropriate extra support in doing daily activities in order to make their own decisions.

Barriers for services: These are described by advocates mainly in the context of the advocacy organisations; however, these barriers are discussed as difficulties in the context of other support services too. The main barriers identified were economic, lack of resources, lack of appropriate training and maintaining professional relationships. Advocates are sometimes forced to leave their support midway because a reduction in the funding does not allow them to continue with their support:

“We’ve done all that practical stuff, visited the solicitor, found out what they’re entitled to, got the benefits sorted for them but we can’t support with that anymore...” (Dolly, lines 1480-1481, T11).

Here, the barrier of funding was repeated by Dolly in the context of advocacy services providing support (as it was for AWLD) because they have to work more in a limited amount of time and for the same or lower wages. Also, advocates believe that in order to provide/add any bereavement support, they need appropriate bereavement support training. This was further clarified by Cathy, Betsy and Lucy:

“...there’s a lack of suitable training as well around loss and bereavement. I did some training around this area, a couple of years ago, and it was utter drivel” (Cathy, lines 1350-1351, T11).

“...the professionals aren’t aware of what’s available so if they don’t know what’s available how can you then pass that information onto somebody...” (Betsy, lines 905-907, T11)

“...the knowledge of what is out there, you know, as a sort of a barrier. Because I don’t know what they are looking for, probably” (Lucy, lines 579-581, T12).

As Cathy refers to her bereavement training as ‘utter drivel’, it highlights that there are varying degrees of experience in different services for AWLD and the lack of funding/resources is making it difficult to target who needs what information on bereavement for AWLD. In the event of a lack of training, there is also a lack of knowledge, which could lead to lack of confidence to guide the

AWLD to appropriate support services. Better availability of resources could save their time and increase their expertise in supporting AWLD, as Betsy shared:

“I don’t think there’s enough of accessible information available. You know social workers, I’ve never seen a social worker go out to any assessment with any accessible information so, you know, they’re relying on doing a full assessment, with or without an advocate...” (Betsy, lines 1393-1398,

T11)

Betsy discussed the lack of ‘accessible resources’ for those who support bereaved AWLD (such as social workers) whereas some information prior to assessment could save time and the distress that AWLD go through repeatedly.

In summary, a number of barriers were recognised for both professionals and AWLD in the field of learning disabilities that hinder services from working efficiently and at the same time make access difficult for bereaved AWLD. For AWLD, these barriers constituted mainly the appropriate time to access support, dependency on others, lack of financial support and lack of knowledge of what is available for them to access. For the support services, lack of training and lack of funding were major barriers to providing support. While advocates have discussed the support available and their role in providing support; they also briefly explained that regular supervision and working from an office with other peers to facilitate discussion has been helpful for them in providing support to AWLD in the areas of loss and bereavement.

5.2.4 Theme 4: What could help?

This theme provides information on the perceptions of advocates about what could help bereaved AWLD to cope with loss, based on their experiences of working with them. Good practices to be used in communicating about loss with AWLD include positive perceptions towards learning disabilities and the use of creative activities with a person-centred approach. Additionally, accessible information and following a set routine for AWLD could be helpful in coping with loss.

Theme 4, Subtheme a: Communication

Information related to loss and bereavement must be given using appropriate language and this has been stressed by all the advocates. Dolly's example presented earlier (Theme 2, Subtheme b, from p154), from a bereaved lady who wanted to go to heaven as she was told her mother has gone to heaven:

"...I think you have to be very careful of the language you use with somebody with a learning disability because if you say somebody has passed on or we've lost so and so, well, let's go and find them..." (Dolly, lines 597-599, T11).

The importance of checking the level of understanding of AWLD after giving the difficult/bad news is crucial. After passing on the difficult/bad news, time must be assigned to answer the questions that a bereaved person may have. As illustrated by Lucy in her example of an AWLD who was told that her mother had died, her understanding of what dying actually meant was not checked:

“...at first if somebody says to them, “Mum’s died”, perhaps in some cases it won’t mean much but they may sort of, later, when they realise that perhaps mum hasn’t been to visit or they have not been back to the parents’ house anymore, maybe that has had some sort of effect further down the line...” (Lucy, lines 401-405, T12).

Lucy observed how no change in behaviour after receiving the difficult/bad news can sometimes be misinterpreted as there being no effect of bereavement. However, this could be because that particular AWLD had never heard words such as ‘mum’s died’. Hence, checking AWLD’s comprehension could be beneficial in providing appropriate support. As communication has been previously recognised as a barrier for AWLD, advocates believed that the use of creative approaches in communication to help people understand could be useful, as illustrated by Lucy:

“...suppose if somebody can’t communicate verbally then if there are other ways they do communicate, then I think using those ways people should still be able to try and spend the time with them...if people would benefit from looking at pictures to enable them to point to how they are feeling...”

(Lucy, lines 360-365, T12).

Although ‘verbal communication’ is a barrier to receive and provide support, creative ways of communicating could be used in providing support.

To summarise, open, honest and truthful communication based on a person-centred approach is the best form of support that could help the bereaved AWLD to cope with loss and bereavement in a better way.

Procedures and activities: Advocates believe that more positive perceptions and fewer assumptions are needed about how much AWLD are capable of understanding with regard to loss and bereavement. Proactive approaches can be helpful towards the provision of appropriate support at the right time. Betsy believes it is essential for parents to create opportunities for interaction between AWLD and the world outside their home:

“...people like that have lived with mum and dad and they get to their forties, fifties and something happens to mum, and dad and they have no living skills whatsoever, they don't even know how to make a sandwich, turn the heating on...” (Betsy, lines 1336-1340, T11).

Proactive approaches used by parents in order to equip AWLD with basic skills to live from early stages in life make them less dependent on others, which can help them live independently when they lose their parents. Having a family, or anybody that is trusted by AWLD were suggested as helpful by Lucy:

“...people that they know and trust, they are probably the best people to be helping them [AWLD] prepare for it, really...” (Lucy, lines 611-613, T12).

However, when it comes to post-bereavement experiences, AWLD usually lose their ‘trust’ in people, hence work needs to be done to build trust and establish a good relationship. Once the trust is built, knowledge and training to understand the needs of AWLD and support or signpost accordingly could be beneficial according to Gill; however, Nancy believes that not everyone would

benefit from the same type of support; hence, a person-centred approach is very important:

“People [advocates and in caring roles] lack the confidence...sometimes just having that training or that discussion around it [bereavement], just pointing people a bit in the right direction because again I don’t think any of us would deal with it in exactly the same way...” (Gill, lines 1267-1272, T11).

“...sometimes because it is almost like so, all people with a learning disability need this and then suddenly, oh, this is absolutely inundated because everybody’s got to have counselling. Well, some people don’t need it and some people wouldn’t want it and some people actually wouldn’t know...” (Nancy, lines 885-889, T12).

Although Gill and four other advocates strongly believe that ‘training’ around how and who can support bereaved AWLD is crucial, Nancy’s point was thought-provoking. As not all bereaved AWLD would want/need to access support services outside, sometimes they may just need time and affection and recognition of these basic yet vital needs.

Daily routines have been recommended by all advocates as a good support in coping with loss for AWLD, as it gives them an opportunity to learn from others’ experiences while socialising and supporting others in similar situations. Routines could be followed by visiting day care services or joining some group activities, as described by Lucy:

“...some sort of almost social groups for people going through...sometimes people get comfort...Knowing that they are with people in a similar situation” (Lucy, lines 900-903, T12).

As finding out about a bereavement is something new and a daunting experience for AWLD, socialising with people in ‘similar situations’, as Lucy suggested, could actually make them feel part of society. However, day service visits could be argued as temporary relief if appropriate bereavement work is not carried out with the bereaved AWLD.

To summarise, appropriate training to offer support and knowledge of bereavement and learning disabilities can be useful to support AWLD to cope with grief. However, it is essential that bereaved AWLD are seen with positive perceptions that they will understand and cope with loss if supported with proactive approaches. Daily routines and socialising with other AWLD and the general population could also be beneficial in coping with grief.

Role of advocates: AWLD visiting the advocacy organisation are not referred to them for loss or bereavement; they are primarily referred to advocacy organisations for issues related to mental health. Sometimes, bereavement leading to mental health issues or vice versa brings AWLD to the advocacy organisation, as illustrated by Erica. Although AWLD could self-refer to advocacy, most of the referrals were made by professionals., as demonstrated by Erica and Nancy:

“...bereavement can bring people into our service specifically as well with mental health. You’ve got somebody who suffers a bereavement and then

can't deal with things, maybe they've got a mental health issue that prevents them from dealing with things..." (Erica, lines 225-227, T11).

"...a few people...they've made their own referral to say, "This has happened, I don't know what to do, can you help me at all?" Because they've got no one else they've been able to contact..." (Nancy, lines 371-374, T11).

Regardless of who makes the referral and the reason for referral, it was reported that more issues needing to be addressed unfolded in addition to the ones related to loss, as illustrated by Erica and Cathy:

"...quite often what the referral says isn't what the person actually wants to talk about anyway" (Erica, lines 995-998, T11).

"...most people will talk about the loss very quickly and very openly"
(Cathy, lines 307-308, T11).

Erica and Cathy described the different communication styles used by AWLD who are referred for different issues to an advocacy organisation. Loss and bereavement have been noticed as surfacing, even if the person was referred for some other reason, reflecting that AWLD would talk about these issues, provided they have someone to listen to them.

5.2.5: Conclusion

In summary, loss and bereavement in the context of AWLD should not be perceived as taboo and there is a need for proactive and creative

approaches to design appropriate and fit-for-purpose communication for grieving AWLD. Everyone working in the field of learning disabilities (family carers, professional carers, social workers and advocates) needs to use a person-centred approach with discussions among themselves and plan support strategies in advance. Although the advocacy organisation does not specialise in bereavement support, nonetheless advocates work around bereavement issues. This is because loss and bereavement are complex issues and surface in different forms, which could reflect the unmet needs faced by AWLD that need consideration. The advocacy organisation was found to be a platform to engage the bereaved AWLD in different activities while providing support through signposting and involving on-site bereavement experts.

This section has presented the results from focus groups with advocates. The results from professional carers are now presented in the next section (5.3, p247).

5.3 Introduction of findings from professional carers

“...she had lost her father, and she wasn’t told about it, about the funeral. She knew that he had died but she wasn’t allowed to go to the funeral. It really, really distressed her, so much so that every day, a fortnight later, she was dressed in black all the time, waiting to go to the funeral, which she wasn’t allowed to go to...” (Sally, lines 114-118, T14).

Owing to pre-conceived ideas around learning disabilities and sensitive information, AWLD are not usually informed or involved in issues involving loss and bereavement. Sometimes professional carers know but decide not to inform the bereaved person about loss, which may leave the AWLD in despair and confusion.

In this section, results from data collected from professional carers are presented. Although the intention was to collect data from this group of participants using focus groups, owing to time constraints (from the day care service where the professional carers worked) only two participants could participate in discussion at a time. The data collected was less than that from a focus group but more than a single interview and is described as joint interviews in the literature (for more information see chapter 3, p110).

The profiles of the participants involved, and the pseudonyms used for them in this research are provided in Table 5.3.1, p248 offer a flavour to the reader of the job roles of the professional carers discussed in this chapter. Table 5.3.2, p249 presents four main themes and a range of sub-themes produced from the data collected from three joint interviews with six professional carers (n=6).

Views of participant professional carers on other groups of people working around AWLD are shown in different colours in Table 5.3.2 For example, pink text demonstrates the views of professional carers about themselves with regard to AWLD.

Table 5.3.1: Participant's profiles

Participants	Sally	Alice	Trudy	Katie	Penny	Myra
Age range	35-45	35-45	30-40	45-55	30-40	45-55
Talking about	Service users with mild, moderate and severe learning disabilities					
Job role	Professional carer	Professional carer	Professional carer	Professional carer	Professional carer	Professional carer
Job Base	Day care service	Day care service	Day care service	Day care service	Community	Community

Table 5.3.2: Themes from professional carers (n=6) regarding bereaved AWLD

1) Perceptions of losses that *AWLD are exposed	2) Communication related to loss	3) Support	4) Barriers to access/provide support
a) Multiple losses: <ul style="list-style-type: none"> Bereavement (people parents, carers and pets) Multiple moves (respite, separated family/friends) Resources 	a) Difficult/bad news is: <ul style="list-style-type: none"> Not told Information is delayed Cover up the loss Not always truthful 	a) What is available: <ul style="list-style-type: none"> Respite care Support at day care Bereavement organisation 	a) Barriers to access support for AWLD: <ul style="list-style-type: none"> No time given to grieve Physical difficulties Over-protective attitudes Take time to being open to talking
b) Expressions to loss: <ul style="list-style-type: none"> All express loss Delayed expressions Changes in behaviour 	b) How AWLD find about loss: <ul style="list-style-type: none"> From parents/carers Bereavement staff More informed in the community 	b) What helps <ul style="list-style-type: none"> Bereavement counselling Continuity at the day-service Communication Distractions Faith 	b) Barriers for **PC: <ul style="list-style-type: none"> Lack of knowledge/training Guided by family Overprotective attitudes Lack of partnership
	c) Rituals: <ul style="list-style-type: none"> Important Daunting experience Not involved usually Ability of person is important Unacceptable behaviour 	c) Useful procedure: <ul style="list-style-type: none"> Proactive approach Partnership among all Understanding behaviour/knowledge Bridge stigma gap 	
	d) Impact <ul style="list-style-type: none"> Underlying issues Mental health issues Family's grief 		

*AWLD- adults with learning disabilities **PC- professional carers

Red
AWLD

Pink
Professional Carers

Blue
All working with PWLD

Dark Green
Family Carers

Dark grey
Medical services

All themes are now presented and supported with quotes from participants.

5.3.1 Theme 1: Perceptions of losses experienced by AWLD

In this theme, the thoughts and beliefs based on the work professional carers experience at the day service with bereaved AWLD are provided. AWLD use the day care service regardless of the stage of loss they are experiencing, hence it gives the professional carers an opportunity to understand and support their clients across a range of support contexts.

Theme 1, Subtheme a: Multiple losses

Professional carers reported that AWLD face a range of losses including the death of family members, pets, and friends and moving residence (transitional losses). Alice and Penny illustrated such losses as:

“They’ve lost parents, yes. I think that’s, yes, mainly parents” (Alice, line 72, T14).

“Sometimes it’s carers as well...or people are living in residential homes, then it can be other people living, yeah, or the other residents or the service users” (Penny, lines 15-17, T15).

After experiencing a primary loss (such as of parents, carers, other residents of residential homes), as described by Alice and Penny, AWLD are initially moved to respite care. From there, they are usually, sooner or later, moved to other residential places and not back home, leading to multiple losses, as Myra described:

“Lots of people because of circumstances, family circumstances, have to move from within the family and go somewhere else. And then if they are in a residential home now from day service they sort new friends...They can't come to day service anymore because of obviously funding and other things so they go and lose lots of friends” (Myra, lines 51-55, T15).

Professional carers understand that AWLD undergo multiple losses after the death of the main family carer because they are often straight away sent to the temporary accommodation (respite care) and from there to another residence. They might have made new friends in the temporary residence that are also lost. A lack of resources such as funding restrictions adds further to the loss, as AWLD cannot access the same facilities at day care services following the bereavement.

Theme 1, Subtheme b: Expressions to loss

Bereaved AWLD are believed by professional carers to express loss in the same way as someone without a learning disability. However, Trudy and Sally shared that everyone expresses loss uniquely and that it depends on the complexity of the disabilities and the ability of the person to articulate their feelings.

“...if you mention dad or the person that's passed away, you can see from their face, lips will go, eyes will fill up. They understand that they're not there, but they can't convey to you how they are actually feeling” (Trudy, lines 140-142, T13).

“...Confusion, disorientation, their world’s blown up and something’s happened. Much the same as everybody else...The only difference is with non-communicative, it’s really difficult because they can only express with actions...” (Sally, lines 299-304, T14).

AWLD can express loss in their own ways. Trudy shared the emotive language used by bereaved AWLD to signal that they are struggling to express their grief. At other times when there is lack of verbal communication, grief is reflected in uncharacteristic behaviours. Professional carers were quite skilled in recognising the strong feelings displayed by AWLD following a loss, as reflected in Trudy’s comments. It was also highlighted that sometimes the grief reaction comes much later following the loss. Talking about loss (or not talking at all about loss); body language; and behaving totally opposite to what is expected are also commonly used approaches to loss, as illustrated by Trudy:

“the particular young man I’m thinking of came in the day after and said, ‘He’s died. My dad has died’. We were just, Oh, has he died or is he just poorly and in hospital? He was okay about it at the time, but then negative behaviours followed later on that month” (Trudy, lines 154-156, T13).

Sometimes, as explained by Trudy, grief is not expressed straight away and professional carers just assume it from the negative behaviours displayed, which are presumed to be related to bereavement. Trudy and Sally explain negative behaviours and anger are used as appropriate expressions to loss:

“...For some of ours, they haven’t got the ability to show any empathy. We can see from negative behaviours that there’s an underlying issue, and

usually it is attached to the grieving process, but they can't put that over in any way..." (Trudy, lines 283-286, T13).

Trudy here pointed to the differences in expressions of loss by some of the AWLD who have no 'empathy' and their 'negative behaviours' bring up the 'underlying issues' caused by bereavement, whereas Sally and Penny discuss the similarities between AWLD and general population in expressing the loss and grief:

"...We all get upset at funerals, don't we? That's perfectly natural. That anger is a part of the grief as well..." (Sally, lines 165-166, T14).

"...I wouldn't say there is a difference at all whether there is a learning disability or not. Bereavement has an impact on everybody" (Penny, lines 197-198, T15).

Sally compares the similarities in expressions of loss between AWLD and the general population, for example 'we all get upset' and 'perfectly natural'. Additionally, as Penny said, expressions of bereavement have similarities regardless of the abilities of the bereaved person. In such circumstances the responsibility of professional carers is increased because they have to remain alert for any changes in behaviour that could be signs of grief expression

To summarise, some commonly observed grief reactions used by AWLD were anger, frustration, crying, becoming very quiet and feeling disorientated. As the professional carers spend a lot of time with bereaved AWLD, they commented on some unique ways of expressing loss through the behaviours and facial expressions displayed by them. Clearly professional carers have a major role in

the lives of bereaved AWLD to identify and differentiate between the grief reactions and general reactions. This could further be used in planning the support for the bereaved AWLD.

5.3.2 Theme 2: Communication related to loss

This theme introduces the experiences that professional carers have with bereaved AWLD, focussing on their roles of giving individuals with learning disabilities information about a loss. Practices they follow are illustrated by their quotations.

Theme 2, Subtheme a: Truth of difficult news

According to the professional carers, parents/family carers at home usually take the decision regarding the informing of the AWLD about loss and also decide about their involvement in funerals, as they know them best. Katie shared that some of the decisions made by parents are made in the best interest of AWLD. Katie further expands that if AWLD are informed of losses, the information given is minimal; is based on the level of disability; and usually given after a long time:

“...I believe some parents think the less they know, the better for them...”

(Katie, lines 38-39, T13).

“...It depends on the individual, but usually you find that they're not told straightaway either. They're left wondering what's happened or worrying. Then they're told, but very, very little, only that they've passed away...”

(Katie, lines 39-42, T13).

Here, Katie draws attention to how AWLD are left 'wondering' about a loss after the decision is taken by some parents to not tell them about the loss. They may sometimes be informed using a factual statement of someone dying, which could add further distress and be of less benefit than informing them of the death openly and honestly when it occurs. Trudy believed AWLD do not understand the concept of death, but they can sense something is not the same. Such understanding was discussed in the context of the loss of a pet or possessions, as Trudy described:

"...they [AWLD] haven't got that concept of somebody has died or that animal. They'll [families] just buy them another dog, so they [AWLD] don't get to understand. It's only when they live with mum/dad and that carer suddenly isn't there...They [AWLD] don't understand the death concept, if you like, but they understand the fact that suddenly this person isn't coming home anymore" (Trudy, lines 123-130, T13).

Here, Trudy clarifies that even if the losses are not communicated, information is delayed or is covered up, AWLD do figure out that there is something wrong. Leaving bereaved AWLD in such darkness is not healthy but there are reports of this being common practice. Katie also shared how AWLD were often not even informed of possible future losses, such as serious illness in the family. This prevents them from anticipating and preparing for the loss and being part of the normal grieving process. The actual loss then becomes a shocking experience for them.

"...It might not be a sudden thing; sometimes they're not encouraged to go to the hospital, maybe for their own protection or because it's going to

upset them. They know someone is poorly. They're not seeing them and then the next thing they're not there. They're not going through what everybody else would go through, the stages..." (Katie, lines 329-333,

T13).

As Katie highlights, the opportunity to visit an ill family member and say goodbye was sometimes taken away under the pretext of 'their own protection'. AWLD during these events are left with a gap in their understanding where they may see the ill person and then never see that person again.

To summarise, Professional carers shared stories as evidence to discuss how difficult/bad news is hidden/delayed/covered up from bereaved AWLD. They recognise the importance of sharing the difficult news with the bereaved AWLD; however, there was also brief mention of some ethical implications of truth telling as the professional carers sometimes abide by the instructions of parents/families and hide the truth about a death from their service users.

Theme 2, Subtheme b: How AWLD find out about loss

Usually, AWLD find out about their loss at home from parents/family carers. On occasions, the family requests that the professional carers hide the truth about a death:

"...we can be requested not to say anything. Rightly or wrongly, we have to abide by the request of the family" (Katie, lines 64-65 , T13).

Although Katie and Trudy justified hiding the news about a death from bereaved AWLD as something not in their control, there was, however, some conflict surrounding telling the truth because, as professional carers, they are expected

to tell the truth to their service users. Trudy goes to explain that understanding and expressing grief may depend on the way the news of death is given; hence, news should be given carefully and sensitively. Refraining from using the correct words such as 'dead' and its meaning could create confusion for an AWLD, as illustrated in following quotation:

"... 'He's gone to be with Jesus' or, 'He's gone with the angels,' it's put in a very nice, flowery way, it's easier for them to understand and to accept. If it's put in a way of, 'Your dad isn't here anymore and there is no explanation,' they're then left hanging. 'Well, where's dad gone? Why isn't he here?'..." (Trudy, lines 318-322 , T13).

Terminologies used to inform AWLD about a loss are referred to by Trudy, such as "gone to be with Jesus" or "angels", which can be comforting but is not a good practice for those who are not aware of the true meaning of these terminologies. Although using the right words with a full explanation may not sound right at first, they can be helpful in coping. The type of communication that an AWLD would get after a loss was affected by the place of residence, as illustrated by Myra, who works in the community:

"...I work out in the community with more physically and more able people and the people that I work with they do know, they talk about it all the time and they do know, the families keep them informed..." (Myra, lines 104-106, T15).

To summarise, family carers were identified as the main source followed by bereavement staff (occasionally) of information about difficult news for AWLD.

There was an understanding amongst half (n=3) of the participants that AWLD who live in the community are more informed by and involved with their families after bereavement.

Theme 2, Subtheme c: Rituals

Professional carers stated that they are in favour of AWLD attending funerals and some had supported AWLD visiting day care services by accompanying them to funeral services. They also believed that not telling the whole truth about the loss before the funeral could be disturbing and Trudy explains that it is difficult for professional carers to tell AWLD of loss in their short stay in day services:

“...if they aren't part of the whole process, it's very difficult then...they need to know every step of the way. To suddenly just take them into a church or to the crematorium and this is going on and it's a picture of their dad, their mum, etc., on that coffin could be, I feel, quite a daunting experience for them” (Trudy, lines 95-101, T13).

Trudy talks about how bereavement turns into a ‘daunting experience’ for AWLD and such feelings can be controlled to some extent by involving people straight after loss, in the same way that other family members might have been involved. Though there were mixed views of AWLD participating in funeral rituals, it appears that some service users had attended whereas others did not. Changes in behaviours were discussed in the context of AWLD with complex needs, such changes that reflect the AWLD’s understanding and the difficulties they might be experiencing in coping with the loss:

“... [people with] complex needs are not always involved...lady who has lost a parent and she didn't go but she is non-vocal...she was always a happy girl...now constantly crying so you know she knew so it's more difficult on the other side...” (Penny, lines 122-126, T15).

As Penny shared, AWLD with more complex needs (such as mobility issues and reliance on others to satisfy basic needs of feeding and using the toilet) are not normally involved in any rituals, even if they are aware of the loss. This is understandable to some extent for those parents who may not be able to grieve and care; however, this could be tackled by having some professional carers on the particular day of attending a funeral, for example. Trudy and Penny recognised and contradicted that AWLD are sometimes not involved in death-related talks owing to their limited cognition and their level of understanding:

“...Quite often for some of ours, they have got a very, very high level of understanding. I don't think sometimes they're given credit for that level of understanding” (Trudy, lines 324-326, T13).

“Even though they complex, and they got no voice, they still understand”
(Penny, line 382 , T15).

‘Having no voice’ should not be a criterion to presume the understanding AWLD may possess about loss and bereavement. The involvement in loss and bereavement must be based on the ability and levels of understanding and not based on the lack of ability such as verbal communication, which was also pointed out by Trudy and Penny. Sally further shared that sometimes the level of understanding is reflected clearly in the behaviours and actions of the

bereaved AWLD but may not be recognised by the family/professionals because of a lack of knowledge on the expressions of loss. She provides an example of a lady whose father died, and she was not informed:

“...she had lost her father, and she wasn’t told about it, about the funeral. She knew that he had died but she wasn’t allowed to go to the funeral. It really, really distressed her, so much so that every day, a fortnight later, she was dressed in black all the time, waiting to go to the funeral which she wasn’t allowed to go to...” (Sally, lines 114-118, T14).

If the news of death is not formally conveyed to the AWLD, as discussed by Sally, it should not be assumed that the bereaved doesn’t know because others’ behavioural changes could be observed by AWLD and they could guess there is something wrong and may become uneasy. The best practice in such circumstances would be to inform and involve the AWLD in everything related to bereavement; however, this was not the case with the woman to whom Sally referred. Although the examples were mainly shared by professional carers where the bereaved AWLD were not informed of loss and bereavement, they were all were in favour of involving AWLD in information about death and rituals, which, in their experience, does not happen owing to preconceived ideas about disabilities rather than abilities, or the individual’s understanding. Attending a funeral is seen as a difficulty for AWLD for many reasons, including cognition levels (when one cannot decide) and the potential for challenging behaviours, as Alice explained:

“It’s more difficult with learning ‘dis’ than others, because some people can’t make those decisions for themselves...those decisions are taken

away, even if you had an advocate, there's just no way that that person is going to be exposed to a funeral” (Alice, lines 197-203, T14).

“...Sometimes they are taken away from that situation because it might bring behaviours [challenging]. No, they can't go there because of behaviours, or it might increase behaviours if they did go...” (Alice, lines 144-146, T14).

Although advocates are believed to provide information and support during decision making by providing details about the impact of any decision, professional carers added that it may not be the same for AWLD. Assumptions regarding AWLD in the form of the potential for challenging behaviours were reflected in the professional carers' data. Without any empirical knowledge, people do make sweeping assumptions that AWLD generally do not understand or react to death owing to limited cognition levels.

Theme 2, Subtheme d: Impact of loss and limited communication

Professional carers reported that the impact of withholding information about loss is equally distressing as the loss and could leave AWLD in confusion and fear. Bereaved AWLD cannot be protected from loss forever, thus the information related to loss and bereavement must be given to them. Professional carers believed information was not given owing to over-protective behaviours of family carers, which can make the coping even harder, as it will start only after they are informed of death. AWLD could face mental health issues when not involved in bereavement properly. As illustrated by Katie and Sally:

“...it creates confusion for the person because obviously something has happened, that person isn't there anymore. The other parent, if they're still there, is grieving, so they're upset...It just becomes confusing and they get quite distressed about it” (Katie, lines 50-55, T13).

“...somebody doing that to protect them, but in the end, it doesn't give closure because they can't move on. A funeral generally is a time where people will actually say farewell and move on in their lives. She was stuck in this mode for quite a while, for years...” (Sally, lines 118-122, T14).

In summary, AWLD are not automatically informed of loss or involved in funerals. If the bad news is given, then information is either delayed, disguised or incomplete. Preconceived ideas play a major role in the decision to withhold difficult/bad news from AWLD and this has a long-term impact on their coping with loss. Owing to their non-involvement in loss and funeral, there is no opportunity for AWLD to begin a normal grieving process, such as that illustrated by Kübler-Ross and Kessler (2014).

5.3.3 Theme 3: Support for bereaved AWLD

This theme explains what type of support is available in the local area and evidence of activities that have been useful in supporting AWLD to cope after loss. Certain procedures to follow that can be useful in supporting them, followed by other suggestions on who can help, are presented.

Theme 3, Subtheme a: What is available

Respite care and the day care service were discussed as the solutions after bereavement in the lives of AWLD. One bereavement organisation was

available and there was provision for bereaved adults attending the day care service to access support from this organisation with the support from the families:

“Usually that’s after consultation with the carer or the parent to say, ‘Would you agree to refer them to a bereavement organisation?’ Then [local bereavement service] would come in...” (Katie, lines 113-115, T13)

“If we feel that they need the [local bereavement] service, for example, we would then put a referral in... If we feel that that is going to be beneficial for them, we would refer them on” (Trudy, lines 106-111, T13).

Katie and Trudy discussed the opportunity for bereaved AWLD to be referred to a bereavement support organisation from the day care service. However, the route followed for the referrals was based on ‘if the parents say’, ‘if the professional carers feel the need’ and only then would the referrals be granted. Involvement of bereaved AWLD needs to be a greater focus of the referrals before any decisions are made. Respite care was another available support discussed by the professional carers. It could mean the loss of the familiar home for AWLD; however, professional carers discussed it as a support to those who have no one left at home to look after them. The need to access bereavement support was highlighted; however, it was to be decided by either the high level professional carers or families and not the bereaved person with learning disabilities.

Theme 3, Subtheme b: What helps

The professional carers believed that proactive provision in the day care services to access bereavement support when needed could be useful. In support of the bereavement counselling organisation, participants explained the creative work done by the bereavement counselling staff (e.g. using drawings to work with memories and creating a memory box to express feeling). Bereavement counselling and the creative activities performed during a session were further explained by Myra and Sally:

“...he got very angry, very upset...he went for so many weeks and we have seen a vast difference. And he is able to talk about things now, he doesn't get angry as much...he was pleased, and the family was very pleased with the results as well, so it's not just in him but the impact was beneficial for the rest” (Myra, lines 233-239, T15).

“...they've gone to [local bereavement service] bereavement counselling, and they'd had boxes. They were given boxes to start filling with memories, memory box, that helps. I found that helped a lot, because it would get them to talk about the person” (Sally, lines 135-138, T14).

Although professional carers were not fully aware of the procedures involved in the bereavement counselling services, memory boxes were appreciated as they were seen as an opportunity to ‘talk about the deceased’. Thus, talking using some creative methods could be useful for coping with grief. Followed by the bereavement organisation, the day care service was seen as an important support and participants believe that coming to the day care service, spending

time with friends and talking to staff are all very useful during the period of coping with loss. It was seen as a type of continuity in support in the lives of service users after loss:

“...There's this negativity all around because the only positive they've actually got is coming here every day...” (Trudy, lines 60-61, T13).

“...what they like, stability in their life. Even if that part's gone, they can still come, and they're very much appreciative...” (Sally, lines 267-268, T14).

As discussed by Trudy and Sally, day care service is one of the options that spreads ‘positivity’ and provides ‘stability’ to bereaved AWLD. This is apparently true for those bereaved AWLD who have lost their main carer and are still living in the same house with a lack of appropriate care facilities. Professional carers shared that they sometimes used creative activities such as drawing, painting, music, and photographs to help their service users express their feelings, as expressing grief is part of coping process:

“...certain songs that parents liked and it remind her, so she often asks for that to be played. And it always makes her feel a lot better. Every day we use different things when they come through photographs, music if they can deal with it...” (Penny, lines 81-83, T15).

Like creating a memory box as part of bereavement counselling support, professional carers described the creative elements that they have been using with their service users, including music and photography. Indeed, creativity could increase the inclusion of bereaved AWLD in different activities at the day

care service. However, Myra shared an example where music was not useful, as a reminder that support needs to be person-centred:

“...I have got a lady that I work with and music, as it does with me with my mom, triggers an experience that she gets very upset. [Name] is different because it's comforting so it depends on the individual and person and how they will respond” (Myra, lines 109-112, T15).

The professional carers shared a range of experiences of using creativity at the day care service to help bereaved AWLD cope with grief. This clarifies that everyone in caring roles needs to be mindful of the ‘not one size fits all’ approach, thus support needs must be assessed before planning any activities. For example, music could be a happy reminder of time spent with the deceased and it could also be a reminder of a loss with which an individual might have struggled to cope. A supportive environment to talk about loss at the day care service also helps AWLD in coping with their grief. As Trudy further explains:

“...young man who loves his animals and when one of his birds dies it's as if it's the end of the world for him because, ‘Oh, they've passed away.’ He deals with it quite openly and he will tell you and you'll discuss it. He moves on quite quickly, but for others it's a very, very drawn-out, very long process” (Trudy, lines 178-181, T13).

Trudy provides a comparison of an AWLD who talks “quite openly” about his losing his pet, which helps him to cope with the loss, while others find it difficult to talk about loss and hence overall coping becomes a ‘very drawn-out, very

long process'. Penny, on the same note, shares an example of an AWLD who, unlike the one in the example provided by Trudy, didn't express loss by talking:

"...he has seizures when he sees a dog it's like an instant reminder, which sort of sets him off so then you have to talk about something different and sort of divert his attention" (Penny, lines 34-36, T15).

As bereavement is sometimes expressed in behaviours, one such example shared by Penny was of an AWLD who used to get 'seizures' after seeing a dog that was like a trigger for difficult emotions. In this particular situation, to save the AWLD from getting a seizure, the staff informed the practice of changing the topic from loss (or the dog that he may have seen). Although this practice was found useful by professional carers, it must be recognised here that distractions must not be assumed as a permanent solution in grief work.

To summarise, the use of creativity to help people to express the feelings of loss has been discussed as useful with AWLD in the day care service; however, professional carers did mention that they use person-centred approaches. Although distractions were found useful by professional carers in providing support however, they must not be used as grief work as they may lessen emotional pain for a short time but, to achieve long-term healing, people need to grieve, talk and express in their own ways.

Theme 3, Subtheme c: Useful procedures for AWLD to cope with loss and who can help

In the views of professional carers, the use of proactive approaches by the families and giving time with an empathetic attitude can be useful in preparing people to cope with loss. They also believe that they can be helpful in preparing

AWLD to cope with loss with some form of bereavement support training and require the authority to act with permission from parents. Myra also suggested that preparation should be done before the loss:

“...that could be done way before that time, just prepare so that they are not emotionally involved in the time...” (Myra, lines 285-286, T15).

It can be difficult to explain a loss to an AWLD, especially if it is the first time they will be hearing about it and if it is explained at the time of the death. Hence, some basic information needs to be provided beforehand, primarily because the family would be grieving themselves and it may not be possible for them to focus on AWLD. One way of using proactive approaches by families could involve the professional carers working in some areas at the time of loss when the family is grieving, as suggested by Katie:

“...I think if we give them more information when they're coming here...we could give that support. We can explain what a hospital does. Unless we're asked to, unless we're given that position, if you like, which I think we'd need training for, then we can't do anything” (Katie, lines 337-341, T13).

As Katie discussed, the professional carers, owing to their role with AWLD, could be a good source of primary information about loss and bereavement. However, the families and professional carers need to plan together on this instance to protect the welfare of AWLD. Sally further, suggested the provision of training around bereavement counselling for professional carers as a useful strategy to plan and provide better support:

“...have a bit of bereavement counselling. The stages of it, and so on and so forth, so you can actually see whereabouts they are in their way forward” (Sally, lines 499-501, T14).

Sally pointed to the provision of some training in ‘bereavement counselling’ for professional carers that she believes could be useful in understanding the needs and providing appropriate support. However, it may be more beneficial if instead of doing bereavement counselling, the professional carers are introduced to some counselling skills that they can link to their everyday support activities. This could be more achievable with partnership among families, carers, professionals, community services on the planning of support provided to AWLD after loss and bereavement throughout the grief process. All professional carers believed that there was a need for a suitable plan that everyone follows in their role to overcome the lack of communication between families, carers and professionals. This is further illustrated by Trudy and Myra:

“...if everybody was singing from the same hymn sheet, if you like...This is how we approach it when a parent or carer is hospitalised or, "We know it's terminal and the prognosis is not good," then we all are following the same - we'd all be dealing with it in the same way” (Trudy, lines 364-368, T13).

Here the attention was drawn to the ‘medical services’ not being very open about involving bereaved AWLD in discussions openly, this comes into conflict with what is best for the AWLD. In order to build a partnership in the best interest of AWLD, each group needs to involve AWLD as much as possible when under their care. Further partnerships were in progress, as the day care

service was following the procedure of talking to schools and other community groups to remove the underlying stigma associated with learning disabilities.

In summary, despite there being only one local bereavement support organisation specifically for AWLD in the area, professional carers fill many gaps by providing informal bereavement support and in particular by using creative activities. Appropriate communications about loss, bereavement counselling, adopting a proactive approach and partnership among all groups of people involved with AWLD was recognised as beneficial. A need for bereavement counselling training for professional carers to avoid any harm to AWLD by practising unhelpful procedures was discussed as potentially useful. However, professional carers may accomplish benefits by having knowledge of simple counselling skills rather than training as a counsellor, as it is good practice to not play a role of counsellor as well as the carer. Familiarising communities with the facts about learning disabilities and their need to bridge the gap and help AWLD to live a normal life could also be useful.

5.3.4 Theme 4: Barriers to support

This theme discusses the barriers to AWLD not accessing support and the professionals not being able to provide support. Communication problems and associated physical disabilities, in addition to learning disabilities, were reported by professional carers participating in this research as a major barrier for someone receiving support and for those who provide support.

Barriers for bereaved AWLD to access support included lack of time to grieve, lack of communication, lack of support when needed and over-protective attitudes towards AWLD. The importance of providing adequate time to grieve for anyone who has been through a bereavement was discussed as equally important for AWLD as for people without learning disabilities by Katie:

“...carry on and jolly the person along and encourage them to carry on as the normal activities, which we know for ourselves, we wouldn't want that...We would want that time to express how we're feeling and to have a cry or to sit and do nothing or to not go to the day service that day...”

(Katie, lines 224-227, T13).

No time to grieve after a loss was the main barrier because before AWLD could even understand one loss, it is usually followed by many more. Additionally, when a lack of verbal communication from AWLD is seen as a huge barrier to access support as they are not able to talk about their needs and express their feelings:

“I think it's the verbal communication with some people, with some of our learning 'dis,' because you don't know. There is no meeting of minds...”

(Alice, lines 376-377, T14).

Alice further adds to the commonality running throughout the information gathered from professional carers that a lack of verbal communication leads to 'no meeting of minds'. This reflects a general lack of knowledge among professional carers on providing support to those who cannot verbally

communicate. A lack of bereavement support when it is most needed was another barrier as illustrated by Katie:

“...It takes time for these things. You refer someone and then they have to wait and then time ticks on. It really would be something that, if needed or wanted, to be there straightaway...” (Katie, lines 292-294, T13).

Here, Katie talks about the ‘waiting time’ between a referral and receiving support from the bereavement support services, which usually is long. The waiting period makes the AWLD either less interested or not interested at all in attending the support. According to Trudy, the over-protective behaviour of parents caring for bereaved adults at home are barriers to accessing support:

“It could be the actual other parents or carers. They could feel that they are offering all the support that that person needs. ‘I know that person best. We can deal with it as a family...they can see it as somebody else is coming in, as they’re interfering, or they don’t know this person. They don’t look at it as this person is here to help...” (Trudy, lines 277-282, T13).

A conflict between the professional and family carers is revealed by Trudy on providing support to bereaved AWLD. Sometimes the families see the support sources such as professional carers as an ‘intrusion’ from outsiders. Here the lack of partnership was clearly visible.

To summarise, professional carers believe that AWLD are not given similar time as the general population to cope and if they suffer from physical disabilities or communication problems, then the problems increase even more as they cannot say what they want. This leaves them either being misunderstood or not

understood at all by others. Families' attitudes of protecting their family members from harm from an outsider also sometimes acts as a barrier for AWLD to reach out for help.

Barriers for carers in providing support primarily included lack of knowledge and information to provide bereavement support, which leaves professional carers in a difficult situation, as illustrated by Sally:

"...I would put myself as one of them as well, knew nothing about it till I actually came into learning disability...When I saw Down's syndrome, I wasn't sure how they would behave...They just have the same needs, and wants, and desires as everybody else. It's fear, some of it is as well, because they were always locked up before..." (Sally, lines 435-441, T13).

Sally's personal comment here, and the other discussions, show that although there have been changes, they have been at a slow pace in terms of people's understanding of learning disabilities from the time when AWLD 'were always locked up'. However, there is still more work needed to shift the perceptions of people towards bereavement and learning disabilities. Bereaved AWLD are believed to be more likely to talk about their loss with familiar people this was also seen as a barrier by Penny:

"...some of them will talk, some of them won't, just depends on the individual whether they are comfortable with a new person. Because they won't always talk to everybody they find..." (Penny, lines 76-78, T15).

Here, some type of basic counselling skills that could be helpful in rapport-building could be used to address Penny's issue of having no

training/awareness to make AWLD talk to them. Furthermore, some participants explained the difficulties they face owing to a lack of training to understand people's behaviours too when they are non-vocal.

"...It's very, very difficult to know what the need is if someone isn't displaying behaviours. If they sit in a chair all day, can't move, and they're non-verbal..." (Katie, lines 136-137, T13).

"...always wondering what they're thinking, the people that aren't able to express verbally" (Alice, lines 239-240, T14).

A barrier such as a lack of communication could be slightly easier to address if there is partnership between families and professional carers because the knowledge can then be shared between the two groups. However, partnership was lacking among all groups, as described by Alice in her example of a lady who attended bereavement counselling support:

"...she still said that she was going home to mum and dad, and then she went in herself. Whether she was realising then that dad was no longer at home when she went home, I don't know, but she did go to the funeral. I don't think she understood why or what she was doing there..." (Alice, lines 126-129, T14).

It is clear from Alice's example that there was no formal way for the professional carers to find out about their service users once they were out of the day care service. Clearly if there is no reciprocal communication between family, professional carers and bereavement staff about how useful counselling

is, or whether attending the funeral was helpful, this could leave the professional carers unclear about how to intervene in the future.

To summarise, a lack of understanding of bereavement and AWLD and a lack of knowledge in professional carers about how to understand different behaviours and communicate with those who lack verbal communication were listed as barriers to providing support. However, addressing the main barrier of collaboration among professionals, families, advocates and the bereaved AWLD themselves can be beneficial in providing the support and overcoming some of the other barriers. The expertise from each group and resources can overcome the barriers to reach out for support.

5.3.5 Conclusion

In summary, owing to the stigma attached to learning disabilities, AWLD are often not given time to understand and grieve in their own way. Owing to a range of reasons (such as lack of verbal communication and lack of knowledge of accepted ways of expressing grief) it is sometimes difficult for AWLD to express their grief. This makes it difficult for AWLD to access support when needed, as at that time, their grief may not be recognised. AWLD experience the effects of grieving family members, which sometimes overshadows their own grief. Furthermore, limited knowledge of providing bereavement support and lack of communication and partnerships creates a major barrier for the planning and execution of person-centred support by the professional carers.

Results from data collected during the interviews with family carers are now presented in section 5.4, p276.

5.4 Introduction of findings from family carers

“...when his dad died, he didn't know where he'd gone. He looked for him, he put his slippers tidy, wondering where he was. He couldn't say, where has he gone? So, what he did was, he put his pyjamas on the radiator upstairs, and sat by the radiator, so he'd see his dad when he came to put his pyjamas on...” (Julie, lines 20-24, T16).

In attempts to protect AWLD from the effects of grief, sometimes families underestimate their capacity to mourn and forget their rights to participate in mourning rituals. It is essential that clear information is used with AWLD to inform them of loss and that any reactions afterwards are recognised as potential grief responses. Background information of the participants (with pseudonyms) is useful for understanding their roles in the lives of AWLD (see Table 5.4.1).

Table 5.4.1: Participant's profiles

Participants	Julie	Sara	Monica
Age range	60-70 years	40-50 years	40-50
Person referring to in the discussion	(Son) Steve	(Daughter) Alicia	(Brother) Mark
Level of disability	Mild-moderate	Severe	Mild-Moderate
Losses experienced by the AWLD discussed in interviews	Father Uncle Home Separation from family/carers	Friends Aunt Pet Separation from carers	Grandfather Grandmother Benefits

In this section, results from the interviews with participants in caring roles (n=3) for their family member with learning disabilities at home are presented. Analysis produced three themes and a range of sub-themes (Table no 5.4.2, p278). Views of family carers on other groups of people working around AWLD are shown in different colours in this table (5.4.2, p278) for example, the red text demonstrates views of family carers that are perceived to be coming from AWLD.

Table 5.4.2: Themes from interviews with family carers

1) Perceptions of losses experienced by AWLD	2) Communications related to loss	3) Support
<p>a) Multiple losses</p> <ul style="list-style-type: none"> ○ At home (People/death/pet/move) ● Transition <ul style="list-style-type: none"> ○ Move to respite ○ People moving ○ Routines changed ○ Closing of day care service ○ Changes/shortages in staff ● Loss of financial support 	<p>a) Difficult news: Source of information</p> <ul style="list-style-type: none"> ● Family ● Carers, professionals ● Informed/not informed ● Limited/false information ● Delayed information <p>b) Funeral</p> <ul style="list-style-type: none"> ● Engagement/exclusion ● Choice to attend funeral 	<p>a) Availability</p> <ul style="list-style-type: none"> ● Bereavement support ● Family carers ● Attitude to support <p>Barriers in providing support</p> <ul style="list-style-type: none"> ● Non-verbal *AWLD ● Lack of partnership ● Lack of knowledge <p>Barriers to accessing support</p> <ul style="list-style-type: none"> ● Lack of knowledge ● Dependency on others ● Pre-conceived ideas
<p>b) Reactions to loss</p> <ul style="list-style-type: none"> ● Sad ● Crying ● Challenging behaviours ● No talking 	<p>c) Causes of non-involvement</p> <ul style="list-style-type: none"> ● Lack of verbal communication ● Type of disability ● Over-protective attitude ● Preconceived ideas of society 	<p>b) What could help *AWLD</p> <ul style="list-style-type: none"> ● Support from family ● Proactive approach ● Advocates
<p>c) Expressions of Understanding death</p> <ul style="list-style-type: none"> ● Different ● Detecting of loss 	<p>d) Impact</p> <ul style="list-style-type: none"> ● Withdrawn ● Turn away from their living parent ● Miss the person 	

Key

*AWLD- Adults with learning disabilities

Views of advocates on other groups of people are shown in different colours such as:

Red

PWLD

Dark Green

Family Carers

Blue

All working with PWLD

Purple

Advocates

These themes are now explored individually and supported by quotes from participants.

5.4.1 Theme 1: Perceptions of losses experienced by AWLD

This theme demonstrates the understanding that family carers (n=3) have regarding the losses faced by AWLD. Quotations from participants indicate that the range of losses faced by AWLD were primarily owing to death in the home setting or transitional loss owing to moving of family members or AWLD into respite/care homes. Perceptions of family carers about the responses used by people with learning disabilities to express grief followed by the understanding of loss are also presented. According to all three participants, AWLD experience multiple losses and usually the death of a parent leads to more losses, such as loss of home. Losses reported owing to death involved parents, grandparents, uncles, aunts, friends, relationships and pets.

Theme 1, Subtheme a: Multiple losses

The number and type of losses experienced by AWLD were perceived to grow chronologically as the person aged, in the same way as it does for people without learning disabilities, as indicated by Julie:

“...it isn't always family and relations, because as learning disability people get older, my son is 53, they lose their friends, they lose people that they know...” (Julie, lines 11-13, T16).

A rise in the life expectancy of AWLD has been noticed over the last 70 years (BILD, 2018) and this has had an impact on the number of losses (mainly of

people) they go through, which is also illustrated by Julie. The loss of home as a result of moving into respite care following the death or illness of a parent is recognised as a loss. However, Julie justified how sometimes the need arose owing to family circumstances:

“...When his dad died, I was poorly, so he needed a care home, because he couldn't speak, and if I had one of my blackouts, then he couldn't phone...at the time, the losses he suffered, he lost his home, he lost his mum, he lost his dad, and his brother and his nieces and nephews...”

(Julie, lines 42-46, T16).

Although Julie justified her reason for sending Steve to respite care followed by a care home, it could be argued that these actions were immoral in the light of the multiple losses that a bereaved AWLD goes through after a death. Additional losses that are never recognised or may be perceived as trivial are faced by AWLD and include loss of food preferences; closure of day care services; loss of staff or therapists who stop visiting owing to unexplained reasons. These are all significant multiple losses, as recognised by Julie and Monica:

“...They can't have the food that they love...if they've been to a day care centre, and the day care centre has closed. The amount of friends that they lose there...” (Julie, lines 56-59, T16).

“...if he lost his favourite cap, that would mean a lot to him, where, me, it'd be, 'Oh, it doesn't matter'...” (Monica, lines 143-144, T17).

Each loss is difficult and its experience is unique for AWLD, in the same way as it is for the general population. Sometimes relatives keep the AWLD away from the grieving process, leading to loss of opportunity to grieve with the family. Monica describes the situation where her brother was not able to visit his grandparents' house:

“Grandad didn’t want it at the time. He didn’t want that extra pressure, because he was grieving for his wife...” (Monica, lines 335-336, T17).

Even though it is beneficial for the bereaved AWLD to be with family to grieve, they (AWLD) are sometimes considered an ‘extra pressure’ to deal with on top of the grief experienced by bereaved family members and thus they are prevented from visiting their family. Loss of financial support for AWLD was another issue discussed by the family carers, as lack of resources led to additional losses, as shared by Monica:

“...he’s [Mark, brother] going through losing some money from the Independent Living Fund, so that affects him quite a lot. He probably sees that as a loss, because, in turn, it will stop him from doing the things that he likes...” (Monica, lines 129-131, T17).

Clearly family carers recognise that AWLD experience the same type of losses as others; however, on occasions, the multiple losses they are exposed to (such as moving to respite care and then to another residence instead of back home), are somethings that can be controlled and informed by families. One major reason behind some of the losses that could be overcome is a lack of

resources (i.e. a lack of funds to care for AWLD at home; arrangement of transport; and staff to accompany AWLD to counselling appointments).

Theme 1, Subtheme b: Reactions to loss

Reactions to loss noticed and shared by family carers of AWLD varied from sadness, crying, exhibition of challenging behaviours to sometimes no reaction at all. Such reactions were recognised to be dependent on the ability of an AWLD to understand the death and reflect the understanding by talking, as described by Julie where she talks about Steve who has autism and is unable to communicate verbally. The use of sign language to communicate and express the feelings of loss was reported in this case, but Julie was not sufficiently aware of it to judge its effectiveness:

“...he's autistic, so he can hear, but it takes a while for him to process things. This is one of the difficulties we have. He doesn't react straight away...” (Julie, lines 146-148, T16).

Here, Julie talks about Steve's characteristics, informing that he 'takes a while to process things'. However, in the context of bereavement, this is something that could be true for many because everyone reacts in a different way to loss. Differences in reaction to loss were explained by participants when comparing expressions from adults with and without learning disabilities:

“...equally just as there are differences between people that can walk, talk and see and communicate adequately, there are people in different cultures that actually may have a slight disability that still can't express...”

(Sara, lines 516-519, T18).

“...the expression of grief isn't as apparent in somebody with a learning disability as somebody who hasn't” (Monica, lines 617-618, T17).

Although AWLD were believed to react to loss in their own unique way, Monica noted that sometimes there were no visible reactions, as demonstrated by Mark, who had shown his feelings of loss after his grandmother's death but did not react after his grandfather's death:

“...His reaction is nothing. It'd be more like he'd just carry on and get the shopping, what we'd bought. He'd want to show mum the new pair of jeans he'd bought rather than the information sinking in...” (Monica, lines 238-240, T17).

Monica's description of Mark's reaction as 'nothing' is indicative of how in circumstances when loss is not demonstrated by a typical grief reaction, it can be easily ignored. Steve and Alicia, both used their own ways of expressing their feelings through behaviours. Sara noticed differences in Alicia's behaviour on two occasions, once after the death of Sara's sister and the second time when the professional carer temporarily moved. Julie talks about Steve's behaviours in general:

“...I can appreciate her manner and her behaviours change. She behaved differently when I lost my twin sister...” (Sara, lines 32-34, T18).

“...because he doesn't cry, his carers that he's with now perhaps don't pick up that he's upset or sad. The only way you really can see it is when he goes depressed or goes down” (Julie, lines 325-327, T16).

Here, Sara appreciates Alicia's changes in behaviour, but Julie informed of some conflict with professional carers, who she believes do not pick up the different signs of reacting to loss displayed by Steve. Nevertheless, Julie shared that sometimes challenging behaviours were used by AWLD to convey their frustration after loss in some form. However, she did not explain exactly what the challenging behaviour (described on p226) was. Monica believed that AWLD sometimes express loss in front of chosen people:

"...it shows itself in challenging behaviour. They can't cope with how they feel, or, "Where has he gone?" Because even if you tell them that they've died, it's difficult to grasp..." (Julie, lines 721-723, T16).

"...Even though you know how close he was, that emotion was hard for him to probably express. He was given every opportunity, and we'd talk about my nan. The only person he showed any sort of reaction to was my grandad..." (Monica, lines 257-260, T17).

Sometimes assumptions are made about the AWLD who cannot communicate about death effectively. Work is required on the practices to avoid misunderstanding that AWLD are unable to understand loss if there is a lack of a typical grief reaction.

Theme 1, Subtheme c: Expressions of Understanding death

Each family carer explained that their bereaved family member with learning disabilities could understand the loss; however, they were uncertain if they (AWLD) knew that death was permanent. This was owing to them using

ambiguous terms such as 'sad' or 'missing', instead of expressing themselves directly, as Monica illustrates:

"...for instance, that an old episode of something would come on [TV]. He'd [Mark] say, 'Me and Nan used to watch that'..." (Monica, lines 413-414, T17).

Mark may not have used simple terms such as, 'I am sad' but his understanding was reflected to some extent as he mentioned his grandmother in the context of a TV programme. Julie believes that even though she had not given the details of the death of his father to Steve (son), his actions reflected that he understood it and tried to show it in his own actions:

"...when his dad died, he didn't know where he'd gone. He looked for him, he put his slippers tidy, wondering where he was. He couldn't say, 'Where has he gone?' So what he did was, he put his pyjamas on the radiator upstairs, and sat by the radiator, so he'd see his dad when he came to put his pyjamas on..." (Julie, lines 20-24, T16).

The behaviours displayed by Steve clearly demonstrate that he was looking for continuity between his old and new life by going through the familiar routine. Continuity after loss is crucial as it could pause some of the multiple losses and help with coping.

In summary, multiple losses were reported by all the participant family carers in the lives of AWLD at home and after losing their home. Nevertheless, there were other losses reported (such as loss of home-cooked food, loss of belongings) that may not be perceived as that significant for people without

learning disabilities. All participants agreed that AWLD can understand loss, regardless of their disability. However, the expressions are different from the general population. To support bereaved AWLD, appropriate reactions to their understanding and needs are recognised as important by all family carers. However, assumptions were noticed at times where there was a lack of a typical grief reaction.

5.4.2 Theme 2: Communications related to loss

This theme focuses on the views of family carers on communication with AWLD related to loss. Views including breaking difficult/bad news, attending death rituals and reasons for sharing/not-sharing the sensitive information with AWLD are discussed. Furthermore, the impact of loss and the importance of sensitive communications shared/hidden from AWLD are explored and described.

Theme 2, Subtheme a: Source of information

Usually the news of a death with AWLD was perceived to be shared by family, siblings and professional carers. Sara and Monica shared their views on how generally loss was communicated with AWLD; decisions were often made on behalf of AWLD. Monica further explained with an example of where the difficult news of death was deliberately delayed and the AWLD was excluded from involvement with the family:

“There was a lady working here. Her sister phoned up and the dad had passed away, but she wanted the lady with learning disabilities to remain

at work for another four hours and not to tell her” (Monica, lines 531-533, T17).

The decision to either share or not share the difficult/bad news with the AWLD is usually taken because of a lack of communication from AWLD. The information is delayed, as described by Monica, because the families do not consider the AWLD as the same status adults and do not feel that they have the right to participate in the loss and bereavement. The three family carers who participated in this research presented contrasting cases of how they informed their family member AWLD about a loss. Julie had never informed Steve about the death of his father, even five years since the death, and justified her decision as appropriate. As Steve lacks verbal communication, she assumed that Steve could not understand the death of his father because he had stopped using the Makaton sign for asking about his father. The following quotation illustrates the lack of communication from Julie:

“He's never used the Dad sign since...I have said, ‘He's gone and we miss him’, but I haven't explained that he's died and gone. But I have explained that we won't be seeing him anymore...It would be terrible to say, ‘Your dad's died now. He's not coming back.’ That's a bit brutal...” (Julie, lines

287; 539-540 and 530-531, T16).

Julie's quotation is an example of how families/carers try to protect their children by using euphemisms such as 'he's gone'. This could easily be understood as if his father has gone to the office or a place from which he would be coming back. Parents/carers need to be mindful of using the correct language to inform an AWLD of a loss.

Sara explained that language used for talking about loss is not commonly used, so AWLD understand easily that it is about something that is not common. She illustrated her point:

“...she heard the phone so I went and just said, ‘[Alicia] the phone’s just rang and I need to tell you that it was a very sad phone call from [Aunt’s name]. I’ll tell you more about it tomorrow but mummy is really, really sad.’ As I said the word sad I got a tear coming down...” (Sara, lines 325-328, T18).

Sara believed that even though AWLD might not communicate about loss, they still possess an understanding of loss; hence it remains important to practise clear communication. Like Sara, Monica believed that clear communication with AWLD is important and practised the same:

“Even if you think that person doesn’t fully understand, they may just get a snippet. My brother did understand, but even if the person doesn’t understand, they’ve still got a right to know” (Monica, lines 778-780, T17).

Although Sara practised clear communication with Alicia, she still advocated that someone with better knowledge of bereavement counselling and learning disabilities is more suitable to break the difficult/bad news:

“...Breaking bad news I think is a big topic anyway but who delivers that first initial blow sometimes is out of our hands because it happens and that is it...somebody that would say in their own way or even in a trained way because hopefully if they are trained in bereavement counselling and again understand about learning disability that they would express it with a

tentative way that that person could understand” (Sara, lines 461-468, T18).

Sara recognises that support from an expert in bereavement is more beneficial for AWLD, and that expert could even work on the reactions or expressions of grief that families may not be aware of.

To summarise, mixed views regarding informing AWLD about loss were shared by the participants. Two participants were in favour and one against the use of clear communication related to loss; however, all three participants justified giving/not giving the bad news. Assumptions were again visible in the views of one participant who did not inform the AWLD of the death of his father. Clearly, on occasions where they didn't use the word 'dead', carers could keep an AWLD away from the finality of loss forever, hence clear words must be used and explained.

Theme 2, Subtheme b: Funeral

All three participants considered attending the funeral equally useful for AWLD, yet only Sara had involved Alicia in one funeral. However, she later reflected that involving Alicia who has multiple disabilities in a funeral was not a good decision. Julie clearly shared that Steve (her son with learning disabilities) was not involved or informed of the funeral of his father and was kept away until the rituals were over. She assumed that was in the best interest of Steve because he cannot communicate verbally. Both Sara and Julie explained:

“...I felt like I didn't grieve properly because I was too busy caring for her and it was a family member...” (Sara, lines 150-151, T18).

“...when the funeral was over and all the paperwork and whatever was done, he came home [from the respite home where he had spent the time after loss and around the funeral] ...I think that [funeral] would be better for the ones that could speak, to be part of it...” (Julie, lines 81-85, T16).

Sara shares the intense emotional stress and pressures that come with being a bereaved carer of an AWLD; however, in this circumstance, a professional carer could have been a convenient person to support the AWLD while the mother was grieving for her own loss. From Julie’s conversation on attending the funeral, assumptions were clearly made on the basis of ability to communicate verbally. According to Monica, Mark had not attended the funeral but he was later encouraged to attend other rituals such as visiting the grave to help him to cope; however, Julie held the same views about visiting the grave as she had for funerals; namely, that the AWLD would not understand if they could not speak. Monica and Julie further stated on visits to graves:

“...Where her [deceased grandmother] ashes are buried is not far from our house. My mum still goes round there regularly, and he’s [Mark] given the opportunity to go with my mum. He does occasionally - birthdays or Christmas...” (Monica, line 370-373, T17).

“...He wouldn’t have understood what was happening. When we go to his dad’s grave, he doesn’t really understand. This is the difficulty: either he doesn’t know, or he doesn’t want to know...” (Julie, lines 89-91, T16).

Here, both Monica and Julie present very contrasting practices on visiting the graves. It is essential that assumptions regarding the understanding AWLD may

possess are avoided. Owing to a lack of knowledge and some preconceived ideas towards the abilities of AWLD, families sometimes make decisions that may not be in the best interests of AWLD. Support needs for AWLD are increased when the parents/carers are also grieving, as they may not be able to cope with their own grief as well as that of the AWLD family member.

Theme 2, Subtheme c: Reasons for non-involvement

All three participants agreed that sometimes the opportunity to attend the funeral was taken away from the AWLD by other family members of the deceased. This may be because of the stigma attached to learning disabilities and/or the assumptions made by people who fear unacceptable behaviours at the funeral. This is further explained by all three participants:

“...Well, don't do that [involve Steve in funeral], because we [relatives] don't want him [Steve] to see us upset...” (Julie, line 365-366, T16).

“...we [Alicia's parents] would want her [Alicia] to be there [in friend's funeral].” But whether the parents [of deceased friend of Alicia] would want her [Alicia] to be there is another... So, sometimes the decision gets taken away from you...” (Sara, lines 143-145, T18).

“...being in the funeral car with my granddad, hoping that he [Mark] wouldn't perhaps say anything inappropriate that would hurt people's feelings or get people upset...we're obviously more conscious of it, but the family that aren't quite as close. Would they perceive it as being disrespectful?... It would just be part of his [Mark's] learning disability”

(Monica, lines 385-390, T17).

The perceptions of extended families and relatives about learning disabilities and how AWLD may behave during a funeral was a major reason behind their non-involvement in funerals. Ignorance of learning disabilities among the general population was reflected in the discussions with all three participants. Sara and Monica both believed that an informed choice to attend the funerals should be given and Sara further discussed that AWLD may use body language to make an informed decision:

“...She [Alicia] can’t speak, she can’t see, and she can’t walk so we watch her body language as to whether we think we may be making the right decisions on her behalf...if she is okay, rather than take it too far to the limit that we are wrapping her in cotton wool...” (Sara, lines 59-63, T18).

While Sara believes that overprotecting their children or implementing a ‘cotton wool’ policy is not beneficial for anyone, Julie presented practices that were opposite to Sara and Monica’s views. The recommendations for general AWLD were different from what was practiced at home by Julie.

To summarise, communication about loss and funerals with the AWLD was a key point for all the participants, regardless of the level of engagement of their family members. Sometimes the parents and siblings might have wanted to include the AWLD in funerals but were stopped by extended family members. This was owing to the stigma attached to learning disabilities and the assumptions that AWLD could not understand death and rituals; hence, they might not behave appropriately. Additionally, limited verbal communication and physical health needs were among other reasons for not involving AWLD in funeral rituals.

Theme 2, Subtheme d: Impact

Regardless of disabilities, all participants strongly believed that loss affected the bereaved AWLD and the usual signs discussed were the AWLD becoming withdrawn; turning away from family; missing the deceased and emotions being reflected in behaviours. However, the relationship between loss and communication was not recognised by Julie. Her son (Steve) had turned away from her (Julie) since his father's death and she was not sure of the reason but fully appreciated the impact on her son:

"...he [Steve] didn't seem to want anything to do with me...I don't know what the reason was, but he was definitely thinking something, that he didn't want to be around me sometimes. Whether I was a reminder of his dad, or like I say, whether he thinks, If I'm fond of somebody, they disappear..." (Julie, lines 261-268, T16).

Again, owing to the inability of parents/carers to communicate with the bereaved AWLD, sometimes assumptions are made as to what they must be thinking. It is not right to assume that the bereaved does not know about the loss of a significant member of family. Instead, their behaviours should be acknowledged as normal grief reactions. Sara recognised that bereavement is a universal experience and regardless of the level of disabilities, everyone is affected by it. The impact of loss on the life of an AWLD often depended on the relationship with the deceased and this was explained by Monica, who compared the impact on her mother without learning disabilities and brother with learning disabilities in the context of the same loss:

“...My mum still shows signs of grief now over her mum, where Mark [brother with learning disabilities] perhaps doesn't. So, perhaps the length of the process is shorter, and time moves on quicker for the person with learning disabilities” (Monica, line 632-634, T17).

To summarise, all carers believed that bereavement left an impact on everybody but there was lack of information and evidence about whether attending the funeral or giving difficult/bad news appropriately had any impact on AWLD. The impact of loss was believed to stay with everyone for different amounts of time and it was believed to be dependent on each person (AWLD) and his/her relationship with the deceased. However, although some AWLD may not have seen their relative for years, still get upset when they die. This demonstrates that even though attachment is weak, the impact of loss is high because they (AWLD) do not just lose the relative but also the labels attached to them.

5.4.3 Theme 3: Support for bereaved AWLD

In this theme, the knowledge and attitude of the family carers towards support available to AWLD after bereavement are presented. This was supported by the information available on different activities performed by the available support services and family carers. Barriers for carers in providing support and for AWLD to access support are also presented and supported with quotations.

Theme 3, Subtheme a: Support available

All three participants had knowledge of the local bereavement organisation supporting bereaved AWLD; however, their understanding of the actual functioning of the organisation was very limited. Julie and Monica both recognised the importance of the support in the form of bereavement counselling and for Julie in particular, the making of a memory box was engaging:

“...you can have one-to-one counselling or group sessions to talk about how you’re feeling and just explore, really, what you’re going through and how they [staff at bereavement service] can help...” (Monica, lines 503-505, T17).

“...the Bereavement Centre went into see him [Steve]...We did a box with photographs of his records and things, and photographs of his dad, and the things he did with his dad...he [Steve] was totally engrossed in what she [bereavement counsellor] was saying...he [Steve] totally ignored us [Julie and carer] and concentrated on what Bereavement counsellor was saying...” (Julie, lines 69-71 and 176-180, T16).

External support was only accessed by Steve and Julie stated that he found it engaging. However, she didn’t have much knowledge about the support sessions provided. All three family carers discussed the support they provided in different ways to their family member with learning disabilities. Julie and Monica used photos as an integral part of the grieving process and Sara discussed the use of tactile approaches (such as letting Alicia touch/smell the

food before eating, letting her touch and listen to any new carer) for her daughter with multiple disabilities:

“...we put photographs in frames. He [Steve] did that. I've got loads of photographs of him with his dad, and photographs of things we did with his dad...It gave him something to do, and we talked about it as we were doing it” (Julie, lines 506-509, T16).

“...We have ways of showing her [Alicia] what these things all mean. Probably to us in the visual world and to the touch and tactile world but we try to put it through to her so that she understands that this is what is going on...” (Sara, lines 43-46, T18).

Evidence was discussed with regard to the use of creativity and involving AWLD in activities at home. However, it was not clear from Julie if she told Steve that his father is dead while doing the photographs. Sara provided some examples of using different senses with people with complex needs to communicate and make the support process smooth. All the participants had positive attitudes towards the support available outside of the home; however, Monica felt that family support worked well and was open to taking a family member with learning disabilities to external support if needed. Julie believed that sometimes the other people working with the AWLD distracted the bereaved AWLD from loss to cheer them up temporarily, instead of explaining the loss:

“...you [others caring for AWLD] see them [AWLD] a bit down, and you try to cheer them up, don't you? Instead of being able to discuss it, you say,

'Oh, come on, let's have an ice cream', or whatever, to try to cheer them up. From my way of thinking, how I coped with it, you don't want cheering up; you want to live through it...' (Julie, lines 347-350, T16).

Julie's quotation here contradicts, in some ways, the information that she has provided regarding her son elsewhere in the interview. For instance, she didn't tell her son about her father's death, however here she is in conflict with professional carers who might have used other strategies to support the bereaved. She clearly says, 'you want to live through' the loss, however she did not give this opportunity to her son.

To summarise, the support from external services was known to all and appreciated as being suitable for the general population, but not for their own family members for two of the carers. It reflected the uncertainty that family carers have developed regarding the external services. The lack of knowledge about the benefits of bereavement support was noticeable as the continuous bereavement support was considered as a constant reminder of loss and the use of a memory box was the only positive activity shared from bereavement counselling. The decision to access support was down to the family carer and was seen as a last resort.

Barriers for carers to provide support included issues related to limited or no verbal communication because it was difficult to plan and provide support without knowing their real (opposed to perceived) needs. Julie and Sara shared their concern as their children (AWLD) could not talk; hence it was difficult at times to provide them with the support without knowing their needs, as illustrated by Julie:

“...You want to help them, but you can't always, because you don't pick up the signs of the ones that can't speak...” (Julie, lines 108-109, T16).

Julie described that sometimes people in supporting roles do not offer support and are reluctant to talk about bereavement because they thought it was a sad topic. She further discussed that the bereavement support (if provided to the AWLD) the family is not involved before or provided any feedback after the session, which could leave the family with lots of questions about the support sessions. Both examples are discussed by Julie:

“...the lady who takes the class said, ‘I don't think it's a good idea, because it's a very sad issue’. A lot of people [supporting the AWLD] don't want reminding...and say, ‘No, I don't want him [AWLD] upset. I don't want to tell him. I don't want to upset him about this’...” (Julie, lines 827-831, T16).

Here, Julie again contradicts the others, who do not want to talk about loss and bereavement with AWLD while she herself didn't want to upset her son by telling him the news of his father's death. Sara believed that not knowing the functional age of someone with a learning disability also made it difficult to understand the needs and to plan the support accordingly:

“...Am I supposed to be nodding and shaking here. Because, actually, we don't know her mental age, there has never been a diagnosis if we were to say, this is what we think she is...” (Sara, lines 375-377, T18).

To summarise, the primary barriers discussed by the family carers in providing support were: the limited or no verbal communication from AWLD; lack of knowledge of available support and services; and lack of partnership among family carers and bereavement staff. Furthermore, based on one of the carer's interests to find her daughter's mental age, a need for the family carers was reflected to understand that the adult individuals (AWLD) need to be treated as adults and not according to their mental age.

Barriers for AWLD to access the support were identified as the perceptions of family carers that the AWLD may or may not think the same. Monica highlights the mistrust in services offering support:

"...if people with learning disabilities do access the services, are they appropriate for that person?" (Monica, lines 816-817, T17).

Here a lack of knowledge about the support services owing to the lack of collaboration among all those in caring roles was reflected by Monica. AWLD are usually dependent on others to access the support service, thus the lack of resources, a lack of planning, language barrier, different cultures and religions and a lack of rapport discourage AWLD from accessing the support services as described by Sara. Additionally, Julie added that pre-conceived ideas towards AWLD believing that they cannot engage in creative support activities sometimes excludes AWLD from being involved in support, as illustrated:

"...they [bereaved AWLD] have got to be able to get there [support service], which they would either need a support worker or a carer...There

has got to be an initial plan. Language, whether it be they are from another country or culture, religion...” (Sara, lines 473-476, T18).

“...people that do understand, like children going to the park and releasing a balloon, and sending it to their dad...People with a learning disability can't do that sort of thing. Some of them can, let's be honest, but there are quite a lot that can't...” (Julie, lines 636-638, T16).

The absence of a proactive approach, especially for people who have problems with language and insufficient resources to access the support services, puts the AWLD off from accessing the support. Additionally, Julie shared her views based on assumptions that AWLD are usually not capable of engaging with support activities.

To summarise, a lack of knowledge of suitable support, dependency on others and the preconceived ideas about learning disabilities were believed to be the main barriers for AWLD in accessing any bereavement support. To overcome these barriers, a strong need to work on the preconceived ideas towards learning disabilities and clear communication among AWLD and everyone working in the caring roles was identified.

Theme 3, Subtheme b: What could help AWLD

The extended family's contribution has been suggested as important when involving AWLD in bereavement to help them (AWLD) understand the difference between loss owing to death and continuing relationships with other

family members. This was highlighted by Julie, and she further illustrated that family carers know their AWLD and their needs better than anybody, especially when they could not speak, so family carers should be consulted for any decision concerning the support. Monica also shared similar views on the family support compared to outside support. Views from both Julie and Monica emphasising the importance of family support are expressed below:

“...with the people who can't speak, I think it's the carers [family] that you [professionals] have to consult, who know them [AWLD] better...carers that aren't family, they think... 'Oh, they're [AWLD] coping wonderfully' or even, 'They're not bothered'...” (Julie, lines 246-249, T16).

“...For a person with learning disabilities, I think the key to it is family, because they know the person better. Some people might find Bereavement and CAMHS more beneficial, but I think it's that initial response from the family. That person [AWLD] needs to be the centre of that, like any other person in the family” (Monica, lines 519-522, T17).

Although family has been suggested as the best support and they need to be in charge of their AWLD family member's support decisions, interestingly, none of the family carers discussed any example in which a referral was made by family to access bereavement support. While family as the main support source for AWLD was suggested by Julie and Monica, in contrast, this was not suggested as beneficial by Sara. She believes that sometimes external support can be more helpful:

“...as far as we are concerned, with some of her [Alicia’s] grieving experiences, we grieve with her and she feels. We are so connected that sometimes I think that is a dangerous thing but getting the balance right...it [involving someone for external support] would shorten the process of her [Alicia’s] feelings or pain because they are very good at their job and equally their own feelings wouldn’t overflow...” (Sara, lines 171-173 and 440-442, T18).

Some external support for AWLD after a bereavement in a family has been suggested as useful by Sara. This could be provided by professional carers if needed all the time, or the bereavement counsellors could help with some specific therapeutic sessions. People providing external support could also help by providing practical help, such as accompanying an AWLD to a funeral. This was particularly relevant at the time of loss when everyone was coping with their own grief and AWLD could easily be ignored, as further illustrated by Julie:

“...it’s something that should be addressed and discussed before it happens. Because when it does happen, sadly, you don’t always think about a person with a learning disability; you’re suffering the grief yourself...” (Julie, lines 860-862, T16).

Sara supported that adopting a proactive approach was important when she introduced new people to her daughter, which helped her to adapt to changes/losses, as explained:

“...We have encouraged her [Alicia] to be social and encouraged lots of new...We have had to adapt our life to be open with people [therapists,

carers, friends] coming into the home, new people trying to do the right thing by her and we have always been introducing new people..." (Sara, lines 239-243, T18).

Julie and Monica believed that anticipatory losses created opportunities to involve AWLD in the bereavement process as it gave them time to understand, express and ask any questions when someone was terminally ill. However, Julie believed that it was beneficial only if people had good comprehension and communication:

"...if someone is ill for a long time, I think you could talk about it then, and say, 'You know that they'll be going away'...Well, that would apply to someone who understood, obviously, that you could converse with..."

(Julie, lines 758-761, T16).

"...If something comes on telly, then talk about it in that sense. It doesn't always happen, but in my nan's case and my granddad's, there was lots of time to prepare, because my nan had cancer and my granddad was nearly 90...It was that preparing time...Even though it was upsetting for everybody to talk of where it would lead and end sadly, he [Mark] was always involved...", (Monica, lines 644-652, T17).

Julie intimates that even anticipatory losses cannot be understood by those who lack verbal communication; however, this can be argued against because the period of time before a death can be used to find some way of informing the AWLD about potential bereavement. There are experts who work around breaking difficult/bad news that can be useful in preparation for the death and

its aftermath. Media has also been used by Monica with Mark, it can be used as a creative tool to initiate the discussions around loss and bereavement with AWLD. Although advocates, support workers and personal assistants were all recognised by the participants as helpful support groups, primarily family members were considered to be the strongest to cope with their own grief and support their family members with learning disabilities. Monica suggested that involving people advocates could be useful as they could often see things that were overlooked by family and sometimes information shared with them by AWLD could be different from that understood by the family:

“...perhaps they’d [advocacy staff] see things differently than we would, because they’re not going through it at the time...Perhaps this is where an advocate comes in. They [advocates] would perhaps get to know the person. Then, in turn, speak to the services and say, ‘This person needs this, this and this to help them to get through this counselling session’, or whatever” (Monica, lines 699-700 and 882-885, T17).

Families know their AWLD relatives better than anybody; however, involving an advocate or an expert with knowledge of bereavement in AWLD outside the family could offer more useful support while they are experience their own difficult grieving period.

5.4.4 Conclusion

To summarise, lack of verbal communication from AWLD was held responsible by family carers for difficulties around providing support and owing to the same reason, assumptions were made on their understanding of loss and

bereavement. Proactive approaches from the families with the input of professional carers and advocates were considered as valuable support by all family carers. However, there were some contradictory beliefs, in that the families understand their family member with learning disabilities better, hence could support them better. Nevertheless, it could be in the best interest of the families as well as for AWLD to involve a bereavement support expert.

The following chapter 6, discussion, will examine the results from different participant groups in relation to the research questions, findings of the current research and the existing literature.

Chapter Six: Discussion of findings

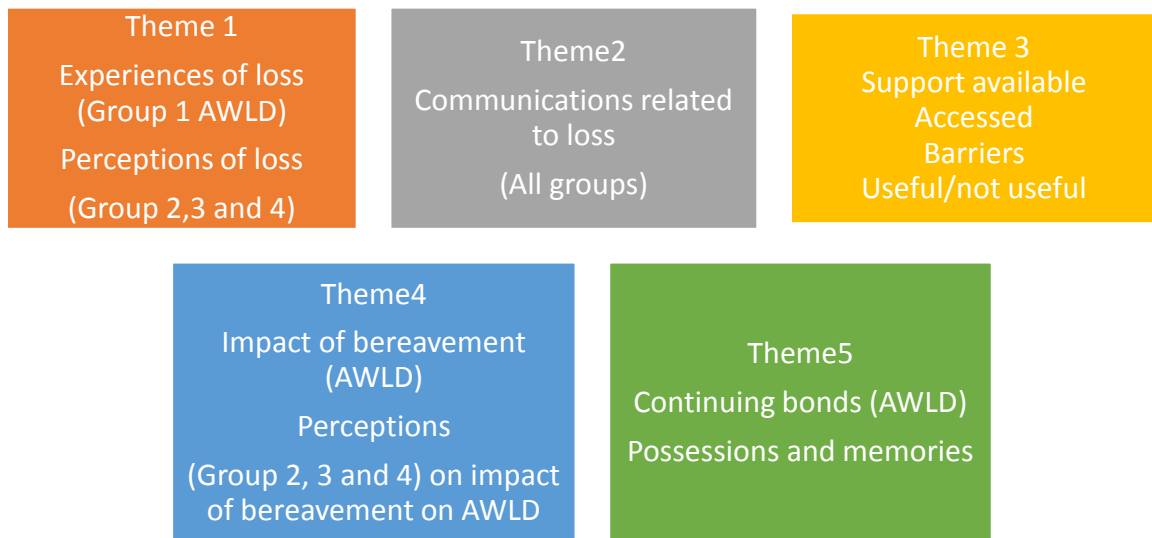
This study investigated the loss and bereavement experiences of AWLD focussing on the tools and interventions used to support bereaved AWLD. The primary focus of this chapter is to critically discuss the findings in relation to what support is available and what works best for AWLD to cope with loss and bereavement based on the opinions of AWLD themselves, advocates, professional carers and family carers. This chapter also discusses the implementation and evaluation of the use of Photovoice as a research tool with bereaved AWLD and the new knowledge generated. To recap, as explained in chapter 3 (p90-111), methods for data collection in this research included: interviews with bereaved AWLD (n=10); focus group and a joint interview with advocates (n=8); joint interviews with professional carers (n=6); and interviews with family carers (n=3). These methods were used to answer the following research questions:

- What types of support are available for AWLD at the time of loss?
- What are the experiences of the range of support received: How often? How long? How do people access the support services? What have been the challenges in accessing the support?
- What is the loss and bereavement profile of AWLD who access support services?
- What is the role of advocates, professional carers and family carers in providing support?

- How are staff, carers and advocates prepared to support AWLD during loss and bereavement?

Findings from the current study suggest that AWLD do experience grief in the same way as the general population. This finding reinforced the fact that AWLD need to know about the loss; however, sensitive and practical methods are needed to inform, involve and support them during this difficult time. The uniqueness of this research study lies in the fact that Photovoice with bereaved AWLD was successfully used in the process of investigating the experience of loss and grief; additionally, it offered the opportunity to compare the viewpoints of AWLD and other participant groups in finding out 'what helps' AWLD to cope after loss. Using this process, information about the experiences of loss was collected and five main themes (Figure 6.1, p308) emerged from the thematic analysis, each of which had a range of sub-themes.

Figure 6.1: Summary of themes



Key

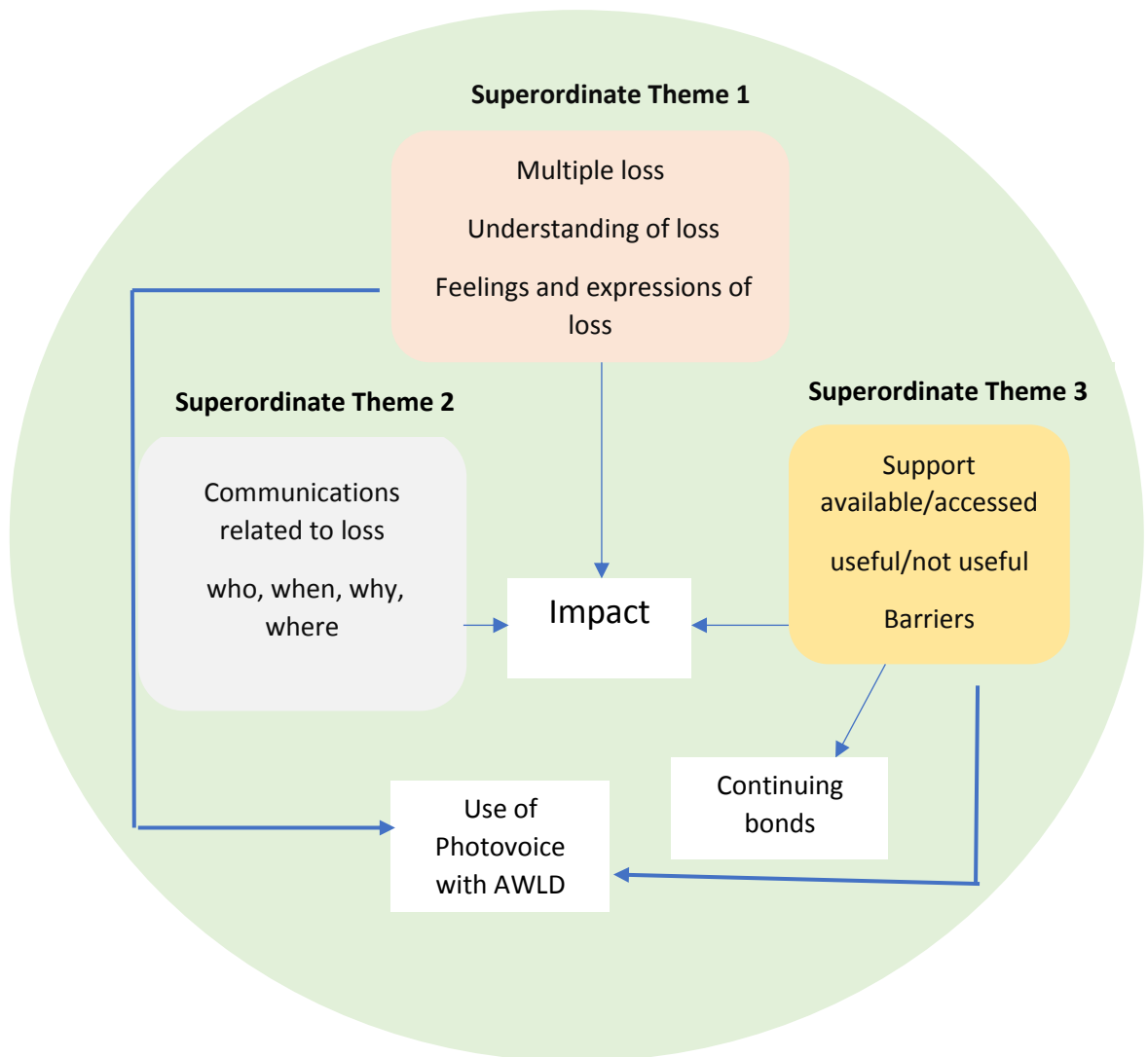
AWLD: Adults with learning disabilities

All groups: Group 1- AWLD, Group 2- Advocates, Group 3- Professional carers, Group 4- Family carers

The experiences of loss and bereavement for AWLD are not found to be significantly different to the experiences of bereaved people without learning disabilities, according to the generic literature. The main differences are among the coping strategies used owing to a lack of appropriate support for AWLD. Based on the results from all participant groups, these differences can be attributed to society's preconceived ideas about learning disabilities that are often still based on out-dated misinformation and prejudices of the past. This chapter discusses changes in attitudes over time and the extent to which practices have changed. After comparing the five main themes from the results from all participants against the research questions, this chapter devotes itself to answering the research questions using these themes. The five themes (see Figure 6.1) are discussed under three superordinate themes: multiple losses

(understanding, feelings and expressions); communications related to the loss (who, when, why and where); and support after loss (available, accessed, useful and not useful). This grouping was carefully chosen in order to discuss the five themes in an integrated and meaningful way. Themes 1, 2, and 3 were the reoccurring key areas; whereas the remaining Themes 4 and 5 consisted of results that appeared most frequently in the analysis of data. For example, the 'impact' that bereavement leaves on AWLD is visible from the multiple losses they go through, followed by the type of communications related to breaking difficult/bad news and the nature of the support they receive. In the same way, while examining the results together, 'continuing bonds' were conceptualised as a type of support and hence discussed under the subordinate theme of support. The outline of how the five initial themes are discussed in three superordinate themes for the purpose of this chapter is illustrated in Figure 6.2, p310.

Figure 6.2 Discussion outline

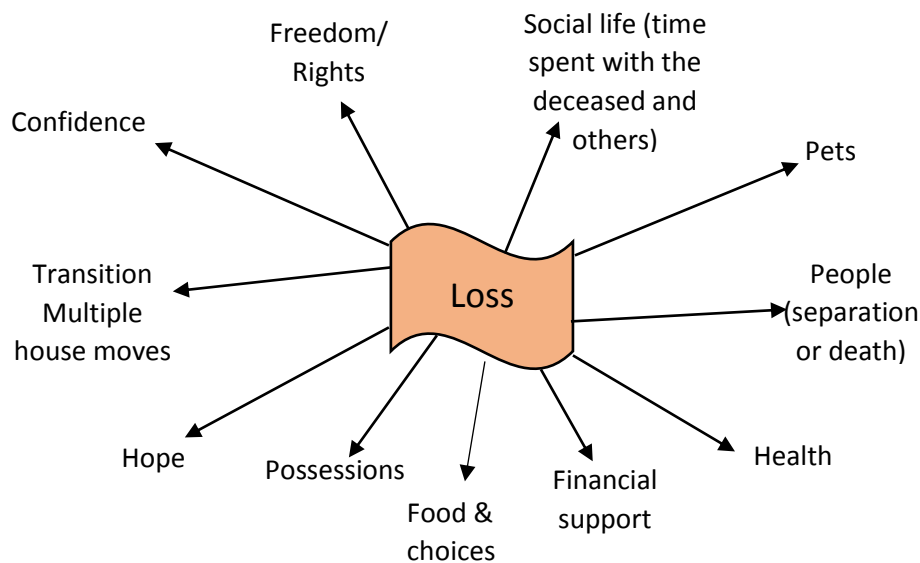


This chapter also discusses the use of Photovoice with bereaved AWLD and how the participant AWLD used it to talk about their experiences of loss. However, owing to the lack of its use with bereaved AWLD in existing literature, its use in previous research with AWLD in general is discussed.

6.1. Multiple losses (understanding, feelings and expressions)

Over the past 70 years, because of medical and social advances, AWLD live longer, experience more fulfilment in relationships and are consequently more affected by death and separation (Hollins and Esterhuyzen, 1997; Emerson and Baines, 2010). It is highlighted in the current research that AWLD are prone to multiple and successive losses, as echoed by Hollins and Esterhuyzen, (1997); Oswin, (1991). Multiple losses refer to grieving for more than one loss at the same time in response to a single loss (also see Encyclopaedia, Grief, Loss, and Bereavement, 2017). In the current research, the most commonly experienced loss that led to further losses was owing to the death of a family member who was also a main carer. Various other losses experienced by AWLD reported by themselves, advocates, professional carers and family carers are shown in Figure 6.3, p312. The findings of this study with regards to types of loss experienced by AWLD are similar to those reported by Kloeppel and Hollins (1989); Read (2001); and MacHale and Carey (2002).

Figure 6.3 Losses experienced by AWLD



The participating AWLD discussed a range of losses; whilst each loss was problematic in some ways, the effects were categorised by the multiple losses following the initial loss. The results were comparable from all the participant groups, which recognised the exposure of AWLD to multiple losses owing to death or separation, yet multiple losses reported by AWLD were fewer than reported by the other groups of participants. This was owing to the lack of information shared with AWLD about loss and bereavement. Based on the information from family carers of AWLD, it was recognised that family carers have fewer accounts of losses faced by their family member AWLD, and this could be because AWLD face multiple losses after they leave or are forced to leave their parents' home and families. For example, if an AWLD is forced to leave the house after the death of their main carer, the siblings and extended

family members may not find out about the multiple losses that person might have gone through owing to limited contact. Family carers were aware of the multiple losses experienced by AWLD; however, when discussing their own family member with learning disabilities, their practices were sometimes different from the views shared. For example, the loss of home followed by a parent's death was described as devastating for any AWLD by a family carer, but her own son could never return back home in the same manner after he (son) was sent to respite care after his father's death (see p280).

Another key loss was the memories that AWLD held for the time spent with their families before the loss, which is similar to those without learning disabilities. There were differences in the quality of life of bereaved people who still had one or both parents alive (after the loss of grandparents); those married or living with a partner are able to manage better compared to those who are living either alone or with siblings after losing one or both parents. Having one or both parents alive helped bereaved AWLD to maintain usual activities to some extent as they had done so before their loss (see p163-164). The difficulties faced by AWLD owing to the death of their main carers are vast because still, the main carer facilitates every activity, maintains contact with the rest of the world, and ensures all decisions are taken in the best interest of the AWLD. This is suggested by participants of this research (advocates and professional carers) in line with Hollins & Sireling (1991). However, following the loss of a main carer, all the decisions are suddenly made by a range of people who may know little about the bereaved person, which adds a significant additional loss of continuity of care. This leaves people in disturbed and lonely situations and such experiences were shared by the AWLD and reported by

other participant groups. Van Dyke (2003, p.38) also presented a similar view that AWLD, "...who lose their only parent, it is not the finality of the loss, but the after effects of poor planning or no planning whatsoever that leave the deepest emotional scars".

For someone without a learning disability, following the death of a family member, life may remain much the same, as similar activities can be continued. But for bereaved AWLD there may be no-one else to support the continuation of the same activities or they may not be sufficiently independent to do those activities themselves. For example, as discussed in chapter 5, p163-166 going on holidays, performing day-to-day activities such as cooking or shopping, playing bingo, or going to the pub had been such important activities for AWLD to do with the deceased person, and they were no longer able to carry out these activities. It is clear from the findings of the current research that death is seen and understood as the ultimate loss; however, it was not necessarily the most significant loss for all the bereaved AWLD. For some participants, the primary loss of an ill parent moving from the family home was more significant than the death of the same parent, and for another, the death of a parent was less noteworthy than the loss of the family home, which followed straight after the death (see p152).

AWLD who are dependent on their family members for care sometimes leave home for the first time only after the death of the main carer and move to respite/residential care. Sometimes the move is the only solution after the loss of the main carer, especially if the death is sudden and the move may be temporary; however, sometimes it is permanent and without adequate preparation or information sharing. Loss of home without the consent of

bereaved AWLD and with little/no time to pack their possessions adds further competing losses. On occasions, this was because of the norms of society that dictate that AWLD do not have the capacity to make such decisions to manage their lives; they may not understand the death; besides becoming more stressed, the opportunity to grieve and cope with family is taken away from them. Examples were debated by advocates and family carers where AWLD had to go through difficult losses owing to bereavement followed by a forced move of residence (see p212). Moving out of the family home was painful for most of the participant AWLD with learning disabilities; however, three participants found such a move helpful in coping with the loss. This was because staying in the same house with the remaining parent was not always helpful and was provoking disturbing visions of the deceased in the AWLD (see p134).

Historically, it was believed that AWLD could not process information related to loss, but this was not apparent in this study (echoed by McRitchie, McKenzie, Quayle, Harlin, and Neumann, 2014). The stigma attached to having a learning disability plays a major role in multiple losses, as AWLD are not believed to have understood many of the losses in their lives (Kloeppel and Hollins, 1989; Harper & Wadsworth 1993; McEvoy, MacHale and Tierney 2012). Understanding loss and bereavement was variable among AWLD, as some AWLD used very clear language and others used unique metaphors such as 'blank canvas', 'erased' and 'empty painting' (see p141). A lack of verbal communication from AWLD was the main reason behind the uncertain perceptions of family carers towards their (AWLD) understanding of loss in this research (see p287-288).

Most of the participating AWLD had a clear understanding and lasting memories of the place and cause of death and the series of incidents that took place at the time of loss of their family members. This was also in line with the existing literature (Read & Elliott, 2007; McEvoy et al., 2012; McRitchie et al., 2014), which concluded that if we give people knowledge and information, they will understand loss, and knowing about loss is important in order to grieve healthily. As reported by advocates and both carer groups, AWLD generally face sudden losses even in situations in which there is time for anticipatory grief, as suggested by O' Nians (1993). However, some of the losses faced by the AWLD group in this study were in fact anticipatory in nature. The literature suggests that traumatic deaths and unexpected deaths such as accidents and suicides often lead to complicated bereavements (Parkes and Weiss, 1983; Gamino, Kenneth, Sewell, Larry and Easterling, 2000). This was well-supported by both advocates and professional carers. However, interestingly, the AWLD who reported losses owing to accidents and suicide did not talk about them in detail, leading to further questions such as whether they knew the meaning of these losses, if they were still struggling to cope, hence they avoided the topic, and if what happened to their family member/friend was explained to them (p154).

All AWLD described the retrospective feelings of loss they had at the time of death, including physical and emotional symptoms; however, some took a while to find the words and share their experiences during the interviews. Regardless of the time since loss, AWLD were able to give words to their feelings of loss, such as 'upsetting', 'annoying', 'violent', 'angry', 'guilty', 'sad', 'crying', 'bad time', 'insecure', 'bitterness', 'twisted', 'broken down', 'unhappy'

and 'the need to talk to someone' (see p149-151). These findings contrasted with the findings of Shuchter and Zisook (1993), where a very low percentage of their study participants could describe their emotions. AWLD spoke about expressing their emotions by crying and venting their anger on others, for example on the hospital staff who might have given them the difficult news (p 161). Some participants also made reference to having an epilepsy attack or falling over after loss, which is somatization of symptoms, as suggested by Mikulincer, Florian and Weller, (1993). These were also reflected by AWLD where they discussed their physical symptoms like pain in knees, dry lips and poor health. Professionals and families working with bereaved AWLD must look for such symptoms and address them before they lead to more serious issues.

The feelings discussed by AWLD in this study are common to the general population and evident in the generic grief literature (Rosenblatt, 1988; Burnett, Middleton, Raphael, & Martinek, 1997; Bonanno and Kaltman 1999; Parkes and Prigerson, 2013). Perceptions of feelings of loss by AWLD described by the advocates and the professional carers also included feelings of shock, helplessness and disbelief in the early stages of bereavement in accordance with the existing literature (e.g. Kubler-Ross, 1969; Sanders, 1999; Worden, 2002). Additionally, the outcomes from advocates, professional carers and family carers are in line with the findings of Shuchter and Zisook (1993) in believing that AWLD cannot express emotions in the form of commonly used expressions. But some additional information from advocates and professional carers suggests that AWLD expressed their emotions of loss in different ways that are unique to every individual, hence they cannot be compared among other populations with/without learning disabilities. Sometimes the expressions

are not what is expected from AWLD and they are perhaps learnt from others (see p216-218). On occasions where no common expression was used to express the feelings of loss, closely monitoring the non-verbal signs, changes in behaviours and body language was found useful by three participant groups (excluding AWLD, see p251-252). Such changes in behaviours can reflect the signs of expressions of grief and it can be useful to address the emotional needs of the grieving person that are often neglected in the absence of visible verbal expressions of grief, as has also been suggested by Arthur (2003).

Family carers faced more problems in understanding the expressions of loss owing to a lack of knowledge about the different ways of communicating in the absence of verbal language. Although it was believed by two family carers that AWLD cannot express their feelings, most of the AWLD in this research shared examples where they understood loss, recognised the feelings expressed sometimes and withheld at other times so as not to cause any sadness to their family members (see p139). It was clearly visible that feelings after loss were similar, but the expressions differed from the general population. This indicates a lack of knowledge in people who work in this area, as there is limited information available about the particular ways in which AWLD express grief.

6.2 Communications related to loss (who, when, why, where)

Usually the news related to loss and bereavement is addressed as 'bad news' (Buckman, 1984); however, it is called 'difficult/bad news' in this research as it is always difficult but may not automatically be bad. Even if someone has a

learning disability, many may remember the difficult/bad news explicitly if it is communicated clearly. Difficult/bad news in this research was mainly delivered by family members, but occasionally by bereavement staff and in a single instance, the vicar from the local church. AWLD shared some striking memories of finding out about the death, including the memories of place, cause of death, source of difficult/bad news, and most importantly how the news was given. Regardless of how AWLD find out about loss, the recollections are powerful, such as Rose remembering clearly that on day of her father's death, she had been to the shops and that there were no eggs in the shopping bags, otherwise they could have been damaged (see p152). AWLD in this research reported the meticulous ways in which they could remember the details of how they were given the difficult/bad news, underlining the importance of giving the difficult/bad news in an appropriate manner (see p155-156).

Following loss, seven participant AWLD had attended the funerals for most of their losses, and two of the AWLD were further involved in organising them. On occasions, participant AWLD had chosen not to attend the funeral; however, they made visits to the cemetery after the funeral if the funeral was not attended. Attending/not attending the funeral was not the only criterion to judge the coping procedure after loss. Lisa had attended the rituals after loss but still, she found it difficult to talk about them, whereas Charles had not attended but was able to discuss it more openly. Thus, conveying that each AWLD is unique and so are their experiences of loss, it is not essential if one person benefitted from attending funeral, then all will. There were stories advising that sometimes the AWLD were not permitted to visit their sick relative;

however, some AWLD had nursed their ill family members before death. Advocates and both carer groups recognised that a period of mourning after loss is vital but for AWLD in this research, the time spent before the death and the incidents around finding out about the death were often more significant than mourning itself. The last words of the deceased, the place they died, how they were told about the death and discovering the death on their own were clearly remembered by most (n=8, 80%) of the AWLD.

Although the majority of AWLD were informed clearly of their losses in the current study, outside of this research, advocates and professional carers considered that it is very common to use euphemisms (James, 1995), withhold or hide the news of death for a long time (sometimes forever) and tell lies, which is in line with Bicknell (1983) and Oswin (1991). This was evident with one family carer who decided not to inform a family member with learning disabilities of his father's loss and used the euphemism 'he's gone' without describing what the term meant (see p287). There were practices discussed by professional carers like using replacements (such as buying them a new pet) in an attempt to cover up the loss and minimise the distress (see p255). Also, it was found that sometimes the word 'dead' was not used while talking to AWLD about death. Such practices can create more difficulties for the AWLD to understand the finality of death and dying. Overall, the participant AWLD in this research formed a group that is rare to find because usually AWLD are not informed of loss or involved in any rituals, as discussed by the advocates and professional carers. This is partly in line with the findings of Raji et al. (2003) with funeral directors, where only a few funeral directors contacted AWLD in the organisation of funeral; however, in the current study, most of the participant

AWLD were part of the funeral of a deceased family member. Getting involved in organising funerals is found to give a sense of empowerment to the bereaved AWLD participants and is useful in coping with loss, which is also suggested by Gamino et al., (2000).

The literature suggests that AWLD are not usually encouraged to say goodbye to the ill/dying relative (Hollins and Esterhuyzen, 1997). Similar information was shared by advocates and professional carers in this research, too, and demonstrated by a family carer, who believed that funerals can be upsetting for AWLD and should be avoided (see p291). However, advocates, professional carers and family carers recognised that not giving people an opportunity to say goodbye reduces the chances of understanding the cause of death, as also suggested by Strachan (1981). It takes away the opportunity for AWLD to grieve with their family and learn from others about coping strategies, in line with McLoughlin (1986) and Hollins and Esterhuyzen (1997); hence, goodbyes should be practiced. Most of the AWLD were also in favour of saying goodbye to their dying family member and some had the opportunity to perform such rituals (see p156-157). Despite the literature available on the importance of rituals in coping with loss, it was reported by advocates and professional carers that most of the AWLD outside of this research are not given the difficult news and are prohibited from attending the funeral and other rituals after death.

The responsibility for informing an AWLD of difficult news remains a controversial issue, as advocates feel that it is not a part of their job and better done by family members. On the other hand, family members believe difficult news should be given by professional carers; and the professional carers believe AWLD need to be prepared by the family members first. This finding

suggests that we have not come very far from what was suggested by Oswin (1991), where she clearly highlighted that in large institutions, everyone argued that giving difficult news to AWLD is someone else's job. The present research extends the knowledge around telling or not telling the news of death and/or funeral attendance as follows:

- **Pre-conceived ideas** that AWLD cannot understand death were found as a key cause of not giving the difficult news to AWLD, based on the perceptions of advocates and professional carers. Although participant AWLD clearly demonstrated their understanding of loss and bereavement it was evident from a family carers's practice and other's assumptions.
- **Stigma associated with learning disabilities** is another cause of not informing and involving AWLD in loss and funerals. Supported by the participant advocates, there are families even in the present day that leave their family member with learning disabilities in a care home at a young age, away from society, owing to the shame of learning disabilities (see p220). When a bereavement takes place in the families of such AWLD, they usually never find out about a loss.
- **Communication by bereaved AWLD** has been discussed as very important and if not carried out well, it could create challenges to bereavement support, as also suggested by Kerr, Fraser and Felce (1996). This was confirmed primarily by the advocates, family carers and also by the professional carers. The amount of information needed must be assessed before giving any difficult/bad news. Lack of an appropriate

verbal repertoire in AWLD to communicate the news of death was a challenge for participant carers in this research (see p291).

- **The participant carers' feelings** of fear, inadequacy and uncertainty (also suggested by Emerson, 1977; Oswin, 1991; and Wiese, 2014) play an important role in not communicating the loss to AWLD. For the successful application of any intervention it is essential that the service providers and the service users share a good relationship, also highlighted as important by Ray, Milne, Beech, Phillips, Richards, Sullivan, Tanner and Lloyd (2015). The relationship among the service user and the carer must be based on truth and trust. Although a registered nurse/carers is obliged to tell the truth to their clients with learning disabilities (DH, 2007), some ethical implications of truth telling were discussed by the professional carers, as they believe they are guided by the families' wishes more than the needs of the bereaved AWLD in telling the truth (see p256).
- **Some practicalities** such as lack of training, shortage of staff to give difficult news, and lack of bereavement expert staff in care homes are some of the reasons for professional carers not informing an AWLD about a loss.

Advocates strongly favoured giving the difficult/bad news to AWLD without any delay; however, a need for professional and family carers to understand the necessity has surfaced. As suggested by Tuffrey-Wijne, (2012, p 16) "Not telling someone about bad news doesn't make the bad news disappear", must be followed by all in caring roles.

The impact of loss and grief is varied and often complex (see Conboy-Hill, 1992; Hollins & Esterhyzen, 1997; Sheldon, 1998; MacHale & Carey, 2002); clearly, the loss has impacted on the AWLD participating in this research in different ways, too. The way difficult news is given can determine the impact of bereavement on the individuals. For the participant AWLD, if the difficult news is given abruptly, hidden or they are not involved in the funeral, they are left in a disturbed state for a long time; this is true for the general population of AWLD outside this research and supported by the participant advocates, professional and family carers. Bereavement can have the worst impact when the difficult news is given abruptly, as reported in the current research by AWLD who faced severe anger, suicidal thoughts, being afraid of their own death, mental health issues, feeling withdrawn, and using alcohol (see p163-170).

However, AWLD who were informed properly have coped well in a way that they have accepted the loss of their loved ones and are sharing happy memories in present times more than the difficulties they might have faced after the loss. Advocates and professional carers believed that communicating clear information about death is vital and phrases such as 'gone to heaven' should not be used; however, this has been suggested as a source of comfort by Shuchter and Zisook (1993). One of the detailed cases discussed by advocates in support of not using these terms was of a lady who wanted to go to heaven to see her mother, as that is what she was told, and she had no concept of what heaven is (see p223). Such examples reflect that not using clear communication when talking about death can have a significant impact on the bereaved AWLD and they must be given all the necessary details. For example, while using 'gone to heaven', the AWLD's understanding of 'heaven' must be

checked or information including the real words, i.e. related to death and dying, must be provided alongside such euphemistic language.

Considering the range of losses experienced and the communications around the loss from different sources, it is clear that loss owing to bereavement leads to multiple losses for AWLD and requires specialist support. Hence, the focus of the remaining discussion will be to explore the support available, the way it is accessed and highlighting the most useful sources of support with brief reference to what was not found useful and barriers to accessing support.

6.3 Support after loss (available, accessed, useful/not useful and barriers)

The positive changes in the recognition of bereavement support needs for bereaved AWLD after the closure of institutional homes and the release of the White Paper (DH, 2001) cannot be overlooked. Additionally, a range of therapeutic interventions (Persaud and Persaud, 1997; Read, 2001; Summers and Witts, 2003) are available, such as bereavement counselling (Read and Bowler 2007), guided mourning (Kitching, 1987), cognitive therapy (Lindsay, Howells and Pitcaithly, 1993), group support (Read, Papakosta-Harvey and Bower, 2004; Clements et al., 2004; Dowling et al., 2006), written resources (Hollins, Sireling, and Webb, 2004; Cathcart 1995), communication resources such as picttalk (Read, Nte, Corcoran and Stephens, 2013). However, a lack of knowledge about what is available locally was noticed in professional carers, family carers and advocates, followed by AWLD. Furthermore, there is a

general lack of evidence regarding what is useful, as highlighted by Oswin (1991).

Interestingly, all participant AWLD provided clear data on what they believed is/is not useful in coping with their loss. From their perspective, AWLD prioritised bereavement support from family members first and foremost, followed by friends; then carers and advocacy organisation staff; and support from bereavement counselling staff was the least preferred option. This is in line with Moreland (2000), who suggested various family relations as the main support source, followed by others in the same order as the findings of this research. However, the source of support that is missing in the current study compared to Moreland (2000) were professionals such as General Practitioners (GPs). Other professional carers in day care services and advocates in the advocacy organisation are reported as being a useful source of support by those who attend these services. A reference is made to respite care as useful support for those who have no carer; however, essentially it is associated with multiple losses and thus not recognised by AWLD.

Therapeutic support outside the home environment was only accessed by about half of the AWLD, even though all of them were aware of bereavement support and it was found useful by three of them. Surprisingly, it did not surface spontaneously in the interviews with the AWLD; sometimes a direct question was required to find out if the participant AWLD had an awareness of bereavement support and to ascertain their views on it. Responses of AWLD on not attending the bereavement support conveyed that two of them believe that bereavement counselling was only for those who are weak and less able to

cope with the bereavement on their own. Attending a bereavement counselling service is not always seen as a positive thing to do by half of the AWLD.

Bereaved people felt comfortable with someone who they think understood their grief and knows their relationship to the deceased (Edelstein, 1984; Walter, 1996). This was true with the participant AWLD in the current research, as most of them had families around at the time of bereavement and support from families worked for them. On two occasions it was highlighted that support coming from a grieving carer and a grieving spouse is more useful. Support coming from a grieving person was more appreciated by AWLD, owing to the belief that one bereaved person can better understand the feelings of another bereaved person (see p182-183). However, this was not true with some AWLD who were not able to share their grief with their family members on occasions and even kept their emotions hidden so as not to disturb the family carer (see p140).

The following list of 'what helped' is based on the information collected from the bereaved AWLD:

- Keeping busy - following a daily routine, activities at day care/advocacy service
- Friendships - talking, spending time together in activities
- Family support - talking, continuing activities as before the death
- Advocacy organisation - talking, being involved in projects to speak up
- Recognition of choices - to attend funeral
- Independence to do things - outside home
- Attending rituals - funeral, visiting grave, going to church
- Support from professional carers
- Bereavement counselling/support
- Support when needed (to go out or to talk)

- Thinking about the deceased

The advocates and carers also perceived routines as useful for the bereaved AWLD in line with the information from AWLD. Routines including going out to day care services and participating in usual activities such as drama and singing were described as a platform by all to provide and receive support from other AWLD experiencing grief. Findings useful for some AWLD to cope with loss such as talking about loss, doing activities like pottery/painting/drawing, spending time alone, going out with family, having a social life, thinking about the deceased at times and then continuing with routines clearly fit with the Dual Process Model of coping with bereavement (Stroebe and Schut's, 1999). This model suggests that healthy grieving means engaging in an active process of oscillating between loss-orientated and restoration-orientated coping. A griever will oscillate between challenging the loss and avoiding the loss.

Although only three of the bereaved AWLD found bereavement counselling a very positive and valuable experience, all advocates, professional and family carers perceived it as useful for AWLD, as proposed by Conboy-Hill, (1992); Read, (2001); Dowling et al., (2003); and Summers and Witts, (2003). Making a memory box, as described by Young and Garrard (2015), as part of the bereavement counselling process was found to be the most useful by all AWLD who accessed bereavement counselling in the current research. In line with Corcoran (2014), the advocacy organisation was highlighted as a beneficial support owing to its person-centred approach in facilitating AWLD to

share their experiences and work on the co-production of resources (see p186-187).

Knowing about the loss and rituals is seen as beneficial by AWLD and supported by advocates, professional carers and two-family carers. Examples discussed by advocates and professional carers clarified how involvement in funerals benefitted some of their clients in the long term, although the behaviours of the AWLD during the rituals were not always acceptable to the families (see p230). Formal education, as suggested by Yanok & Beifus (1993), related to the topics of loss and bereavement has been proven useful in improving the knowledge in AWLD about this area and the resources can be useful to the experts. Proactive approach toward the life course knowledge could also be useful in providing support to cope with bereavement. In order to make sure that bereavement is not dominating the continuous process of human development as also suggested by Lerner and Ryff (1978). Thus, resources can be developed and introduced to AWLD to teach concepts of loss and bereavement with other necessary education resources.

According to advocates, visiting graves is very useful, which is in line with Sheldon (1998); the needs of AWLD to attend the funeral, visit the grave of the deceased or pay their respects to the deceased's memory on the anniversary of their death are essential for the grieving process. Irrespective of the stress it may cause, these needs must be recognised with reference to grieving AWLD. Some AWLD in this research do visit the cemetery and church to remember their deceased; however, generally AWLD may wish to do the same but a lack of support to attend and sometimes not knowing the location of the grave makes it difficult. Some AWLD who attended the funeral explained

the importance of attending with the whole family, as described by Littlewood, (1992), and appreciated the bereavement cards they received (see p162). One of the important features of attending funerals suggested by advocates, professional carers, some family carers and some AWLD was to help to make sense of the loss, as also suggested by Dursten (1998). AWLD in the current research wanted to attend the funerals and visit the church to remember (see p156-160) the deceased and possibly share their grief.

All the participant AWLD communicated about the deceased mainly by using photographs; some shared very personal memories using photos and a few also used possessions and belongings related to the deceased in the photos. This is in line with Klass (1993), who in contrast to traditional grief theories also suggested that the emotional bond with the deceased need not be broken to cope with the loss. The majority of participant AWLD mirrored continuing bonds with their deceased family members that are defined as “the presence of an ongoing inner relationship with the deceased person by the bereaved individual” (Stroebe & Schut, 2005, p. 477). This is evident, as most of the AWLD are still holding the memories of the deceased by reminiscing about the time spent with the deceased, sharing the stories that had taken place before the loss, showing photographs and possessions that are related to the deceased, having similar interests to the deceased, and remembering the significant dates like birthdays, their last holiday together or death anniversary (see also Marwit & Klass, 1996; Foster, Gilmer, Davies, Dietrich, Barrera, Fairclough, Vannatta, and Gerhardt 2011; Bright 1996).

Continuing bonds were also evident in other examples where one AWLD felt that his deceased grandparents are still around (as suggested by Tyson-

Rawson 1996) and he feels good about pretending to talk to them (see p164), a finding similar to the work by Foster et al., (2011) and Silverman & Nickman (1996). However, in another similar situation, an AWLD got upset to the extent that he moved to a new house owing to the perceived presence of his deceased father (see p134). Nightmares about the deceased, as suggested by Silverman & Nickman (1996), praying for the deceased and writing letters were also used as a means of thinking of the deceased and continuing bonds in the current research. These behaviours and feelings, sometimes displayed openly and sometimes subconsciously (such as in dreams), clearly show the similarities in the expressions of loss experiences unique to each individual.

The deceased person is seen as an inspiration with a strong influence in the lives of the AWLD. For example, one AWLD believed that she looks like her deceased father and most others liked the same things as the deceased and did similar activities as their deceased family members used to do (also see Tyson-Rawson, 1996; Russac, Steighner, & Canto, 2002; Foster et al., 2011). In another example, the deceased grandparents were believed to be in heaven in the form of angels by one AWLD and he believed he was seeing them (see p164). The presence of these hallucinations for a period ranging from two to several years of mourning has been suggested by Rees (1971) and Littlewood (1992) and this behaviour is seen as continuing bonds when there are no accompanying serious mental imbalances, as shown in the current research.

Some participants also believed in fulfilling the last wish of the deceased as this gives them a sense of relief (see p203), reflecting the completion of Worden's (2002) task of mourning. Talking about the deceased and the belief that they are around was found to be very comforting, as AWLD felt they were

able to speak to, hear and keep up a relationship with the deceased by using memories related to the deceased. This is in line with the stages of grief provided by Marris (1992) and Worden (2002). The ways in which grief was expressed by AWLD in this research reflects that every individual and their techniques of grieving are unique, regardless of their disabilities. The key findings of the model of grief described in the current research are close to the dual process model (Stroebe and Schut, 1999), continuing bonds (Stroebe & Schut, 2005), and Worden's (2002) tasks of grieving. This is owing to the independence they provide to an individual to grieve in their own way and move between different tasks/oscillations whenever needed.

Proactive approaches can prepare AWLD to cope with loss in a better way to avoid extra stress at the time of loss because it is easy to address if everyone just has to think of their own grief in the immediate aftermath of a bereavement (Bennett, 2003). Life course perspective is necessary to introduce across life while supporting bereaved AWLD whether they behave as younger than actual age. Support should be planned by thinking of the long term and not just short term clinical perspectives because bereavement and loss follow AWLD across the whole continuum. The use of proactive approaches were suggested as beneficial by all advocates and carers and further utilised by a family carer at home in preparation for the potential losses her daughter with learning disabilities may experience (see p296). However, some creative approaches, as suggested by Read, (1999) need adopting and designing according to individual needs.

Information from all participant groups disclosed that the primary need of AWLD after bereavement was not necessarily formal bereavement support but

the opportunity to talk to someone (see p196), a need that is usually ignored (also suggested by Dowling et al., 2006; Read and Carr, 2014). Communication with someone, as described by Read and Carr, (2014), is necessary for advantageous support from any source provided to the bereaved AWLD. Unexpected grief expressions by AWLD were described by Kitching (1987) and similar unexpected expressions in behaviour were reported by advocates and carers, which they usually notice during the practice of looking for behaviour changes (see p251-253).

As informed by the advocates and carer groups, there is a local bereavement support organisation that focusses on bereaved AWLD; however, not all bereaved AWLD attend such a service. The barriers in a bereaved AWLD accessing such a service are highlighted by the participant advocates and carers mainly. Lack of referrals of bereaved AWLD by the professionals to bereavement support services is usually owing to preconceived ideas about the ability of AWLD to understand and benefit from support. The way in which the need for bereavement support (especially bereavement counselling in the context of AWLD in this research) is determined is a huge barrier for AWLD because they are usually referred for bereavement support straight after a loss, when some AWLD may not be ready for it (see p171, 235, 272-273). On these occasions AWLD may refuse the bereavement support and want to stay with the family; however, if the bereavement support is refused or not attended in the first place, then it can be difficult to get a referral again when it is needed. For example, one AWLD who was referred to bereavement support straight after a bereavement did not find it useful, as he displayed severe anger and went on to refuse the support. As suggested by Bright (1996), the support

should be offered based on the needs of the individual. If the referrals are not made at the time support is needed, then the need for support may go unrecognised, which in turn creates unresolved issues for AWLD.

Mobility and speech problems affecting the level of disabilities are two of the main issues that increase the dependency of AWLD on others. It affects the access to support that could be useful for AWLD to cope, such as visits to graves or churches, or access to support services. A lack of resources also acts as a barrier for AWLD to access support services, as well as hindering the ability of support services to work in this field. Lack of resources sometimes leads to discontinuity and low frequency of bereavement counselling, which may lead to a loss of interest and disengagement by the AWLD. For example, when the counsellor kept changing or did not turn up with information, two of the participant AWLD felt disappointed and didn't think the support was of much use (see p197-198). Most of these barriers for AWLD to access bereavement support are interrelated and could be overcome with the help of extensive planning, for example planning the availability of resources may contribute to overcoming the mobility issues by offering accessible transport and staff. Additionally, a person-centred approach to meet the barriers is required and highlighted in the current study in relation to each barrier.

The barriers to bereavement support were not only in front of AWLD, they were also faced by advocates and carer groups (see p237-239, 273-275, 297-299). These participant groups willingly discussed some of their incompetencies in some areas of providing support to the bereaved AWLD. Not knowing the best course of action owing to a lack of verbal communication from the bereaved AWLD about what could be useful to provide support to AWLD to

cope with bereavement is a significant barrier. Whilst advocates are aware of these resources, a general lack of knowledge is observed among carers. Lack of education and specialist training for carers about supporting after loss and bereavement is a barrier to providing support and this echoes research undertaken by Read (1996) and Bennett (2003). Lack of knowledge was clearly reflected in examples where one carer was unaware of the positive effects of an AWLD attending a funeral (see p290), which correlates with findings suggested by Davis, Nolen-Hoeksema, & Larson (1998). Professional carers were sometimes short of confidence to provide support owing to their fear of creating more difficulties for AWLD. Owing to such a lack of awareness, knowledge and confidence among people in caring roles, important coping methods (different from the general population) can be overlooked.

Lack of resources leading to staff shortages, or closure of services, prevents people from offering support as much as possible at the crucial times. Some of the AWLD would like to visit the cemetery on a regular basis after the funeral; however, owing to a lack of resources it is difficult to meet the needs for extra staff. Lack of resources thus affects all in different ways, for example, even if the advocates want to provide extra support sessions by talking to the bereaved AWLD, they cannot do that. This barrier takes away the opportunity to grieve in one's own way or sustain continuing bonds. Advocates additionally see maintaining professional relationships as a barrier and described this further as not being able to support their clients out of working hours, even if it is just signposting them. Professional carers also feel a lack of control in providing support; for instance, if they want to inform the bereaved person of

the loss that has not been communicated, they cannot do so until they have permission from families.

In the current research, the family and professional carers tend to use reactive rather than proactive approaches, which is in line with Crick (1988), suggesting that the carers' emphasis was on dealing with the symptoms rather than the cause of an issue related to the bereavement. This barrier could be worked on by building partnerships among all providing support to bereaved AWLD (see p269-270, 301), as in current research a lack of partnership was clearly evident in the information from participants (advocates, professional and family carers). For example, advocates and professional carers are sometimes not aware of what information has already been given to the AWLD at home and the family carers do not know what activities their family members are involved in during bereavement counselling sessions. It is rare that the care proceedings are discussed among all those responsible for one client, who may be receiving care from different sources (see p302). For example, one individual with learning disabilities living in home with family, attending the day care service and receiving bereavement counselling would benefit if the family, professional carers and the bereavement staff worked in collaboration and not in isolation.

6.4 Use of Photovoice

Photovoice is suggested as a useful alternative method for communication with people with disabilities participating in research (Rojas and Sanahuja, 2011). Photovoice was thus intended to engage AWLD and be used

as a communication tool, but it has ended up as supporting data for the whole research process, specifically in the interviews. Different photos of people who have died, pets, and memories of doing different things were used by participants to back up and create a scene to talk about the deceased. Some AWLD had a concrete understanding of loss, particularly when it means 'death of people', as David illustrated by giving examples of how his grandparents died, where they were and what he does now without them. Photographs helped them to articulate that concrete understanding in words because they could see them and remember more information that sometimes is easy to forget. Another benefit of using Photovoice was that some participants took photographs of old photographs and brought them as well; participants were very focussed on what they wanted to show and tell about the deceased. However, it was sometimes argued by the gatekeepers (family members) that their bereaved family member AWLD might get upset if someone talks about the deceased and taking photographs could make it worse.

Some participants had brought photographs related to their loss; however, when asked, it was difficult for them to explain the link. For example, George had taken photographs of a blossom tree, which was something that his parents had liked, and even though he did not articulate that clearly, this was evident after joining the information and photographs together. Even though the photographs provoked sad memories for the participants, they still wanted to share and talk about them. It was fascinating that even though the photographs were reminders of loss, still most people wanted to share and reflect on the positive role the photographs were playing as a coping mechanism. It was incredible to see when, on some occasions, the photograph

of a person who had given the difficult news was discussed as the person who helped the participant to cope, because the difficult news was given in a thoughtful way. Hence, photographs were a reminder of the memories related to difficult times that sometimes require a prompt in order to have open, thought-provoking discussions.

As all the photographs were mainly taken independently by AWLD (apart from two who required extra support), they provide the viewpoints of participants, as supported by Radley and Taylor (2003). The topic of loss and bereavement can be distressing for anyone; moreover, to talk about it could be even more difficult for AWLD in particular owing to the range of reasons already discussed, such as the way news of death was communicated and multiple losses after a significant bereavement. Telling people to take photographs related to their experiences of loss focusing on what helped was useful. Each participant AWLD had the photographs to support their information about experiences of loss and bereavement retrospectively. Photographs gave the participants an opportunity to go back in time talk about the difficult period and compare it to life after loss, as the researcher was focused on keeping a flexible interview schedule. It was helpful to have all of the photographs around because people could choose what they wanted to talk about and in which order. For example, one participant who became upset while talking about how she was informed of her loss found it useful to move to the next photo and talk about who supported her. Most of the time, the participants kept adding information about different aspects related to the photographs as they went along to answer different questions from the flexible interview schedule.

Photographs taken by AWLD and the detailed stories shared in the interviews reflected their active engagement in the current research. Reading the literature on Photovoice with the general population, it was realised that apart from the quality of some photographs, there was not much difference in the in-depth information produced on a sensitive topic. This reinforced the fact that encouraging bereaved AWLD to take photographs highlights their capacities rather than incapacities, which is in line with Aldridge (2003).

6.5 Conclusion

The current study provides original insight into the experiences of loss and support by AWLD in their own words with photographs as evidence to support what they were saying. Thematic analysis of verbal data and photographs revealed that owing to a range of reasons such as multiple loss, complex communication, or dependency on the deceased, bereaved AWLD have a high tendency to experience disenfranchised grief. The current research is not an exception in showing that bereavement is indeed a traumatic condition for AWLD; however, the process utilised to reach this conclusion is certainly unique.

The findings regarding the support for bereaved AWLD suggest that there is a lack of available support and lack of knowledge as to what is available in the local area. Clearly, professional carers have been influential in providing support but to a greater degree AWLD have felt that families are more supportive, followed by friends, personal assistants (PA), having some form of routine, activities at the day care service and the advocacy organisation followed by bereavement counselling. However, lack of continuity and the

timing of referrals to bereavement counselling is an issue. Productive support could be provided by having: proactive approaches with creative methods incorporated into the everyday life of AWLD; positive attitudes to learning disabilities; working in collaboration with everyone working in the field; and availability of training and resources for all in caring roles to increase their expertise to support bereaved AWLD.

Striking conclusions from the experiences of bereaved AWLD are the ordinariness in the types of loss and the huge range of differences in the support, communications, and other procedures when compared with people without learning disabilities. Most of the differences faced by AWLD in accessing support compared to the general bereaved population were owing to others' thoughts and beliefs about learning disabilities. The participant AWLD of this research were quite able to talk about their experiences retrospectively (owing to their involvement in the advocacy organisation on speaking around loss and bereavement); additionally, the information collected from the other participants provides a picture of a population outside this research who were not supposed to know of their losses or talk about them openly.

The success of using Photovoice in the current research is measurable in terms of outcomes such as all participant AWLD attended the Photovoice workshop, took photographs, sent memory cards back with photographs, and participated in the interviews. The photographs of deceased family members are useful in enhancing the abilities of some of the participants, as they were used as a way to reflect on the past and were a future coping tool to work with the sadness. Photographs are memories, evidence as well as proof of the skill AWLD either already possessed or learnt from participating in the current

research. Overall, the benefit of using Photovoice is not just engaging participants, teaching them skills and collecting data, but also to provide evidence for future research with bereaved AWLD and other vulnerable groups so that it can be used successfully. As suggested by Booth and Booth (1996, p237), photography can bring back the “emotional content of human experience”; the current research also established Photovoice as a beneficial tool when the emotional content is related to a sensitive topic such as loss and bereavement with AWLD.

6.6 Recommendations and areas for future research

The six recommendations that come out of this research are:

1. As it is widely recognised that AWLD understand death and are able to grieve, further studies need to explore the interventions used after a bereavement. Additionally, participatory action research with Photovoice could be used on suitable control groups to draw conclusions on its effectiveness.
2. The lack of life course perspective around the issues of loss and bereavement are evident. Communication around the life course perspective should be more concretely considered in educational practice with children and AWLD.
3. New techniques need to be developed to explore societies' beliefs and attitudes towards learning disabilities and work needs to be done to improve the inclusion of bereaved AWLD in society at the time of loss.

4. A structure of support could be developed for parents and families to access and understand grief reactions that could be useful for them to offer support.
5. A research-based platform is needed for all to work together in caring roles for bereaved AWLD, as the importance of working together surfaced in the viewpoints of advocates as well as the carer groups.
6. An area for further research could also explore the processes of referrals of AWLD to support services, as referrals when needed could make a difference in the support accessed.
7. Research could be conducted to compare support across different cultures by considering different ethnic groups to determine if there are any useful practices.
8. Research is needed that looks for the best ways of signposting carers as well as AWLD to support services, as this was an area where participants experienced significant stress.

Chapter 7: Reflections

Every aspect of this research has generated a mixture of emotions, ranging at times from serenity to thought-provoking, whereas at other times bringing frustration and challenges. To reflect on the selection of this area for my research, on a personal note during my childhood in India, though I was always informed of any bereavement that happened in my extended family, I was never involved in the rituals after a death. This was not a practice just in my home but was a norm that was followed by all: that children, girls specifically, and people with mental illnesses (learning disabilities inclusive) were not involved in such rituals. The topics of bereavement and learning disabilities have always been two areas of interest for me and I studied the basics of both during my Masters in India. I had only minimal training of working with children with learning disabilities during my Masters.

Although I had no experience of working with bereaved AWLD, I strongly believe that my background qualification as a psychotherapeutic counsellor was beneficial from the beginning of this research. As I was not working as a counsellor, I had set clear boundaries for myself to follow. My listening and communication skills and maintaining confidentiality and professional boundaries, which I developed during my previous qualifications, were practiced during this research. Another key skill I learnt during my previous education experience that is essential for any research is to be non-judgemental and this was useful overall during data collection. For example, during the discussions with professional and family carers, in interviews and outside interviews I had the impression that two of the participants (AWLD)

might not participate fully by taking photographs and talking about them. However, a conscious effort was made to not be influenced by such information and data was collected and analysed without premature judgements. While the counselling skills were helpful in conducting different activities during this research, especially during rapport building opportunities and interviews, there were occasions when I had to stop myself from talking about counselling. For example, during the interviews with the participants there were times when they (AWLD and professional/family carers) showed a lack of knowledge about the counselling procedures used for AWLD. I had to make a conscious effort to not influence them with my views in the middle of interviews, however I signposted them after the interviews.

During my qualification as a psychotherapeutic counsellor, I received the chance to learn about the underlying (psychological/emotional) issues and how difficult they can make lives if not dealt with appropriately. During my exploration of the loss and bereavement experiences of AWLD in this research, that knowledge was particularly useful, as most of the participant AWLD were talking about experiences that were not dealt with appropriately at the time of loss. Additionally, during my previous education, I had opportunities to explore my skills and understand my style of working with people during the practice sessions. I realised during these practice sessions that I like to be creative and this was indeed useful as a researcher to use with AWLD.

I began this research by extensively reading relevant literature and attending training modules to provide a solid foundation and knowledge basis around loss and bereavement associated with learning disabilities. This helped me to strengthen my understanding about learning disabilities and loss

experiences in AWLD. During my initial literature searching, I became aware of the fact that there was a lack of empirical research involving bereaved AWLD sharing their own experiences of loss; and the very limited use of Photovoice to engage AWLD in research on sensitive topics such as bereavement. This research was therefore planned to fill the gap by involving bereaved AWLD to find out their experiences of loss with the help of Photovoice. Selecting a research site and recruiting the participants was challenging, as explained in Chapter 3 (p73-75). Another challenge I faced was my fear about “what if AWLD say that they don’t want to talk to me?”. To overcome this fear, I had very constructive and encouraging meetings with my supervisors. I took their suggestions on board, spent time at the research site, attended events such as parliament meetings and shadowed the advocates. This proved to be very helpful for me to gain confidence and to learn how to work with AWLD. Other opportunities to increase my confidence and knowledge to work in the current research field were accomplished by disseminating my research at the University of Keele in general and at an international level at conferences focussing on learning disabilities and mental health.

Extensive preparation and full commitment and the dedication and flexibility to work on the terms of AWLD were a few reasons behind the full participation of AWLD, which in turn led to the successful completion of this project. For example, Jack and Lisa were a married couple; they were allowed to come together to the interview as per their wishes; however, they were interviewed individually. Another important aspect I was attentive to was limiting physical contact in any form, including holding hands, hugging or touching, as it is not recommended in any research method; however, it became unavoidable

at times, for example when the participants started to cry while talking of their deceased family members. This was dealt with thoughtfully, in a professional and compassionate manner, although it was not discussed substantially in the previous research. This matter is also highlighted by Aldridge (2007).

Although I had read the literature on how to conduct interviews with AWLD, I realised while transcribing the initial interview that further skills were required. I did further working out and the following points summarise my learning and reflection on how to conduct interviews with AWLD:

- Sometimes AWLD may say what they feel the researcher wants to hear, hence, it is very important to avoid any misleading expressions.
- Repetition of questions from the researcher and answers by the AWLD could be painful and boring; hence, discussions and dialogues outside the interviews, such as while walking to the research room or while they are chatting to others in the research site, were also noted and not repeated.

The sample size of this research was limited and although it is acceptable for qualitative/exploratory studies, the findings could have been more generalised if the sample was a mix of AWLD coming from different backgrounds, especially those who were not involved with an advocacy organisation given that the connection to the advocacy organisation was in itself a support. Additionally, the sample size of family carers was small, even though very deep information on the experiences of loss was provided by each family carer and information from each family carer was unique and detailed. The

difference in the situations of all three carers contributed very diverse information but it cannot be generalised, as is the case for much qualitative research. For example, it was difficult to compare the findings from one participant who was talking about her daughter who had severe learning disabilities with another participant who was talking of her son, who was very able, and the third family carer, who was talking of her brother from yet another different perspective.

The data analysis (photos and interview transcripts) was another challenge and a lot of experimenting was done to create a template for the data from each participant (AWLD) to present the results in a way that would portray the experiences truthfully, as suggested by Wang & Burris (1997). The process was engaging but consumed a lot of time and restricting the participants to take just 3-5 photos might have helped to analyse data. However, it was assumed that putting a cap might restrict the participants from taking a photo of something more important. To aid rigour and reflexivity during data analysis, one complete transcript (and parts of other transcripts) were coded by me and both supervisors at the same time for other opinions on the appropriateness of data collection and analysis.

To maintain confidentiality and preserve anonymity, steps were taken, as explained in chapter 3 (see p112-115). Confidentiality and anonymity were further maintained when I had to move to a new house and had to hire a temporary office to analyse my data. Although my house move was a planned decision, still it was disrupting, and it gave me an opportunity to think about the experiences of my research participant AWLD who had to move to a new place to live with little notice. It made me think how lifestyles are affected after a loss

or change in life. I carefully chose a medical centre near to my house, which was involved in other research, and reiterated the need to have full privacy and confidentiality for my project. I managed to get a private and personal room and put a sign on the door (Figure 7.1) to restrict any unauthorised entry.

Figure 7.1



Writing the literature review and other chapters in this thesis with the use of academic English was also a challenge for me as I tend to write as I speak. Although English was a compulsory medium of my previous education in India and in England, this PhD thesis is the biggest document I have produced in English. I often found myself behind schedule with my writing; however, with timely support and appropriate training, I have managed to accomplish this stage. The constructive role of my supervisors at different stages of the

research has been extremely beneficial. Both my supervisors routinely offered practical guidance to deal with the challenges that arose at the time of selecting the research site, sampling, data collection, analysis and writing the thesis. In addition, they helped me on a personal level to deal with my worries and anxieties and regularly encouraged me and boosted my confidence.

As bereavement stays with us forever, the ways of coping with it continue, too, and this was demonstrated by the participants who wanted to continue taking photos and bring them in for discussion. While the photos taken by participants added to the valuable data for this research, the Photovoice workshop and the whole process was beneficial for the bereaved AWLD as they learned a skill for life that encouraged them to participate till the end. For example, a quote from Charles describes how learning to use the camera and owning the camera after this research helped him to plan to use his skills in the future too:

“I have got a wedding. I have got a wedding on the 18th July”. “At the hotel so I will be taking photographs of the hotel. Hopefully if I can get it, because I am not invited to the whole day but if I can get down early enough as the bride is driving up to the hotel and coming out of the car”

(Charles, line 1007-1013).

Photographs were like evidence of the experiences of loss and support accessed by AWLD and without this evidence, it would have been difficult to have obtained such in depth and clear information that I obtained from a combination of photos and the interviews (see Rudkin & Davis, 2007). It was

fascinating to see how the order of preference was chosen and described in the form of selection of photographs. For example, Scott discussed photos showing his daily activities and his friends but did not select his mother's photo. It was his decision to share what he felt supported him most to cope. Loss and bereavement is a difficult area for anyone to talk about; it was equally difficult for bereaved AWLD, too; however, participating in this research gave some of the participants an opportunity to release emotions that may or may not have been expressed previously. Although it was not the aim of this research, still some participants found it useful to talk about their loss experiences by taking photographs and using them in the interviews. As shared by Rose:

“taking photos and feeling who supported me and...”, “it helped me get over it more I think” (Rose, line 547-551).

The use of Photovoice in this research reflected a positive attitude and curiosity towards the abilities of bereaved AWLD, the researcher and everyone else involved in the research. All participant groups and people who heard about the current research during formal/informal talks showed their interest in finding out about how AWLD were going to use the camera, what would be the content of the photographs etc. Photovoice with bereaved AWLD followed by interviews allowed for participant-led responses and data from other participants further added in-depth information about each other's' perceptions. After conducting different activities for this research with the AWLD, my theoretical beliefs also became empirically true. This research was a unique experience and I have learnt key research skills that are going to be valuable for my work in this field in the future.

To conclude on the reflections of what I have learned from this research, for AWLD, loss and bereavement is not just an incident that happens once and is forgotten. It is something that stays with them forever and the majority of bereaved AWLD find comfort while talking of their loss experience again and again to someone with good listening skills. The way AWLD participated in this research, the photographs they brought, and the way they discussed them reinforced the fact, to me, that we must not judge people on the basis of their disabilities.

7.1 Strengths of the research

The majority of literature used in the current research was based on case studies, observations and viewpoints of others on the bereavement experiences of AWLD. On rare occasions, research studies that included AWLD were still based on old literature and lacked empirical evidence. In the current study, a thorough procedure for data collection was followed using interviews; training to engage in research activity; photographs; and people's voices, in order to make it as inclusive as possible. The current study has produced empirical evidence through empirical data that gives credence to what people have generally talked about.

A highlight of the current study is that it flourished by collecting the experiences of loss and grief of AWLD by AWLD. They were not the subjects of research, instead they participated in this research by taking the lead to decide what they wanted to share from their experience. The data in the form of photographs and the descriptions all came from AWLD directly; hence, the results were expected to be a fair representation of the experiences of loss by

the group of the participants with as the least prejudice possible from the researcher.

A significant strength of this research was the use of Photovoice as part of the methodology. It engaged the participant AWLD in the research and even after data collection, participants wanted to work on the same theme and take photographs. Information on recollections and memories can easily be forgotten and it may have been challenging for the participants too, to talk about the sad times they experienced after a loss. There was a possibility that participants could have become distressed looking at the photographs of the deceased (if they had any). However, the way in which the whole process of Photovoice followed by the interviews was planned and executed, the photographs worked as reminders of loss experiences, and the extensive support offered by advocates before and after sessions also helped.

This research involved a unique group of research participants including bereaved AWLD; advocates; professional carers; and family carers, such as has not been used before to my knowledge to explore the loss experiences of AWLD. In addition to enhancing the unique methodology suitable for bereaved AWLD, the current research adds valuable empirical evidence to what has been useful for AWLD to cope and what are the perceptions of other people at the same time. It may be useful to plan support in the future based on the different viewpoints from all participant groups. Although the findings cannot be generalised owing to the small sample group, still the photographs and other data add new evidence to the existing literature in this field.

Another strength was the information collected at the end of each interview from the AWLD about their viewpoint on the Photovoice research method. I have not come across any research asking the AWLD about the methodology and their participation in research. Information was collected from AWLD on how they found their participation in this research and although it was not part of any theme in data collection, it still remains a major strength of this study.

7.2 Limitations of the research

Video recording of the interviews with AWLD could have been more useful. Although the body language was noted in the field diary, still at times the silence needed to be recorded with expressions. Owing to time constraints, physical symptoms like tiredness noted in the body language of AWLD and only 3-5 photographs were discussed during each interview. There is a possibility that the remaining photographs contained more valuable information. As explained by Darbyshire, MacDougall and Schiller (2005), Photovoice without the voice is a limitation of using Photovoice in research. Even though the remaining photographs were not used in analysis, they were recorded in a separate photo log table based on the content of the photo (Appendix- S).

Allowing participants (including AWLD) to take photographs during research raises the issue of ethical photography and how the project is further explained by them to others before taking photographs. Although steps were taken, and ethical photography was explained where applicable, still it is likely that it may not have been followed in its entirety. Time restrictions were further realised on checking each transcript carefully against the audio recording as

there were some unanswered questions and some opportunities to ask questions that were missed. Another meeting with some of the participants for checking the data would have been advantageous to cover the missed opportunities for asking questions. This could have been helpful to some participants as well who had missed taking some important photos that helped them to cope with loss, hence, these were missed out completely from the discussion during interviews. Also, there was a possibility of missing out discussing some of the useful sources of support that were not captured in photographs owing to various unknown reasons.

Although it was not intended, the sample of all participant AWLD and the majority of other groups were White British. Owing to my own beliefs and some literature out of context in the current research, I feel that people from different cultures may grieve differently. It would have been interesting to find out how other cultures support the AWLD after loss and bereavement and if there were recommendations for all to practice.

7.3 Next phase

This research makes a unique contribution to knowledge and provides empirical evidence on involving bereaved AWLD in research creatively to talk about the experiences of loss, bereavement and support. Certain areas of this research such as the methodology focussing on the involvement of bereaved AWLD using Photovoice and the results highlighting what is the best form of support according to bereaved AWLD will be published. To feedback the findings to the participants of this research with a focus on the bereaved AWLD, an event will be organised where the photographs will be displayed and a

creative photo token (using the photographs taken by participant AWLD), to say thank you will be presented to each participant with learning disabilities.

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Appendix A: Overview of the literature reviewed

Nos.	Name of the Article	Author and profession	Source	Was there a clear statement of aims	Methodology appropriate?	Ethical issues considered?	Clear statement of findings?	Point of note?
1.	Helping people with mental handicaps cope with bereavement: A case study with discussion	N. Kitching Clinical psychologist	Journal of the British Institute of Mental Handicap (APEX), 1987	Yes, guided mourning can be useful to relieve distress, explore bereavement needs and capacity and right to grieve.	Yes, qualitative: used case study to explain guided mourning	Ethics approval or processed consent not mentioned.	Guided mourning can be very useful sometimes even if the grief is delayed	There are many difficulties in supporting bereaved *AWLD. However, they can be overcome by using common sense principles and human approach.
2.	Bereavement and the person with a mental handicap	J. Kennedy Community nurse	Nursing Standard, 1989	Aim not clear just briefly mentioned that it is about 'bereavement and mentally handicapped'.	Yes, qualitative methods: case study used.	Ethical issues not described.	Different steps suggested for carers to prepare *AWLD for anticipated grief like multidisciplinary approach. Creative methods, knowledge and understating by carers and information	Time out, formalised diary, life book, compare and contrast set is useful for information on how to support bereaved *AWLD.

							easy to access.	
3.	Bereavement and grief in adults with learning disabilities	S. Hollins and A. Esterhuyzen Consultant psychiatrists	The British Journal of Psychiatry, 1997	Yes, to investigate the effects of bereavement and involvement of *AWLD in events related to bereavement.	No, quantitative design: Semi-structured bereavement questionnaire; the Life Events Checklist; ABC and Informant based ****PIMRA. Qualitative methodology would have been more useful for in depth information.	Ethics approval not mentioned.	Yes, aberrant behaviours, psychological morbidity is more in bereaved *AWLD and this has not been recognised by staff.	Effect of loss on *AWLD has been underestimated.
4.	Bereavement and grief in adults with learning disabilities. A follow-up study	E. Bonell-Pascual, S. Huline-Dickens, S. Holiins, A. Esterhuyzen, P. Sedgwick, A. Abdelnor and J. Hubert	The British Journal of Psychiatry, 1999	Aim was to see if increase in aberrant behaviours and psychopathology found in participants of first study had continued 6-8 years after	No, Quantitative methods: **ABC and ****PIMRA used for data collection however some qualitative information	Approval was tried for interviews but not granted. Detailed information not provided.	Yes, aberrant behaviours were slightly increased but there was improvement in psychopathology.	Bereaved *AWLD are more prone to mental health issues and require more emotional support from carers.

		Consultant psychiatrists and clinical professionals		bereavement.	used from bereavement history. Involvement of *AWLD in interviews or focus groups would have been more useful.			
5.	A year in the life of a bereavement counselling and support service for people with learning disabilities	S. Read University academic	Journal of Intellectual Disabilities, 2001	Yes- to introduce, describe and evaluate a bereavement counselling service for *AWLD. Explore challenges and characteristics of such a service.	Yes, action research approach: focus groups used for feedback from counsellors and descriptive statistical data used.	Yes, ethics approval taken, process consent followed	Yes, all aims accomplished in addition to production of a counselling manual	Knowledge of resources in bereavement counsellors is important in providing support to bereaved *AWLD
6.	How far are people with learning disabilities involved in funeral rites?	O. Raji, S. Hollins and A. Drinnan Consultant psychiatrists	British Journal of Learning Disabilities, 2003	Yes- to see how *AWLD involved in funerals	Yes, Qualitative methodology: semi structured interviews used.	Ethics approval not mentioned	Yes, this study also confirmed the exclusion of *AWLD from bereavement related activities like funerals	Designing a pamphlet after this study was a good idea following this research to give information on inclusion of *AWLD in funerals and availability of support at

								the time of loss.
7.	Grief in the shadows: exploring loss and bereavement in people with developmental disabilities	P. T. Clements, G. Focht-New and M. J. Faulkner University academics and health care professionals	Issues in Mental Health Nursing, 2004	Not given in a statement but it is about 3 cases of unique losses and interventions provided to them.	Yes, qualitative methods: case study used	Ethical approval or processed consent not mentioned	Yes, *AWLD do not always grieve immediately. Carers and professional need to monitor the reactions after loss if communication ability is limited in *AWLD.	Less or no information on death results in delayed grief.
8.	Families perceptions of the grieving process and concept of death in individuals with intellectual disabilities	J. McEvoy and E. Smith University academics	The British Journal of Development Disabilities, 2005	Attitude of families towards grieving process and understanding of death by *AWLD; support for **AWLD after loss.	No, Quantitative methods: questionnaires used for data collection which could have been supported with qualitative information. views from *AWLD would have been more useful in same	Ethics not explained	Yes, post bereavement reactions found similar in *AWLD as with other population. Lack of knowledge in majority of participants as they perceived that *AWLD do not understand death and parents of challenging behaviour *AWLD did not supported the concept of death education and their ability to support.	It has been suggested in this study that parents need education about therapeutic content of interventions used to support bereaved *AWLD

					research.			
9.	Bereaved adults with intellectual disabilities: a combined randomized controlled trial and qualitative study of two community-based interventions	S. Dowling, J. Hubert, S. White and S. Hollins University academics, psychiatric clinicians	Journal of Intellectual Disability Research, 2006	Yes, to find an effective intervention to improve mental health and behavioural outcomes for bereaved *AWLD.	Yes, mixed methods used: semi-structured interviews and observations for qualitative data. **ABC-C and ***HoNOS-LD for quantitative data.	Ethics approval not mentioned but consent described.	First comparative study to see effectiveness of two interventions and it was found that counselling was more useful and practical than integrated intervention.	Creative ways used in counselling intervention were useful.
10.	An exploration of the support received by people with intellectual disabilities who have been bereaved	U.Gilrane-McGarry and L. Taggart University academics	Journal of Research in Nursing, 2007	Explore supports available and perceptions to various supports provided after loss.	Yes, qualitative methods: semi-structured interviews.	Ethics approval taken, and consent explained.	Involvement of bereaved *AWLD in rituals after death considered positive, support in form of counselling was lacking.	Different type of useful interventions need to be integrated into bereaved *AWLD's* daily lives to make more effective.
11.	Planning, facilitating and evaluating a bereavement group for adults with	C. Borsay, M. Halsey and A. Critoph Clinical psychologists	British Journal of Learning Disabilities, 2012	Yes, evaluation of a bereavement group of *AWLD, experiences	Yes, Mixed methods used in this research using group work.	Ethics approval not mentioned but consent described.	Bereaved *AWLD found the group work useful to learn ways of coping and share their experiences.	More of participant's views during group exercises could have been interesting to read.

	learning disabilities living in the community	and community workers (LD team)		and coping strategies during loss.				
12.	The road barely taken: funerals, and people with intellectual disabilities	R. Forrester-Jones University academics	Journal of Applied Research in Intellectual Disabilities 2013	Yes, aim was to explore how practitioners deal with issue of funerals and see what different age range of adults with and without learning disabilities think about funerals.	Yes, qualitative methods: Semi-structured interviews and focus groups	Ethical approval was taken and £10 given for participating in this research to which I don't personally agree.	Confusion about support for bereaved and disclosing death to *AWLD in professionals. All bereaved *AWLD respected funerals, rituals related to death but most were refused to participate in these.	Funerals have been described as social gatherings by bereaved *AWLD in this research to meet other people and get social support.
13.	Living with Loss	S. Read and M. Carr University academics and member of advocacy organisation (person with learning disabilities)	Book: Supporting people with intellectual disabilities experiencing loss and bereavement theory and compassionate practice, 2014	Clear statement of aims- to share own story of grief and illustrate what helped to cope with loss.	Yes, by using the story of bereaved *AWLD by herself shows exactly how it feels to live with loss	-	Yes, with reference to story by co-author support available and what helps *AWLD to cope with bereavement explained in detail	"...help and support can take many different shapes and forms..."

14.	Bereavement and loss: developing a memory box to support a young woman with profound learning disabilities	H. Young and B. Garrard University academics	British Journal of Learning Disabilities, 2015	Yes, use of memory box to support bereaved women with profound learning disabilities.	Yes, Qualitative methods: case study with a person with profound learning disabilities	Ethical approval taken. Discussed consent from the parent and carer on videoing the sessions but no mention on consent from the lady with profound LD.	Process of making a memory box is beneficial and invaluable for bereaved *AWLD and parent according to this study. Also paid carers got more insight of emotions of bereaved person and her parent in this study.	Time given to bereaved *AWLD (in this study during memory box) also act as healer to deal with loss. Use of video feedback to evaluate was also a good idea.
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*AWLD - Adults with learning disabilities

**ABC- Aberrant behaviour checklist

***HoNOS-LD- Health of the nation outcome scale for people with learning disabilities

****PIMRA Psychopathology instrument for mentally retarded adults; Matson

Appendix B: Invitation to attend Photovoice workshop

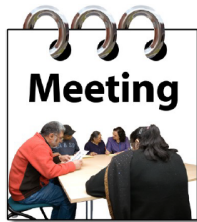
'Exploring the therapeutic interventions used to support bereaved adults with a learning disability:
a mixed methods study using Photovoice'



Research project



Hello _____, my name is Gulshan Tajuria, I want to find out about the type of support and help available to people with learning disabilities when someone they love dies.



You have agreed to take part in this work and attend a meeting to learn more about it.

Tuesday 21st April 2015 at 10:00am - 2:00pm

Winton House, Shelton



At the meeting you will find out more about:

- My work at Keele university and Reach.
- Learn how to use camera.
- Getting ready to take part in this work.



You have agreed to make your own way to attend the meeting.



Lunch will be provided.



For further information you can contact Patsy:

01782747872 **OR**

Gulshan: 01782 733885

Research Institute of Social Sciences

Research Centre, Keele University

Email: g.tajuria@keele.ac.uk



Clear information made with photo symbols

Appendix C: Photovoice workshop plan

21st April 2015, 10am to 2pm

1. 10:00- Arrival and signing consent forms

Take permission for photographs.

2. 10:30- Introductions

Gulshan will introduce herself and team to participants. Briefly explain and point to ground rules on walls.

Ask participants to introduce themselves and talk about the photo (if they have brought one from home).

Explain: We have got a lot to do today and time is going to be very important. We have a lot of information to share with you and we want you to have the time to ask questions about it. We will try to keep to time as much as possible. We will be using red, amber and green cards to let us all know when time is running out. You can always ask any question to me or the team if what we talk about is not clear.

Start with open question like Can anyone tell us what Research is? Then say I am going to explain now. Project and aims of workshop will then be explained by referring to participant information sheets.

Relate people's views to photographs from Patsy of people taking part in research. Explain that most people have already taken part in research in the past.

3. 10:55- Treasure hunt to explain how to use camera, separate information sheets for activity, props like flower vase, decoration pieces will be kept in room)

Gulshan will explain: this game will help us to understand what extra support you might need to join in this research. As well as fun exercise it also helps us to check out what help each one of you might need. After this exercise all participants will be expected to say a couple of lines about the photograph they take in room. (Explain separate information on using camera, treasure hunt and taking photos)

4. 11:05- tea break (Photos will be uploaded during this time)

Gulshan will save the photos to folders created before workshop numbered according to cameras and memory cards. Will make a list of what has been taken in the photographs, who has understood certain points and who

needs more help. Which participant need more support to use camera and which ones are okay without support?

5. 11:20- Discuss photos taken by participants

Show photos one by one on projector and invite participants to talk briefly about them.

6. 12:20- Explain ethical issues (see separate check list to give ideas where permissions must be taken before taking photo)

Gulshan will ask participants- what will happen if somebody took a photo of you and you did not wanted your photo to be taken? Tell participants 'in research language what we understand by that is you need to take approval before taking somebody's photo and we call it ethics'. If you are unsure about taking somebody's photographs then please don't take that photo. For this research photographs do not have to be of people they can be of anything that remind you of things about your loss or bereavement, such as memory boxes, places you have visited, books that remind you of your loved ones. It can be of anything or anybody that helped you to cope with your difficult times.

Sue will explain ethical issues from some past experiences.

7. 12:55- Ending exercise

Gulshan will ask participants to name one thing they liked/not liked about workshop today or what they looking forward to during their participation in this research (this part will be recorded). Will make this as fun exercise and give a little treat to everyone as reward for naming one thing they liked about workshop/ project.

8. 1:15- Recap

Gulshan will explain in the end that this camera, memory card and battery charger is yours to keep now. You have been given these to take part in this research and you can keep afterwards. Please post back the memory cards to me in the envelope provided to you after 2 weeks. This envelope has got my address and stamp on it; you only need to put it in any letter box. Memory cards will be given back to you on the day of interview.

1:30- lunch

Appendix D: Ethical approval letter



RESEARCH AND ENTERPRISE SERVICES

1st April 2015

Gulshan Tajuria
Claus Moser Building
Keele University

Dear Gulshan,

**Re: Exploring support available to adults with learning disabilities following loss and bereavement:
A mixed methods study using photovoice**

Thank you for submitting your application for review. I am pleased to inform you that your application has been approved by the Ethics Review Panel. The following documents have been reviewed and approved by the panel as follows:

Document	Version	Date
Summary Proposal	5	March 2015
Letter of Invitation: Leaflet	3	January 2015
Information Sheet: Adults with learning disabilities	7	March 2015
Information sheets for professional carers	2	March 2015
Information Sheets for family carers	2	March 2015
Information Sheet for advocates	2	March 2015
Consent Form: Adults with learning disabilities	5	January 2015
Consent Form: advocates and carers	2	March 2015
Consent Form for use of quotes: Adults with learning disabilities	3	January 2015
Consent Form for use of quotes: Advocates and carers	2	January 2015
Consent Form for the use of photographs: Adults with learning disabilities	3	January 2015
Interview Topic Guide for adults with learning disabilities	1	August 2014
Open ended questionnaire	1	January 2015
Focus Group discussion guide	1	January 2015

If the fieldwork goes beyond the date stated in your application, you must notify the Ethical Review Panel via the ERP administrator at uso.erps@keele.ac.uk stating ERP1 in the subject line of the e-mail.

Research and Enterprise Services, Keele University, Staffordshire, ST5 5BG, UK
Telephone: + 44 (0)1782 734466 Fax: + 44 (0)1782 733740



RESEARCH AND ENTERPRISE SERVICES

If there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator stating ERP1 in the subject line of the e-mail. This form is available via <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries, please do not hesitate to contact me via the ERP administrator on uso.erps@keele.ac.uk stating ERP1 in the subject line of the e-mail.

Yours sincerely

A handwritten signature in cursive script that reads "Jackie".

PP

Dr Jackie Waterfield
Chair – Ethical Review Panel

CC RI Manager
Supervisor

Appendix E: Participant information sheets AWLD

Appendix :Information sheets Adults with learning disabilities



**Keele
University**

Research project



A research project is a way of finding out things about people.

The finding out work can be done by talking and asking questions.

The finding out work can be used to improve services for people.



Loss can be when someone you care about died or moved away.

Loss can be when a person loses their belongings, home, support or service.



I want to find out what helps people with learning disabilities after loss and when someone they care about dies.



Gulshan Tajuria,

I am the researcher that will be leading this finding out work.

Telephone number: 01782 733885

Contact address:

Research Institute of Social Sciences
Claus Moser, Research Centre
Keele University



Email: g.tajuria@keele.ac.uk

Appendix :Information sheets Adults with learning disabilities



The team doing this finding out work:



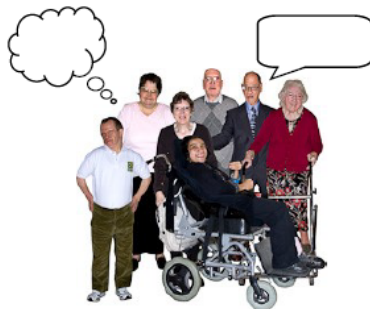
Sue Read works at Keele University as a Professor of Learning Disability Nursing. Sue will be giving me support for this finding out work.



Helena Priest works at Keele and Staffordshire University as a senior teacher. Helena will be giving me support with this finding out work.



I am working with people at Reach in this finding out work.



I want to find out about the support and help available for people with learning disabilities to cope with loss.



You can help me in this finding out work by joining in and taking photographs about your story of loss and bereavement.

Appendix :Information sheets Adults with learning disabilities



You can take photographs for 2-3 weeks and then talk to me about your photographs.



When you talk about your story and photographs I want to tape record it so that I do not miss anything you say.



Later, I will listen to the tapes and write them all down as words.

They will be kept safely in a locked office.



Your photographs will be kept private and stored on computers.

I will not use your photographs unless you agree.



Your words will be used in reports and journals to share with others, but no one will know it is you.

Your name and address will be kept private and not shared with people.

Appendix :Information sheets Adults with learning disabilities



People involved in this finding out work will see what you have said.

People from Reach may also see what you have said.

No-one will know who has said what.

What you say to me will not affect your care or support.

If you say anything that means you or someone else is in danger I will have to tell someone and ask for help.



You do not have to talk to me if you do not want to.



If you decide to take part in this finding out work, you can choose someone to be with you.

This could be a friend, family member or carer.



You can choose where you want to talk to me.

Appendix :Information sheets Adults with learning disabilities



You can stop this finding out work at any time you want, without telling me why.



If you do not understand about this finding out work you can ask me or a member of the team.



If you want to stop joining this finding out work at any time, I will keep and use what you said to me before.



If you need support after taking part in this finding out work, contact:

Professor **Sue Read**

School of Nursing and Midwifery

Keele University

Clinical Education Centre

University Hospital of North

Staffordshire

NHS Trust, City General Hospital,

Newcastle Road, Staffordshire,

ST4 6QG

Tel: +44(0)1782 679 653



Clear information made with



Appendix F: Consent forms AWLD

Consent form: Adults with learning disabilities



Research project



Tick if you agree with the below comment.



I understand the information I have just read.



I agree to talk to Gulshan about what has happened to me.



I agree to take photographs and talk about them to Gulshan.



I agree for what I say to be recorded



I agree to take part in this Research Project about:

support available for adults with learning disabilities to cope with loss and bereavement.

Consent form: Adults with learning disabilities



I agree that the work can be shared with the Research Project Team.



All this information about you will be kept private and no one will know who said what.



Name

Address

Date



Signed



Clear information made with



Appendix G: Participant information sheets Group 2, 3 & 4



Title of Study: Exploring support available to adults with learning disabilities following loss and bereavement: A mixed methods study using Photo voice

Aims of the research:

- To identify and critically explore the use and helpfulness of a range of support and interventions used to help adults who have a learning disability.
- To critically explore the use of Photovoice as a research tool with adults with learning disabilities.

Invitation: You are being invited to consider participating in the research study 'exploring support available to adults with learning disabilities following loss and bereavement: A mixed methods study using Photo voice'. This research project is being undertaken by Gulshan Tajuria – PhD candidate, with supervision from Prof. Sue Read and Dr Helena Priest, Keele University. Please read this information carefully to ensure you understand what the research involves and aims to do. If you have any additional questions please contact the research team for more information.

Why have I been chosen? You have been chosen to participate in the study because of your role as an advocate/professional/family carer for adults with learning disabilities who have been through loss and bereavement. For advocates because you are working with Reach at Asist advocacy services.

Do I have to take part? There is no obligation for you to take part in this study. If you decide you do wish to participate you will be asked to sign two consent forms; one for your own records and one for the researchers' records. There will be separate consent forms to take part in focus group/interviews and use of quotes. You may withdraw from the study at any time without giving reasons as to why you may wish to withdraw.

What will happen if I take part? If you do decide to participate in the research, you will be asked to participate in a focus group/interview. In focus group discussion you will be part of a group of 6-8 participants who have worked with adults with learning disabilities following loss and bereavement. The research methods will focus on asking you information about the type of support used and what helps adults with learning disabilities to cope with their loss and grief.

What are the benefits (if any) of taking part? There may not be any direct benefits to you during this research but you will have the opportunity to reflect on your involvement in providing support to adults with learning disabilities in loss and grief. As well information from other participants may help you in using different approaches in your work.

What are the risks (if any) of taking part? There are no 'anticipated' risks involved with taking part in the study. If you ever feel distressed during participating in this research you are free to stop taking part temporarily or permanently, without giving reasons.

How will information about me be used? Information on tape recorder during focus group discussion and interviews will be transcribed. Transcribed information will then be analysed and used to generate knowledge about therapeutic interventions used with adults with learning disabilities in grief. This data will be included in researcher's PhD thesis and will be published in reports, journals etc.

Who will have access to information about me? Only the researcher; Gulshan Tajuria, and the researchers' supervisors; Prof. Sue Read and Dr Helena Priest will have access to the information. Data will be secured in a locked office and on a password protected computer. All data will be stored in line with Keele University's Data Protection Policy. Data collected will be anonymised and will not be used against your wish in any way that could cause harm to anyone.

What if there is a problem? If you have any concerns about any aspect of the research please contact the researcher who will try to answer any questions you may have. You can contact the researcher; Gulshan Tajuria at g.tajuria@keele.ac.uk.

If you do not wish to contact the researcher you may contact, **Prof Sue Read** at s.c.read@keele.ac.uk, who is my first supervisor and is Professor of Learning Disability Nursing; School of Nursing & Midwifery, Keele University.

If you are still unhappy with any aspect of the study or wish to make a complaint, please write to **Nicola Leighton** who is the Universities contact for this type of issue at:

Nicola Leighton,

Research Governance Officer,

Research and Enterprise Services,

Dorothy Hodgkin Building, Keele University, ST5 5BG

Email: n.leighton@keele.ac.uk Telephone: 01782 733306

Appendix H: Consent form Group 2, 3 & 4



**Keele
University**

CONSENT FORM: Group 2, 3 and 4

Title of Project: Exploring support available to adults with learning disabilities following loss and bereavement: A mixed methods study using Photo voice

Name and contact details of Principal Investigator: Gulshan Tajuria,
Research Institute of Social sciences, Keele University, Staffs, ST5 5BG, Tel:
01782 733885, email: g.tajuria@keele.ac.uk.

Please tick the box if you agree with the statement

I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to ask questions

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason

I agree to my interview/focus group being audio recorded

I understand that data collected about me during this study will be anonymised before it is submitted for publication

I understand that although data will be anonymised because of my role it may be possible that I could be identified in reports and publications

I agree that the researcher can contact me on the below telephone number to arrange an interview

I agree to take part in this study

Name of participant:

Name of researcher:

Signature:

Signature:

Contact number:

Appendix I: Invitation leaflet AWLD

Appendix: Letter of invitation



Research project



A research project is a way of finding out things about people.

I want to find out about the type of support and help available to people with learning disabilities after loss and when someone they care about dies.

It is about finding out what helps a person with a learning disability to cope with loss.

Would you like to talk to me?

If yes please contact:

Gulshan Tajuria

Telephone number: 01782 733885

Contact address:

Research Institute of Social Sciences
Keele University

Email: g.tajuria@keele.ac.uk



Or please contact:

Patsy Corcoran

Telephone number: 01782747872

Contact address:

Reach



Clear information made with



Appendix J: Invitation leaflet Group 2, 3 & 4

Invitation leaflet Group 2, 3 & 4



Research project



You are being invited to consider participating in the research study 'exploring support available to adults with learning disabilities following loss and bereavement: A mixed methods study using Photo voice'.



This research project is being undertaken by Gulshan Tajuria – PhD candidate, with supervision from Prof. Sue Read and Dr Helena Priest, Keele University.



Reach members are working in this project with support from Reach.



Would you like to talk to me about your experience of working with adults with learning disabilities after loss and bereavement?

If yes please contact:

Gulshan Tajuria,

Telephone number: 01782 733885

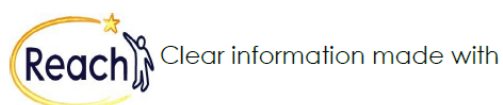
Contact address:

Research Institute of Social Sciences

Research Centre

Keele University

Email: g.tajuria@keele.ac.uk



Clear information made with



Appendix K: Information about camera

Information about camera

Camera image



Battery



Memory card



USB card reader



Charger



Image showing on/off button
with red dot

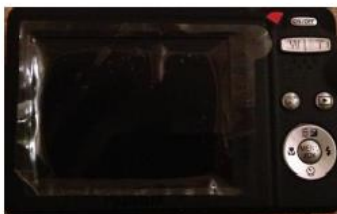


Image showing click button
with green dot



Image showing how to insert battery



Image showing how to insert memory card



Image showing how to insert battery in charger



Image showing charger plugged in



Please post these:



Appendix L: Consent forms (AWLD) for use of photographs

Consent form for use of photographs: Adults with learning disabilities



Research project



All this information about you will be kept private.



Tick if you agree with the below comment.



I agree to share my photographs that I take during this finding out work.



Name:

Date:

Signed:



I agree that the photographs can be shared with the Research Project Team.



Clear information made with



Appendix M: Consent form (AWLD) for use of quotes

Consent form for use of quotes: Adults with learning disabilities



Research project



All this information about you will be kept private and no one will know who said what.



Tick the boxes below if you want to join in.



I agree that what I have said can be used in reports, talks etc. in this finding out work.



I agree that the quotes can be shared with the Research Project Team.



Name:

Date:

Signed:



Clear information made with



Appendix N: Interview schedule for AWLD



Keele University

Exploring support available to adults with learning disabilities following loss and bereavement: A mixed methods study using Photo voice

Introduction to the process

My name is Gulshan Tajuria; I would like to thank you for agreeing to be interviewed regarding your experiences of bereavement and support. Have you had a look on the information sheets given to you last time? Would you like to ask me anything about it before we start?

Read and explain consent form briefly.

Once they sign consent form (if not done beforehand) then ask for approval to switch the tape recorder on and then do it.

Questions and prompts

Order of prompts and questions will depend on the response of participants.

Start with general introductory questions to make participant comfortable like:

1. Do you know why you are here today?
2. You agreed to talk to me but do you know about this work?
3. Tell me something about today- how did you come here? How was your journey?
4. Do you like taking photographs?

If they have taken photographs then go to next section if not then ask:

1. Did you not like taking photographs?
2. (if they had taken photographs but didn't send) Did you not feel that I should see them?
3. Tell me about any other thing or photograph at your place that reminds you of the person you lost.

Start talking about the pictures with prompts like:

1. Tell me something about this picture. What is special about this picture?
2. Who is in this picture?
3. What type of things you used to do with..... (e.g mom/dad/or any other person)?

Is it okay if I ask more questions?

4. What do you remember most about your?

5. What do you miss most about your
6. Where were you living when yourdied?
7. Where has been your favourite place to live?

Is it okay if I ask more questions?

8. How did you come to know about the death of.....?
9. What happened after your died? Was there a funeral?
10. Question about: if they saw the dead body? If they wanted to see it or not?
11. Whatever they had to do was it appropriate or could have been different?

(When they mention about their feelings like sadness, anger etc) then ask

12. What/who helped you when you miss your?
13. If they name any person or organisation, then ask: what did they do to help you?
14. Where did you get your support from?
15. What helped the most?
16. What didn't help you?
17. What have you learned from your loss experience?

Is it okay if I ask more questions?

About today (present time)

18. Where do you live now?
19. How do you feel today when you think about your
20. Whom can you talk to about your
21. What things do you like to do now? Who does those things with you?

How was the experience of using the camera?

22. Is there anything you want to ask me before we finish for today?

Thank you for sharing your experiences and talking with me today.

Appendix O: Letters to invite AWLD for interviews

Appendix O: Letters to invite AWLD for interviews



Research project

Hello —, my name is Gulshan Tajuria, I want to find out about the type of support and help available to people with learning disabilities when someone they love dies.



You have agreed to take part in this work by taking photos and talk about them.

Tuesday 12th May 2015 at 10:00am - 11:00am

Winton House, Shelton



At the meeting we will find out more about:

- Have you lost anyone?
- Who helped after your loss?
- Have you taken photos to show what helped you to cope with loss?



You have agreed to make your own way and we will refund your train ticket fare.



Snack will be provided.



For further information you can contact Patsy:

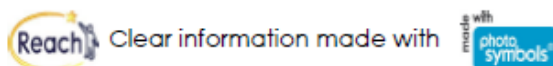
01782747872 OR

Gulshan: 01782 733885

Research Institute of Social Sciences

Research Centre, Keele University

Email: g.tajuria@keele.ac.uk



Appendix P: Focus group/interview discussion schedule with Group 2, 3 & 4



Keele University

Exploring support available to adults with learning disabilities following loss and bereavement:

A mixed methods study using Photo voice

Clients (Adults with learning disability) related questions:

1. What are the types of losses experienced by most of your clients?
2. How do they find out primarily about their loss or death or dying of someone?
3. When do they get to know about it?
4. Do they attend funeral/memorial services?
5. Reasons for referrals due to death of a parent or loved one (e.g. behaviours or triggering events).
6. How is grief shown by your clients?
7. What has been commonly helpful for clients in dealing with their losses?
8. What are the barriers for adults with learning disabilities in accessing support during loss?
9. Types of training workshops organised at the research site and their benefits.
10. Names of interventions used with adults with learning disabilities in loss.
11. What has been useful in helping these clients cope with their loss?
12. What effect does death of someone leaves on the rest of life of your clients.
13. What are the differences in clients with learning disabilities in grief and other clients in grief?
14. How are the clients with learning disabilities in grief similar to clients without learning disabilities in grief?
15. How can adults with learning disabilities be better prepared to deal with different type of losses?
16. What has been most helpful for you in preparing yourself to work with adults with learning disabilities in grief?
17. Recommendations for other advocates or carers to increase their expertise to work with adults with learning disabilities in grief?
18. Which areas need improvement?

Thank you for your time.

Appendix Q: Photographs of flipcharts from data analysis (P1-Q9)

Appendix Q1: Flipcharts taped onto the walls, small size photographs printed, grouped according to content and pasted for each participant.



Appendix Q2: Photograph from walls with all participants' photos



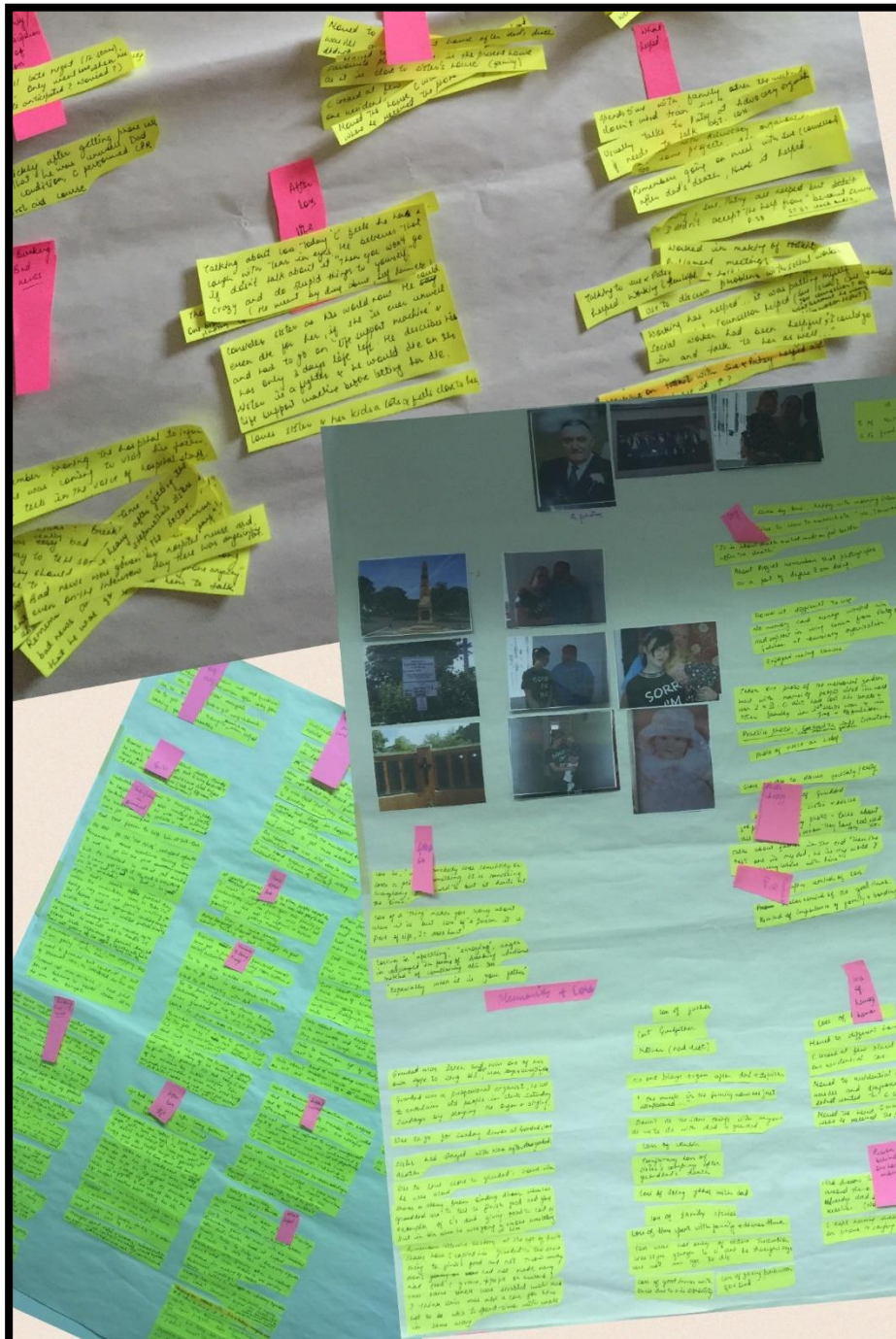
Appendix Q3: Photograph containing data from Scott

Data extracts with information relevant to the research questions were written on post it notes using different colours for each participant.

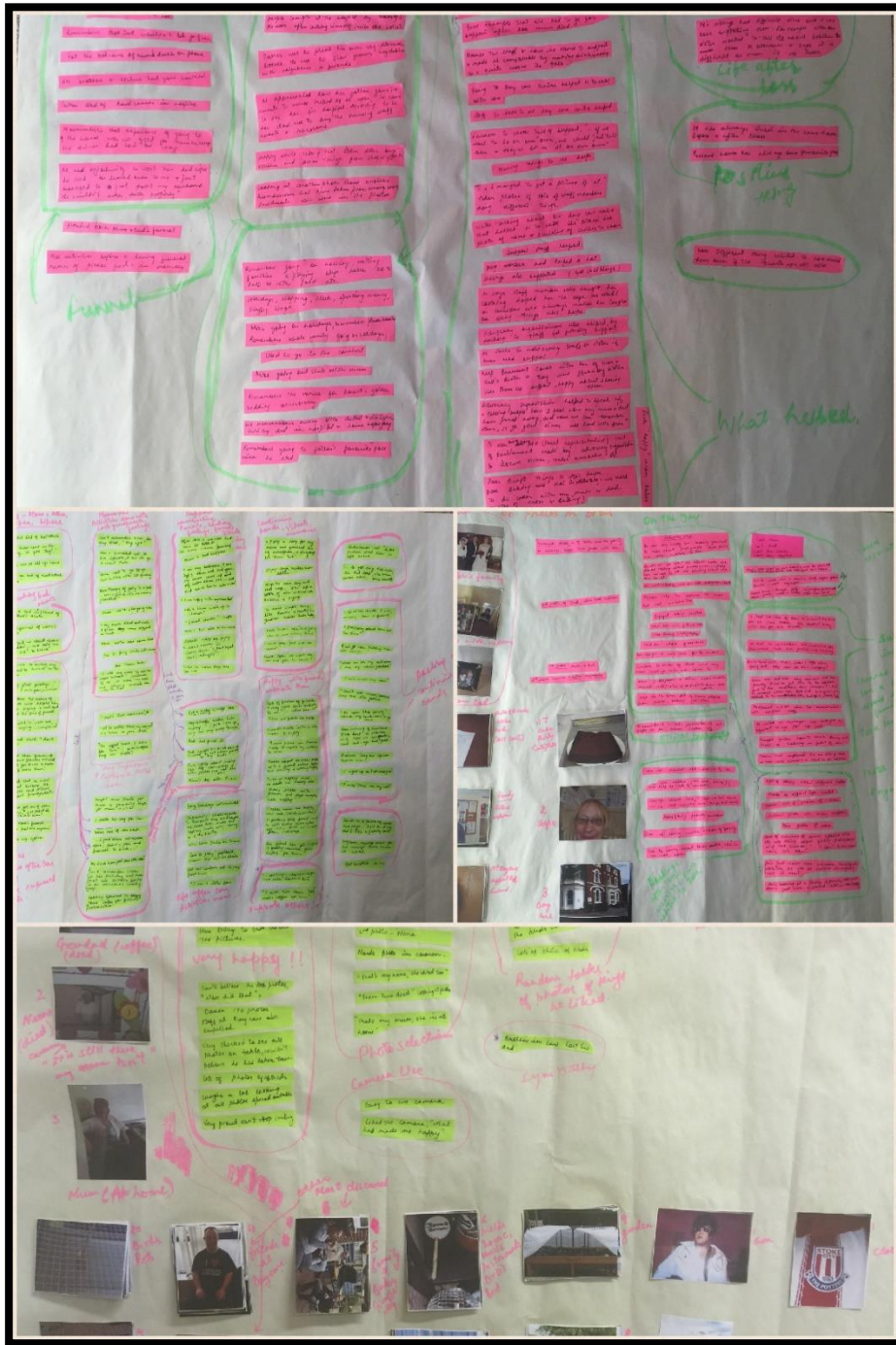


Appendix Q4: Photograph containing data from Charles

After cutting and grouping, the post it notes were pasted under the codes generated from the information.



Appendix Q5: Photograph containing data from Megan and David



Appendix Q6: Photograph containing data from Adam and Rose

The image shows a large, multi-page handwritten document, likely a field notebook or a research journal, containing numerous photographs and extensive text notes. The notes are organized into several sections, including:

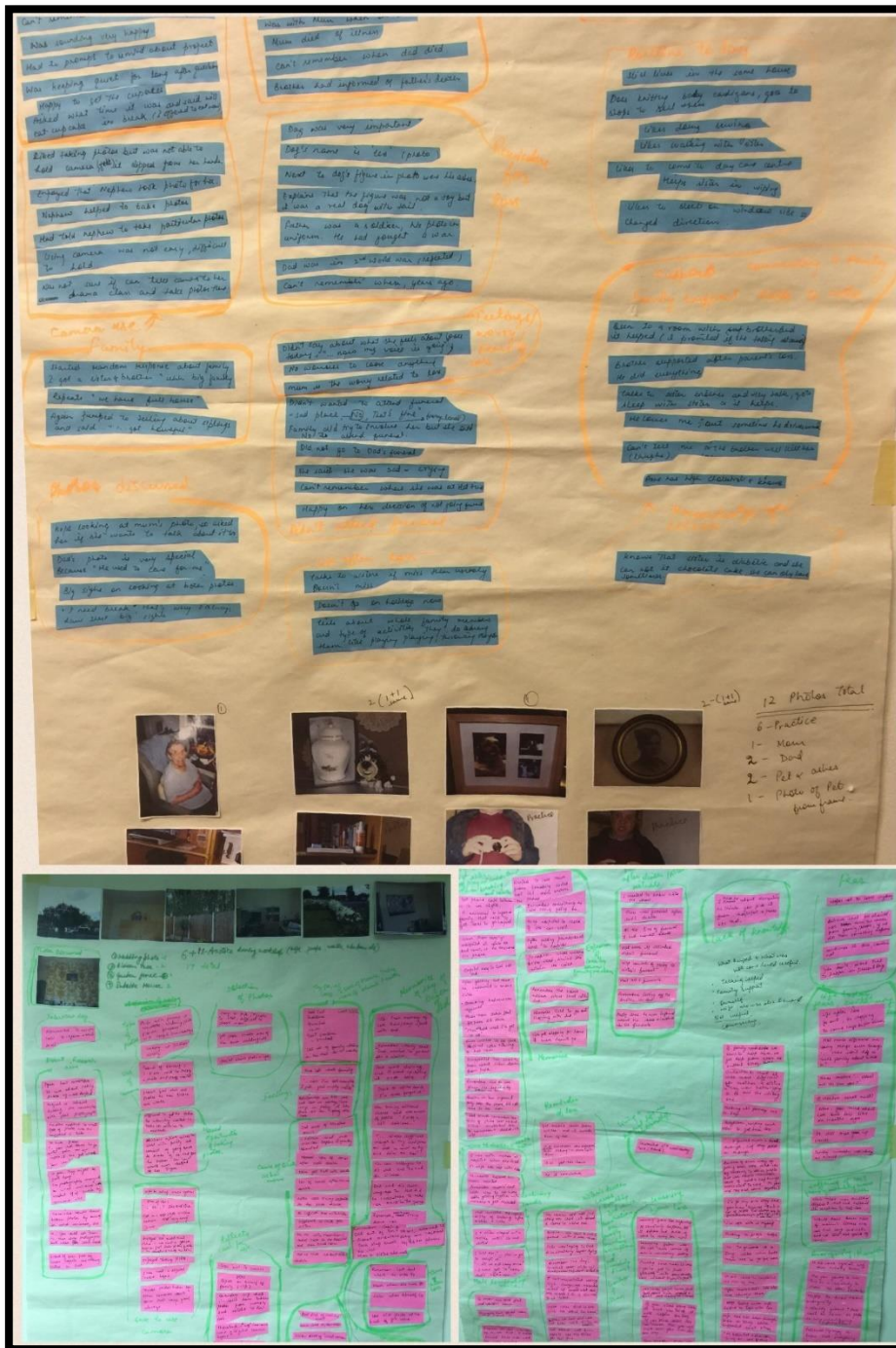
- Patriotism Day:** A section at the top left with notes about a walk on Saturday and a walk on Sunday, mentioning a walk on the beach and a walk on the beach.
- Cause of Loss:** A central section with notes about a walk on the beach and a walk on the beach, mentioning a walk on the beach and a walk on the beach.
- Reminders of Loss:** A section on the right side with notes about a walk on the beach and a walk on the beach, mentioning a walk on the beach and a walk on the beach.
- Changes:** A section on the right side with notes about a walk on the beach and a walk on the beach, mentioning a walk on the beach and a walk on the beach.
- Loss:** A section at the bottom left with notes about a walk on the beach and a walk on the beach, mentioning a walk on the beach and a walk on the beach.

There are also several numbered lists of photos and a 'Total Photos' section. The photos are arranged in a grid-like fashion, with each photo accompanied by a small number and a brief description. The text is written in a cursive, handwritten style, and the overall layout is dense and organized.

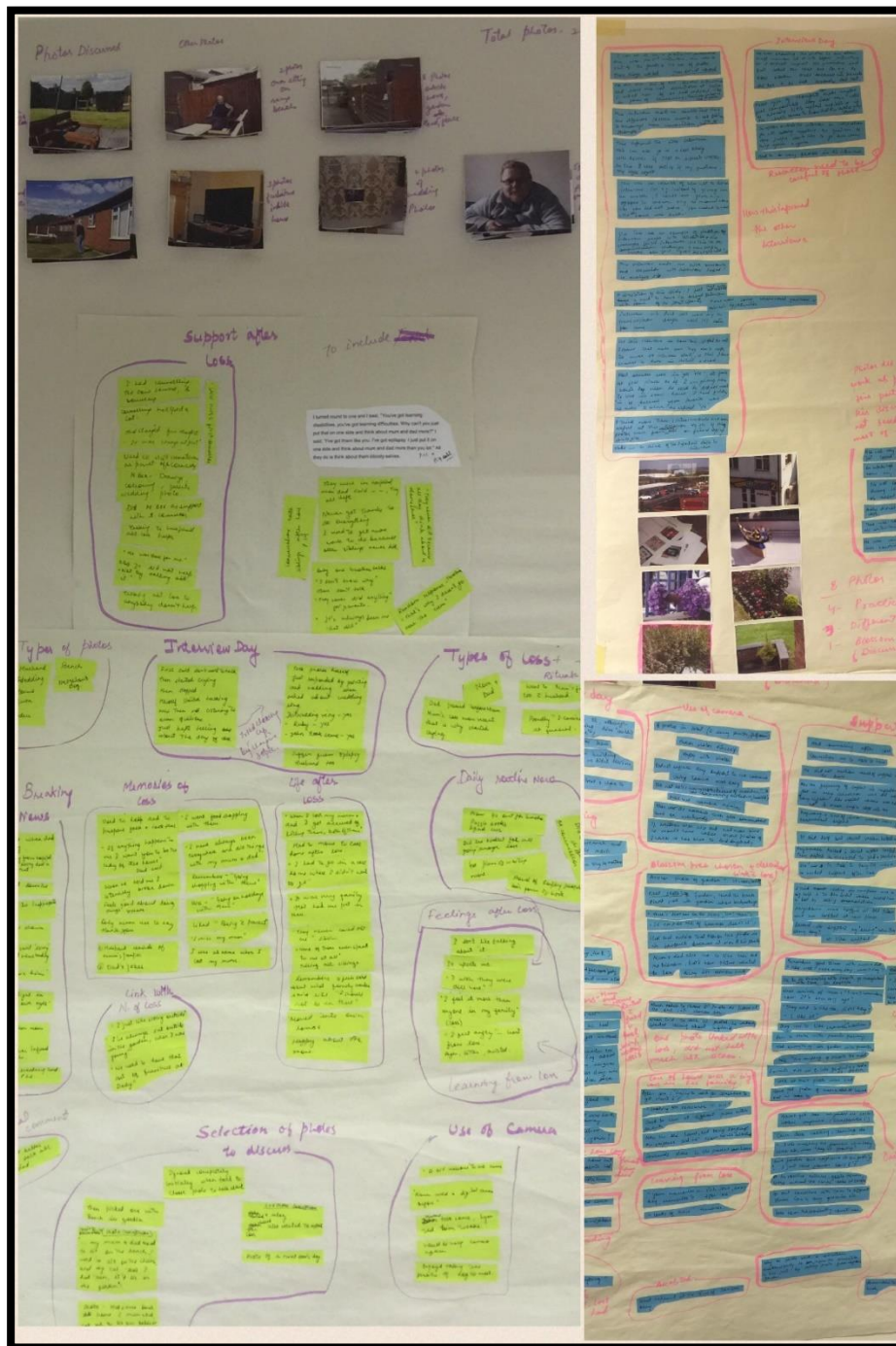
Total Photos:

- 4 - Sun of Memorial Day
- 20 - D-Day (Remembrance) from August
- 3 - Own
- 2 - English House (Lovers)
- (one of each type) 2 - Beach

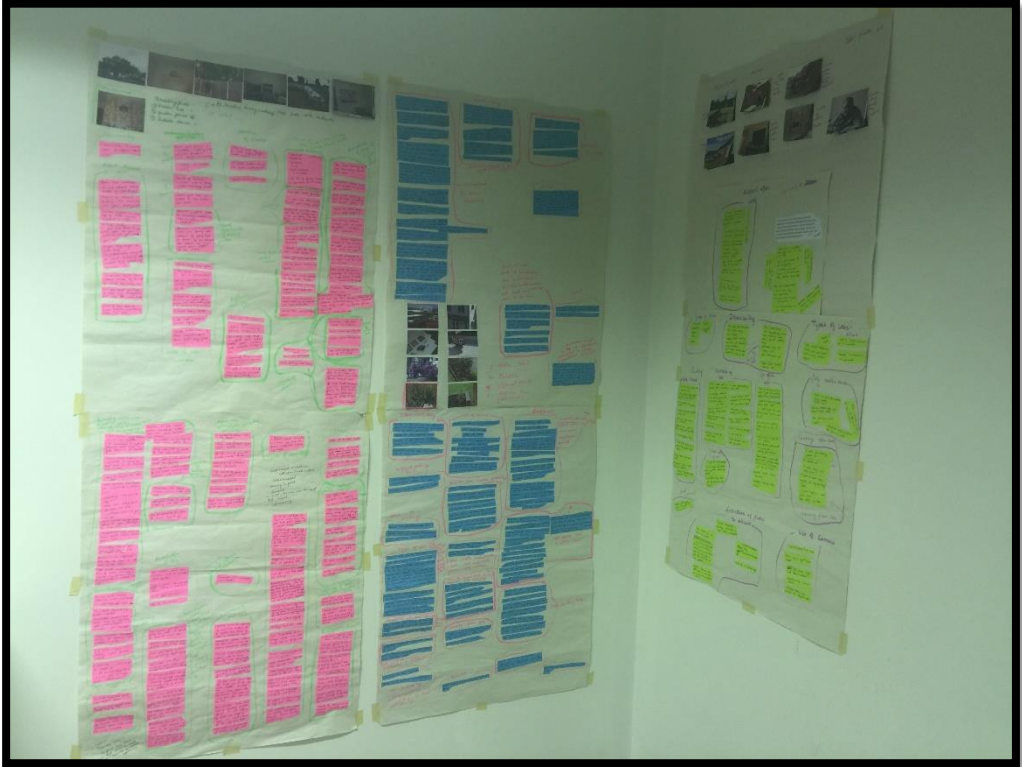
Appendix Q7: Photograph containing data from Abbey and Jack



Appendix Q8: Photograph containing data from Lisa and George



Appendix Q9: Photograph of all codes and grouped themes and subthemes



Appendix R: Consent forms for use of quotes Group 2, 3 & 4



Consent Form

Title of Study: Exploring the therapeutic interventions used to support bereaved adults with a learning disability: a mixed methods study using Photo voice

Name and contact details of principle investigator:

Gulshan Tajuria, Research Institute of Social sciences, Keele University, Staffs, ST5 5BG, Tel: 01782 733885, email: g.tajuria@keele.ac.uk.

Please tick the box, if you agree with the statements below

1. I agree for any anonymised quotes to be used.

2. I do not agree for any quotes to be used.

Name of participant:

Date:

Signature:

Contact number:

Name of researcher:

Date:

Signature:

Contact number:

Appendix S: Photo log

7.3 Table no Photo log table

Name	No. of Photos	Type of photos	Selected in interview	Not selected in interview (Categories)
Rose	46	<p>Deceased father's photo from old photo-2 same</p> <p>Putting flowers on grave- 3 same</p> <p>Self at day care center- 5</p> <p>PA/staff- 4</p> <p>Friends- 3</p> <p>Doing group activities like dance and drama at day care- 27</p> <p>Making pottery and painting- 2</p>	<ol style="list-style-type: none"> 1. Doing pottery 2. With deceased father 3. Putting flowers on grave 	<ol style="list-style-type: none"> 1. Own photos 2. At day care center: 3. PA, staff, friends; Group activities; pottery painting
Charles	23	<p>Deceased family members photos from old photos- 3</p> <p>Sister and her children- 6</p> <p>Own photo with nieces- 2</p> <p>Own photo with sister- 2</p> <p>Memorial garden- 5 same</p> <p>Names of people died in wars- 1</p> <p>Signboard of memorial garden- 1</p> <p>Sculpture at memorial garden- 3 same</p>	<ol style="list-style-type: none"> 1. Deceased granddad 2. With sister 3. Family with some deceased family members 	<ol style="list-style-type: none"> 1. Deceased family members 2. Memorial garden (different photos) 3. Family members
Adam	29	<p>Family members- 4 same</p> <p>Different flowers and herbs from magazines (lost)- 20</p> <p>Own-self- 3</p> <p>TV inside house- 2</p>	<ol style="list-style-type: none"> 1. Family members 2. And 3. Lost plants 	<ol style="list-style-type: none"> 1. Similar to chosen photos of plants 2. Selfies 3. TV
Abbey	12	Deceased family members photo	1. Deceased dad	1. Practice

		<p>from photo- 3 (2same)</p> <p>Lost pet figure and its ashes- 2 same</p> <p>Pet from photo- 1</p> <p>Practice to use camera at home (not clear)-6</p>	<p>2. Deceased mum</p> <p>3. Dog's figure with ashes</p>	<p>photos</p>
Jack	17	<p>Own wedding photo from photo- 1</p> <p>Blossom trees- 2</p> <p>Garden fence- 1</p> <p>Furniture in the house- 2</p> <p>Practice to use camera at home (fireplace, cupboards, walls, family member)- 11</p>	<p>1. Wedding photo from photo</p>	<p>1. Blossom trees</p> <p>2. Garden fence</p> <p>3. Furniture</p> <p>4. Practice photos</p>
George	8	<p>Blossom tree- 1</p> <p>Different plants in garden (rose blossom and one unknown)- 3</p> <p>Practice at using camera (inside room, through window)- 4</p>	<p>1. Blossom tree</p>	<p>1. Plants</p> <p>2. Practice photos</p>
Lisa	25	<p>Family member- 2 (same person)</p> <p>Bench and table in garden- 3 same</p> <p>Own self- 2</p> <p>Garden with road, fence and neighbor's dog- 8</p> <p>Furniture inside house- 3</p> <p>Own wedding photo from photo- 2</p> <p>Practice using camera- 5 not clear</p>	<p>1. Bench and table in garden</p> <p>2. Family member</p>	<p>1. Own photos</p> <p>2. Garden</p> <p>3. Furniture</p> <p>4. Wedding photo</p> <p>5. Practice photos</p>
Scott	107	<p>Family member- 1</p> <p>Entertainment equipment's (DVDs; TV; Stereos)- 9</p> <p>Calendar with volunteers photo- 2 same</p>	<p>Not selected any but discussed:</p> <p>1. Favorite DVD</p> <p>2. Photo of calendar from work</p> <p>3. Fighter plane</p>	<p>None selected initially</p>

		<p>Fighter planes from painting books- 14</p> <p>Musical instruments (15 guitars from real and from photos; 4 drums)- 19</p> <p>Sketches (9 of fighter planes; 4 of dogs; 2 of birds; 2 of elephants; 3 of people in space and 4 not sure)- 24</p> <p>Own photo playing guitar from old photo- 5</p> <p>Decoration pieces/ornaments inside house- 10</p> <p>Outside house from window and trees sky with trees- 3</p> <p>Paintings of dog- 3</p> <p>Miscellaneous while practice using camera (furniture items; clothes and some unknown)- 17</p>		
David	84	<p>Deceased family members from old photos- 2</p> <p>Family members- 2</p> <p>Toy giraffe- 1</p> <p>Pet birds- 20</p> <p>Pet dog- 4</p> <p>Friends at day care- 13</p> <p>Own with friends- 4</p> <p>Inside house (music instruments; DVDs; bed)- 6</p> <p>Garden- 9</p> <p>Doing gardening- 1</p> <p>Own photo from old photo- 1</p> <p>Favorite football team tshirt- 1</p> <p>Things at day care (clock; desk; cupboard)- 5</p> <p>Outside house (not sure)- 8</p> <p>House from outside- 1</p> <p>From practice- 6</p>	<ol style="list-style-type: none"> 1. Granddad with coffee 2. Nanna in motorhome 3. Mum 	<ol style="list-style-type: none"> 1. Toy 2. Pets 3. Friends 4. Selfies with friends 5. Things inside house; outside house; building 6. Garden and gardening 7. Own photo from old photo 8. Football team t-shirt 9. Practice photos

Megan	66	<p>Bereavement cards and photos from photos of deceased- 9 Deceased family members with alive members (2 same of mum and dad; 3 same of sister's family; 3 same of family photo from photo)- 8 Family member- 11 Staff at day care- 16 Activities (baked cakes; painting; crafts; favorite DVDs; certificate from courses attended)- 17 Own self- 2 Day care center building with name- 3</p>	<ol style="list-style-type: none"> 1. Sister's family from old photo 2. Whole family with nephews from old photos 3. Mum and dad from old photo 	<ol style="list-style-type: none"> 1. Bereavement cards of family members 2. Family members 3. Staff at day care center 4. Daily activities like baking; certificates. 5. Selfies 6. Building day care center
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End of thesis