



**Risk and Resilience in Bereaved Children with Learning and
Neurodevelopmental Disabilities: Perceptions of parents, schools and
bereavement practitioners**

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Summary

Part A: Literature Review

This begins by exploring theoretical and research literature relating to bereavement, including ‘common’ and ‘pathological’ manifestations of grief in typically developing children. Following this, a number of risk and resiliency variables are presented which contribute to coping, adaptation or prolonged psychological disturbance. Although limited, the next section focuses on ‘common’ and ‘pathological’ grief responses in adults with learning and neurodevelopmental disabilities. Utilising this evidence base, and the research with typically developing children, the final section considers potential variables that might impact on risk and resilience for children with learning and neurodevelopmental disabilities (L/ND).

Part B: Empirical Research Study

The empirical research study investigates risk and resiliency in bereaved children with (L/ND). This was addressed with participants who had in-depth experience either caring for or working with a bereaved child with L/ND. This information was gathered from interviews with parents (N=3) and two focus groups, one with school-based professionals in a special school setting (N=5), and one with bereavement practitioners working for a national bereavement service (N=8). The data was analysed through a process of thematic analysis. The findings are discussed in relation to the literature. Strengths, limitations, future research directions and implications for educational psychologists are considered.

Part C: Major Reflective Account

The major reflective account provides critical reflections on a number of different elements of the research. Section two provides a critical account of the methodology, including research paradigm, data collection and data analysis. Reflections on the ethical issues are included. Section three focuses on the distinct contribution to knowledge, originality of the research and future research directions. Finally, section four provides a brief personal reflection on the research process and how this has impacted on the professional development of the researcher.

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Part A: Major Literature Review

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1.0 Introduction

The death of a parent or someone close is a profound and challenging life experience for any child. Over the last decade, the panorama of care and provision for childhood bereavement has been significantly enriched. This has largely been attributed to a significant growth of interest within psychological literature and pioneering organisations which have raised the profile of bereaved children within the UK (Penny, 2010). Despite an increase in awareness of childhood bereavement and the growth of services to support children with their grief, the impact of bereavement for children with learning and/or neurodevelopmental disabilities (L/ND) has been largely neglected within psychological research (Markell & Hoover, 2010). This dearth has further been reflected in current professional practice with the needs of this population remaining largely unmet by leading services and thinkers in the field (McEnhill, 2010). The lack of research and of adequate support services is particularly concerning considering that adjustment to bereavement may be especially difficult for children with L/ND, who experience a wide range of impairments that may exacerbate the hardships of grief.

1.1 *Structure of the literature review*

Following clarification of key terms, the literature review will commence with a critical discussion of contrasting theoretical models of bereavement and grief with a specific focus on the developmental context of childhood. This provides an appropriate background to the following section which outlines the empirical research into child bereavement including ‘common’ and ‘pathological’ manifestations of grief. This leads succinctly into the next section which presents further research evidence exploring risk and resilience in bereaved children and variables which contribute to coping, adaptation or prolonged psychological disturbance.

Given the dearth of research into bereavement for children with L/ND, although limited, the next section focuses on the research evidence for bereaved adults with L/ND including some exploration of ‘common’ and ‘pathological’ grief responses. Finally, utilising this evidence base, and the research with children, the final section considers some variables that may impact on risk and resilience for children with L/ND. Overall, this review builds the argument that there is a gap in the literature with regards to exploring bereavement, risk and resilience in children with L/ND. It will culminate in the rationale for the current study, including research questions and aims.

1.2 Searches and sources of information

The literature was reviewed and compiled through the use of various online search facilities including Google Scholar, PsycINFO, Science Direct and WileyInter-Science. Key text books on child bereavement were also utilised. The literature search was completed in November 2017 so research conducted after this date is not included. Whilst the review provides an extensive overview of relevant research, it was not possible to carry out an exhaustive review. Therefore, the research deemed most pertinent to the current study is presented. For a detailed description of search terms please see Appendix M.

1.3 Key definitions

Children with learning disabilities are by no means a homogeneous group, with there being substantial differences in the experience, environment, personality and ability of these individuals (Dodd, Dowling & Hollins, 2005). Nevertheless the term will benefit from clarification. When referring to learning disabilities there are often a variety of definitional issues and confusion between terms (e.g., learning difficulties/learning disabilities/intellectual disabilities/developmental delay) and between formal and less formal classification systems including mild, moderate, severe and profound (Rossiter & Armstrong, 2015). Defining what is meant by the term learning disabilities can therefore be a complex task. Without entering into lengthy discussion about the issues of diagnostic procedures and discourses of disability, the definition that will be used throughout this thesis has been taken from Rossiter & Armstrong (2015). For them, this encompasses a range of abilities and disabilities relating to cognitive impairment (typically a score lower than two standard deviations below the mean on a validated test of general cognitive functioning) and adaptive behaviour (communication, interpersonal skills, daily independent living, and community participation). These conditions are irreversible and manifest during early child development.

There is an important distinction between that of learning disabilities and neurodevelopmental disabilities. Although the latter term is not well defined, it can be used to refer to a wide range of difficulties that are understood to have a neurodevelopmental basis. According to Hunt & Craig (2015), neurodevelopmental difficulties can include autism spectrum conditions (ASC), attention deficit conditions (including ADHD and ADD), social communication disorders, foetal alcohol spectrum disorders, Tourette's syndrome, and motor co-ordination difficulties. Differentiation is necessary as children with neurodevelopmental difficulties do not always experience impairments in cognitive functioning.

This research also focuses on a specific life event for children with L/ND, the experience of bereavement. Within the study of thanatology (e.g., the scientific study of death), there are often discrepancies in the usage of terms such as bereavement, grief, coping and mourning (Corr, Nabe & Corr, 2000). The term ‘bereavement’ is generally understood as the state of having experienced the loss of a close relationship (Rando, 1995), and this definition corresponds with the accepted practice of describing an individual as ‘bereaved’, rather than ‘bereaving’ (Servaty-Seib, 2004). The term ‘grief’ however describes the passive and involuntary reaction to the state of bereavement. Rather than being a purely emotional state, grief is often associated with complex responses which span the affective, cognitive, physical, behavioural, social and spiritual domains of human functioning (Corr et al., 2000). ‘Coping’ is generally understood to encompass “the person’s cognitive and behavioural efforts to manage (reduce, minimise, master or tolerate) the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the resources of the person” (Folkman, Lazarus, Gruen & De Longis, 1986, p. 572). Finally, the term ‘mourning’ involves the active process of coping with bereavement and grief (Rando, 1995).

2.0 Conceptualising bereavement, grief and coping

Grief is fundamental to human life and in many ways can be considered a normal and natural consequence of forming close emotional bonds and attachments to other people (Hall, 2014). Since the early 1900's, numerous theories have been forwarded to increase our understanding of the human experience of grief. At this stage it is important to distinguish between *general theories of grief*, that explain manifestations and processes of grief from *models of coping*, which distinguish and elucidate adaptive versus maladaptive ways of grieving. The following section will provide a brief overview of some theories of grief and models of coping that have received the most prominent attention within bereavement literature.

2.1 Psychoanalytic theory

The first major theoretical contribution on grief was provided by Freud (1917/1957) in his paper *Mourning and melancholia*. This has been a highly influential approach that has profoundly shaped professional intervention (Hall, 2014). Freud proposed that 'grief work' involved a process of severing ties and de-investing libidinal energy from the deceased person. This involved three elements: (a) freeing the individual of their bond with the deceased; (b) readjustment to a new life without the deceased; and (c) forming new relationships. Freud believed that this gradual detachment involved an energetic process of reviewing the past and dwelling on memories of the deceased, including acknowledging and expressing painful emotions like anger and guilt. The grief work model stresses the importance of 'moving on' as quickly as possible in order to return to a normal level of functioning. For Freud, if an individual failed to engage in their grief work then this could lead to a complicated grieving process that increased the risk of psychological disturbance and compromised overall recovery. Despite receiving much critical examination (e.g., Stroebe & Schut, 1999), the grief work concept retains its theoretical and practical significance.

2.2 Stages of grief

Borrowing concepts from Freud (1917/1957), several later theorists conceptualised grief as proceeding along a series of predictable stages and phases. The best known model is one postulated by Kubler-Ross (1969) which suggested that individuals proceed through five stages of grief: (1) shock and denial; (2) anger, resentment and guilt; (3) bargaining; (4) depression; and (5) acceptance. Similar to Freud, Kubler-Ross (1969) suggested that if individuals failed to complete the stages of grief, then complications would occur. However, this model has been

heavily criticised for proposing that individuals need to move through a sequence of fixed stages, and as a result, it has largely been empirically rejected (Hall, 2014).

2.3 Attachment theory

Stemming originally from a psychodynamic tradition, concerned with the impact of temporary separation from parents on the developing child, attachment theory evolved to include a focus on the biopsychosocial transitions caused by the permanent separation from a loved one through death (Bowlby, 1980). Drawing on ethological and social scientific research on the attachment behavioural system, researchers in this tradition have outlined the functions served by maintaining proximity to an attachment figure who provides safe haven at times of threat, and a secure base from which to explore the environment (Field, 2006). Of course, death of an attachment figure represents the ultimate threat to this relationship. Bowlby (1980) suggested that grief is an instinctive, universal response to separation where an attachment has been broken and typically triggers a prolonged process of protest, despair, and reorganisation as the individual attempts to adapt to the loss.

In terms of coping and adaptation to loss, similar to Kubler-Ross (1969), Bowlby (1980) proposed that individuals needed to complete their 'grief work' by negotiating a sequence of overlapping phases: shock and numbness, yearning and searching, despair and disorganisation, reorganisation and recovery. Classically, this process was considered to encourage detachment of emotional investment in the bond of the deceased in order to permit adaptation through investment in new relationships (Freud, 1957). However, it is worth noting that Bowlby (1980) was ambiguous about whether detachment from or continued attachment to the deceased was the more adaptive course of bereavement (Servaty-Seib, 2004). In a revision of attachment theory and grief, Fraley & Shaver (1999) maintained that in his later writings, Bowlby (1980) allowed for both the disconnection and the maintenance of a connection to the deceased. Either way, many have concluded that from an attachment perspective, the critical goal of grief is acknowledging change in the nature of the bond, rather than its severance (Schut & Stroebe 2005). From this perspective, working through a sequence of phases allows individuals to maintain a secure bond with the attachment figure while simultaneously acknowledging that the person is not physically available to provide security, comfort and care.

2.4 The task model

Rather than being a theory of grief as such, the task model represents an intrapersonal bereavement-specific coping model. Specifically, Worden's (1996a) 'Tasks of Mourning'

model has been important in understanding the process of coping adaptively with bereavement. For Worden (1996a), the grief process is viewed to encompass four unique tasks; to accept the reality of the loss, to work through the pain of grief, to adjust to an environment in which the deceased is missing, and to emotionally relocate the deceased and move on with life. In contrast to psychoanalytic and attachment perspectives, this model represents coping as a far more dynamic process because the griever actively works through grief rather than passively experiencing it, something which represents a more realistic experience of grief in the reports of bereaved adults (Stroebe & Schut, 1999). However, it is evident that not all grievers will undertake all of these tasks, nor will they do so in this specific order. Indeed, Worden (2002) argued for a fluid understanding of the task model, one in which these tasks can and do exist simultaneously and can be revisited over time (Servaty-Seib, 2004).

2.5 Continuing bonds

In more recent times, there has been a movement away from the idea that successful grieving entails ‘letting go’ of the deceased. The work of Klass, Silverman & Nickman (1996) suggests that it is actually normative and adaptive for bereaved individuals to accommodate to loss through maintaining a dynamic connection to the deceased through a ‘continuing bond’. This concept represents recognition that death ends a life, not necessarily a relationship, and so allows for the deceased to be both present and absent in the lives of the bereaved. This continuing bond is conscious, dynamic and ever-changing and can be expressed in a multitude of different forms (relocating the deceased, visiting the grave, participating in rituals or linking objects, feeling the presence of the deceased and talking to the deceased for example). Rather than resulting in pathology (Freud 1917/1957), continuing bonds in this way is thought to provide bereaved individuals with “solace, comfort and support and eases the transition from past to future” (Klass et al., 1996, p. xvii).

Nonetheless, assumptions should not be made that continuing bonds are necessarily *always* healthy and adaptive. Recent research has identified forms of continuing bonds which actually represent a failure to integrate the loss due to extreme denial and avoidance in processing the loss and its implications (Field, 2006). Consistent with Bowlby’s (1980) attachment framework, growing evidence suggests that individuals with an insecure-ambivalent attachment style, who tend to be clingy and anxious in relationships, may be more likely to experience a prolonged grief reaction, contributing to maladaptive rather than adaptive forms of continuing bonds (Fraley & Shaver, 1999). In essence, a healthy and adaptive continuing

bond is one in which individuals are able to accept their loss and remain allied to the deceased through an internalised, symbolically-based connection (Hall, 2014).

2.6 The dual process model

Rather than a completely novel framework, Stroebe & Schut (1999) describe their ‘Dual Process Model’ (DPM) of coping as an integration of existing ideas and acknowledge the influence of general grief theories (e.g., Freud 1917/1957; Bowlby, 1980) and other models of coping (e.g., Worden, 1996; Klass et al., 1996). However a distinct difference of this approach is that, although individuals need to experience grief and the pain associated with it, Stroebe & Schut (1999) proposed that they also need to take time out from grieving specifically. The DPM proposes that grief is a process of oscillation between two contrasting models of functioning: ‘loss orientation’ and ‘restoration orientation’. The former refers to the griever focusing on the death, exploring and expressing a range of emotional responses associated with their loss. This might be something which is consistent with Freud’s (1917/1957) concept of ‘grief-work’. The latter however refers to a focus on secondary stressors, including diversion from the loss and attention to ongoing life and its demands. For the DPM, adaptive coping involves oscillation between loss versus restoration-orientated coping:

At times the bereaved will confront aspects of loss, at other times avoid them, and the same applies to tasks of restoration...what emerges is a complex regulatory process of confrontation and avoidance (which is considered) necessary for adaptive coping (Stroebe & Schut, 1999, p. 395).

Through this concept of oscillation, the DPM maintains the benefits of two of the most difficult to reconcile aspects of grieving and coping; the desire to remain connected to the deceased and the need to move on with life (DeSpelder & Strickland, 2002).

2.7 Reflection

Since Freud’s initial (1917-1957) contribution, the field of grief and bereavement has undergone a transformational change in terms of how the human experience of loss and coping is understood. Specifically, there has been a shift away from the concept that successful grieving requires ‘letting go’ of the deceased, and a move towards the recognition of the potentially adaptive role of maintaining continued bonds with the deceased. Although these approaches have gone some way in increasing our understanding of the unique and multifaceted grief experience, no ‘one-size-fits-all’ theory, model or approach to grief is

justifiable and as *Rolls (2000)* concludes, there are no ‘true’ theories or models that can accurately describe the experience of personal loss, and the emotions, experiences and cultural practices that characterise grief and adaptive coping.

In terms of the latter criticism by *Rolls (2000)*, none of the approaches appear to have a socio-cultural aspect. The theories and models presented largely represent a Western conception of death and grief. However, cultures vary considerably in how they conceptualise death and what happens when a person dies. In some cultures, death is conceived to involve different conditions (e.g., sleep, illness and reaching a certain age) whereas in other cultures death is said to only occur when there is complete cessation of life. Similarly, certain cultural traditions view death as a transition to other forms of existence whilst others propose a continuous interaction between the dead and the living. Finally, some cultures conceive of death as a circular pattern of multiple deaths and rebirths whereas others view death as the final end. Undoubtedly, these different conceptions have a profound influence on people’s expressions of grief, coping and mourning (*Gire, 2014*).

In addition, these approaches have largely been developed for adults rather than children. In a review of theoretical perspectives, *Rolls (2010)* contends that there has been little theorising of childhood bereavement in a way that is similar for adults, and that often adult-based theories are applied when trying to understand the discrete processes of childhood grief and coping. This constitutes a risk of imposing adult conceptions on children and overlooks the fact that children are undergoing development of important brain areas involved in emotion and cognition, as well as rapidly experiencing new life events (*Dyregrov & Dyregrov, 2013*). The next section will therefore consider how a child’s grief and coping mechanisms may differ in light of fundamental developmental differences.

3.0 Grief, coping and the developmental context of childhood

There has been a lengthy and often contradictory debate among theorists as to when children acquire the capacity to grieve following bereavement. On one side, early clinical theorists raised scepticism about the relevance of grieving for children at all (Wolfenstein, 1966), believing that this capacity cannot be acquired until adolescence. On the other side of the debate, in his consideration of the effects of attachment on early childhood development, Bowlby (1980) provided the first theoretical framework for the proposition that young children can and indeed do grieve following the separation from, or loss of, an attachment figure. This exists very early (around the age of six months), and may even predate a realistic concept of death (Worden, 1996b). Overall, it now appears widely accepted that bereaved children undertake some form of grieving process, although there is still no clear definition of what constitutes ‘normal’ or ‘complicated’ grief in children (Dyregrov & Dyregrov, 2013).

Manifestations of grief, including the availability of certain coping mechanisms, are undoubtedly related to a child or young person’s cognitive, emotional and social development (Worden, 1996b; Dyregrov, 1999; Oltjenbruns, 2001). As a result, although bearing some similarity to an adult’s bereavement reaction, “...children’s grief differs in the constellation of responses, their intensity, and their duration” (Deveau, 1997, cited in Oltjenbruns, 2001). Grief and coping are therefore exclusively unique to a child’s developmental capacities, with a stage of development providing a foundation for their response to loss. Although primarily based on adult’s responses to bereavement, Worden’s (1996a) ‘Tasks of Mourning’ model has been modified and extended to childhood grief and coping by a number of different theorists (Baker, Sedney & Gross, 1992) This section will therefore employ Worden’s (1996a) approach to critically consider how a child’s grief and coping may differ to that of an adult’s, focusing on four pertinent developmental factors:

- Cognitive development and death understanding
- Immature coping mechanisms
- The re-grief phenomenon
- The developmental significance of ‘Continuing Bonds’

3.1 Cognitive development and death understanding

According to Worden (1996a), the first stage of mourning for adults involves accepting the reality of the loss itself. Although adults can struggle with feelings of disbelief, over time, they come to realise and accept that their loved one is not coming back (Worden, 1996a). Although this might also be the task for children, it requires a clear and detailed understanding of the concept of death itself (Baker et al., 1992). However, striving to understand death is an extremely difficult task for children. It is a highly abstract concept that incorporates multifaceted conceptual understandings, social and cultural beliefs, personal and emotional issues, and religious assumptions (Slaughter, 2005). In the majority of cases adults can recognise that death comes to all living things, is the final stage of the life cycle, is inevitable and irreversible and is ultimately caused by the breakdown in the functioning of the body. However, a child's understanding (or misunderstanding) of these concepts of death is likely to be confounded by his/her maturity which is related to age, cognitive ability and life experiences (Dyregrov, 1991).

Between 1960 and 1970, a wave of research emerged primarily from the Piagetian tradition, focusing on the cognitive aspects of children's conceptual understanding of death. To investigate children's death concepts, researchers delineated subcomponents of death understanding and carried out structured interviews to evaluate their capacity to answer questions correctly that tapped these various elements of the death concept (Slaughter, 2005). Although there is some variation in the different sets of subcomponents proposed by researchers, a review of over 100 research studies concluded that there are four principle subcomponents involved in developing a complete cognitive awareness of the concept of death: irreversibility, finality, inevitability and causality (Speece & Brent, 1996). A mature understanding of death was defined as a mastery of all of these subcomponents. Across the studies, a fairly consistent developmental pattern emerged. The more concrete, clearly defined subcomponents (e.g., universality and irreversibility) are acquired first between the ages of five or six years (Koocher, 1973; Speece & Brent, 1996). However, the relatively complex and more abstract subcomponents (e.g., inevitability and causality) are acquired later (Koocher, 1973). Researchers within this tradition concluded that children do not achieve a full understanding of all subcomponents of death, and therefore lack a mature understanding of the concept, before the age of seven at the earliest (Corr et al., 2000).

It was further proposed that the development of an understanding of death and full subcomponent acquisition largely parallels general aspects of children's cognitive development (Koocher, 1973; Speece & Brent, 1998). With the advent of what Piaget (1959) termed 'concrete operational' development (ages 7-11), children can perform the majority of cognitive tasks that are required for a comprehensive understanding of death (e.g., classification abilities; the ability to perform transformations and reversible operations; a linear notion of time; the universal application of rules and reciprocity skills). At this stage it is assumed that children hold an adult view of death as inevitable and the universal final stage in the life cycle of all living things, characterised by the cessation of biological bodily functions (Speece & Brent, 1985). Indeed, in more recent times, understanding the concrete, biological elements of the life cycle has been highlighted as pivotal in facilitating a mature adult view of death (Slaughter, 2005).

Despite these assumptions, researchers have questioned the utility and validity of assimilating developmental changes in death understanding to Piagetian stages (Speece & Brent, 1984; 1996). Despite a general consistency in findings, the research still lacks specificity about why the achievement of a certain Piagetian stage is necessary for the achievement of a particular level of understanding of the death concept. Studies often lack a detailed description of the specific cognitive abilities that are implicit in developing a mature understanding of each subcomponent of the death concept. Finally, Piagetian theory emphasises the development of context-independent reasoning abilities. Modern research suggests that children who have direct prior experience of illness or death show relatively advanced cognitive understanding of the subcomponents of the death concept (Bonati, Leondari & Mastora, 2013). Other individual differences including a child's distinctive personality, their gender, socio-cultural background, socio-economic status and spiritual/religious beliefs may also impact how they think about death and their understanding of specific subcomponents (Corr et al., 2000; Slaughter, 2005).

3.2 Immature coping mechanisms

According to Worden (1996a), for adults the second stage of mourning involves experiencing the pain or emotional aspects of the loss. However, Oltjenbruns (1999) contends that a child's developmental immaturity (e.g., immature cognitive-language capacities, constricted life experiences, shorter attentions spans) limits his/her repertoire of coping strategies, particularly at a young age. For example, young children do not have the language capacity to describe their feelings and emotions or draw comfort from spoken statements in the same way that adults

can. Differences in these developmental capacities mean that children frequently communicate their needs with others in behavioural or symbolic terms including regression to an earlier developmental stage, repression, denial, displacement and acting out behaviours (Dyregrov, 1999).

Many theorists further hold that children often fluctuate between experiencing brief emotional aspects of their loss and engaging in new activities. In clinical practice, this has been referred to as the 'puddle-jumping' phenomenon (Stokes, 2009). This brings into mind the theoretical framework of the DPM (Stroebe & Schut, 1999) that describes adult coping as oscillating between 'loss orientation' and 'restoration orientation' and therefore, this model may hold some merit in its application to a child's grief response, particularly in early and middle childhood (Brickell & Munir, 2008). From this perspective, because they experience death differently to adults, maybe children do not need to experience the intense pain and emotionality of loss in quite the same way.

Finally, a child's emotional response to loss is also highly influenced by socialisation in that children learn through observing others around them (e.g., *Social Learning Theory*, Bandura & Walters, 1963). A child's ability to process the pain and emotionality of a loss will therefore be influenced by observing the adult's experience of this process (Worden, 1996b). Children often mirror the types of coping or communication styles modeled by adults or significant attachment figures (Bowlby, 1980). If the child observes the adult expressing his/her grief without becoming overwhelmed, this can serve as a healthy model for the child's grief response. On the other hand, if a child observes adults dysfunctional with grief, he/she may respond by constraining his/her emotional reactions (Worden, 1996b).

3.3 *The re-grief phenomenon*

For Worden (1996a), the third stage of mourning for adults involves adjusting to an environment in which the deceased is missing. However, for children, this adjustment is likely to be more complex and continually shifting due to ongoing developmental changes (Oltjenbruns, 1999). As children mature and move into late childhood, their understanding of death and perceptions of the world change. New capacities develop and they begin to process the experience of the bereavement from a different vantage point than was possible at an earlier stage of development (Himebauch, Arnold & May, 2008). Loss of an important person therefore can vary in significance, and be interpreted in different ways depending on the child's developmental stage (Oltjenbruns, 2001). For example, a very young child may experience

separation distress from an attachment figure, grieving the loss of them as provider and nurturer (Bowlby, 1980), whilst an adolescent may struggle with the loss of a parent in relation to his/her own self-identity (Harrison & Harrington, 2001). In this sense, children's developmental needs partially define the significance of a loss during a particular life stage with earlier losses being revived or 'regrieved' during different stages of development (Cook & Oltjenbruns, 1998). Therefore, rather than adjusting to an environment without the deceased (Worden, 1996a), the task for children might be more accurately defined as: a) to cope with the periodic resurgence of pain, b) to re-evaluate the relationship to the person who has died c), to develop a new sense of identity that incorporates the experience of the loss (Baker et al., 1992).

3.4 The developmental significance of continuing bonds

Worden (1996a) contends that the final task for adults is to find a new and appropriate place for the deceased in their emotional lives, one that enables them to go on living effectively in the world. Many have contended that, in order to do so, adults benefit from maintaining a dynamic connection to the deceased through a continuing bond (Klass et al., 1996). Similar to adults, as children try to cope with their grief, they typically find themselves looking both backward, to the death event itself and what they have lost and forward, to what all these events will mean for their present and future lives. Quite often, these coping processes will be aided by efforts to maintain an ongoing connection to the individual who has died (Corr et al., 2000). These connections involve continuing bonds through developing an internal representation of the deceased so that they have an on-going presence in the life of the bereaved child. Evidence from clinical casework suggests that children use a variety of strategies to retain a continuing bond with the person who died (Stokes, 2009). As discussed above, these strategies will change over time as the child negotiates and renegotiates the meaning of his/her loss (Silverman, Nickman & Worden, 1992). It has been proposed that maintaining emotional investment in the dead parent enables children to uphold and continue normal developmental processes (Oltjenbruns, 2001), and so helps a child to move on in constructive living (Corr et al., 2000).

4.0 Childhood grief: empirical research evidence

A plethora of empirical research has been published in the area of childhood bereavement. Because it is not possible to thoroughly explore all of these in this literature review, the focus will be on two interrelated and highly researched areas: common manifestations of grief and the pathological grief response. Before this however, it is important to highlight some general critiques of methodologies used to study childhood bereavement. Despite there being a significant number of studies published in regard to this subject, research findings can often be contradictory, and therefore present an inconclusive and confusing perspective of a child's experience of grief and its related outcomes (Oltjenbruns, 2001). As a result, there continues to be no clear understanding of how a child grieves (Dyregrov & Dyregrov, 2013). In part, this is due to serious methodological limitations of childhood bereavement research, which are summarised in Table 1.

Table 1. General critique of methodology used in childhood bereavement research

Sources: Worden (1996b), Oltjenbruns (2001), Dowdney (2000), Haine, Ayers & Wolchik (2008), Brewer & Sparkes (2011)

	Methodological issues
Research design	<ul style="list-style-type: none"> ▪ Retrospective in nature and gathered years after the death (depends on participants' memory of the bereavement which may be different to the reality). ▪ Most studies are cross-sectional in design with few longitudinal, prospective approaches. In terms of childhood bereavement, longitudinal designs are desirable as children are always growing and developing, with adaptation to loss being a process that takes place over time (Baker et al., 1992). ▪ Shortage of qualitative studies specifically looking at the bereavement experiences of children and young people. ▪ Rather than the child, parents are often the informants on their child's grief reactions (Brewer & Sparkes, 2011). Reviews by Dowdney (2000), and Haine et al. (2008) suggest that parents report fewer symptoms and disorder in their children than children do themselves
Sample	<ul style="list-style-type: none"> ▪ Small in size. ▪ Failure to use demographically matched non-bereaved control groups. ▪ Use of non-representative, clinical-based populations. ▪ Lack of representation from minority groups. ▪ Samples often cross developmental sub-stages include various types of death and timeframes since the death occurred. These are often discounted from analysis and interpretation.
Data collection	<ul style="list-style-type: none"> ▪ Lack of standardised assessment tools (makes it difficult to compare across studies). ▪ Assessment tools rarely measure 'grief' per se (depression, general health etc.).

	<ul style="list-style-type: none"> ▪ Many data gathering techniques reflect a narrow focus on childhood bereavement rather than reflecting the multiple dimensions of grief.
Data analysis	<ul style="list-style-type: none"> ▪ Even when variables are identified that are likely to have an effect on outcome (e.g., developmental stage, time since death, suddenness of death), they are rarely mentioned in relation to bereavement outcome.
Interpretation	<ul style="list-style-type: none"> ▪ Little attention to mediating factors (risk/protective) or confounding variables such as developmental stage. ▪ Most researchers do not report (or even know) the level of functioning or emotional state prior to the death.

Empirical research has been conducted with stronger methodologies. The most extensive research project on child bereavement to date is the Harvard Childhood Bereavement Study, implemented by Silverman, Worden and colleagues in the 1990's. This was a prospective piece of research, conducted over a two year period, which aimed to gain a clearer picture of childhood bereavement and identify specific behaviours that were overrepresented in bereaved children when compared with controls. It involved a non-clinical sample of 125 bereaved children, between the ages of six and seventeen who were compared with a non-bereaved control group, matched by age, gender, family religion and community. Both the child and surviving parent were included as informants and the researchers adopted a range of measurements including semi-structured interviews and checklists that aimed to assess children's grief responses including death understanding, locus of control, self-perception, depression and behaviour as well as more systemic factors including family adaptation, cohesion and life events. This research has been largely regarded as a hallmark study in childhood grief and bereavement (Oltjenbruns, 2001), and since its publication, a number of researchers have drawn subsets of data from the larger pool collected to examine various facets of childhood grief (e.g., Silverman & Worden, 1992; Silverman, Nickman & Worden, 1992; Worden & Silverman, 1996). The following section will therefore include the key findings from the Child Bereavement Study with a consideration of more current empirical research evidence and studies which have employed qualitative methodologies to explore the unique and distinctive experiences of bereaved children and young people (Brewer & Sparkes, 2011).

4.1 *Common manifestations of grief*

Although there has been a lack of methodologically rigorous studies that explore childhood grief and bereavement, certain consistencies have emerged within the literature (Dowdney, 2000; Akerman & Stratham, 2014). Common manifestations of grief among children are frequently divided into three major areas: emotional, behavioural and physical. Table 2

includes a list of grief reactions commonly exhibited by children as identified within the literature.

Table 2. Common manifestations of grief among children

Sources: Silverman & Worden (1992), Worden (1996b), Dowdney (2000), Oltjenbruns, (2001), Haine et al., (2008), Akerman & Stratham (2014)

Emotional	Behavioural	Physical (somatic)
<ul style="list-style-type: none"> ▪ Sadness ▪ Mild depression ▪ Separation distress ▪ Anxiety (about death and safety of surviving parent and personal safety). ▪ Guilt ▪ Anger ▪ Helplessness ▪ Feelings of isolation and difference ▪ External locus of control ▪ Low self-esteem ▪ School problems (e.g., phobia, learning difficulties) 	<ul style="list-style-type: none"> ▪ Regression ▪ Crying ▪ Magical thinking ▪ Acting out ▪ Tantrums ▪ Withdrawal ▪ Nightmares ▪ Disinterest in play ▪ Overdependence ▪ Clingy ▪ Prone to accidents 	<ul style="list-style-type: none"> ▪ Headaches ▪ Stomach aches ▪ Loss of appetite ▪ Bedwetting ▪ Sleep difficulties ▪ Illness

Interviews with bereaved children and their parents reveal marked affective, behavioural and physical responses to death (Worden, 1996b; Dowdney, 2000; Haine et al., 2008). Certain manifestations of grief appear to be more prevalent during early and middle childhood including regression, separation distress, helplessness, somatisation and magical thinking related to guilt over causing death or thinking that the deceased can return. In contrast, school problems and anger appear to be more prevalent during late childhood (Oltjenbruns, 2001).

Two crucial insights from the Harvard Bereavement Study were that a) children's grief reactions often appeared more intermittent in character than those of many adults and that b) they were often prone to late effects of bereavement. For example, the majority of differences between the two groups (bereaved and non-bereaved) were not apparent until two years following the death. In terms of serious dysfunctional behaviour, Silverman & Worden (1992) found little difference between the two groups at the one-year mark but when the time frame was increased to two years, (Worden & Silverman 1996) found higher levels of social withdrawal, social problems, anxiety, as well as lower levels of self-esteem and self-efficacy,

in the bereaved group compared with the control group. This clearly has implications for researchers as methodological designs that collect data during the time-frame immediately after the death will not be sensitive to the possibility of delayed grief reactions.

Overall, the research findings suggest that, most commonly, children present with an extremely wide range of emotional, behavioural and physical symptoms that constitute a ‘nonspecific disturbance’ (Dowdney, 2000). Although the majority of children experience some of these grief responses, it is unlikely that they will experience all of them. Indeed, there is considerable variation in the intensity and duration of responses which is often mediated by a number of different variables (Haine et al., 2008), which will be covered in a later chapter. Generally, it is thought that initial grief reactions abate over time with children adapting well and not experiencing any serious long-term difficulties (Worden & Silverman, 1996; Melham, Porta, Shamsedden, Payne & Brent, 2011). However, reviews of the literature indicate that parental death does place children at some degree of risk of negative outcomes (Dowdney, 2000; Haine et al., 2008). Findings from the Child Bereavement Study revealed that a significant minority of children (33%) were at some degree of risk for high levels of emotional and behavioural problems (Worden, 1996b) and it has been proposed that around one in five parentally bereaved children are likely to manifest clinical level symptoms that extend beyond a year and require referral to specialist services (Stokes, 2009; Melham et al., 2011).

4.2 Grief and mental health disorders

Although the grief responses cited above are considered a normal, natural and somewhat inevitable response to bereavement, it is now accepted that grief may, in certain cases, be deeply distressing, persistent and functionally impairing (Akerman & Stratham, 2014). Early childhood bereavement research linked parental loss with the development of psychiatric disorders both during childhood and in later adult life (Rutter, 1966). Associations between parental death and subsequent psychological maladjustment continue to receive support with research finding parentally bereaved children to be at greater risk of depressive symptoms and depression (Harrington & Harrington, 2001; Mack, 2001), attempted suicide (Wilcox, Kuramoto, Lichtenstein, Långström, & Brent, 2010; Jakobsen & Christiansen, 2011) and hospitalisation for all types of psychiatric disorder (Wilcox et al., 2010). However, there is little evidence of generalised anxiety disorder in bereaved children. Often, children give accounts of increased anxiety but this tends to be confined to specific concerns around the safety of the

surviving parent and separation anxiety from their remaining attachment figure (Dowdney, 2000).

The validity of the link between early parental death and the onset of psychiatric problems in adulthood has been challenged. Research data linking early loss to psychiatric disorders are often conflicting and only suggestive. Indeed, a significant number of studies have contradicted the findings presented above (Akerman & Stratham, 2014). The difference in conclusion is often attributed to methodological flaws of child bereavement research, including a reliance on retrospective data and clinical hospital samples, the use of inadequate control groups and a lack of attention to mediating variables (Dowdney, 2000; Oltjenbruns, 2001). This means that it is difficult to establish whether or not psychiatric conditions were present before the bereavement and creates difficulty with disentangling the impact of bereavement from other life events as the passage of time since the death increases (Christ, 2000). Methodological shortcomings continue to be emphasised in more current reviews of childhood bereavement (e.g., Akerman & Stratham, 2014), with many studies concluding that it is not feasible to draw any tangible conclusions about the causal relationship between childhood bereavement and subsequent mental health conditions. At most, it is understood that parental bereavement in childhood can be a significant stressor, which could lead to symptoms of depression, particularly when paired with certain risk factors including parental depression in the surviving parent and other family-related stressors (Cerel, Fristad, Verducci, Weller & Weller, 2005).

4.3 Complicated grief or prolonged grief disorder

Over the past decade, there has been recognition of a pathological grief-related syndrome in adults that has been referred to within bereavement literature using a plethora of different terms including grief that is: Complicated (Prigerson et al., 1999), Abnormal (Pasnau, Fawney & Fawney, 1987), Morbid (Sireling, Cohen & Marks, 1988) and Traumatic (Horowitz, et al., 1997). In the late 1990's two research teams independently published a set of diagnostic criteria to assess this disorder. Whilst Prigerson et al. (1999) laid emphasis on separation distress symptoms (Bowlby, 1980), including longing and searching for the deceased, pre-occupation with thoughts of the deceased and difficulty accepting the death, Horowitz, et al. (1997), centred more on the traumatic elements of the disorder. Recently, these two diagnostic entities were integrated and the concept of 'Complicated Grief' (CG) was renamed as 'Prolonged Grief Disorder' (PGD) (Hall, 2014). Currently, PGD is thought to describe experiences of certain

grief related symptoms at a time beyond what is considered to be adaptive (Dodd, et al., 2008). This includes:

A combination of separation distress and cognitive, emotional and behavioural symptoms that can develop after the death of a significant other. The symptoms must last for at least six months and cause significant impairment in social, occupational and other important areas of functioning (Hall, 2014, p. 4).

Research suggests that CG or PGD occurs in around 10% of all bereaved people (Prigerson, et al., 1999), with higher rates among those bereaved by disaster or violent death (Shear et al., 2011). The symptoms of CG or PGD have been found to be distinct from normal grief reactions, any comorbid depression, PTSD and other anxiety disorders (Shear et al., 2011). Resultantly, there was strong support for including CG or PGD as a distinct diagnostic entity within the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). However, it failed to be included in the DSM-5. The most recent edition has included a ‘candidate’ disorder within the appendix named ‘Persistent Complex Bereavement Disorder’ (PCBD) which has been established to encourage further investigation and research (Hall, 2014).

Given that there is not enough evidence to fully specify the features of CG or PGD in adults (Hall, 2014), knowledge and understanding about this disorder in children is extremely limited (Dyregrov & Dyregrov, 2013). In terms of direct research with children, Melham and colleagues have made some advances in our understanding of CG symptoms within this population. In an on-going longitudinal study of 129 children bereaved through sudden parental death, Melham et al. (2011) found that 10.4% of the sample showed high and sustained prolonged grief manifestations nearly 3 years after the death. Furthermore, grief scores were associated with functional impairment beyond other psychiatric conditions like depression, anxiety and PTSD. They concluded that, convergent with findings in bereaved adults, CG or PGD was found to be a clinically significant and distinct syndrome. The symptoms of CG were also found to be similar to the adult consensus criteria of CG outlined above (e.g., intense yearning and longing for the person; preoccupation with thoughts of the deceased).

Conversely, other researchers have paid more attention to the traumatic symptoms of CG. For example, in their studies of traumatically bereaved children, Mannarino & Cohen (2011) posited that intrusive and distressing trauma-related thoughts, memories and images actually encroach on the child’s ability to grieve. These symptoms were also found in a sample of children bereaved of a parent through the September 2011 attacks on the World Trade Centre

in the US (Brown & Goodman, 2005). Therefore, rather than experiencing separation distress and a prolonged grief reaction, trauma symptoms might preclude the child's ability to reminisce about their loved one entirely.

Rather than focusing on specific symptoms, some researchers have found it more useful to consider the developmental context of childhood (e.g., Worden, 1996b; Oltjenbruns, 2001). They suggest that when the child's social, emotional, or physical capacities indicate signs of prolonged interference, the grief process can justifiably be considered 'complicated'. Using questionnaires to delineate CG in children, Dyregrov & Dyregrov (2013) found support for this proposition. According to a group of experienced clinicians, whilst normal grief allows for growth and change, CG forces the child to remain in a static state, with development becoming inflexible or frozen.

Despite attempts to define and explore CG in children, there continues to be no clear definition of what constitutes CG for this population (Dyregrov & Dyregrov, 2013). At most, it is thought that both a prolonged or traumatic grief response can interfere with adaptive grieving processes and can therefore cause difficulty for children with completing the tasks of grieving as previously highlighted by Worden (1996a).

5.0 Risk and resilience in bereaved children: empirical research evidence

The empirical research evidence indicates significant variation in child outcomes following parental death. Whilst some children adapt well and even thrive, finding new resources and strengths in response, others struggle to cope at all and appear more vulnerable to on-going emotional difficulties and disturbances including CG (Haine et al., 2008; Stokes, 2009). The study of childhood risk and resilience focuses on identifying the transactional processes that account for positive and/or negative adaptation following significant life adversities (Luther, Cicchetti, & Becker, 2000). A plethora of studies have investigated variables that differentiate bereaved children who manifest clinically significant symptoms from those who do not (Haine et al., 2008). Some can be considered as *moderating* the outcome (e.g., they exist prior to the death), whilst others can be considered as *mediating* the outcome (e.g., those which typically exert influence after the death). Rather than being considered alone, it is important to highlight that all variables will overlap and interact in dynamic, multifaceted and subtle ways (Dowdney, 2000; Haine et al., 2008).

5.1 *A positive parent-child relationship*

A secure attachment and positive relationship with the surviving parent has been found to be pivotal in building resilience and fostering positive outcomes following parental death (Worden, 1996b; Stokes, 2009). A positive parent-child relationship is thought to reflect the parent's creation of a caring, supportive and structured environment which includes a balance of both parental warmth and discipline (Haine et al., 2008). Several quantitative studies have demonstrated links between a positive relationship with the surviving parent and child's adaptation following the death (e.g., Haine, Wolchik, Sandler, Millsap & Ayers, 2006; Raveis, Siegal & Karus, 1999).

5.2 *The surviving parent's mental health*

The mental health of the surviving parent is highly influential in facilitating a positive parent-child relationship and is frequently cited as one of the most powerful mediators that influences overall child outcome (Dowdney, 2000; Akerman & Stratham, 2014). Research indicates that young widows and widowers are particularly prone to psychological disturbance including complicated grief, restlessness, irritability, physical distress and drug use. Furthermore, surviving spouses living alone with dependent children report greater psychological distress than those living without (Dowdney, 2000). Findings from quantitative studies have

demonstrated that high levels of parental mental health problems are consistently and positively associated with negative outcomes for children including anxiety, depression, somatisation, helplessness and general emotional and behavioural problems (Worden, 1996b; Dowdney, 2000; Christ, 2000).

5.3 Communication about death and associated feelings

The intensity and duration of children's reactions are often influenced by different family practice regarding communication of feelings, emotions and of facts surrounding the death (Dyregrov, 1991). Acknowledging the death of a loved one and the physical, emotional, cognitive, behavioural and spiritual manifestations of grief can help children feel valued and in control, which in turn facilitates adaptive coping and the development of resilience (Siegal, Karus & Ravais, 1996; Saldiner, Porterfield & Cain 2004; Haine et al., 2008). As highlighted previously, typically developing children are considered to achieve a full understanding of death around the age of seven (Corr et al., 2000), and this largely parallels general aspects of children's cognitive development (Piaget, 1959; Koocher, 1973; Speece & Brent, 1996). Oltjenbruns (2001) proposed that misunderstanding one or more of the four death subcomponents can increase the risk of a CG reaction, particularly symptoms of yearning and searching for the deceased. Research and clinical practice with this population highlights the importance of exploring children's death understanding and providing cognitively appropriate material to supplement the learning process to build resilience. This includes clearly explaining the facts of the death and its related logistical and psychosocial aftermath as clearly as possible and avoiding euphemisms (Stokes, 2009; Sormati & Ballan, 2011).

Conversely, many parents find it difficult to communicate with children about death and associated feelings and research suggests that breakdowns in factual and emotional communication are quite common (Silverman & Worden, 1992; Siegal et al., 1996) and can lead to longer term psychological difficulties including increased feelings of helplessness and powerlessness (Ribbens McCarthy, 2007).

5.4 The child's relationship to the deceased

The process of reconstructing the relationship with a deceased parent through a 'continuing bond' can be particularly significant in helping children to cope (Silverman, et al., 1992; Klass et al., 1996; Brewer & Sparkes, 2011). Findings from qualitative research studies indicate that children use a variety of different tools to formulate and maintain a continuing bond and secure

attachment with the deceased. This includes attempting to locate and experiencing the deceased, remembering various facets relating to the deceased and attaching to the deceased through transitional objects (Silverman et al., 1992). In a two-year ethnographic study of parentally bereaved young people attending a child bereavement service, Brewer & Sparkes (2011) elaborated on the findings of Silverman et al. (1992) through illuminating the central role of the 'senses' in maintaining this connection. Although there is an extremely limited research evidence base about memory processes and continuing bonds, having the capacity to talk and reminisce about the person who died in a way that brings comfort and worth to the relationship is thought to be a key resilience building block (Valentine, 2008; Stokes, 2009).

5.5 Involvement in mourning rituals

The child's involvement in mourning rituals following the death has been identified as a mediator that influences adaptation to loss (Worden 1996b; Dowdney, 2000). According to a number of different factors including cultural and ethnic origin, families will likely vary in their mourning rituals, and the ways in which children are involved in these (Sutcliffe, Tufnell & Cornish, 1999). One marker taken to represent involvement in the family mourning process has been attendance at the deceased's funeral. Research suggests that, for bereaved children, attending their parent's funeral facilitates coping and an appropriate grieving process (Dowdney, 2000). Funerals may assist in helping children understand the finality of the death whilst also offering an opportunity to say goodbye (Everatt & Gale, 2004). Such involvement might further facilitate connectivity to the deceased through a continuing bond (Klass et al., 1996). Quantitative studies have found no significant relationship between funeral attendance and psychiatric symptoms (Weller, Weller, Fristad Cain & Bowes, 1988) and lower levels of anxiety in children who attended their parent's funeral (Kranzler, Shaffer, Wasserman & Davies, 1990). From a slightly different perspective, qualitative evidence from young people points to ways in which they can feel excluded from key family decisions such as whether or not to attend the funeral, which in turn can contribute to a sense of powerlessness over their bereavement experience and feelings of loneliness and isolation (Ribbens McCarthy, 2007).

5.6 Secondary losses

Parental death is likely to be succeeded by a series of life events for bereaved children including family and school moves, economic changes, changes to the health of family members or additional adults coming to live with the family (Lin, Sandler, Ayers Wolchik & Luecken,

2004). This might result in the breakdown of a child's former relationships, important friendships and community support networks (Dowdney, 2000), and might even include the loss of innocence, identity and role (Ribbens McCarthy, 2007). There is considerable empirical evidence that an accumulation of multiple losses or stressful life events is related to higher levels of mental health problems in bereaved children (Silverman & Worden, 1992; Meltzer et al., 2003). The extent to which children feel that their lives have changed as a result of bereavement has also been shown to significantly mediate any association with measured depression (Harrington & Harrington, 2001).

5.7 Social and community support

The quality of social and community support available to families is an important factor in determining how well they are able to cope following the death of the parent (Silverman et al., 1992). Communities that are likely to impact positively on the resilience of bereaved children are those with quality neighbourhoods (safe, non-violent, affordable housing, recreation areas etc.), effective schools (both academically and in their capacity to respond to bereavement), employment opportunities and quality health and care services (Masten, et al., 2001). This kind of support can have a profound effect in developing the child's protective coping skills and maintaining their sense of coherence and security (Ratnarajah & Schofield, 2007). In contrast, evidence suggests that bereaved children from socially vulnerable or economically disadvantaged communities are particularly at risk of developing mental health difficulties (British Medical Association, 2006; Stokes, 2009).

5.8 Protective resources

Lower mental health problems in bereaved children may be positively related to: their ability to maintain a positive sense of self in the face of adversity (Worden & Silverman, 1996); healthy control beliefs (Haine et al., 2008); and coping efficacy including positive reframing, problem-solving and support seeking (Sandler, Tein, Metha Wolchik & Ayers, 2000). In contrast, bereaved children may be at greater risk of mental health problems if the bereavement has a significant impact on their self-worth and self-esteem (Worden & Silverman 1996); if they feel helpless, threatened and that they have less internal control over their bereavement experience and proceeding life events (Worden & Silverman, 1996; Lin et al., 2004). Indeed, studies investigating the control beliefs of children experiencing parental divorce found that having a lack of understanding about why events occur and being excluded from key

information and decisions is a particularly strong predictor of mental health problems (Kim, Sandler & Tein, 1997), a finding which has been echoed in the narratives of bereaved young people (Ribbens McCarthy, 2007).

5.9 Reflection

The following variables have been selected for discussion as they represent some of the most empirically supported risk and resilience factors. Other variables that have been investigated and evidenced, although to a lesser extent, include child age, gender and cause (suicide, murder, illness) or type of death (sudden vs unexpected). Furthermore, as mentioned previously in Chapter 2, there has been minimal theorising of the relationship between culture and bereavement and resultantly, very little empirical work has been conducted regarding cultural differences in bereavement experiences. For example, to date, no study has examined the role of culture in children's adaptation to parental death (Haine et al., 2008). Indeed, the research presented above has largely been conducted in the US or UK and therefore contains numerous cultural-bound assumptions concerning death, grief and the 'normal' course of bereavement. It is important to recognise that different cultures and families will ascribe to different assumptions and practices regarding these phenomenon.

6.0 Grief, coping and L/ND

Although there has been a lack of methodologically rigorous research in the study of childhood bereavement, there is no doubt that this is an area that has been studied abundantly and with great interest (Oljenbruns, 2001). Consequently, this has led to significant advances in our understanding of the needs of bereaved children and pioneering professional services that have been specifically designed and funded to meet these needs (Penny, 2010). However, the picture is somewhat different for children with L/ND in that there has been a dearth of research investigating the loss experiences for this population. Current literature on bereavement with individuals with L/ND has focused primarily on the responses of adults. Although this research is extremely limited and mostly anecdotal, this literature serves as a logical, albeit tentative, starting point for understanding grief and coping for children with L/ND.

6.1 *The ability of individuals with L/ND to grieve*

The paucity of literature about, and services to support, individuals with L/ND has been attributed to two erroneous long-standing assumptions. Firstly, it has been argued that individuals with learning disabilities, irrespective of their age, are incapable of comprehending the four subcomponents of death understanding (Speece & Brent, 1996), and as a result have little understanding of its impact to result in the experience of grief. Secondly, it has been assumed that these individuals do not possess the necessary capacity to form meaningful emotional bonds and intimate relationships that could culminate in feelings of grief and personal loss (Dodd et al., 2005). Although it does appear quite likely that the degree of learning disability will affect an individual's ability to comprehend abstract concepts like death (McEvoy, Reid & Guerin, 2002), understanding the concept of death is not necessarily a prerequisite for experiencing the emotions associated with grieving (Dodd et al., 2005; Sormati & Ballan, 2011). For example, if we consider attachment theory, Bowlby (1980) proposed that very young children experience emotional pain including anxiety and sadness following separation or loss of an attachment figure. From this perspective, the absence of the person who has died is the tangible manifestation of their death, and people with learning disabilities are able to experience the absence of a significant other as a very distressing loss (Dodd et al., 2005). McEnhill (2010) elucidates very few individuals with learning disabilities, no matter how severe their disability, would not be able to understand that a significant other is no longer present or available.

6.2 Grief and coping for adults with L/ND: empirical research evidence

Research suggests that adults with L/ND do experience grief and sadness following bereavement (Dowling, Hubert, White & Hollins, 2006), and their behaviour and mental health can deteriorate (Dodd et al., 2005). As with the research on typically developing children (e.g., Dowdney, 2000), a myriad of possible grief responses have been identified. Using structured interviews of adults with moderate to severe learning disabilities, Harper & Wadsworth (1993) identified grief as a disruptive and disturbing event that caused symptoms of anger, confusion, discomfort and loneliness. Grief in this population has also been associated with psychopathological outcomes including depression, mania, anxiety and psychosis (Kloeppel & Hollins, 1989; Hollins & Esterhuyzen, 1997). Research has further identified increases in aberrant behaviours that may be incongruous to untrained observers including increases in compulsivity, ritualisation and repetitive, self-stimulating behaviours (Bonell-Pascual et al., 1999).

Nonetheless, understanding the emotional effects of bereavement for adults with learning disabilities continues to be largely in its infancy. Similar to studies with typically developing children, there remains little understanding of what constitutes a ‘normal’ or ‘complicated’ grief reaction in this population (Dodd et al., 2005; 2008). Brickell & Munir (2008) propose that this has largely been the result of numerous methodological challenges including an overreliance on descriptive case reports, inappropriate measures of grief and psychological responses (complexity of language and abstract concepts inherent within these measures) and a tendency to use caregiver reports which can lead to “diagnostic overshadowing” which refers to the inclination to ascribe emotional and behavioural difficulties to the disability itself, rather than the bereavement. Indeed, studies indicate that caregivers often minimise and underestimate the impact of grief on adults with learning disabilities (Dodd et al., 2005). Finally, individuals with learning disabilities are not a homogeneous group. There are significant individual differences in experience, environment, personality and ability.

Although minimal consideration has been given to the distinction between typical and atypical grief in adults with learning disabilities (Sormati & Ballan, 2011), some authors have concluded that there is growing evidence that many people with learning disabilities experience a complicated grief (CG) reaction following the death of a loved one (Dowling, et al., 2006). Indeed, adopting a previously used measure of complicated grief in children, Dodd et al. (2008) found that one-third of bereaved adults with learning disabilities experienced complicated grief

symptoms. Moreover, separation-distress symptoms (e.g., yearning, longing and searching) occurred more frequently than symptoms of traumatic distress. This is in keeping with the proposition that grief is an extension of a general response to separation where an attachment is broken (Bowlby, 1980). Many authors have concluded that this research, along with existing studies, provides evidence that complicated grief may be near “universal” in this population (Dowling et al., 2006). Although conclusions about the relationship between complicated grief and learning disabilities are premature (Brickell & Munir, 2008) and some would even argue entirely invalid (McEnhill, 2010), it might be reasonable to suggest that having a learning disability does increase vulnerability following the loss of a significant person. Even before experiencing a bereavement, individuals with disabilities are vulnerable due to the many barriers that they face (e.g., attitudinal, physical, social, financial) and research has identified higher rates of mental health problems in people with learning disabilities compared with the general population (Meltzer et al., 2003). It might therefore be reasonable to suggest that this population represents a group of particularly ‘high-risk’ mourners (Brickell & Munir, 2008; Sormati & Ballan, 2011).

6.3 Risk and resilience in adults and children with L/ND

Despite the proposition that bereaved individuals with L/ND are at higher risk of ongoing difficulties following bereavement, there has been no empirical examination of the critical factors of risk for children with L/ND (Sormanti and Ballan, 2011). Drawing on the empirically supported risk (and resiliency) factors identified in Chapter 5 for typically developing children, Table 3 presents some of the research with adults and children with L/ND (the latter being speculative) to outline ways in which risk could be elevated for this population.

Table 3. Risk and vulnerability factors for adults and children with L/ND

Potential risk factors	Research Evidence
Relationship with surviving parent	Studies have identified challenges to the development of a secure attachment for individuals with L/ND either initiated by circumstances of the birth, knowledge of the disability or family reaction (Hollins & Esterhuyzen, 1997; Blackman, 2003). Ryaskin (2004) found this to be the case in children with ASD who did not establish bond-enhancing behaviours with their carers and were therefore more likely to exhibit insecure attachments. Links have been made between attachment types, complexity of grief and adaptation following bereavement (Fralely & Shaver, 1999).
Surviving parent’s mental health	Research suggests that parents or caregivers of individuals with L/ND are more likely to suffer mental health problems, particularly when linked with a lack of social support (Yamaoka et al., 2015).
Communication about death	The risk of communication breakdown could be elevated for individuals with L/ND in the misplaced belief that they are, (a), too vulnerable and (b), will not comprehend

(factual and affective)	<p>or hold the emotional reality of loss (Brickell & Munir, 2008). Anyone who experiences a significant loss and receives little or no support, is, as Doka (2002) has noted, ‘disenfranchised’ in their grief. This can be defined as “the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publically mourned or socially supported (p. 434).</p> <p>Research with adults suggests that carers often downplay the loss or fabricate a death story (Hollins & Esterhuyzen, 1997) or sometimes do not tell the individual about the death at all (Oswin, 1991). Even when caregivers of bereaved adults with L/ND are trained in talking about death, they continue to have considerable difficulty in discussing these issues (Dowling et al., 2006).</p>
Speech and language difficulties	<p>Talking about death and associated feelings may be hampered by verbal communication difficulties inherent in many forms of L/ND (Brickell & Munir, 2008), including problems with expressive, receptive and pragmatic skills.</p> <p>Difficulties with expressive language might place children particularly at risk of distress. For example, some children may not be able to use speech effectively to express their feelings and emotions or to gain support for their loss (Markell & Hoover, 2010). Being able to experience the feelings of loss but not to articulate them to others is likely to be extremely distressing (McEnhill, 2010).</p>
Relationship to the deceased through a ‘continuing bond’ (Klass et al., 1996)	<p>If memory is central to resilience in bereavement (Stokes, 2009), then limitations in cognitive functions like memory might affect the ability of individuals with such difficulties to recall events and facts from the past (McEnhill, 2010).</p> <p>Since this inner representation is likely to be constructed from the shared memories of other family members (Silverman et al. 1992), if individuals with L/ND are disenfranchised in their grief (Doka, 2002), this could likely hinder the individual’s developing image of and relationship with the deceased.</p>
Involvement in mourning rituals	<p>With disenfranchised grief in mind (e.g., Doka, 2002), individuals with L/ND may be more at risk of being excluded from mourning rituals. In studies of parentally bereaved adults with learning disabilities, under half were known to have attended the funeral of a deceased parent (Oswin, 1991; Hollins & Esterhuyzen, 1997).</p>
Secondary losses	<p>Bereavement specific losses for adults with L/ND include placement into residential care settings, with some moving as often as five times a year following a bereavement, significant changes to domestic routine and in primary caregiver (Oswin, 1991). Although the loss of a primary caregiver would be devastating for all, this loss may be heightened for individuals with L/ND if the primary caregiver played an indispensable role in their care (McEnhill, 2010).</p>
Social and community support	<p>Individuals with L/ND are at highest risk for unstable family and social situations (Brickell & Munir, 2008).</p>
Understanding of death	<p>Less than one in four adults with learning disabilities have a fully developed concept of death (McEvoy, Reid & Guerin, 2002).</p>
Protective resources	<p>There has been a significant dearth in research looking at the protective resources of individuals with L/ND (McEnhill, 2010). However, they may be at greater risk of having unhealthy control beliefs and a negative sense of self (Brickell & Munir, 2008).</p>

In addition to there being minimal empirical examination of risk factors, there has also been no investigation of resilience in children with L/ND (McEnhill, 2010). As well as experiencing a

wide range of complications, children with L/ND have a multitude of strengths and abilities which could support their capacity for resilience in bereavement. However, current studies into resilience in the context of bereavement have not yet included children with these additional needs.

7.0 Purpose of the study and its academic rationale

This study explores factors that might affect grief and responses to bereavement for children with L/ND. The research addresses significant gaps in the literature between typically developing children and those with L/ND which Sormati and Ballan (2011) positioned as a “remarkable research gap” (pg. 181). An extensive literature review revealed only five published articles that have considered this phenomenon specifically (Everatt & Gale, 2004; Trueblood, 2009; McEnhill, 2010; Markell & Hoover, 2010; Sormati & Ballan, 2011). However, rather than being grounded in methodological empiricism, these five articles have largely relied on personal reflections. In particular, this research uses a qualitative methodology to report on critical factors of risk and resilience, of which there has currently been no examination (McEnhill, 2010). This will be explored by gaining the views of parents/caregivers, school-based professionals working in special school provisions (e.g. teachers, pastoral and learning support staff) and bereavement practitioners from specialist services.

7.1 Research questions and aims

The current aims of the research are to assist relevant adults and professionals in reducing risk factors following bereavement whilst illuminating the attitudes, behaviours and methods which facilitate adaptive coping, supporting and developing capacity for resilience in bereaved children with L/ND. In doing so, the following research questions are addressed:

- What factors are perceived to increase risk and vulnerability for children with learning and neurodevelopmental disabilities following bereavement?
- What factors are perceived to help children with learning and neurodevelopmental disabilities adapt, cope and build resilience following bereavement?

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Part B: Empirical Research Study

Word Count: 6000 (not including titles, indented quotes and references)

1.0 Abstract

The death of a parent or someone close is a profound and challenging life experience for any child. Over the last decade, the panorama of care and provision for childhood bereavement has been significantly enriched. However, the impact of bereavement for children with learning and/or neurodevelopmental disabilities (L/ND) has been largely neglected within psychological research and professional practice. This research aimed to address this gap through exploring bereavement and factors relating to risk and resiliency for children with L/ND. This was addressed with participants who had in-depth experience either caring for or working with a bereaved child with L/ND. Three interviews were conducted with parents (N=3) and two focus groups were conducted, one with school-based professionals (N=5) and one with bereavement practitioners (N=8). The findings revealed that children with L/ND do experience grief and might be particularly vulnerable following bereavement. The research further highlights a number of factors which could facilitate the acquisition and enhancement of coping skills and resilience. Strengths, limitations, future research directions and implications for educational psychologists are considered.

2.0 Introduction

2.1 Conceptualising bereavement, grief and coping in children

The experience of grief following bereavement is fundamental and can be considered a normal and natural consequence of forming close emotional bonds with other people. For most of the 20th century, there was a prevalent notion that individuals moved from distress to ‘recovery’ through engaging in grief work (Freud, 1917/1957; Kubler-Ross, 1969; Bowlby, 1980). However, people grieve in different ways, some more effectively than others. Later theories therefore laid emphasis on elucidating adaptive versus maladaptive ways of grieving (e.g., Worden’s 1996, *Tasks of Mourning* model and Stroebe & Schut’s 1999, *Dual Process* model). Whilst Worden (1996a) described adaptation as the dynamic navigation of grief-related coping tasks, Stroebe and Schut (1999) proposed that individuals need time out from grieving specifically. There has further been a movement away from the idea that successful grieving involves ‘letting go’ of the deceased and a move towards a recognition of the potentially adaptive role of maintaining continuing bonds (Klass, Silverman & Nickman, 1996).

These approaches to conceptualising grief have largely been developed with adults in mind (Rolls, 2010). However, grief and coping are inextricably linked to a child’s cognitive, emotional and social development (Oltjenbruns, 2001; Dyregrov & Dyregrov, 2013). Although originally developed for adults, Worden’s (1996a) approach has been modified and extended to childhood grief (Baker, Sedney & Gross, 1992). Table 4 has been adapted from Oltjenbruns (2001) and compares adult tasks of mourning to children’s focusing on important developmental influences.

Table 4. Tasks of grieving for adults and children

Adults’ Tasks of Mourning (Worden, 1996a)	Child’s Tasks of Mourning (Baker et al., 1992)	Developmental Context
Accept the reality of loss	Understand that someone has died	A review of 100 research studies concluded that there are four principal subcomponents involved in developing a complete cognitive awareness of the concept of death: irreversibility, finality, inevitability and causality (Speece & Brent, 1984; 1996). A mature understanding of death was defined as a mastery of all subcomponents.

		<p>Children do not achieve a full understanding of all subcomponents before the age of seven at the earliest (Corr, Nabe & Corr, 2000).</p> <p>Understanding of death largely parallels general aspects of children’s cognitive development (Piaget, 1959, 1969; Koocher, 1973; Speece & Brent, 1984, 1996).</p>
Experiencing the pain and emotional aspects of the loss	Face the psychological pain of the loss	<p>Immature cognitive-language capacities influence grief responses and limit coping strategies (Aldwin, 1994).</p> <p>Emotional response is influenced by observation (e.g., <i>Social Learning Theory</i>, Bandura & Walters, 1963). Children often mirror coping strategies displayed by attachment figures (Bowlby, 1980).</p> <p>Children ‘puddle jump’ in that they fluctuate between experiencing the emotional aspects of their loss and engaging in new activities (Stokes, 2009). This brings into mind the theoretical framework of the Dual Process Model (DPM) which argued that people need to take time out from grieving specifically. It conceptualises grief as a process of oscillation between two contrasting models of functioning: ‘loss orientation’ and ‘restoration orientation’. The former involves engaging in “grief work” whereas the latter refers to a focus on external, secondary stressors, including attending to ongoing life and its demands. For the DPM, adaptive coping involves oscillation between these two modes of functioning (Stroebe & Schut, 1999).</p>
Adjust to an environment in which the deceased is missing	<p>Cope with the periodic resurgence of pain</p> <p>Develop a new sense of identity that includes the loss experience</p>	<p>As developmental tasks shift and cognitive capacity matures, children often begin to process the experience from a different vantage point than was possible at an earlier stage of development.</p> <p>Loss of a parent relationship can be interpreted in different ways depending on the child’s developmental needs (Oltjenbruns, 2001).</p> <p>“Developmental transitions...may precipitate a resurgence of grief which provide opportunities for further accommodation of the loss in relation to current life stage” (Miller, 1995 in Oltjenbruns, 2001, pg. 178).</p>

Emotionally relocate the deceased and move on with life	<p>Re-evaluate the relationship to the deceased</p> <p>Maintain an internal relationship with the deceased</p> <p>Return to age-appropriate developmental tasks</p>	<p>Children use a variety of strategies to retain a continuing bond with the person who died (e.g., Klass et al., 1996)</p> <p>These strategies will change over time as the child negotiates and renegotiates the meaning of their loss (Silverman, Nickman & Worden, 1992).</p> <p>Maintaining emotional investment in the deceased enables children to uphold and continue normal developmental processes (Oltjenbruns, 2001).</p>
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2.2 *Grief in children: empirical research evidence*

Common grief reactions in children span the emotional, behavioural and physical domain (Akerman & Stratham, 2014) and generally constitute a ‘non-specific’ disturbance (Dowdney, 2000). Most of these initial responses are considered a normal and natural response to bereavement and generally abate over time with the majority of children adapting relatively well (Worden & Silverman, 1996). However, in the general population, grief can be considered ‘pathological’ if it persists for at least six months after the death (Sormanti & Ballan, 2011). Research has found associations between parental death and subsequent psychological maladjustment (see Akerman & Stratham, 2014). There has further been recognition of a pathological grief-related syndrome in adults called Complicated Grief (CG) or Prolonged Grief Disorder (PGD) (Dodd, et al., 2008; Hall, 2014). However, there is currently not enough evidence for inclusion within the DSM-5 (Hall 2014; Doka, 2017). Knowledge and understanding about this disorder in children is therefore extremely limited (Dyregrov & Dyregrov, 2013) but research suggests that it could encompass symptoms of separation distress (Prigerson, et al., 1999; Melham, Porta, Shamsedden, Payne & Brent, 2011), trauma (Holowitz, et al., 1997; Mannarino & Cohen, 2011) or could simply force a child to remain in a static state, with developmental capacities becoming inflexible or frozen (Dyregrov & Dyregrov, 2013).

2.3 *Grief in adults with L/ND: empirical research evidence*

Current literature about bereavement among individuals with L/ND has focused primarily on the responses of adults. Although this research is limited and mostly anecdotal, it serves as a logical, albeit tentative, starting point for understanding grief and coping for children with L/ND. The experience of grief for individuals with L/ND has largely been overlooked. This

has been attributed to erroneous assumptions about perceived incapacity to form meaningful emotional bonds with others and to fully understand death and its wider impact (Dodd, Dowling & Hollins, 2005). However, understanding death is not a prerequisite for experiencing the emotions of grief (Sormati & Ballan, 2011). As attachment theory demonstrates, young children experience distress following separation from an attachment figure (Bowlby, 1980). Therefore, individuals with L/ND are indisputably very able to experience the absence of a significant other as a very distressing loss (McEnhill, 2010).

Although adult research is limited, grief responses have been identified including anger, confusion, discomfort and loneliness (Harper & Wadsworth, 1993), and psychopathological outcomes like depression, mania, anxiety and psychosis (Hollins & Esterhuyzen, 1997). Increases in aberrant behaviours including compulsivity, ritualisation and repetitive, self-stimulating behaviours have further been highlighted (Bonell-Pascual, Huline-Dickens, Hollins, Esterhuyzen & Sedwick, 1999). However, these behaviours are often ascribed to the disability itself, rather than the bereavement and studies indicate that overall caregivers often minimise and underestimate the impact of grief for this population (Dodd et al., 2005; Brickell & Munir 2008).

Although debate is ongoing about whether CG or PGD can be classified as a distinct clinical disorder (Hall, 2014), Dowling, Hubert, White & Hollins (2006) suggest that CG is common in adults with L/ND and there is some research evidence that highlights pronounced symptoms of prolonged separation distress within this population (Dodd et al., 2008). Although conclusions about this relationship are premature (Brickell & Munir, 2008), individuals with disabilities are undoubtedly vulnerable and research has identified higher rates of mental health problems in people with learning disabilities compared with the general population (Meltzer, Gatward, Goodman & Ford, 2003). As a result, this population represents a group of particularly high-risk mourners (Brickell & Munir, 2008).

2.4 Adaptation to bereavement: risk and resilience

The childhood bereavement empirical evidence indicates significant variation in child outcomes following parental death (Dowdney, 2000). Whilst some children adapt well, others struggle to cope and appear vulnerable to on-going emotional difficulties and disturbances including CG (Haine, Ayers, Sandler & Wolchik, 2008; Stokes, 2009). The study of childhood risk and resilience focuses on identifying the transactional processes that account for positive and/or negative adaptation following significant life adversities (Luther, Cicchetti, & Becker,

2000). Numerous studies have investigated variables that differentiate bereaved children who manifest clinical symptoms from those who do not (Haine et al., 2008). Drawing on this and on research with adults, Table 5 outlines variables which could influence risk and resilience following bereavement. It is reasonable to infer that some of these variables may be relevant for children with L/ND.

Table 5. Risk and resilience following bereavement: research evidence with typically developing children and adults with L/ND.

Variables	Research with typically developing children	Research with adults with L/ND
Relationship with surviving parent	This relationship is pivotal in building resilience and fostering positive outcomes (Worden, 1996a; Dowdney, 2000).	Blackman (2003) identified challenges to the development of a secure attachment in adults with disabilities. For example, Ryaskin (2004) found that individuals with ASD failed to establish bond-enhancing behaviours with parents. Links have been made between attachment types, complexity of grief and adaptation following bereavement (Parkes, 1991; Fraley & Shaver, 1999).
Surviving parent's mental health	This is frequently cited as one of the most powerful mediators that influences overall child outcome (Dowdney, 2000)	Research suggests that parents or caregivers of individuals with disabilities are more likely to suffer mental health problems, particularly when linked with a lack of social support (Yamaoka et al., 2015).
Communication about death (factual and affective)	Acknowledging death and grief helps children feel valued and in control, which facilitates adaptive coping and resilience (Haine et al., 2008). Open communication has been found to reduce the risk of psychological disturbance in bereaved children (Worden & Silverman, 1996).	Adults are often disenfranchised in their grief (Doka, 2002). Carers down play the loss, can fabricate death stories and even fail to tell the individual about the death at all (Oswin, 1991; Hollins & Esterhuyzen, 1997).
Understanding of death	Children do not achieve full understanding by the age of 7 (Corr et al., 2000), which is largely	Less than one in four adults with learning disabilities had a fully

	thought to parallel general aspects of cognitive development (Piaget, 1959; 1969; Koocher, 1973).	developed concept of death (Dodd et al., 2005).
Speech and language difficulties	Talking about death and associated feelings helps children to cope and build resilience (Dyregrov, 1991)	Communication may be hampered by speech and language difficulties inherent in some forms of L/ND including problems with expressive, receptive and pragmatic skills (Brickell & Munir, 2008),
Involvement in mourning rituals	Involvement in funerals promotes coping and adaptation in bereaved children (Worden 1996b; Dowdney, 2000).	Adults are often excluded from mourning rituals (Oswin, 1991), with under half known to have attended the funeral of a deceased parent (Hollins & Sinason 2000).
Relationship to the deceased	Consistent with Klass et al., (1996), children use a variety of different tools to maintain a continuing bond with the deceased (Silverman et al., 1992; Brewer & Sparkes, 2011), which is a key resilience building block (Stokes, 2009).	Memory is central to resilience in bereavement (Stokes, 2009). Limitations in cognitive functions might affect the ability of individuals with L/ND to recall events and facts from the past (Brickell & Munir, 2008). Since this bond is often constructed from shared memories of family members (Silverman et al. 1992), previously highlighted maladaptive communication patterns in the adult research might hinder the developing image of and relationship to the deceased.
Secondary losses	An accumulation of secondary losses following bereavement is related to higher levels of mental health problems in children (Silverman & Worden, 1992).	Adults with learning disabilities end up moving as many as four or five times in the year following bereavement (Oswin, 1991). The loss of a lifetime carer has been linked to other immutable 'silent losses' (Read, 2000).
Social support	The family unit and social support can have a profound effect in maintaining the child's sense of coherence and security and will likely influence how well children are able to adjust to loss (Ratnarajah & Schofield, 2007).	Individuals with disabilities are at highest risk for unstable family situations (Brickell & Munir, 2008).
Protective resources	Research has found lower mental health difficulties in children who	There has been a significant dearth in research looking at the

	<p>were able to maintain a positive sense of self despite adversity (Worden & Silverman, 1996); had healthy control beliefs (Haine et al., 2008).</p>	<p>protective resources of individuals with disabilities (McEnhill, 2010).</p> <p>Individuals with disabilities may be at greater risk of having unhealthy control beliefs and a negative sense of self (Brickell & Munir, 2008).</p>
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2.5 Purpose of the study: academic rationale and research aims

This study explores factors that might affect grief and responses to bereavement for children with L/ND. The research addresses significant gaps in the literature between typically developing children and those with L/ND which Sormanti and Ballan (2011) positioned as a “remarkable research gap” (pg. 181). An extensive literature review revealed only five published articles on this topic (Everatt & Gale, 2004; Trueblood, 2009; McEnhill, 2010; Markell & Hoover, 2010; Sormati & Ballan, 2011). However, rather than being grounded in methodological empiricism, this research focuses on personal reflections. In particular, this research uses a qualitative methodology to report on critical factors of risk and resilience, of which there has currently been no examination (McEnhill, 2010). This was explored by gaining the views of parents/caregivers, school-based professionals from a special school provision and bereavement practitioners from a national service.

The aims of the research are to assist relevant adults and professionals in reducing risk factors following bereavement whilst illuminating the attitudes, behaviours and methods which facilitate adaptive coping, supporting and developing capacity for resilience in bereaved children with L/ND. In doing so, the following research questions are addressed:

- What factors are perceived to increase risk and vulnerability for children with learning and neurodevelopmental disabilities following bereavement?
- What factors are perceived to help children with learning and neurodevelopmental disabilities adapt, cope and build resilience following bereavement?

3.0 Methodology

3.1 Research paradigm

The approach taken for this research can be located within the interpretive paradigm, which seeks to “understand the subjective world of human experience” (Cohen, Manion & Morrison, 2007, p. 21). Interpretivism maintains that the role of the researcher is to share the realities of individuals within their social contexts, developing an understanding from within and interpreting actions through the eyes of the participants (Bryman, 2008). Specifically, the researcher took a constructionist epistemology which holds a transactional/subjectivist position whereby findings were co-constructed between researcher and researched (Willis, 2007).

3.2 Participants

A purposeful criterion sampling strategy was adopted whereby all participants (n = 16 adults) experienced the same phenomenon (Miles and Huberman, 1995). The phenomenon in this case included either caring for or working with a bereaved child with L/ND. Purposive sampling allowed the researcher to select individual cases to build specific knowledge and was a convenient method for a qualitative research study in which the findings would not be generalised beyond the specific sample (Cohen, et al., 2007).

Table 6 provides a summary of information regarding parent/carer participants (N=3), including relevant child, L/ND and bereavement details. Pseudonyms have been given for the purpose of confidentiality.

Table 6. Parent/Carer participant information

Name	Relation to child	Child name	Child age	L/ND details	Bereavement details
Judy	Mother	Josh Luke	14 13	Josh has a diagnosis of Down syndrome Luke has a diagnosis of Down syndrome	Josh and Luke’s dad died from a sudden heart attack
Nicola	Mother	Ben	16	Ben has a diagnosis of Autism	Ben’s dad died following a short battle with cancer
Sammie	Mother	Alex	15	Alex has a diagnosis of Cerebral palsy	Alex’s father died in a road traffic collision

Table 7 provides a summary of information regarding the participants from the bereavement service (N=8) and the special school (N=5). Pseudonyms have been given for the purpose of confidentiality.

Table 7. Participant information from the bereavement service and special-school

Name	Job role	Gender
Dean	Senior Bereavement Practitioner	Male
Clara	Senior Bereavement Practitioner	Female
Susan	Bereavement Helpline Manager	Female
Kam	Bereavement Services Team Leader	Male
David	Senior Bereavement Practitioner	Male
Steph	Bereavement Researcher	Female
Fiona	Bereavement Practitioner	Female
Steve	Volunteer Bereavement Practitioner	Male
Jo	Teacher – Special School	Female
Kelly	Teacher – Special School	Female
Nick	Teacher – Special School	Male
Hannah	SENCo – Special School	Female
Adam	Deputy Head – Special School	Male

At this point it is crucial to note a key difference between parent participants and those from the bereavement service and special school. Although all participants experienced the same phenomenon by either caring for or working with a bereaved child with L/ND, the experience of parent participants was notably different in that they were also bereaved of a close relationship. This is something which likely influenced their behaviour and responses during the research process.

3.3 Data collection

Two distinct but related qualitative methods of data collection were considered most suitable for this research. Two separate focus group interviews were employed; one with school-based professionals and one with bereavement practitioners. However, because the focus group does not afford privacy, confidentiality or a non-condemnatory attitude (Wellings, Branigan & Mitchell, 2000), semi-structured interviews were considered to be more appropriate for

parents/carers whose experiences and views were likely to be particularly emotive. Accordingly, three parental interviews were conducted. Together, these methods allowed for the collection of rich data.

The interview and focus group questions (Appendix G and H) were open-ended and afforded participants a degree of freedom to express themselves, attaching rich meaning to their experiences (Sparkes & Smith, 2014), whilst probing questions, as well as guiding the process, assumed that no fixed sequence was suitable to all respondents and allowed for the possibility of obtaining some unanticipated findings (Silverman 2006; Berg 2007).

3.4 Data analysis

The focus groups and semi-structured interviews were recorded using a dictaphone and transcribed verbatim. The transcripts were then subjected to Thematic Analysis using Braun and Clarke's (2006) six phases approach (Appendix K), in which themes were constructed and interpreted by the researcher. For them, this ensures a recursive practice, where the researcher searches for patterned responses and repetition of embedded themes. During the process of thematic analysis, the researcher identified patterned responses and recurrence of themes with the research questions in mind. For example, responses that identified risk and vulnerability were separated from those which alluded to more positive or resilience-based experiences.

3.5 Procedure

The procedure for participant recruitment to the interviews for parents and focus groups for school and bereavement professionals is described in Appendices I and J.

3.6 Ethics

The study presented various ethical considerations, many relating to the sensitive nature of the research topic, which were addressed in accordance with the British Psychological Society's (2014) *Code of Human Research Ethics*. An overview of these ethical considerations is presented in Appendix L and examples of gatekeeper letters, invitation letters, consent forms and debrief information in Appendices A, B, C, D, E and F.

4.0 Findings and discussion

Using Thematic Analysis, six themes were identified together with a number of subthemes which are outlined in Table 8 below. See Appendix N for a thematic map which portrays links and connections between the themes.

Table 8. List of main themes and subthemes

Theme	Subtheme
Grief responses of children with L/ND	<ul style="list-style-type: none"> • <i>Idiosyncratic responses</i> • <i>Prolonged grief</i>
Concept of death	<ul style="list-style-type: none"> • <i>Restricted understanding</i> • <i>Concrete thinkers</i> • <i>The importance of seeing the body</i>
Communicating about bereavement	<ul style="list-style-type: none"> • <i>Expressive language difficulties</i> • <i>Support to communicate</i>
Loss and L/ND	<ul style="list-style-type: none"> • <i>Multiple losses</i> • <i>Loss of a lifetime carer</i>
Sense of self	<ul style="list-style-type: none"> • <i>Social support</i> • <i>Levels of dependence</i>
Specialist bereavement support	<ul style="list-style-type: none"> • <i>Changing the approach</i> • <i>Working together</i>

The following section will illuminate the current themes using relevant quotes from the data. Key findings will be discussed with reference to existing psychological theory and research in order to “breathe life and yield insight and understanding of people’s behaviour” (Cohen, et al., 2007, p. 22).

4.1 *Grief responses of children with L/ND*

Two subthemes emerged relating to the grief responses of children with L/ND: *Idiosyncratic responses* and *prolonged grief*.

4.1.1 *Idiosyncratic responses*

Participants identified multiple grief responses including sadness and crying, increase in low mood and anxiety-based difficulties including separation distress, clinginess and concerns

about the health and safety of the surviving parent. Many of these responses are consistent with ‘non-specific disturbance’ in typically developing children under five (Dowdney, 2000):

Josh was crying...he definitely was affected badly and he’d come and say ‘miss Daddy’ [pause] it’s also a change in the way he’s much more of a worrier than he ever was...he’d be worried over me being ill [pause] what’s going to happen to me [pause] (Judy, talking about Josh, 14, Down syndrome).

Consistent with the adult research (Bonell-Pascual et al., 1999), some participants noted an increase or exaggeration of behaviours relating to the disability including hypersensitivity and overstimulation, irritability, repetitive self-stimulatory actions, obsessive ritualisation and behavioural meltdowns:

He’s never liked crowds of people but it became more exaggerated...the one time at the bowling place [pause] he just lost it...hitting out...arms everywhere ...you couldn’t pick him up or move him it was too many people [pause] too many noises...” (Nicola talking about Ben, 16, Autism).

In contrast to the adult research, rather than minimising the impact of grief by ascribing emotional and behavioural difficulties solely to the disability (Dodd et al., 2005), participants recognised that these responses might indicate increases in stress, anxiety and an overall awareness that something significant had changed. Given this, children with L/ND, as well as displaying ‘normal’ grief responses, might express grief idiosyncratically depending on their unique differences, something that has been considered in the speculative research (Everatt & Gale, 2004; Trueblood, 2009). This was reflected within the following example from Dean, a Senior Bereavement Practitioner:

He had severe learning disabilities with no verbal communication...he was about eight and his grief was displayed in becoming consumed with his dad’s yellow t-shirt [pause] he couldn’t relate to anything else other than this t-shirt...not feelings...emotions...photos or faces...it was the smell the shape the feel that was important.

Difficulties were thought to occur in instances where grief was more solitary in nature (e.g., repetitive, obsessive behaviours) or lacked empathy, particularly during emotive family work:

The ASD was a challenge for the family and the therapy...the way the grief materialised in the relentless obsessions with dad’s room and micro machines and it definitely acted

as a blocker to an empathetic response...this sometimes caused mum to get really upset (Clara, Senior Bereavement Practitioner).

In this example, the ASD was difficult for others to manage in therapeutic sessions as the child wasn't able to connect to the grief experienced by other family members. As Ryaskin, (2004) indicates, ASD can impact negatively on the development of the parent-child relationship and the behaviours described above might perpetuate this, particularly during highly sensitive times. This could have implications for the development of a positive relationship with the surviving parent, something which has been considered pivotal to resilience building following bereavement (Worden, 1996b). This is something that has been acknowledged by bereavement practitioners, particularly around supporting parents to manage their 'grieving expectations' and to understand that these different ways of grieving may serve a function for individual children. For example, preoccupation with certain items may be a way of managing the strong emotions associated with grief. In their work on continuing bonds, Brewer & Sparkes (2011) indicated how children can maintain a connection with the person who has died using their senses, something which may be particularly important for a child who has limited expressive language and benefits from sensory experiences.

4.1.2 *Prolonged grief*

The general view among participants was that children with L/ND may take longer to process their grief compared with typically developing peers. In many parental accounts, their child's grief was often notably sustained:

We were sort of getting our heads round it...whereas for Alex it had been three years and he was still very low...getting very tearful...and I think I was very conscious because of his additional needs and his communication issues that he wasn't coping (Sammie, talking about Alex, 15, Cerebral palsy).

As well as taking longer to process the experience, participants described a variety of behaviours that appeared to relate to separation distress (Bowlby, 1980), including longing and searching behaviours:

He had the iPad and Google maps...trying to find daddy's heaven and he was so upset because he couldn't find it [pause] I was distraught...he hasn't stopped doing it (Judy, talking about Josh, 14, Down syndrome).

A prolonged grief response of more than six months following bereavement and separation distress symptoms could be indicative of a CG response (Dodd et al., 2008; Melham et al., 2011), something which has been proposed as being universal in adults with learning disabilities (Dowling et al., 2006). However, rather than being pathological per se, these behaviours might be indicative of various developmental differences. In some cases, it could be that over time, active searching behaviours described above support children to come to terms with their bereavement and therefore may have an adaptive function:

He used to get loads of balloons and tied them up just like the film 'Up' to see if he could float and find Daddy in heaven but this stopped...think he began to realise that even if he could get there then he wouldn't be able to see daddy...now he's settled. (Nicola talking about Ben, 16, Autism).

In keeping with the re-grief phenomenon (Oltjenbruns, 2001), as different developmental capacities develop, children with L/ND may also be able to process and express their grief from a different, more advanced vantage point than was possible at an earlier stage. Nonetheless, there was a general feeling that children with more complex needs might be more likely to become 'stuck' in their grief and in cycles of need that required constant revisiting by family or other professionals.

4.2 *Concept of death*

This theme reflects perceptions around death understanding and has been divided into three subthemes: *Restricted understanding, concrete thinkers and the importance of seeing the body.*

4.2.1 *Restricted understanding*

Research into death understanding for typically developing children concluded that, on average, they achieve full understanding by the age of seven at the earliest (Corr et al., 2000), which is largely thought to parallel general aspects of cognitive development (Piaget, 1959, 1969; Koocher, 1973; Speece & Brent, 1996). However, research with adults (Brickell & Munir, 2008) suggested that the degree of disability would likely affect their ability to comprehend the four subcomponents of death as outlined by Speece and Brent (1996), irrespective of their age. Many of the participants within the sample reflected on similar difficulties with understanding the concept of death for children with L/ND. All of the children discussed did not appear to have acquired full subcomponent acquisition by the age of seven as previously suggested in the research with typically developing children:

He sits in the window waiting for Daddy to come home and it's been three years [pause] how do I get him to understand that Daddy has died and hasn't just gone to live with someone else...how do you test that...how do you find that out...for somebody who isn't able to talk to you and isn't able to express feelings... (Nicola, talking about Ben, 16, Autism).

Every night she waits outside the house and says 'mummy coming home yet', even though we have done so much work around death and what it means (Steph, Bereavement Practitioner, discussing a girl, 13, Down syndrome).

Although it was generally felt that cognitive ability might limit understanding, this was not thought to limit the significance of bereavement or mute the powerful feelings and emotions associated with grief:

Sadly, people still think 'oh they don't get it they don't have the ability' but I'm sorry [pause] yes they may not fully understand but even the most profoundly disabled child gets it on some level (Kelly, teacher).

This mirrors the speculative research that understanding the concept of death is not necessarily a prerequisite for experiencing the emotions associated with grieving (Sormati & Ballan, 2011). Further supporting attachment theory (Bowlby, 1980) and the proposition that separation from an attachment figure might serve as the tangible manifestation of death, and that children with limited death understanding are still able to experience this absence as a painful loss.

Nonetheless, Oljenbruns (2001) proposed that misunderstanding one or more of the four death subcomponents would likely increase the risk of CG for typically developing children, particularly symptoms of yearning and searching for the deceased. This was found to be the case under the subtheme, *prolonged grief response*, with children displaying a large number of searching and seeking behaviours. However, as previously mentioned, whether or not this can be justifiably categorised as a *pathological* response for children with L/ND is questionable.

4.2.2 Concrete thinkers

Consistent with ideas from Sormanti and Ballan (2011), this subtheme reflects perceptions that some children with L/ND might be more prone to concrete and literal thinking which influences understanding of abstract concepts like death. The particular risk factor that emerged was that unclear facts about death and its logistical and psychosocial aftermath, can cause misunderstandings and on-going complications:

So when his Dad died I said things like...Dad is all around us...Dad is everywhere and he's close by but after that he started calling my male friends who always came to the house 'Daddy' and that was on-going for almost two years...for me that was a real issue [pause] and took a long time to clear up (Judy talking about Josh, 14, Down syndrome).

Although similar findings have been identified in clinical work with typically developing children (Stokes, 2009), literal thinking often dissipates over time, particularly with the advent of concrete operational development (Piaget, 1959) and a comprehensive understanding of death (Speece & Brent, 1996). However, these patterns of thinking might be more likely to persist well into adulthood for children with L/ND:

I told him that Daddy was a star when he died and so I guess when he keeps searching for Daddy's star then it shouldn't be a surprise [pause] when we go up in a plane now he's always searching for it" (Nicola, talking about Ben, 16, Autism).

As well as being a challenge for parents, this was further highlighted as a challenge for bereavement services, with many children's books about death continuing to contain unclear and potentially confusing messages:

They say use stories about a dragon fly or dinosaurs that die...really confusing...it has to be concrete for these children...if it doesn't look like them and their family...in their context...how are they going to be able to relate to a dinosaur or a dragon fly [pause] it's fluffy and contradictory (Nick, Teacher).

This highlights the ongoing and central importance of regularly exploring understanding, explaining the facts of the death and avoiding euphemisms to support adaptation for bereaved children with L/ND.

4.2.3 The importance of seeing the body

Research with typically developing children suggested that involvement in mourning rituals helps establish concepts of death finality (Everatt & Gale, 2004) and facilitates coping and the development of resilience following bereavement (Worden, 1996b). However, research with bereaved adults with L/ND suggested that they are more likely to be excluded from rituals (Hollins & Sinason 2000) due to others disenfranchising their grief (Doka, 2002). In contrast to the adult research, participants discussed how important they considered mourning rituals to be, particularly with supporting understanding of death. Although not explicitly highlighted

within adult research, participants discussed the benefits of actively seeing the body to support an understanding of death:

They wanted to see him in the mortuary...I said Daddy can't move...he's not hungry...his body is there but Daddy is not there...so he can't hear you and he can't see you and he can't touch you but you can say goodbye to him because Daddy is gone [pause] and actually when they looked at him they were both exactly the same...they bent down and looked and said 'Daddy's not there' [pause] 'no Daddy there he gone' (Judy talking about, Josh, 14 and Luke, 13, Down syndrome).

This visual and concrete representation of death appeared to facilitate greater understanding about its finality which in turn was perceived to be beneficial for some children and their adaptation. This holds support for the proposition that understanding the biological elements of the life cycle is pivotal in facilitating a more mature view about death (Slaughter, 2005).

4.3 *Communicating about bereavement*

Communicating with children about bereavement, both factually and emotionally emerged as an important theme in the lives of participants. Two subthemes emerged in the data: *Expressive language difficulties* and *support to communicate*.

4.3.1 *Expressive language difficulties*

In cases where children were completely non-verbal, exploring death and associated feelings was challenging. Although parents were able to identify that their child was grieving, being unable to use speech or communication effectively to discuss these feelings was highlighted as being particularly difficult:

Ben is non-verbal and although he knows some signs...he doesn't really do signing...It's hard to communicate about anything...let alone how Dad died and how he might feel [pause] it's pretty hard" (Nicola, talking about Ben, 16, Autism).

This is consistent with the speculative research (Sormati & Ballan, 2011; Markell & Hoover 2010) which proposed that difficulties with language might hamper a child's ability to articulate his/her emotions. Although assumptions cannot be made that this caused significant, long-term distress, there was a general feeling that these difficulties left some children 'stuck' in their grief:

Alex has no speech because that's one of his motor skills...I would just come downstairs and he would be sat in his wheelchair with tears rolling down his face [pause]... I felt helpless...like he's trapped" (Sammie talking about Alex, 15, Cerebral palsy).

At night there are still tears rolling down his cheeks....like silent crying...in the morning he wakes up giggling saying 'Daddy' [pause] I don't know if he dreams about him...if only he could tell me" (Judy talking about Luke, 13, Down syndrome).

This further highlights the potential pain and difficulty this can cause parents, and as the surviving parent's mental health is the most powerful mediator of child outcome (Dowdney, 2000), this is an important consideration. As well as bereavement services 'managing grieving expectations' for families of bereaved children with L/ND, this further highlights the need for services which help families cope with the overwhelming nature of the loss and subsequent difficulties with communication, building both family cohesion and adaptability (Stokes, 2009).

4.3.2 *Support to communicate*

Although challenges with communication could place children at risk of longer-term disturbance (Everatt & Gale, 2004), providing them with a means to communicate about death and effectively express their emotions could increase resilience. The most salient point arising from this subtheme was giving children the *medium* to express themselves:

He kept saying what about the drawer for Daddy...and I was like oh you mean his coffin! I hadn't even given him the word so he didn't know it! And I realised I needed to explain everything so clearly (Judy, talking about Luke, 13, Down syndrome).

Participants used a number of resources to aid communication including boards or books that contained Widget and Communicate in Print symbols that were bereavement specific. For example, symbols that explained factual information (e.g., funeral, coffin, usher, car accident, heart attack) and affective responses (e.g., missing them, lonely, confused). In some cases, thoughtful and creative strategies were employed. For example, Clara, a Senior Bereavement Practitioner, talked in detail about how she was able to support a child who was non-verbal to communicate his bereavement 'story' in a group setting:

So we had to pre-input his story into his computer weeks before using all the communication symbols. That took ages [pause] and then we played this in the group

and then we carefully asked him if we needed more information using his communication book.

Enabling bereaved children to construct a coherent narrative in which they can present with emotional integrity throughout their lives has been considered to impact positively on coping skills and overall resilience (McIntyre & Hogwood, 2006).

However, not all participants shared positive communication experiences. Firstly, many alluded to a lack of bereavement specific language tools which made communicating about death and grief particularly challenging:

Although some 'Widget' symbols are great there were none for funeral, coffin and hospice...ashes was the worst [pause] I always remember trying to do a social story and couldn't find a symbol for ashes other than that ones used in the cricket (Jo, Teacher).

A number of teachers reflected on a lack of specific support from other professionals about how to communicate with non-verbal children:

The Ed Psych did a little PowerPoint presentation and yeah there was some good stuff but it was that whole thing like 'you know them best and you know what they need'...which I totally get. But we wanted more [pause] what do you do when a child is nonverbal and how do you communicate what's happened to them...there was none of that (Adam, Deputy-Head).

Secondly, when a child had an alternative means of communication, difficulties were highlighted, particularly when exploring feelings and emotions around a complex topic:

He uses eye gaze controlled communication aid...although his access to this is pretty difficult so you kind of have to know what he is saying and support him [pause] we rely on the context of the conversation which is really hard if he wants to communicate about Dad spontaneously (Sammie talking about Alex, 15, Cerebral palsy).

Overall, this subtheme appears to highlight the importance of adults being both flexible and creative when approaching how different children respond to different forms of communication, whilst also remaining extremely reflexive about their interpretations of this communication. Reflexivity in particular has been noted as central in understanding the diverse

identifiers and communication styles of disabled children (Davis, Watson & Cunningham-Burley, 2017).

4.4 *Loss and L/ND*

Loss was a particularly distinctive theme throughout the data and related to multiple and significant losses that children with L/ND face, with two subthemes emerging: *Multiple loss* and *loss of a lifetime carer*.

4.4.1 *Multiple loss*

Research with typically developing children found considerable evidence that linked an accumulation of multiple losses following bereavement to higher rates of mental health problems (Silverman & Worden, 1992). Although this was considered in the adult research (Oswin, 1991; Brickell & Munir, 2008), the extent of these losses for individuals with disabilities appears to have been underplayed. For children with L/ND, loss was highlighted as widespread throughout their entire lives, often even regardless of a bereavement. This included turnover in respite or other medical carers, transport drivers, and educational/health placements. These multiple losses, as well as making the child more vulnerable generally, were also thought to act as potential triggers of a previous bereavement experience:

If every two months you have to rehire a new carer which is what happened with the young person...they would have to meet someone else who would have to learn all about their bereavement story and what happened (Fiona, Bereavement Practitioner).

Consistent with McEnhill (2010), participants further highlighted the multiple bereavement experiences of children with L/ND. This included friends and family members with disabilities or other significant adults in their lives relating to education or health settings. This culminated in constructions of ‘persistent and relentless loss’ for children with L/ND.

4.4.2 *Loss of a lifetime carer*

Research with adults proposed that the loss of a lifetime carer, who may have been the only one with whom they could communicate and who could effectively navigate the ‘system’ of support, could leave individuals with learning disabilities particularly vulnerable (Brickell & Munir, 2008). Likewise, participants highlighted the loss of a parent as particularly distressing when they were fundamental to daily physical care:

Two profoundly disabled sisters with a really rare condition [pause] the father died in a tragic, tragic accident...he was a massive carer in their lives. The girls were very fragile and getting bigger but he was a big guy...we couldn't pick the children up in the way he did [pause] as much as we would say 'look after your back!' he would grab them out of their wheelchairs {pause} shower them with kisses [pause] but when he died...although they had no verbal conversations because they can't...that tactile conversation [pause] nobody can replicate that (Kelly, Teacher).

As well as the loss of tactile experiences, losing a physically strong carer sometimes led to other secondary losses like the ability to engage in physical activity:

Alex and his Dad used to spend time together sailing and obviously that couldn't happen anymore...I wasn't confident enough to do the physical side so [pause] yeah Alex doesn't go out in the boat now (Sammie, talking about Alex, 15, Cerebral palsy).

Although it cannot be assumed that the children actually *enjoyed* these experiences because they were not directly interviewed, given that they had limited or no speech and language, these interactions might well have been experienced as the 'physical' expression of emotion. However, the significance of the more visceral and embodied senses, including sound, smell, touch and taste are often minimised within research (Stoller, 1989). Indeed, qualitative researchers have called for greater attention to be given to these 'lower senses' and how they are part of everyday lived experience (Sparkes, 2009).

If these embodied experiences were meaningful, then consistent with the speculative research (Trueblood, 2009), these findings might suggest that the loss of a lifetime carer might leave children with L/ND at risk of additional complications following bereavement. Read (2000) suggested this was the case for adults with L/ND, particularly when bereavement led to hidden losses including loss of identity, loss of ability, loss of accessibility, loss of opportunity, and loss of independence. Overall, rather than disenfranchising grief (Doka, 2002), this theme highlights the fundamental importance of acknowledging the far-reaching losses faced by children with L/ND, underscoring the need for immediate and open-ended support and guidance.

4.5 *Sense of self*

This theme reflects discussions around factors that appeared to influence the child's sense of self and has been divided into two subthemes: *Social support* and *levels of dependence*.

4.5.1 *Social support*

Similar to Worden & Silverman (1996), participants thought of ways in which children had maintained a positive sense of self in the face of adversity including continuing their sense of humour, cheekiness and loving, sociable nature. This was often highly dependent on a high level of social support for the family unit, something which has been pivotal in influencing the development of protective coping skills and building resilience in bereaved children (Ratnarajah & Schofield, 2007). Examples given included continued involvement in community and disability support groups that appeared to maintain the child's sense of coherence and security. This support also appeared to be central to maintaining the health of the surviving parent, something which is highly important in predicting resilience in the general population of bereaved children (Dowdney, 2000).

In addition, involvement in bereavement support groups appeared to enhance a positive sense of self through providing opportunities to interact and share similar experiences with non-disabled peers:

The group was a turning point [pause] although he wasn't able to get quite as involved...just knowing he wasn't the only child going through this seemed to make such a difference and I then saw some glimpses of the real him (Sammie, talking about Alex, 15, Cerebral palsy).

It was felt that these activities not only normalised the grieving process for children with L/ND but further enhanced a clear sense of 'belongingness' with others. This finding is in line with advice on how to develop a resilient mind-set in typically developing children, through providing them with opportunities to develop empathy and have positive connections with others who have been bereaved (Stokes, 2009). As Meyers notes, when it comes to responses to death "as in most other aspects of their lives [individuals with L/ND] are more like everybody else than they are different" (Brickell & Munir, 2008, pg. 11).

4.5.2 *Levels of dependence*

Worden and Silverman (1996) proposed that bereavement can have a negative impact on sense of self if children feel helpless, threatened and that they have less internal control over their bereavement experience and proceeding life events. The majority of discussions appeared to centre on these difficulties for children with L/ND. In light of their special care needs and because some children are likely to remain largely dependent on others it was felt that they

were more likely to feel helpless and therefore possess little or no internal control over proceeding life events:

After Dad died there was a lot going on for everybody else around Alex. I handed my notice in and got a new job...my son took up adventuring and probably got a little extreme...my other son was busy doing his A Levels...but for Alex he became more dependant [pause] more isolated and had little control over that (Sammie, talking about Alex, 15, Cerebral palsy).

For the rest of us everything was getting bigger. New life changes and stuff planned but because of his limitations he doesn't have as much access to restore his life (Judy, talking about Luke, 13, Down syndrome).

These findings bring to mind the DPM (Stroebe & Schut, 1999) which highlights the importance of restorative stressors for coping including attending to life changes, doing new things, developing new roles and relationships. Parents often discussed how they and other family members had utilised restorative coping strategies to support their adaptation but there was a general feeling that the children discussed were less capable of taking an active role in this restoration phase as a result of their needs and dependency. Lack of ability or access to take part in restorative coping could also be indicative of the multiple secondary losses that were noted under the theme 'loss and learning disability'.

Clinical work with typically developing children recommends an age-appropriate understanding of the DPM to create a mind-set that allows for healthy oscillation between 'loss' and 'restoration' to take place (Stokes, 2009). Even though restoration may be more difficult to achieve, this is an important framework for children with L/ND. When noting positive changes, one mother mentioned the following:

Recently he's been much happier again...and that does sort of coincide with the fact that now his life has been growing. He's been on some trips away with other young people with disabilities...he got to do some sailing and he's looking forward to going off to college and generally talk of the future (Sammie, talking about Alex, 15, Cerebral palsy).

Conversely, a lack of focus on restorative coping or lack of ability to make life changes, do new things and develop new roles and relationships may limit opportunities for positive self-growth and the development of a positive sense of self for children with L/ND.

4.6 *Specialist bereavement support*

This theme reflects perceptions around specialist bereavement support for children with L/ND and has been divided into two subthemes: *Changing the approach* and *working together*.

4.6.1 *Changing the approach*

The Equality Act (2010) stipulates that schools and other organisations have a legal obligation to make reasonable adjustments for children with disabilities. Indeed, many participants highlighted attempts to modify therapeutic sessions to meet the individual needs. This often involved ‘throwing out’ normal ways of working. Particularly notable was the variation in pace of therapeutic sessions including offering shorter sessions on a more regular basis:

We do 20 minute cycles...20 minutes work...20 minutes what he wants to do which is normally Minecraft and then we do 20 minutes of coming back together and finishing off (Dean, Senior Bereavement Practitioner, talking about sessions with a boy diagnosed with ADHD).

Other forms of differentiation included alternative communication systems including Widget symbols, pictures, visual boards, communication books, using eye-gaze communication systems, drawing and methods to manage expectations like the use of sand timers or stop watches.

After experiencing some success, participants reflected on what they thought had made the difference. Rather than it being the particular technique, many suggested that it was the actual *space* offered that appeared to be central to supporting coping, adaptation and in turn, building resilience:

I had a really rigid plan based it on all the visual cards...after the first session I chucked it all out because you have to go with what they bring [pause] what I learnt was that it was the space that you offer them...to be together...the fact that we went out and said ‘you know what something so significant has happened to you’ (Clara, Senior Bereavement Practitioner, talking about working with a boy with Cerebral palsy).

It was the time they spent with him...very reflective...then one day he started pointing to the symbols ‘scared’ and I was astonished...he had never shared that (Sammie talking about Alex, 16, Cerebral palsy).

Fundamental to effective support was having a flexible approach and offering a space to communicate. Indeed, research into self-esteem in children suggests that offering support increases the likelihood that they will feel valued, cared for and resilient (Levy & Wall, 2000).

4.6.2 *Working together*

This subtheme reflects differences in experiences of joined up working between bereavement services, schools and families. In instances where the bereavement sessions appeared successful, the school and family system proactively engaged in sharing key strategies to support the child's strengths and needs. This information was vital as it helped bereavement specialists to change their approach and meet individual needs:

Dad was such an expert in his child's needs...he was so practical and gave so many ideas. He wanted to be involved and was willing to work with us to see what was possible (Steve, Bereavement Practitioner Volunteer).

In some cases, schools became particularly 'hands-on' and actively engaged in the therapeutic sessions:

We had a really brilliant school who said 'how can we support you to support him'...they printed off pictures for us...gave us a space every week to meet...they met with us after the sessions and said how can we drip feed this in school time (Dean, Senior Bereavement Practitioner).

Working together and utilising resources within different systems proved to be a key building block for effective therapeutic support. Conversely, not all participants reflected on positive experiences. Instead, some revealed occasions whereby the school or family weren't able to provide much insight or support:

Whilst we know a lot about bereavement I am not trained in disabilities...the school were not interested in helping...just wanted us to fix it...I didn't feel confident enough or like I had the skills (Fiona, Bereavement Practitioner).

Mum in her grief she wasn't able to support him so she was very much wanting us to offer the magic wand and didn't want to be involved (Dean, Senior Bereavement Practitioner).

As indicated in the above narratives, a lack of joined up working appeared to lead to feelings of anxiety or even 'learned helplessness' (Majer & Seligman, 1976) and deskilled practitioners

who were otherwise competent in dealing with the subject of bereavement. As a result, when schools or families did not actively engage, therapeutic sessions either failed to start or gradually dissipated over time.

In summary, whilst some systems were open to working together to support the needs of the child, others did not appear to be as proactive. Borrowing concepts from Systems Theory, this brings to mind the concept of 'open' and 'closed' systems, the former being open to change whilst the latter being resistant (Dowling & Osborne, 2002). Therefore, in terms of reducing risk and building resilience, this subtheme appears to highlight the benefits of developing a more 'systems' approach towards bereavement support for children with L/ND. Indeed, Bronfenbrenner (1979) urges us to look at child development in the context of the relationships between and among different systems. This might include using 'systemic thinking' (Pelligrini, 2009) whereby rather than there being an 'expert' in a particular domain, different systems work together and co-construct meaning through conversations that facilitate change.

5.0 Summary

Consistent with attachment theory (Bowlby, 1980), it was acknowledged that children with L/ND can and do experience grief and significant distress following bereavement, even in the absence of a comprehensive understanding of death. Moving on from the adult research, rather than disenfranchising grief (Doka, 2002), participants identified numerous grief reactions, often distinguishing these from the emotional and behavioural characteristics relating to the child's disability, and largely recognised the need for explicit grief and bereavement support.

5.1 Perceived risk and resilience variables for children with L/ND

The current research further highlights a number of risk and resiliency variables for this population of bereaved children. Table 9 utilises the current themes to illustrate perceived risk factors and highlights some points to consider when supporting children with L/ND through bereavement. These might serve to facilitate the acquisition and enhancement of coping skills and overall resilience.

Table 9. Summary of perceived risk and resilience variables for bereaved children with L/ND

Themes	Risk factors	Resiliency factors
Grief responses of children with L/ND	<p>Lack of awareness or understanding that children with L/ND may express grief differently to typically developing children, depending on individual strengths, needs and vulnerabilities.</p> <p>Limited consideration that children with L/ND may experience a more 'prolonged' grieving process than typically developing children. This could lead to recurrent 'cycles of need'.</p>	<p>Recognising and valuing these differences and remaining reflective and reflexive of our 'grieving expectations'.</p> <p>Understanding the potential importance of the 'senses' in grief and coping for children with L/ND. In their work with typically developing children, Brewer and Sparkes (2011) highlighted the central role of visual, auditory and kinaesthetic senses in maintaining a 'continuing bond' with the deceased person. This may be even more important for children who have limited speech and language.</p> <p>Children with L/ND might require longer term bereavement support. Parents and professionals may need to revisit grief and coping more frequently than for typically developing children.</p>

<p>Concept of death</p>	<p>Children with L/ND may have difficulty grasping the abstract concept of death, irrespective of their age.</p> <p>Although this might not be a ‘risk factor’ as such, understanding might be confounded by the use of ambiguous and inaccurate terminology or resources surrounding death and dying.</p>	<p>Having an awareness that some children with L/ND may not be able to fully comprehend death and to anticipate the associated emotional and behavioural responses (e.g., searching/seeking behaviours, repetitive questions about the dead person).</p> <p>Some children might be particularly ‘concrete’ in their thinking and will benefit from consistent, clear and accurate terminology.</p> <p>Understanding the biological elements of death and how the human body functions, as described by Slaughter (2005), may facilitate a clearer understanding of death.</p> <p>Although fictional books are a useful tool for explaining death to children (Stokes, 2009), these messages might need to be more literal for children with L/ND. For example, a more personalised story to accurately reflect the child’s world.</p>
<p>Communication around bereavement</p>	<p>Consistent with the research with adults, and the speculative research (Sormati & Ballan, 2011), difficulties with language and communication can hamper a child’s ability to express grief and gain support for his/her loss.</p> <p>Although not explicit within previous research, these issues might cause parents/carers significant distress. An important finding considering that the parents’ mental health is a significant contributor to overall child outcome (Dowdney, 2000).</p>	<p>Use of clear and creative strategies which provide children with a means to talk (verbally and non-verbally) about death and express their grief.</p> <p>Being reflective and reflexive about communication with children with L/ND.</p> <p>Providing explicit support for parents/carers including supporting the overwhelming nature of the loss and subsequent difficulties with communication, building both family cohesion and adaptability (Stokes, 2009).</p> <p>As indicated in the theme ‘<i>specialist bereavement support</i>’,</p>

		<p>this may involve the family, school and other professionals collaborating to understand the child's strengths/needs and preferred communication style.</p>
Loss and disability	<p>Children with L/ND may experience multiple losses that are not always acknowledged. Frequent loss could have the potential to trigger a previous bereavement experience.</p> <p>If they are heavily involved in day to day physical/emotional care, the loss of a parent or carer could put children with L/ND at risk.</p> <p>This loss could be linked to further 'hidden' losses (Read, 2002), including losses of identity, of ability, of accessibility, of opportunity, and of independence.</p>	<p>Explicitly acknowledging and addressing the multiple and far-reaching losses that children with L/ND can experience.</p> <p>As mentioned under '<i>grief responses</i>', greater attention to be given to the visceral and embodied senses and how they might be part of everyday lived experience for children with L/ND, including their relationships with others. This clearly has implications for on-going 'continuing bonds' following bereavement of a loved one.</p>
Sense of self	<p>Bereavement can have a negative impact if children feel helpless, threatened and that they possess less internal control over proceeding life events (Worden & Silverman, 1996). In light of their special care needs, and because some children are likely to remain largely dependent on others, they might be more at risk of developing these negative attributes.</p> <p>As indicated in Strobe & Schut's (1999) DPM, having time out from grieving specifically is important for developing a new and positive sense of self and increases overall adaptation. However, children with L/ND may possess fewer resources to take part in 'restorative coping' (attending to life changes, doing new things, developing new roles and relationships).</p>	<p>Maintaining connections and social support appear to be helpful for both the child's and surviving parent's sense of self.</p> <p>Active participation in bereavement support groups with non-disabled peers might increase a positive sense of self and sense of belonging.</p> <p>Ensuring that children are able, where possible, to take an active role in restorative coping (Stroebe & Schut, 1999) including ongoing participation in activities and new experiences.</p>
Specialist bereavement support	<p>A lack of joined up working between different systems (family, school, bereavement service) might put children with L/ND at risk of not receiving appropriate and timely support.</p>	<p>Modifying therapeutic sessions to meet the strengths, needs and vulnerabilities of children with L/ND.</p>

		<p>Being flexible with the approach and offering a space to communicate about death and grief.</p> <p>Developing a more ‘systemic’ approach towards bereavement support in which different systems jointly co-construct problems and solutions to facilitate change.</p>
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5.2 Strengths, limitations and future research directions

A strength of the current qualitative study is that it addresses a clear gap within the literature through gaining first hand, in-depth and rich perspectives on bereavement and grief for children with L/ND. Through examining risk and resiliency, the research makes a progressive contribution to knowledge by moving towards a more nuanced conception of *how* children with L/ND grieve, potential complications that can occur and the strategies that can be used to help to build resilience. Additionally, in terms of the sample, three different groups of participants were used as informants on the bereavement experiences of children with L/ND and it could be argued that this increased the validity of the themes through providing triangulation of the data.

However, by solely including parents/carers and other professionals as informants on the child’s experience of grief, the child’s own experience has been excluded. Although not considered appropriate for the current study, in order to gain a fuller understanding, it would be crucial to gain access to the voices and opinions (verbal and non-verbal) of children with L/ND. Future research might focus on using other qualitative approaches such as ethnography or dyadic interviewing to elicit the voice of bereaved children with L/ND.

A further limitation of the research was that children were included with different and varying levels of L/ND but disabled children do not represent a homogeneous group (Davis et al., 2017). Future research designs would need to take account of the diversity of conditions that are included under the umbrella of L/ND and define groups of children whose conditions may confer particular psychological strengths and vulnerabilities. It is reasonable to infer that differing characteristics of different L/ND’s may well lead to distinctive patterns of risk and resiliency factors following bereavement.

Please refer to Part C for further detailed discussion on the empirical, methodological, theoretical and practical strengths and limitations of the current study.

5.3 Implications for educational psychologists

The current study has important implications for educational psychologists (EPs) who make a distinctive contribution to promoting the application of relevant theory and research to support work with children and young people with special educational needs (MacKay, 2000). As well as being a key therapeutic resource for individual children (MacKay, 2007), EPs are increasingly initiating therapeutic interventions with systems around the child including families, schools and multi-agencies (Stobie, Boyle & Woolfson, 2005) and are at the forefront of critical incident support in schools, with bereavement being one of these aspects. Finally, within the framework of Consultation (Wagner, 2000), it is evident that EPs can support the needs of bereaved children with L/ND through working collaboratively with key adults. Please refer to Part C for further discussion.

5.4 Conclusion

This study aimed to address a gap in the literature through using a qualitative methodology to explore the experience of bereavement and factors relating to risk and resiliency for children with learning and neurodevelopmental disabilities. The research highlighted that children with L/ND do experience grief and distress following the loss of a loved one, irrespective of a comprehensive understanding of death.

The findings suggest that some children could be particularly vulnerable. This might relate to a wider lack of awareness or understanding about the bereavement needs of this population including how they grieve, how they understand the concept of death and how they communicate and express their feelings and emotions. Further potential areas of vulnerability include losing a parent who was heavily involved in daily physical and emotional care, limited opportunities to restore a positive sense of self through ‘time-out’ from grieving and a lack of joined up working between parents and professionals with different but complementary skill sets. However, numerous factors which could facilitate the acquisition and enhancement of coping skills were also highlighted. It is evident that with the right support, children with L/ND do have the capacity for resilience in bereavement.

Finally, this continues to be an area that is under-researched. Consequently it is unclear whether current theories of grief or models of coping are entirely appropriate for children with such

varying strengths, needs and vulnerabilities which span the cognitive, physical, affective, behavioural and social domains of development. It is important that research continues to refine knowledge and understanding of the experience of bereavement for this population and that crucially, the profile of bereaved children with learning and neurodevelopmental disabilities is raised.

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Part C: Major Research Reflective Account

Word Count: 5, 800

1.0 Introduction

This critical appraisal provides some reflections on a number of different elements of the research and the research process.

Section two provides a critical account of the methodology that was employed including research paradigm, data collection and data analysis. Reflections on the ethical issues raised by this research are also included.

Section three focuses on the distinct contribution to knowledge, originality of the research and future research directions. For clarity, these are addressed under the headings of empirical, methodological, theoretical and practical contributions.

Finally, section four provides a brief personal reflection on the research process and how this has impacted on the professional development of the researcher.

2.0 Critical discussion of methodology

2.1 *Qualitative research, philosophical assumptions and research paradigm*

The current study explores perceptions of bereavement for children with L/ND among key adults with intimate knowledge and experience of this phenomenon. Given this focus of research, a qualitative approach is the most suitable. Qualitative research is difficult to define because it often cross-cuts disciplines, fields and subject topic. Indeed, Smith & Sparkes (2014) note that qualitative research encompasses a complex, interconnected family of concepts and assumptions and therefore privileges no single methodological practice over another. Despite there being no clear-cut or universally agreed definition of the term, Denzin & Lincoln (2011) provide a broad explanation by describing qualitative research as “a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible” (pg. 3). Crucially, within qualitative research, the emphasis is frequently placed on uncovering the subjective experiences of individuals. Qualitative researchers therefore approach the social world using an interpretive and naturalistic approach, studying things in their natural settings and “attempting to make sense of or interpret phenomenon in terms of the meanings people bring to them” (Denzin & Lincoln, 2011, pg. 3).

According to Sparkes and Smith (2014) certain philosophical assumptions inform qualitative research. To reflect the subjective nature of bereavement, in terms of ontology (i.e., how reality is viewed), a *relativist or internal* ontology is adopted whereby social reality is conceived as humanly constructed and shaped in ways that make it fluid and multifaceted. Multiple, subjective realities exist in the form of mental constructions. In reference to *epistemology* (i.e., how this view of reality is studied), a *subjectivist, transactional* and *constructionist* position is further adopted. This position assumes that what is studied is not ‘out there’ independent of inquirers:

From this epistemological position, there can be no separation of the researcher and the researched, and values *always* mediate and shape what is understood. The knower and the known are inter-dependent and fused together in such a way that the ‘findings’ are the creation of a process of interaction between the two (Sparkes & Smith, 2014: pg. 13).

These ontological and epistemological assumptions further inform the researcher's *paradigm* which according to Guba & Lincoln (1994) refers to a "basic belief system or world view that guides the investigation" (pg. 105). The interpretative paradigm, which Cohen, Manion & Morrison (2007) assert, "seeks to understand the subjective world of human experience" (pg. 21) was adopted. Interpretivism maintains that the role of the researcher is not to manipulate the environment but to share the realities of individuals within their social contexts, developing an understanding from within and interpreting actions through the eyes of the participants (Bryman, 2008).

These philosophical assumptions and characteristics shape how qualitative researchers go about understanding and representing the world in which they and others live. They further inform a number of traditions that operate under the umbrella term of qualitative research. Thus, the choice of methodology (decisions regarding methods and measures) is more than a practical exercise and is concerned with understanding how the researcher distinctly perceives and characterises the social world. The current study draws on the tradition of semi-structured interviews and focus groups in responding to the dearth of empirical evidence on bereavement for children with L/ND.

2.2 Participants

A purposeful criterion sampling strategy is adopted where all participants (n = 16 adults) experienced the same phenomenon (Miles and Huberman, 1995). The phenomenon in this case includes either caring for or working with a bereaved child with L/ND. Sparkes and Smith (2014) promote purposeful sampling as a key characteristic of qualitative research. It is a convenient method which allowed the researcher to select individual cases to build specific knowledge (Cohen et al., 2007). In terms of the sample size, Gest, Bunce & Johnson (2006) estimate that 12 participants is sufficient and a robust size for qualitative research and is enough to ensure saturation of themes. Although slightly larger, a sample size of 16 is consistent with this recommendation. In terms of theme saturation specifically, because three different groups of participants were used as informants on the bereavement experiences of children with L/ND, this may have limited saturation, but equally it could be argued that this has increased validity through providing triangulation of the data.

In terms of participant recruitment, the researcher did not face much difficulty in recruiting parents and carers, with N=3 volunteering after being contacted by a bereavement organisation, through which they had previously received some kind of support. In terms of wider

professionals, the researcher initially aimed to recruit them from different schools and bereavement organisations to equip the study with a sample and dataset that was somewhat representative of the wider population's experiences with child bereavement and L/ND. However, the researcher experienced some challenges with this due to a significant lack in response. Ten schools and four bereavement services were contacted, with only one of each agreeing to participate. Given the extremely sensitive nature of the research topic as well as the lack of empirical data and explicit professional practice in this area, this was perhaps not particularly surprising. Nevertheless, the researcher was able to recruit N=5 participants from a special school and N=8 from a bereavement service.

2.3 Data collection measures

When determining how best to elicit in-depth responses, the researcher initially considered a focus group methodology to be the most appropriate for all participants within the study. This was largely due to the considered benefits of group interaction for encouraging natural conversation between participants, facilitating collective remembering and encouraging participation from people who might find it harder to contribute (Kitzinger, 1994). Although focus groups were run with school professionals and a bereavement service, the use of a focus group methodology for parents and carers was eventually disregarded. The researcher reflected on a fundamental issue that focus groups could not afford parents or carers privacy, confidentiality or a non-condemnatory attitude (Wellings, Branigan & Mitchell, 2000). As a result, semi-structured interviews were deemed more appropriate for parents and carers whose experiences and views would likely be extremely private and highly emotive. It was considered that the nature of these intra-personal feelings were such that they needed to be explored in-depth and privately rather than being attempted within a group environment (Denscombe 2003). On reflection, this decision was incredibly important. These conversations were at times highly sensitive and deeply moving, with parents becoming quite emotional and requiring some breathing space to gather their thoughts. In light of the sensitive and intimate nature of these interviews, it is unlikely that a group environment would have facilitated these types of discussions and might have been perceived as disrespectful of individual's experiences and feelings.

Although focus groups and in-depth interviews are different and distinct qualitative approaches, both methods allowed for the collection of rich data by using open-ended questioning which suited the exploratory nature of the study. The flexibility within open-ended questioning allowed for a degree of choice in questions and responses which facilitated a sense

of openness and freedom of expression (Sparkes & Smith, 2014). The use of prompts and probing questions further assumed that no fixed sequence of questions was suitable to all respondents and allowed the researcher to obtain some unexpected findings (Silverman 2006; Berg, 2007). On the other hand, whilst maintaining efforts to remain inductive, a schedule of key topics and questions were pre-prepared and this structured element allowed the researcher to guide, monitor and steer the process, ensuring consistency across interviews and focus groups (Sparkes & Smith, 2014). The advantages of using this less structured approach was that the interaction felt more natural, with the researcher enquiring openly and conversationally about meaning so empirical detail was not lost.

However, the limitations around using a focus group methodology are acknowledged. In both groups it was clear that on occasions, certain individuals dominated the discussion to the detriment of others whose voices were less likely to be heard. The researcher attempted to address this imbalance by diffusing this domination and drawing out the views of quieter members using subtle and supportive probing questions. Transcribing the focus groups was also quite challenging and time-consuming due to voices overlapping and cutting across each other.

2.4 Data analysis

Thematic analysis (TA) is an extremely flexible approach that fitted the constructionist and interpretative research paradigm. TA organises and describes the data collected in detail through identifying, analysing, interpreting and reporting themes within the data (Braun & Clarke, 2006). It therefore has the ability to examine and describe participants' subjective, multiple realities, experiences and views in a rich and thorough way. Furthermore, according to Vaismoradi, Turunen & Bondas (2013), TA is a robust method for exploring novel phenomenon and therefore seemed appropriate given the shortage of research in child bereavement and L/ND. TA is also relatively straightforward. Analysis was facilitated by following the six-stage process as described by Braun & Clarke (2006) which provided the researcher with clear guidelines and a sense of security.

Phase six of this process, '*Writing the report*', was particularly pertinent for the researcher. This stage provides an opportunity to refine analysis as in the writing new ideas can emerge (Braun & Clarke, 2006). As well as being extremely time consuming, this was a deeply moving experience and challenged the researcher by representing these highly complex and sensitive experiences through extended segments of text.

The researcher considered and subsequently rejected Interpretive Phenomenological Analysis (IPA). IPA has the ability to gain an in-depth insight and ‘give voice’ to an individual’s lived experience (Shaw, 2001), whilst the interpretive element allows the researcher to contextualise and ‘make sense’ of these experiences (Sparkes & Smith, 2014). Like TA, it seeks to identify patterns in the dataset and has a relatively straightforward set of prescribed guidelines. It was attractive to the researcher due to its ability to represent the lived experiences of participants as well as its detailed method of understanding and interpreting participants’ experience of reality (McLeod, 2001). However, unlike TA, IPA is bound to a phenomenological epistemology (Smith, Flowers & Larkin, 2009) and is often valued for its commitment to examining a small quantity of cases (Smith, 2004). The researcher concluded that TA would be more appropriate as it is not bound to a theoretical or epistemological framework (Braun & Clarke, 2006) and has the ability to work with a sample larger than 7/8, focusing on patterned responses across a larger set of data rather than maintaining a more idiographic approach (Smith et al., 2009).

The systematic methodology of Grounded Theory was further considered and later rejected by the researcher. This involves the construction of theory through the analysis of data without the constraints of predetermined research objectives and aims (Martin & Turner, 1986). As a result, it proposes that no pre-study literature review takes place and that data collection may be an on-going process (Glaser, 1992). This approach clearly suited the exploratory nature of the current study. It may have led to an in-depth understanding of the ‘theories’ and multiple understandings that parents and professionals attach to bereavement for children with L/ND. However, the current research aimed to look at risk and resiliency specifically and arguably this has more of a practical rather than a theoretical focus. A Grounded Theory approach was further deemed impractical due to the researcher’s limited timescale for data collection.

2.5 Ethics

Cardiff University Ethics Committee raised a number of queries in response to the initial ethics proposal: clarification on how participants would be identified and selected and providing further clarity around the limits of confidentiality in the focus groups for the school and bereavement professionals.

In order to address these concerns, the researcher provided further explicit information in the proposal about the procedure including the identification and selection of participants. In particular, highlighting that participants would be recruited from *different* gatekeepers was

important. For example, for parents/carers and bereavement professionals, the researcher contacted the head of service from a bereavement organisation and for school professionals, the head teacher was assigned the gatekeeper role. To address concerns around the lack of clarity around confidentiality, the researcher adjusted the invitation and consent forms to include appropriate information around the limits of confidentiality in a group setting (Appendix D and E).

3. Distinct contribution to knowledge, originality and future research directions

3.1 Empirical considerations

The majority of research on bereavement among individuals with disabilities has focused primarily on adults whilst bereavement research with children has attended predominantly to the responses of typically developing populations. Furthermore, the former research base has tended to focus upon determining whether, and to what extent this population experiences grief rather than *how* they grieve, cope and adapt (Brickell & Munir, 2008). The present study therefore addresses a gap in the literature by gaining first-hand and rich perspectives on bereavement for children with L/ND from a diverse sample with intimate knowledge of this phenomenon, thus contributing to the empirical knowledge base. In addition, through examining risk and resiliency factors, the current study makes a progressive contribution to knowledge as it moves towards a more nuanced conception of *how* children with L/ND grieve, potential complications that can occur and the strategies that can be used to help them cope, adapt and build resilience.

The current study clearly demonstrates that it is time to move towards a more nuanced conception of *how* children with L/ND grieve and of the coping strategies that can be utilised to support adaption and resilience. Although not considered appropriate for this study due to time constraints, the complexity and sensitivity of the topic, in order to gain a better understanding of this, it would be crucial to begin to gain access to the voices and opinions (verbal and non-verbal) of children with L/ND. This is something which has been excluded from almost all research (Davis, Watson & Cunningham-Burley, 2017). The United Nations Convention on the Right of Persons with Disabilities (2006) argued for the fullest inclusion of disabled people in decisions about their lives and accordingly, academic texts in psychology and education research have begun to discuss how to conduct research with disabled children. It is proposed that authentic ‘inclusion’ for this population means inclusion on the basis of participating in research focused precisely on those issues which exclude them (Roberts, 2017). Accordingly, research into a variety of different phenomenon, like the experiences of disabled children living apart from their families, has included children with severe communication problems and no speech (Morris 1998a), whilst others have focused on *how* to conduct research with children with autistic spectrum disorders (Beresford, 2004) and those who are ventilator dependent (Noyes, 2000).

A possible limitation of this research is that children were included with extremely different and varying levels of L/ND. Although this was done to ensure access to a larger sample of adults with intimate knowledge of bereavement and different forms of L/ND, previous studies into childhood and disability have been criticised for representing disabled children as a homogeneous group (Davis et al., 2017). Therefore, future empirical designs would need to take into account the diversity of conditions that are included under the umbrella term of L/ND and define groups of children whose conditions may confer particular psychological strengths and vulnerabilities. For example, a child on the autistic spectrum, whose condition is related to difficulties with social communication, interaction and restricted behaviours may respond very differently to bereavement than a child with Down syndrome, who can often display uniquely exaggerated emotional responses (Brickell & Munir, 2008; Ahler, Garielsen, Lewis, Brady & Litchford, 2017). It is reasonable to infer that such differing characteristics may well lead to distinctive patterns of risk and resiliency factors following bereavement.

Finally, it is important to keep in mind that even within groups of children with particular forms of L/ND, manifestations of grief and associated risk and resiliency factors will undoubtedly vary from child to child. For example, we should expect not only that a child on the autistic spectrum might manifest grief quite differently to a child with Down syndrome, but that different children with Down syndrome will manifest grief in different ways from one another. As demonstrated within research on bereaved children, adjustment following bereavement is heavily influenced by a large number of variables (e.g., Haine, Ayer, Sandler & Wolchik, 2008) that both *moderate* the outcome, in that they exist prior to the death (e.g., age, gender, type of death), and *mediate* the outcome in that they typically exert their influence after the death. Although some mediating variables were broadly considered within this study (e.g., relationship to surviving parent, secondary loss, social support), future empirical research would benefit from examining the embodied identities, social and cultural “fields” (Bourdieu, 1991) and life events of disabled children to account for the heterogeneity in their bereavement experiences.

3.2 Methodological considerations

There has been a small number of insightful investigations considering the general loss experiences of children with L/ND (e.g. Everatt & Gale, 2004; Trueblood, 2009; McEnhill, 2010; Markell & Hoover, 2010; Sormati & Ballan, 2011) but these have been speculative in nature. In addition, the data collection methods employed in the research of bereaved adults

with L/ND have largely focused on quantitative standardised self-report or carer-report measures which rely on closed questioning and are based on limited evidence (Brickell & Munir, 2008). Although useful, both approaches do not allow for a deeper exploration of meaning. This research therefore contributes to this knowledgebase through employing a qualitative methodology to uncover the first hand experiences of parents, school-based professionals and bereavement practitioners who have close relationships with children who have experienced bereavement. It is assumed that these individuals have an intimate understanding of how children with L/ND have responded to bereavement, providing unique insight into factors like risk and resilience and thus in depth insight into this phenomenon.

Future methodological research directions might focus on using qualitative approaches such as ethnography in special school settings and/or therapeutic sessions with bereaved children with L/ND. Mainly (though not exclusively) using participant observation, ethnography facilitates the flexible and dynamic collection of data across multiple social terrains over time, helping to build deep understandings of everyday interactions, social processes and cultural meanings as well as developing intimate relationships (James & Prout, 1990). It has been considered particularly useful in providing researchers with valuable time for being both reflective and reflexive in approaching an understanding of how children with disabilities communicate and how to communicate effectively with them. Indeed, ethnography has been used to gain access to the meanings of children who are non-verbal in special school settings (Davis et al. 2017). Dyadic interviewing (separate or joint) might further be considered as a useful qualitative method for eliciting the voice of bereaved children with L/ND. This involves an interview structure that includes the individual with the disability and a person he/she identifies as his/her key supporting figure. As well as being a useful method of triangulation, this approach accommodates individuals with disabilities and promotes choices and self-determination in research (Caldwell, Parker & Renko, 2016).

The use of participatory data collection methods may further serve to elicit the voice of bereaved children with L/ND. These could include methods that are fun and those which aid the process of communication between the child and researcher. Innovative participatory research tools which have worked well with children include: drawings, flow diagrams, body mapping, play, drama, games, storyboards and songs (O, Kane, 2017). However, these tools will need to be developed alongside the child, in accordance with individual preferences, strengths and needs. Indeed, research is beginning to investigate more novel approaches to the co-creation of research outputs with disabled children. For example, Beresford (2004) has

developed a number of approaches to elicit the views of children with ASD including using Social Stories, craft-making activities, using photos taken by the children themselves and restricting conversation to concrete experiences.

3.3 Theoretical considerations

This research has taken a multi-theoretical approach in order to explore the experiences of bereavement, grief and coping amongst children with L/ND. In particular, this has allowed for the complexity and multifaceted nature of this phenomenon to be adequately accounted for. For example, whilst the cognitive perspective (e.g., Piaget, 1959) was useful in explaining why some children misunderstood or had not acquired a comprehensive understanding of death, attachment theory (Bowlby, 1980) highlighted that death could be understood as a loss of an attachment bond that could lead to separation distress and potential complications, irrespective of death understanding. Furthermore, more recent approaches like the DPM (Stroebe & Schut, 1999) have been valuable in highlighting how children with L/ND may find it more difficult than typically developing children to utilise restorative coping and have ‘time-out’ from grieving, even though this may be useful for coping, adaptation and resilience. This is definitely in need of further exploration. If this is an accurate reflection of the experiences of children with L/ND, then restorative coping might be a clear focus for support and intervention for this population.

Alternatively, if an individual or specific approach to theory had been taken, this would have diminished the opportunity to develop in-depth and multiple understandings of the bereavement experience for children with L/ND. This offers justification for the approach taken and highlights how future research should not be constrained by taking theoretically driven, deductive approaches to researching this multifaceted phenomenon. Nonetheless, previous research and clinical application indicates that Continuing Bonds (e.g., developing an internalised, symbolically-based connection through various memory processes) is central for coping, adaptation and resilience for typically developing populations but this did not arise as a distinct theme during analysis. Certainly, further research should continue to explore the effectiveness of taking this popular approach offered by Klass, Silverman & Nickman (1996) for children with L/ND, particularly those who have profound and multiple cognitive, physical health and sensory difficulties. It could be that ‘continuing bonds’ for this population is signified through the more visceral and embodied senses, including sound, smell, touch and taste. Qualitative researchers have called for greater attention to be given to these ‘lower’

senses' and how they are part of everyday lived experience (Sparkes, 2009). It might be reasonable to infer that these senses, and the meanings ascribed to them, may be particularly important for bereaved children with L/ND in maintaining an internal representation and on-going bond with a loved one.

3.4 Practical considerations

Childhood bereavement was a previously neglected phenomenon largely due to erroneous misconceptions that young children did not have the ability to grieve (Wolfenstein, 1966) or would need to be protected and sheltered from the pain of a significant loss. With developments in theory (e.g., attachment), research and practice, the philosophy of how to treat bereaved children has changed remarkably. However, bereavement for those populations of children with additional needs, like learning or neurodevelopmental disabilities has evidently been under researched, possibly as a result of those flawed misconceptions that were once held about bereaved children in general. This dearth in research has resulted in a lack of understanding for how children with different needs grieve and the associated risk and resiliency factors. Subsequently, this has impacted on professional practice, with the needs of children with L/ND largely overlooked and unmet by different services. With a clear focus on bereavement for children with L/ND and associated risk and resiliency factors, the present study makes a contribution to this previously neglected area and in doing so has highlighted some practical implications that may warrant further consideration from relevant adults. The following section will therefore outline some practical applications of this study for children with L/ND, parents, schools, bereavement services and EPs.

3.4.1 Children with L/ND

This research highlights that children with L/ND experience grief following bereavement. As well as experiencing similar grief reactions to typically developing children, this study illuminates the idiosyncratic nature of grief for children with L/ND in that it may be expressed according to particular strengths and vulnerabilities relating to the learning and/or neurodevelopmental disability. In addition, this study has highlighted some factors which may increase risk and vulnerability as well as those which may increase coping, adaptation and resilience following bereavement. According to the findings, it is imperative that bereaved children with L/ND are afforded the opportunity, space and time to explore facts about death as well as the complex feelings and emotions that are implicit within grief. As well as focusing

on their grief, it is also clear that children with L/ND, like typically developing children, also need time out and opportunities to rebuild and restore their lives.

It is hoped that by conducting research in this area, and developing a greater understanding of risk and resiliency factors, the needs of bereaved children with L/ND will be better understood and recognised.

3.4.2 Parents and carers of bereaved children with L/ND

This research raises the awareness of parents and carers about grief and bereavement for children with L/ND. Through highlighting grief as particularly idiosyncratic and interconnected to differing elements of the disability, it encourages caregivers to be both reflective and reflexive about grief, particularly of their ‘grieving expectations’. The study further raises awareness about the benefits of remaining open, explicit and factual about death and the feelings and emotions associated with it. It further illuminates parents and carers as crucial information sources and emphasises their central role in assisting schools and bereavement services in understanding their child’s strengths, what works well and areas of potential vulnerability. However, this is an immense responsibility and relies heavily on a number of different factors like a) having a good relationship and attachment with the child, and b) feeling physically and emotionally available to meet these requirements.

It is evident that schools, bereavement services and other professionals like EPs have a key role in supporting parents and carers in this respect.

3.4.3 Schools and bereavement services

This research has raised awareness that schools and bereavement services may need to work together to effectively meet the needs of bereaved children with L/ND. For example, without the support of a bereavement service, staff in special schools settings did not always feel equipped to address the bereavement needs of children whilst on the other hand, without the support of the school, bereavement practitioners felt ill-equipped to communicate with children about their grief, particularly those with more complex communication, interaction and social-emotional needs. Arguably, carefully co-ordinated and joined up working between these services, with different but complimentary skill sets, would likely enhance the effective support for bereaved children with L/ND.

In terms of bereavement services specifically, this research suggests that the profile of bereaved children with L/ND needs to be raised. Although there might be some fantastic work going on,

there is clearly a need to be more explicit about the services that are available so parents find it easier to find and access the appropriate support. This might include producing specific books and resources around how to support children with different forms of L/ND through bereavement. This clearly requires researchers and bereavement services working together to uncover further research evidence to inform professional practice.

3.4.4 Educational psychologists

The current study provides some interesting implications for EPs who make a distinctive contribution to promoting the application of relevant theory and research to support work with children and young people with special educational needs (MacKay, 2000). According to this research, EPs may have a key role in raising the profile of bereaved children with L/ND. This could be done through planning meetings, Consultation and training for example. Evidently, it should not be taken for granted that relevant adults feel confident in managing the bereavement needs of children with L/ND.

In terms of involvement with individual children, EPs have responsibility for the assessment of individual children across a range of skills broadly relating to the five key areas of learning and cognition; language and communication; social, emotional mental health; physical health and skills of independence and self-help. Due to their knowledge of learning and psychology as well as their holistic approach to assessment (e.g., observation, 1:1 work, formal assessment and joint problem-solving), EPs are arguably particularly well-placed to identify the strengths and needs of bereaved children with L/ND.

Within the framework of Consultation (e.g., Wagner, 2000), EPs can effectively serve these needs through working collaboratively with key adults. According to this research, a Consultative approach would be fundamental in meeting the bereavement needs of children with L/ND as a variety of different systems and organisations with different specialisms would need to be involved in the co-construction of problems and solutions (e.g. parents, schools, speech and language, bereavement services). In reference to schools and bereavement services above, EPs may have a key role in supporting them to work together and to share their expertise.

Finally, EPs are increasingly initiating interventions with systems around children (Stobie, Boyle & Woolfson, 2005) and can therefore engage in work with the school and community to promote awareness of bereavement for children with LND, including risk and resiliency factors. After all, EPs are at the forefront of critical incident work in schools with bereavement

being an aspect of this. ‘Systems’ work can empower relevant adults to address these issues at more of a strategic level. According to Kelly, Woolfson & Boyle (2008), the aim of systems work is to penetrate structures at an organisational level in order to implement strategic interventions that enhance the education and wellbeing of children within the particular school or setting. The training of school staff and other relevant adults is considered to be a central element of this process because it equips them with the knowledge, motivation and confidence to promote and sustain such interventions (Fox & Sigston, 1992). However, it has been suggested that this requires long term planning and a framework for monitoring, follow up and evaluation in order to be effective (Harland & Kinder, 1994).

Consequently, EPs may wish to offer training and longer-term follow up support to parents, schools and bereavement services to raise awareness of bereavement and grief for children with additional needs and how to support them in the most effective way. As mentioned previously, this may include information sharing on best practice between services with different but complimentary specialisms.

4.0 Personal reflections

The process of completing this research has facilitated my development as a research-practitioner in a variety of ways. For example, I feel more confident in my ability to design, implement, report, and reflect upon a piece of real-world research. However, my development in these areas has not been without challenge.

With regards to the literature review, due to the dearth of research on the bereavement experiences of adults and children with L/ND, I found this a particularly lengthy and time-consuming activity. The challenge for me as a researcher was to include sufficient theory and research to build an argument that there was a gap in the literature with regards to bereavement, risk and resiliency for children with L/ND. In retrospect, this process may have been simplified through focusing on bereavement and grief in general for children with L/ND rather than risk and resiliency specifically. However, the aim of the research was to be of practical assistance to relevant adults through facilitating an understanding of risk factors and illuminating the attitudes, behaviours and methods which might facilitate adaptive coping and the development of resilience.

With regards to designing the study, I found it challenging to decide on the specific sample that would be targeted to participate in the research. Given the importance of the child's voice, I had initially hoped to conduct the research with children. However, as noted by Davis et al. (2017), gaining access to the genuine lived experiences of disabled children can be a lengthy process. It requires researchers to have a significant period of time to approach and understand how children with L/ND communicate and how to communicate effectively with them. This is something that can be achieved using participant observation across multiple social terrains and over time (James & Prout, 1990) which was not possible given the time limitations associated with the current study. Furthermore, my hesitation to conduct the research with children directly may also have been a result of a lack of personal confidence in how to approach this sensitive issue with disabled children. However, this research process has certainly built my confidence in exploring bereavement for children with L/ND and given the opportunity to conduct the research again, I would feel more assured in adopting a dyadic interviewing technique for example, which could include the child with the disability and their key supporting figure.

Overall, although challenging, I have thoroughly enjoyed the research process. It has developed my skills in many areas of psychology and research and has further demonstrated the valuable

contribution that EPs can make to the research-base. Specifically, this critical reflection has developed my evaluative and reflective skills in line with the Health Care Professional Council's standards of proficiency for practitioner psychologists (HCPC, 2015). As well as illuminating perceived risk and resiliency variables, the current research has further led to an appreciation of the wider difficulties faced by parents and professionals when caring for or working with a bereaved child with a disability. This is something that I am passionate in taking forward in my research and practice following qualification as an Educational Psychologist.

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Appendices

Appendix A: Gatekeeper letter for head of bereavement service

Appendix B: Gatekeeper letter for head teachers

Appendix C: Invitation letters to parents

Appendix D: Invitation letters to professionals (schools and bereavement services)

Appendix E: Consent form

Appendix F: Debriefing form

Appendix G: Interview questions and probes (parents/carers)

Appendix H: Focus group questions and probes (schools and bereavement services)

Appendix I: Procedure for recruitment to focus groups

Appendix: J: Procedure for recruitment to interviews

Appendix K: Braun & Clarke's (2006) Six Steps of Thematic Analysis

Appendix L: Ethical considerations

Appendix A: Gatekeeper letter for head of bereavement service

Holly Burlton
School of Psychology
Cardiff University
Tel: 07411388198
BurltonH@cardiff.ac.uk

Dear [insert name]

I am a student training to be an educational psychologist on the Doctorate in Educational Psychology Programme at Cardiff University, and I have to undertake a thesis research study, as a requirement of the programme. I am interested in exploring perceptions of risk and resilience for bereaved children and young people with learning and neurodevelopmental disabilities. I would like to explore the views of parents who have participated in your service and also, the perceptions of bereavement practitioners working within your service. In particular, I am interested in exploring factors that might support adaptation, coping and resilience and those which hinder the grieving process for bereaved children with these additional needs.

This research will hopefully assist relevant adults in reducing risk factors following bereavement whilst illuminating the attitudes, behaviours and methods which facilitate adaptive recovery from bereavement, supporting and developing capacity for resilience for children and young people with learning and neurodevelopmental disabilities.

Given your position as the head of [insert name] bereavement service, I would like to invite parents who have participated in your service and bereavement practitioners who work within the service to take part in this research. I will conduct a focus group with the bereavement practitioners which will explore their perceptions of risk and resilience for children with learning and neurodevelopmental disabilities. This will last for about 60 minutes and will also be audio taped, with the participant's written consent. Exploring the same subject, I will also conduct an interview with parents which will last about 30-45 minutes and will also be audiotaped, with the participants' written consent. Participants' confidentiality and privacy will be respected, which means not disclosing what an individual said in the interview or focus group. The data will be stored on a password-protected computer and will only be handled by myself and destroyed in accordance with the Data Protection Act (1998). The original tapes will be destroyed three months after the thesis is completed. During the transcription phase, all data will be *anonymised* with the use of pseudonyms. Please note that participants can refuse to answer any question and have the right to withdraw or ask for their data to be removed at any stage during the project, without reason, up until the point at which the data will be

anonymised and amalgamated. This will be after the focus group or interview has been transcribed (approximately two weeks after the each was conducted). After this point, the data will be untraceable to any individual. The transcripts will be held indefinitely in line with Cardiff University's policy.

Information relating to the performance of any individual or service will not be sought or recorded.

Following the completion of the research, a Thesis will be written for university purposes but from this report, no individual participant will be able to be identified. The report might be published, but in an anonymised state. Additionally, anonymised feedback regarding the major findings of the research study will be made available to you on request. Your help in this project will be greatly appreciated.

If you have any further questions before completing and signing the reply slip, please do not hesitate to contact me. I can be reached on 07411388198 or by email on BurltonH@cardiff.ac.uk

The School of Psychology Research Ethics Committee granted ethical approval for the research on (*insert date*). If you would like to contact them for more information you can email on psychethics@cardiff.ac.uk or call on 02920870360.

If you give permission for parents and bereavement practitioners to participate in this study, please complete and sign the attached form, *using the stamped address envelope provided*. Please also pass the invitation letter and consent form to both parents and bereavement practitioners.

Yours sincerely,

Holly Burlton (Researcher)

I do/do not give permission for the parents and bereavement practitioners to participate in your research study

Signed..... Date.....

Print name.....

Contact details.....

If you have any questions relating to this study please do not hesitate to contact me at the School of Psychology, Cardiff University. You may also contact my supervisor, Gill Rhydderch (Academic Director) at the School of Psychology, Cardiff University. If you have any complaints you may contact Simon Claridge (Research Director) at the School of Psychology.

Holly Burlton

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Appendix B: Gatekeeper letter for head teachers

Holly Burlton
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BurltonH@cardiff.ac.uk

Dear [insert name]

I am a student training to be an educational psychologist on the Doctorate in Educational Psychology Programme at Cardiff University, and I have to undertake a thesis research study, as a requirement of the programme. I am interested in exploring perceptions of risk and resilience for bereaved children with learning and neurodevelopmental disabilities. I would like to explore the views of parents/carers and bereavement practitioners from bereavement services and school-based professionals who have supported children in these circumstances. In particular, I am interested in exploring factors that might support adaptation, coping and resilience and those which hinder the grieving process for bereaved children with these additional needs.

This research will hopefully assist relevant adults in reducing risk factors following bereavement whilst illuminating the attitudes, behaviours and methods which facilitate adaptive recovery from bereavement, supporting and developing capacity for resilience for children and young people with learning and neurodevelopmental disabilities.

Given your position as the head teacher of [insert name] school, I would like to invite school-based professionals who have experience working with bereaved children with learning and neurodevelopmental disabilities to take part in this research. This could include for example, teachers, pastoral workers, learning mentors and learning support staff. I will conduct a focus group with staff which will explore their perceptions of risk and resilience for children with learning and neurodevelopmental disabilities. This will last for about 60 minutes and will also be audio taped, with the participant's written consent. Participants' confidentiality and privacy will be respected, which means not disclosing what an individual said in the focus group. The data will be stored on a password-protected computer and will only be handled by myself and destroyed in accordance with the Data Protection Act (1998). The original tapes will be destroyed three months after the report is completed. During the transcription phase, all data will be *anonymised* with the use of pseudonyms. Please note that participants can refuse to answer any question and have the right to withdraw or ask for their data to be removed at any stage during the project, without reason, up until the point at which the data will be anonymised and amalgamated. This will be after the focus group has been transcribed (approximately two

weeks after the focus group was conducted). After this point, the data will be untraceable. The transcripts will be held indefinitely in line with Cardiff University's policy.

Information relating to the performance of any individual or service will not be sought or recorded.

Following the completion of the research, a Thesis will be written for university purposes but from this report, no individual participant will be able to be identified. The report might be published, but in an anonymised state. Additionally, anonymised feedback regarding the major findings of the research study will be made available to you on request. Your help in this project will be greatly appreciated.

If you have any further questions before completing and signing the reply slip, please do not hesitate to contact me. I can be reached on 07411388198 or by email on BurltonH@cardiff.ac.uk

The School of Psychology Research Ethics Committee granted ethical approval for the research on (*insert date*). If you would like to contact them for more information you can email on psychethics@cardiff.ac.uk or call on 02920870360.

If you give permission for the staff within your school to participate in this study, please complete and sign the attached form, *using the stamped address envelope provided*. Please also pass the invitation letter and consent form to both parents and bereavement practitioners.

Yours sincerely,

Holly Burlton (Researcher)

I do/do not give permission for members of staff in the school to participate in your research study

Signed..... Date.....

Print name.....

Contact details.....

If you have any questions relating to this study please do not hesitate to contact me at the School of Psychology, Cardiff University. You may also contact my supervisor, Gill Rhydderch (Academic Director) at the School of Psychology, Cardiff University. If you have any complaints you may contact Simon Claridge (Research Director) at the School of Psychology.

Holly Burlton

Gill Rhydderch

Simon Claridge

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Appendix C: Invitation letter for parents

Holly Burlton
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Dear Participant,

I am a student training to be an educational psychologist on the Doctorate in Educational Psychology Programme at Cardiff University, and I have to undertake a research study, as a requirement of the programme. I am interested in exploring perceptions of risk and resilience for bereaved children and young people with learning and neurodevelopmental disabilities. I would like to explore the views of parents/carers and bereavement practitioners from bereavement services and school-based professionals who have supported children in these circumstances. In particular, I am interested in exploring factors that might support adaptation, coping and resilience and those which hinder the grieving process for bereaved children with these additional needs.

As a parent/carer taking part in a bereavement service and supporting a child/children with additional needs, I would like to invite you to participate in this research. I will conduct one interview with each parent/carer that will explore perceptions risk and resilience for children with learning and neurodevelopmental disabilities. Each interview will last for about 30-45 minutes and will also be audio taped, with participants' written consent. Your confidentiality and privacy will be respected, which means not disclosing what an individual said in interview. The data will only be stored on a password-protected computer and will only be handled by myself and destroyed in accordance with the Data Protection Act (1998). The original tapes will be destroyed three months after the report in completed. During the transcription phase, all data will be *anonymised* with the use of pseudonyms. Please note that participants can refuse to answer any question and have the right to withdraw or ask for their data to be removed at any stage during the project, without reason, up until the point at which the data will be anonymised and amalgamated. This will be after the interview has been transcribed (approximately two weeks after the interview was conducted). After this point, the data will be untraceable. The transcripts will be held indefinitely in line with Cardiff University's policy.

Please further note that in the event that participants become upset or distressed by the conversation, a private room will be made available. This will be prearranged with the bereavement service where the interviews will take place.

Information relating to the performance of any individual or service will not be sought or recorded.

Following the completion of the research, a Thesis will be written for university purposes but from this report, no individual participant will be able to be identified. The report might be published, but in an anonymised state. Additionally, anonymised feedback regarding the major findings of the research study will be made available to you on request. Your help in this project will be greatly appreciated.

If you have any further questions before completing and signing the consent form attached then please do not hesitate to contact me. I can be reached on 07411388198 or by email on BurltonH@cardiff.ac.uk

The School of Psychology Research Ethics Committee granted ethical approval for the research on (*insert date*). If you would like to contact them for more information you can email on psychethics@cardiff.ac.uk or call on 02920870360.

If you are willing to participate in this study, please complete and sign the attached consent form *using the stamped address envelope provided*. The interviews will take place within the local bereavement service. Please could you provide your contact details on the consent form below to arrange an interview date.

Yours sincerely,

Holly Burlton (Researcher)

If you have any questions relating to this study please do not hesitate to contact me at the School of Psychology, Cardiff University. You may also contact my supervisor, Gill Rhydderch (Academic Director) at the School of Psychology, Cardiff University. If you have any complaints you may contact Simon Claridge (Research Director) at the School of Psychology.

Holly Burlton

Gill Rhydderch

Simon Claridge

School of Psychology

School of Psychology

School of Psychology

Cardiff University

Cardiff University

Cardiff University

07411388198

02920875493

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BurltonH@cardiff.ac.uk

RhydderchGA@cardiff.ac.uk

ClaridgeS@cardiff.ac.uk

Appendix D: Invitation letter for professionals from schools and bereavement services

Holly Burlton
School of Psychology
Cardiff University
Tel: 07411388198
BurltonH@cardiff.ac.uk

Dear Participant,

I am a student training to be an educational psychologist on the Doctorate in Educational Psychology Programme at Cardiff University, and I have to undertake a research study, as a requirement of the programme. I am interested in exploring perceptions of risk and resilience for bereaved children and young people with learning and neurodevelopmental disabilities. I would like to explore the views of parents/carers, bereavement practitioners from bereavement services and school-based professionals who have supported children in these circumstances. In particular, I am interested in exploring factors that might support adaptation, coping and resilience and those which hinder the grieving process for bereaved children with these additional needs.

As a [insert role] supporting bereaved children with learning and neurodevelopmental disabilities, I would like to invite you to participate in this research. I will conduct a focus group interview that will explore perceptions risk and resilience for children with learning and neurodevelopmental disabilities. I will conduct a focus group with staff which will explore their perceptions of risk and resilience for children with learning and neurodevelopmental disabilities. This will last for about 60 minutes and will also be audio taped, with participants' written consent. Your confidentiality and privacy will be respected, which means not disclosing what an individual said in the focus group. **In addition, whilst all members of the group should treat what is discussed as confidential, it cannot be guaranteed other members of the focus group will not repeated what has been discussed.** The data will be stored on a password-protected computer and only will handled by myself and destroyed in accordance with the Data Protection Act (1998). The original tapes will be destroyed three months after the report in completed. During the transcription phase, all data will be *anonymised* with the use of pseudonyms. Please note that participants can refuse to answer any question and have the right to withdraw or ask for their data to be removed at any stage during the project, without reason, up until the point at which the data will be anonymised and amalgamated. This will be after the focus group has been transcribed (approximately two weeks after the focus group was conducted). After this point, the data will be untraceable. The transcripts will be held indefinitely in line with Cardiff University's policy.

Please further note that in the event that participants become upset or distressed by the conversation, a private room will be made available. This will be prearranged with the bereavement service or school where the focus groups will take place.

Information relating to the performance of any individual or service will not be sought or recorded.

Following the completion of the research, a Thesis will be written for university purposes but from this report, no individual participant will be able to be identified. The report might be published, but in an anonymised state. Additionally, anonymised feedback regarding the major findings of the research study will be made available to you on request. Your help in this project will be greatly appreciated.

If you have any further questions before completing and signing the consent form attached then please do not hesitate to contact me. I can be reached on 07411388198 or by email on BurltonH@cardiff.ac.uk

The School of Psychology Research Ethics Committee granted ethical approval for the research on (*insert date*). If you would like to contact them for more information you can email on psychethics@cardiff.ac.uk or call on 02920870360.

If you are willing to participate in this study, please complete and sign the attached consent form *using the stamped address envelope provided*. Please could you provide your contact details on the consent form below to arrange the interview date.

Yours sincerely,

Holly Burlton (Researcher)

If you have any questions relating to this study please do not hesitate to contact me at the School of Psychology, Cardiff University. You may also contact my supervisor, Gill Rhydderch (Academic Director) at the School of Psychology, Cardiff University. If you have any complaints you may contact Simon Claridge (Research Director) at the School of Psychology.

Holly Burlton

School of Psychology

Cardiff University

07411388198

Gill Rhydderch

School of Psychology

Cardiff University

02920875493

Simon Claridge

School of Psychology

Cardiff University

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BurltonH@cardiff.ac.uk

RhydderchGA@cardiff.ac.uk

ClaridgeS@cardiff.ac.uk

Appendix E: Consent form

Consent Form

- I agree to participate in the research study, ‘Risk and Resilience for Bereaved Children and Young People with Learning and Neurodevelopmental Disabilities: Perception of parents, schools and bereavement support practitioners’
- I understand the purpose and the nature of this research study and I am participating voluntarily.
- I understand that I will participate in [*insert either interview or focus group*] lasting approximately [*insert duration*].
- I agree to the [*insert either interview or focus group*] being recorded and I am aware that the recording will be destroyed in accordance with the Data Protection Act (1998) and that the transcripts will be held indefinitely in line with Cardiff University’s policy. I understand that my interview will be stored on a password-protected computer that only the researcher will have access to.
- If taking part in a focus group, I understand that it cannot be guaranteed other members of the focus group will not repeated what has been discussed.
- I understand that the data will be transcribed and *anonymised* with pseudonyms. I understand that no individual will be able to be identified in the final written Thesis, which might be published.
- I understand that I can refuse to answer any question, ask for my data to be removed, and/or withdraw, at any time during the project, without reason, up until the point at which the data will be anonymised and amalgamated. After this point, I understand that the data will be untraceable. I understand that this will be after the [*insert either interview or focus group*] has been transcribed (approximately two weeks after it has been conducted).
- I understand that if I become upset or distressed by the conversation, a private room will be made available. This will be prearranged by the researcher in either the school or bereavement service where the interviews or focus groups are taking place.
- I grant permission for the data collected to be used in the process of completing a written Thesis, a requirement of the Doctorate in Educational Psychology at Cardiff University.
- I understand that actual names and places will not be used in order to preserve anonymity. Participants may have feedback on the research upon request.

I, _____(NAME) consent to participate in the study conducted by Holly Burlton, School of Psychology, Cardiff University with the supervision of Gill Rhydderch, Academic Director of the Doctorate in Educational Psychology (DEDPSY).

Signed: _____

Job Title: _____

Contact Details (email/phone): _____

Date: _____

If you have any questions relating to this study please do not hesitate to contact me at the School of Psychology, Cardiff University. You may also contact my supervisor, Gill Rhydderch (Academic Director) at the School of Psychology, Cardiff University. If you have any complaints you may contact Simon Claridge (Research Director) at the School of Psychology.

Holly Burlton

Gill Rhydderch

Simon Claridge

School of Psychology

School of Psychology

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Appendix F: Debriefing form

Study Title: ‘Risk and Resilience for Bereaved Children and Young People with Learning and Neurodevelopmental Disabilities: Perceptions of parents, schools and bereavement support practitioners’

To ensure confidentiality, information will be stored securely on a password-protected computer to which only the researcher has access until transcribed. When transcribed it will be fully anonymous, meaning that no-one can know who said what. There will be a Thesis written for university purposes and it might be put forward for publication, but in an anonymised state. Finally, anonymised feedback on the major findings of the research will be available to you on request.

Please further note that in the event that participants become upset or distressed by the conversation, a private room will be made available. This will be prearranged by the researcher in either the school or bereavement service where the interviews or focus groups are taking place.

About this Study:

This thesis research project aims to fill a gap in the research literature by exploring bereavement for children and young people with learning and neurodevelopmental disabilities and in particular perceptions of risk, vulnerability, adaptation, coping and resilience.

This research will hopefully assist relevant adults in reducing risk factors following bereavement whilst illuminating the attitudes, behaviours and methods which facilitate adaptive recovery from bereavement, supporting and developing capacity for resilience for children and young people with learning and neurodevelopmental disabilities.

The following research questions were explored:

1. What factors are perceived to increase risk and vulnerability for children with learning and neurodevelopmental disabilities following bereavement?

2. What factors are perceived to help children with learning and neurodevelopmental disabilities adapt, cope and build resilience following bereavement?

If you have any concerns or questions relating to this study please do not hesitate to contact me at the School of Psychology, Cardiff University. You may also contact my supervisor, Gill Rhydderch (Academic Director) at the School of Psychology, Cardiff University. If you have any complaints you may contact Simon Claridge (Research Director) at the School of Psychology.

Holly Burlton

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Appendix G: Interview questions and probes (parents/carers)

My name is Holly Burlton and I am a Trainee Educational Psychologist. I am doing a thesis research project exploring perceptions of risk and resilience for bereaved children and young people with learning and neurodevelopmental disabilities.

I would like to ask some questions today and it is important to try and answer them as honestly as you can. It is important to note that there are no 'right' or 'wrong' answers and I am only interested in your views and experiences. The interviews will be audiotaped using a Dictaphone; you do not have to answer any of the questions or give a reason for not wishing to answer that question and you can stop the interview at any point without giving a reason. You can further ask to have data removed from this study within two weeks following interview.

Finally, if you become upset or distressed by the conversation, a private room will be available [give participants details of this].

Rapport building

- 1) I wondered if you could tell me a little bit about your son/daughter?
 - a. *Could you tell me something that makes you laugh or smile when you think about your son/daughter?*
 - b. *Could you tell me about their interests, likes and dislikes? Maybe at home/school?*
 - c. *Could you tell me about anything that is particularly challenging for your child? Maybe at home/school?*

Experiences of bereavement

- 2) Can you tell me a bit about the bereavement that your child experienced?
 - a. *Who died and what was their relationship with the child?*
 - b. *How old was the child when this person died?*
 - c. *What were the circumstances of the death?*
 - d. *Were there any changes to routine/family life following the death?*
- 3) Could you tell me how your child responded to the death?
 - a. *What different behavior/emotions did your child show, if any, following the bereavement?*
 - b. *Did these change and develop over time and if so, how?*

Learning disabilities and responses to bereavement

- 4) As your child has [insert difficulty], or finds X difficult, did you have any particular anxieties about his/her responses to the bereavement?
- a. *How did you talk to your child about the death?*
 - i. *Did you want to talk to your child about the death?*
 - ii. *Did you find this difficult?*
 - iii. *Did your child's [insert difficulty] make communication difficult?*
 - b. *Did your child know that someone had died?*
 - i. *How did you know this?*
 - ii. *Did she/he understand that they were not coming back?*
 - iii. *What effect do you think your child's difficulty had on his/her understanding of death?*
 - c. *How did your child's grief reveal itself?*
 - i. *What were the signs?*
 - ii. *Do you think your child having [insert difficulty] made this problematic? And if so, how?*

Support and Resilience

- 5) How well do you think your child coped with the bereavement?
- a. *How did you know that he/she was coping well*
 - b. *How did you know that he/she was were not coping well*
 - c. *How do you think your child's [insert difficulty] influenced the way that they coped?*
- 6) What did you do to support your child following the bereavement?
- a. *What did you talk about together that helped?*
 - b. *What did you do that helped?*
 - c. *What kind of help did you seek?*
 - d. *What support did you obtain?*

Appendix H: Focus group questions and probes

My name is Holly Burlton and I am a Trainee Educational Psychologist. I am doing a thesis research project exploring perceptions of risk and resilience for bereaved children and young people with learning and neurodevelopmental disabilities.

I would like to ask some questions today and it is important to try and answer them as honestly as you can. It is important to note that there are no 'right' or 'wrong' answers and I am only interested in your views and experiences. The focus group will be audiotaped using a Dictaphone; you do not have to answer any of the questions without giving a reason, and you can stop the interview at any point without giving a reason.

Finally, if you become upset or distressed by the conversation, a private room will be available [give participants details of this].

Rapport building

- 1) I wondered if we could start by discussing your job roles [in school or the bereavement service] and the types of children and young people that you work with?

Experiences of bereavement

- 2) I wondered if you could think about a time you have supported a bereaved child or young person with learning and/or neurodevelopmental disabilities. Could you tell me about the circumstances of the bereavement?

- e. Who died and what was their relationship with the child?*
- f. How old was the child when this person died?*
- g. What were the circumstances of the death?*
- h. Were there any changes to routine/family life following the death?*

- 3) Could you tell me how the child or young person responded to the death?

- a. What different behaviours/emotions did she/her show following the bereavement?*
- b. Did these change over time?*

Learning disabilities and responses to bereavement

- 4) Did you have any particular anxieties about their responses to the bereavement in light of their learning and/or neurodevelopmental disabilities?

- a. Were there any issues with communication?*
 - i. Did you talk to the child/young person about the death?*

- ii. *Did you find this difficult?*
 - iii. *How did the child's learning and/or neurodevelopmental disability affect this communication?*
- b. *Did the child/young person know that someone had died?*
 - i. *How did you know this?*
 - ii. *Did they understand that the person was not coming back?*
 - iii. *In what ways did the learning and/or neurodevelopmental disability affect their understanding of death?*
- c. *How did you identify that the child or young person was grieving?*
 - i. *What were the signs?*
 - ii. *What effect, if any, do you think that the CYP having learning/neurodevelopmental disabilities had on identifying these signs?*

Support and Resilience

- 5) Do you think the child or young person coped well with the bereavement?
 - d. *How did you know that he/she was coping well*
 - e. *How did you know they were not coping well*
 - f. *Do you think your child's [insert difficulty] influenced the way that they coped?*
- 6) What did you do to support the child/young person following the bereavement?
 - e. *What did you talk about together that helped?*
 - f. *What did you do together that helped?*
 - g. *What help did you seek? (for schools)*
 - h. *What support did you obtain?*

Appendix I: Procedure for recruitment to focus groups

The procedure for recruitment to focus groups for school professionals was as follows:

- 10 special schools in one LA in England were randomly selected from the LA website.
- The head teacher of each school was emailed a gatekeeper letter.
- Only 1 school consented to participate. The head teacher completed and signed the gatekeeper letter providing the researcher with relevant contact details.
- The researcher contacted the head teacher and provided further information including invitation letters and consent forms for the school professionals.
- The head teacher disseminated this information to school professionals and those who gave their permission were contacted directly to arrange a time for the focus group.
- All school professionals (N=5) were included in the same focus group. All consent forms were signed and collected by the researcher on the day.

The procedure for recruitment to focus group for bereavement services was as follows:

- 4 national bereavement services were randomly selected.
- The head of service for each was emailed a gatekeeper letter.
- Only 1 bereavement service responded and consented to participate. The head of service completed and signed the gatekeeper letter providing the researcher with relevant contact details.
- The researcher contacted the head of service and provided further information including invitation letters and consent forms for the bereavement professionals.
- The head of service disseminated this information to bereavement professionals. Those who agreed to participate informed the head of service who then arranged a time for the focus group.
- All bereavement professionals (N=8) were included in the same focus group. All consent forms were signed and collected by the researcher on the day.

Appendix J: Procedure for recruitment to interviews

The procedure for recruitment to interviews for parents/carers was as follows:

- To gain access to parents/carers, the researcher contacted 4 national bereavement services.
- The head of service for each was emailed a gatekeeper letter.
- As above, only 1 bereavement service responded and consented to participate. The head of service completed and signed the gatekeeper letter providing the researcher with relevant contact details.
- The researcher contacted the head of service and provided further information including invitation letters and consent forms for parents/carers.
- The head of service disseminated this information to bereavement professionals who then passed this information on to parents/carers with whom they had previously worked with and who fit the purposeful criteria (e.g., having a bereaved child with L/ND).
- If permission was given, parents/carers were contacted directly to arrange an interview time.
- All consent forms were signed and collected by the researcher on the day of the interview.

Appendix K: Braun & Clarke's (2006) Six Steps of Thematic Analysis

Step 1	Familiarise yourself with the data: the data was transcribed and read repeatedly by the researcher.
Step 2	Generate initial codes: interested features of the data were coded
Step 3	Search for themes: codes were then grouped into themes and evidence collected.
Step 4	Review themes: themes were checked, grouped and made into a thematic network.
Step 5	Define and name themes: themes were refined and named to represent the overall story of the analysis.
Step 6	Writing the report: themes and evidence were discussed using extended pieces of text and in relation to the literature.

Appendix L: Ethical Considerations

Protection from harm

In terms of minimising potential harm to psychological wellbeing, the following was considered. Firstly, the parents that volunteered to participate had already received some form of bereavement support through a specialist service, suggesting that they had already shared their experiences with others and were aware of how to access the appropriate support channels. Secondly, school-based professionals from special school provisions and bereavement practitioners were/are professionally trained and/or experienced in the subject and were receiving professional supervision.

If any issues did arise during the research, participants were made aware that they could approach their local EP or head teacher (for special schools), their relevant line-manager (for bereavement practitioners) or a named contact from the bereavement service (for parents/carers). Following liaison with these relevant support channels, contact details for these individuals were made available. Finally, the researcher has a background and is professionally trained in bereavement and approached the topic both appropriately and sensitively.

In terms of minimising any personal harm/risk, the researcher recorded the interviews/focus groups in an online diary that was accessible to her supervisor within the EPS. Furthermore, the researcher informed her supervisor when and where the interviews/focus groups were being conducted and rang at the end of the interview or focus group to confirm that it was completed. The researcher further adhered to the health and safety procedures within the location in which the interviews/focus groups took place.

Informed Consent

Consistent with the British Psychological Society's (2014) *Code of Human Research Ethics*, the researcher obtained written, informed consent from all 15 participants. Gatekeepers were contacted using letters with relevant information about the study (Appendix, A & B). Following written consent from the Gatekeepers, participants were approached and consent was sought using invitation letters and opt-in consent forms (Appendix C, D & E).

Confidentiality

Participants' confidentiality and privacy was respected at all times. For the interviews with parents/carers, the researcher used a private room at the bereavement service. At the interview

stage, participants were reminded of confidentiality and privacy procedures including the fact that their responses would remain unidentifiable to everyone apart from the researcher, pseudonyms would be used for all transcribed interviews and that data would be handled solely by the researcher, stored securely on a password-protected computer and destroyed following transcription (in accordance with the Data Protection Act, 1998).

For the focus groups, the researcher used a private room at the bereavement service (for bereavement professionals) and at a special school (for school-based professionals). At the focus group stage, participants were reminded of confidentiality and privacy procedures as detailed above. **However, they were also made aware of the limits to confidentiality within a focus group setting within the invitation letters and before the focus group began.**

Rights to withdraw

Participants were reminded of their right to refuse to answer any question and their rights to withdraw or ask for their data to be removed at any stage during the project, without reason, up until the point in which the data was anonymised and amalgamated. Participants were made aware that this would be after the data was transcribed (approximately two weeks after each was conducted). All participants were provided with contact numbers in case of complaint and/or any queries they may have and to ensure they were able to withdraw if necessary.

Debriefing

All participants received a debriefing letter summarising the purpose of the research once again and thanking them for their involvement (Appendix F). In case of any further questions or concerns, these letters also outlined the contact details of the researcher, the research supervisors and the Cardiff School of Ethics Committee.

Appendix M: List of Literature Search Terms

The table below provides a list of key search terms which were put into a number of different databases including Google Scholar, PsycINFO, Science Direct and WileyInter-Science.

Search Terms
Children AND bereavement
Children AND grief
Children AND mourning
Children AND bereavement AND grief AND mourning
Theory (ries) AND bereavement
Theory (ries) AND grief
Theory (ries) AND mourning
Theory (ries) AND bereavement AND grief AND mourning AND children
Children AND development AND bereavement
Children AND development AND bereavement AND grief
Children AND development AND bereavement AND grief AND mourning
Death AND dying AND understanding
Children AND development AND death AND dying AND understanding
Children AND bereavement AND grief AND risk
Children AND bereavement AND grief AND mental health
Children AND bereavement AND grief AND psychological health
Children AND bereavement AND grief AND positive AND health
Children AND bereavement AND grief AND resilience
Children AND bereavement AND grief AND resilience AND coping
Moderators AND children AND bereavement AND grief
Mediators AND children AND bereavement AND grief
Learning disabilities AND bereavement AND grief AND children
Learning difficulties AND bereavement AND grief AND children
Developmental disabilities AND bereavement AND grief AND children
Neurodevelopmental disabilities AND bereavement AND grief AND children
Learning disabilities AND bereavement AND grief AND adults
Learning difficulties AND bereavement AND grief AND adults
Developmental disabilities AND bereavement AND grief AND children
Neurodevelopmental disabilities AND bereavement AND grief AND adults
Learning disabilities or difficulties AND bereavement AND grief AND risk
Developmental disabilities AND bereavement AND grief AND risk
Neurodevelopmental disabilities AND bereavement AND grief AND risk
Learning disabilities or difficulties AND bereavement AND grief AND resilience
Developmental disabilities AND bereavement AND grief AND resilience
Neurodevelopmental disabilities AND bereavement AND grief AND resilience

Appendix N: Thematic Map

