

## **THE EFFECTS OF BEREAVEMENT AND LOSS ON PUPILS WITH SEVERE LEARNING DIFFICULTIES**

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### **Aims and Scope of the Assignment**

In recent years, there has been increased awareness amongst professionals as to how bereavement and loss might affect children and young people. Research indicates that children follow a grieving process that is similar to that of adults and also that children conceptualise death in distinct ways at certain ages. Despite the heightened awareness surrounding these issues however, it is suggested that staff in schools continue to find it difficult to talk to pupils within their classes about bereavement and loss. Unfortunately, some staff are then forced to confront these issues following a death of somebody from within the school community, at a time when the adults may be experiencing similar and complex emotions to the children or young people in school.

This was the situation faced by staff working in a special school for pupils with severe learning difficulties (SLD), when one of the pupils died. Following this loss, staff expressed concern that they felt ill equipped to respond to the situation. In particular, they felt that they might make things worse for the children within their care by omitting to provide the opportunities for pupils to grieve, or by missing the signs that a pupil was affected by the loss of their peer. This was not the first pupil death within the school, as the school population contained several pupils with degenerative or life threatening

conditions. In addition, some of the pupils had experienced significant losses or bereavement at home.

The concerns of the staff were discussed with their link educational psychologist, and it was therefore agreed with the school that this area would be explored further in order to support young people within the school community who had experienced bereavement or loss. The staff involved with the initiative would then look to develop a school policy on dealing with loss and bereavement in school, in order to promote consistency and a whole school approach towards pupils in this situation.

The feelings of anxiety that the school staff experienced were not unique to teachers in special schools, but the staff felt that little information was available for them at this time relating to the specific need of pupils with severe learning difficulties following a bereavement. The teachers wanted to know not only how to approach their pupils in talking about death, but also how they might share information and strategies with colleagues and parents about how death and the grieving process might affect children with complex needs. It was discovered through subsequently seeking information on this topic, that this is a much under-researched area and therefore one that requires further consideration.

### **Practice and Content**

Following the death of a young person at a special school for pupils with severe learning difficulties, staff expressed concern to their link educational psychologist that they felt poorly equipped to respond effectively to this sad situation. Several pupils at the school had experienced significant bereavements and other losses within their family life and staff wished to develop their knowledge and skills in this area in order to support children and young people through the grieving process.

### **Developing a working party**

It was agreed that a working party would be formed in order to consider these issues further and invitations were sent to a range of professionals who had an interest in this area. There was a positive response to the invitations and the established working party comprised two educational psychologists, two teachers from the special school who had initiated the original concern, a counsellor from the Brent Bereavement Project and a social worker specialising in learning disabilities

It was agreed at the initial meeting that the group would work together for three months and the five objectives for the group were agreed as follows:

1. To consider areas of bereavement and loss that are relevant to children with severe and complex learning difficulties

2. To develop a theoretical knowledge base about the effects of bereavement and loss within this cohort of pupils
3. To elicit practical ideas and strategies for school staff after experiencing a death in the school
4. To develop an information leaflet for teachers and school staff
5. To provide guidance for policy writing in order that all staff members were aware of school based procedures for responding to the death of a member of the school community.

Subgroups from within the working party were organised for individuals to consider each of the objectives and future meetings were planned to a suggested time scale to complete specific tasks.

### **Meeting the objectives**

#### Objective One: Areas of bereavement and loss that are relevant to children with severe and complex learning difficulties

The group used a brainstorming session to elicit the different 'loss' situations that children and young people might experience. This included loss through the death of a parent or close relative, losses caused by divorce, or parental imprisonment, and complex losses, such as a child from an asylum seeking family might experience. Within this session, many possible loss situations were recorded and it became clear that it would not be possible to research and record all areas relating to children's experiences of loss effectively within the time available to the working party. It was therefore decided that the group would

focus specifically upon the effects of bereavement on children with severe learning difficulties within a school context, although it was felt that the general principles and guidelines that were recorded within the guidance sheet could also be generalised to other contexts.

Objective Two: To develop a theoretical knowledge base of the effects of bereavement and loss within this cohort of pupils

Following the first meeting, letters were sent to a range of organisations to request copies of any information that they had found useful in talking to children about death. The organisations included other special schools and charitable organisations including SANDS (Stillbirth and Neonatal Death Society), cancer charities and the Terence Higgins Trust. This information was gathered from the CAF (Contact a Family) Directory, and elicited a 50% response from those contacted. Although there seemed to be a growing number of resources for children and young people who had been bereaved, none of them were specifically targeted towards individuals with severe or complex learning difficulties. The National Autistic Society however had produced a detailed document directed towards professionals working with children on the autistic continuum who had experienced a loss or bereavement.

Library searches also yielded little information on this subject. The areas of 'bereavement in children' and 'pupils with severe learning difficulties' were therefore initially considered separately within the literature and the concepts were linked together to develop a knowledge base of this area. The expertise

within the group was invaluable in integrating the information from the literature with personal experience of pupils who had been in this situation.

A visit to the Brent Bereavement Project was also helpful both in terms of considering their available resources and literature, and the approach that they have adopted to working with young bereaved individuals. Staff at the project reinforced the view of the working party, that there was little information available relating to the effects of bereavement on pupils with severe learning difficulties.

Objective Three: To elicit practical ideas and strategies for school staff after experiencing a death in the school

This was a difficult area to consider because most bereavement literature focuses upon children who are considered to fall within the 'normal' range of development. Information relating to children's understanding of death was all based upon age related norms, without accounting for children's individual differences, as was the information provided to help parents and professionals in supporting a bereaved child. From reviewing the literature, a staged model of children and young people's understanding of the concept of death was produced by the working party that was not reliant upon individual's ages (See Appendix One). This was helpful in terms of helping to elicit the strategies that might then be used to support children at different developmental stages in dealing with a significant bereavement.

**Objective Four: To develop an information leaflet for teachers and school staff**

From the information that had been acquired in working upon the first three objectives and from expertise within the group, information was brainstormed and recorded under the following headings. It was considered that this would be important information to include within the leaflet for teachers:

1. Theoretical and research information relevant to this area
2. Types of loss that children may experience
3. Consequences of a bereavement for a child
4. How a child may react to a significant loss or bereavement
5. Questions that the child may have
6. Issues for school staff, including policy decisions

This task highlighted the areas that required further work within the group and research that was necessary on a wider scale. Individuals within the working party collated their knowledge in the production of this leaflet.

The guidance leaflet was distributed within the Educational Psychology Service for feedback and the suggestions for adaptations and amendments were considered and incorporated, as deemed appropriate within the group. After the leaflet had been finalised, members of the working party gave a short presentation to staff at the special school that related both to the subject matter and more specifically about the rationale behind and findings of the working party. The response to the leaflet was not formally evaluated as it was felt to be a

small-scale piece of work that was for the benefit of a specific school. It is suggested however that the leaflet could be extended and adapted for a wider audience, including parents of children with SLD.

A request for appropriate resources to be developed in this area for pupils with learning difficulties was made at the staff meeting as was the need for more research into the life experiences of children with SLD. This view was supported by members of the working party.

Objective Five: To provide guidance for policy writing

The purpose of developing guidance for policy writing was to ensure that all staff members were aware of school based procedures for responding to the death of a member of the school community. The working party felt strongly that the policy should be written by the school staff, rather than as part of the project, so that school staff would have ownership of and responsibility for the document.

In working on this objective, information was sought from the literature in terms of curriculum-based approaches for helping pupils understand issues surrounding loss and bereavement that could be used in PSHE lessons. In addition to this, it was felt that staff should develop a clearly written plan that could be referred to in the event of the death of a pupil or teacher. It was anticipated that this should incorporate both short-term actions and longer-term strategies in helping talk to the pupils about what had happened.

A policy guidance 'fact sheet' was developed and presented to staff during the staff meeting. A member of the management team then took responsibility for developing this into a school policy.

### **Reflecting on the task**

The working party adhered closely to the three-month time scale that had been agreed at the initial meeting and it was felt that the objectives had been achieved, as far as was possible within such a limited period.

The main challenge for the group had been the lack of specific information about this subject, which had not been anticipated. This meant that the task of the working party, rather than being one of gathering and reporting information, had to be much more reflective and intuitive. Much of the information that was gained was based on sharing individuals' personal knowledge and experience of loss, bereavement and working with children within a wide spectrum of needs. This knowledge and information was then placed within a theoretic framework from reviewing the available literature.

## **Psychological Theory and Research**

### **Methods used to survey the literature**

In seeking information on the subject of Bereavement and Loss in Children with Severe Learning Difficulties, searches were made on the Internet and through specialist psychology library databases. Key phrases used within the searches initially included; “learning difficulties/disabilities and loss”, learning difficulties/disabilities and bereavement”, “children and loss/bereavement” and “children and learning difficulties”. The latter two searches provided a number of ‘hits’, but there was very little information in relation to children with severe learning difficulties and their experiences of loss and bereavement. Searches were then extended to consider, “Death/loss in schools” and “critical incidents in schools”, but this information also focused on pupils who do not have special educational needs. Information was sought from a range of organisations from the private and voluntary sector whom it was felt might have experience in this area, including specialist counselling services who described themselves as working closely with children who have SLD. Staff working within this context explained that they had also found been little research in this area.

Information was available that described children’s experiences of bereavement and loss relating to those pupils who might be considered as being within the ‘normal’ range of development. Some information was also elicited in relation to children with severe learning difficulties, but there was little information detailing the specific subject matter required. Case study evidence was available from

some sources (Oswin 1991), but the working party felt that this information could be rather idiosyncratic and subject to bias. The members of the working party therefore used information that was available from the literature and combined this knowledge with personal experience in working with children who have severe learning difficulties to develop the information leaflet for schools. The effects of bereavement and loss on children and young people with severe learning difficulties is therefore one area that needs to be researched in order to support this group of young people.

### **How have pupils with SLD been viewed historically?**

Until comparatively recently, children and adults with severe learning difficulties were viewed as having different needs to their peers without learning difficulties. Marriage and sexual relationships in adults with SLD were thought to be at best inappropriate and were prevented, and efforts were made to 'protect' people with SLD from the harsh realities of society. Education was not thought to be appropriate for this group of individuals, who were often hospitalised or cared for in institutions. Individuals had little or no control as to what happened to them and their wants and needs were not generally listened to or acted upon. Tomlinson (1982) describes how in the period 1890 to 1920, individuals with special educational needs were labelled as being 'feeble minded' or 'morally defective'. She argues that institutionalisation occurred largely because society perceived people with SEN as being associated with criminal activity and immorality. This was also a time when the Eugenics movement was increasing in popularity amongst certain groups within society. Their philosophy was that

society should be improved through selective breeding and that individuals viewed as having differences from the 'normal' population should not be allowed to have children. This view is not held universally however, Cole (1990) describes how there were differing opinions relating to the integration of individuals with SEN into society at the turn of the 20<sup>th</sup> century. This ranged from the belief that people leaving special schools should be segregated from society to a more integrationist approach. Therefore there are some discrepancies in today's understanding in how people with learning difficulties have been perceived and treated in society.

Following the 1944 Education Act, children with SEN were entitled to a different range of experiences. This included a curriculum that would provide individuals with a range of skills, including preparation for life in society after leaving school. Educational categorisation was widespread and individuals were generally segregated to be taught with other people who were described under the same category of need as themselves. It was not until the 1970 Education (Handicapped Children) Act and the 1981 Education Act that the categories were revised to those used today and that education became the focus for all children. There is still however, much re-education of society required as well as support for professionals working in schools to encourage inclusion for all.

Educational Psychology encourages those working within the field of education to understand the evidence behind their practice, but for children in schools today, the curriculum tends to focus upon teaching specific skills rather than

looking at the awareness of feelings and behaviours that might be needed in the future. Psychology is beginning to address this imbalance however with research into emotional literacy and through specific initiatives, such as 'Healthy Schools'. There are significant gaps however in the psychological knowledge and theory of many aspects of childhood experience. The effects of bereavement and loss on pupils with severe complex learning difficulties is just one example of a research vacuum and possibly this reflects the lower status with which people with learning difficulties continue to be regarded within today's society.

### **Why consider this area?**

Morgan (1985) described the role of professionals in schools as preparing young people for life and argued that the subject of death should be part of the curriculum as part of this preparation. This perhaps might be considered to be too narrow a subject focus to spend time on in today's busy classroom, but by providing all pupils with strategies for coping with loss, there would be a significant impact that could extend to other aspects of life in school including pupils' learning and behaviours. The Author therefore considers that a curriculum that provides pupils and their teachers with a common language of emotion is of utmost importance to the curriculum.

### **Types of loss that may be experienced**

Any child may experience loss through changes in routine, changing their teacher at the end of the school year, moving house, having a friend move to another area, the death of a family member or pet, or occasionally losing some

aspect of bodily or cognitive function, such as losing a limb or losing the ability to speak. Morgan (1985) reviewed the literature and was discouraged by the lack of research that had been completed with children on the different losses that they might experience. Within the last twenty years however there appears to have been an increase in considering children's experiences of this type and in current searches, a range of discursive literature has been written on this subject. Research studies are still limited, perhaps due to the sensitive nature of the subject and due to the ethical issues involved in working with children who have had these particular experiences.

Brown (1999) is one author who follows the discursive style and he distinguishes between losses that are 'necessary' to human development and, 'circumstantial' losses that not everybody goes through. An example of a necessary loss is weaning, whereas circumstantial losses include the death of a significant person or a family breakdown. Within the information about children who experience loss, searches yielded very little information about the issues that particularly relate to children with complex needs, many of whom would be placed within a special school environment. It can be argued that children placed within special schools have often experienced greater losses than same-age peers in mainstream schools have. Pupils with emotional and behavioural difficulties who are placed in special schools will have almost certainly have experienced exclusions from school which disrupt the relationship between the pupil, their peers, teachers and curriculum. The move to any special provision is likely to take the child away from their immediate family community, which can result in

the loss of friendships and relationships. Some pupils will be in the care of social services and will have had changes of foster family and some children will have received respite care, particularly those young people who have complex needs where their families may feel the need for a break from caring for their child. All of these circumstances may elicit feelings of loss within a young person, which, as will be explored later, may give rise to a range of complex feelings and behaviours.

With increased levels of family breakdown, children and young people may be experiencing loss of contact with a parent and a change of circumstances when parents form new relationships and perhaps new siblings are born. Other potential circumstantial losses may be a result of abuse, serious illness or an accident. These may be particularly difficult for a child with complex needs to understand if they do not have the language skills for formulating or voicing questions relating to their feelings. Many parents may feel a sense of loss at having had a child with severe learning difficulties and have to come to terms with the fact that they might lose the opportunity for future independence from them. Children with special educational needs might experience a loss of their status within society, for example by being teased by same age 'mainstream' pupils.

### **What does the literature tell us about how pupils respond to loss?**

Given the fact that there are lots of opportunities for children to experience such losses, it may appear surprising that so little information is known about their

responses to loss situations. There may be a range of motives for this, including the feelings of wanting to protect children from difficult emotions, adults not knowing how to raise the subject with a child and also as an adult finding it difficult to come to terms with personal feelings about bereavement and loss (Tatelbaum 1996). Today, death appears to be rather a taboo subject whereas historically, children in Britain would have been more likely to live in extended families than they are today and would have experienced at first hand losses of people familiar to them. With poor healthcare and nutrition and a high mortality rate amongst children and young adults, children of a century ago would have been more likely to experience significant bereavements and losses at close range than their modern counterparts. They may also have had a more realistic understanding of the concept of death, for example in appreciating that death is not only associated with the elderly or with violence, as some children do today (Morgan 1985). It is important to state that people continue to live within extended families in different cultures and countries, and sadly it is still the case that adequate hygiene and health facilities are not available to all. It is suggested that a cross cultural study would extend current thinking in this area by comparing and contrasting children's conceptualisation of death in different countries. Limited research in this area however has been identified from current searches.

### **How do children conceptualise death?**

Although it has been questioned whether children can understand what it means if somebody dies, the literature suggests that children's understanding of the

concept is based upon a developmental process (Morgan 1985). Many different books describe the characteristics of children's understanding of death based on their chronological age, for example in 'Grief in Children', Dyregrov (1995) suggests that children under the age of five years have difficulty in understanding that death is final. This therefore describes in general terms how a child whose development is considered to be 'average' at this age might perceive the loss of a known individual. . This is rather a limited view however, because a variety of factors are believed to affect the individual's understanding and reaction to death. This includes their relationship with and the roles occupied by the dead person, previous experiences of loss or death, support networks available to them, the context within which the death occurred and their cognitive functioning (Rando 1984). Other factors, such as personality and resilience within the child are also important in understanding their reaction to loss. Knowledge of Attachment Theory suggests that even young babies react significantly to particular types of loss and that the effects of this might have long-term implications for the bereaved individual. Children and young people with severe learning difficulties would generally be expected to be achieving their developmental goals much later in most or all areas than pupils of the same chronological age who are considered as being within the average ability range. It is therefore suggested that a child's understanding of the concept of death be better defined in developmental stages rather than in ages (see 'Integration of Theory and Research').

### **Consequences of a bereavement for any child**

It is widely documented that when a parent has died, the child or young person who has been bereaved has to face difficult issues not only relating to the death of their loved one, but also in terms of changes within the family. The literature review raised the following issues: there may be practical changes of a material nature and subsequently emotional consequences for the child, the surviving parent may feel overcome with sadness, anger and anxiety and may not have the emotional resources to respond to their child's needs at this time or there may be a change of financial status within the family, a parent who was previously at home may have to seek employment and there may be a resulting house move or change in school. Children will also have to cope with other people's emotional arousal and changes in their behaviour at this time. The child might feel anxious about how to comfort the bereaved person and also to cope with his or her own feelings towards the death. For people with learning difficulties who are cared for in institutions, this may not be the case however as their housing and daily routine is unlikely to be affected by a death within the family. The death of a carer or peer within the institutional setting may have as big an impact on the individual as would the death of a family member. Luchterhand and Murphy (1998) reported that the circumstances surrounding a death might complicate the grieving process for a young person with learning difficulties, however it could be suggested that this is not a unique situation for this cohort of young people as the circumstances surrounding the death of a loved one is significant for all who have suffered a bereavement.

Where information is withheld from a child, they may engage in fantasies about what has happened, or magical thinking, that they were responsible for the person dying. This may be particularly relevant where a child is young or at a young developmental stage.

### **Grief and mourning in children**

It is not contentious to state that the death of someone close can prove to be a major stressor for an individual and that this can result in 'strong emotional and behavioural responses' for the bereaved individual (Frude 1991). There also appears to be consensus within the literature that "for many bereaved people the slightest incident takes on a profound significance" (Frude 1991). Children with learning difficulties sometimes display behaviours that are difficult for parents and teachers to understand or interpret and these behaviours can sometimes appear to be bizarre in nature. It could therefore be suggested that following a bereavement, a change in behaviour could be a symptom of the loss experienced, although this may not be related to cultural expectations or norms. An individual may display obsessive actions such as playing with a particular toy that they have previously shown little interest in because it was an activity that was encouraged by the dead person. This view appears to be supported through some case study evidence, although this should be treated with caution due to limited empirical support.

Grief describes how an individual responds to a loss or bereavement and mourning relates to the feelings experienced after having been bereaved. This is

characterised by a process of working through feelings of pain, grief and loss. In adults, this is generally seen as having three distinct phases, Protest, Disorganisation and Reorganisation, however some authors define these further into four or five phases (Kubler-Ross 1969). Anxiety resulting from bereavement in adults relates fundamentally to the understanding that death is final and universal. Children's anxieties may come from not being told what has happened in a way that they can interpret the information effectively. Children who hear partial conversations about a death may develop creative or disturbing additions to their knowledge through their imagination. They may fear that death is contagious and worry for other members of the family. In addition, they may appear to have irrational fears because they relate an event or place – consciously or otherwise – to the loss that they have experienced.

### **What does the literature tell us about the feelings of pupils with SLD?**

Limited information is available in relation to this subject and it is suggested that for some people, SEN, and particularly individuals with SLD are perceived as a social taboo today. Within our society, which emphasises a particular view of the ideal self, people who are perceived as being different from the mainstream can be avoided or abused or feared. People with complex needs are still to a certain extent hidden in society through being educated in special schools and therefore it is difficult for people who have no experience of SEN to gain an understanding of people with diverse needs. Perhaps the fear and lack of information surrounding these taboos makes it particularly difficult to see the need for overcoming these barriers within society. The fact that pupils with SLD are still

hidden negates the need for there to be high quality research about how they should be supported within the mainstream. The lack of research may feed into the anxiety felt by many professionals and parents about including children with SLD with mainstream peers and therefore segregation is viewed as a preferred method of education. This perpetuates the viewpoint that children with SLD should not be considered as 'high-profile' individuals with whom exciting and useful research opportunities are available. It is suggested therefore that the lack of information elicited in relation to pupils with severe learning difficulties is further evidence of the lower status offered to individuals with SLD within society, even amongst the professionals who are working with children who have SEN.

### **How do children with severe learning difficulties conceptualise death?**

One of the challenges in considering this question is in the fact that children with severe learning difficulties are often portrayed within the literature as being very similar in terms of cognition, social and communication skills and emotional and behavioural development. In fact, children and young people with SLD are enormously complex to consider because of the wide range of abilities that can be seen in groups of individuals who share this particular label. McEvoy (1989) suggests that pupils with special educational needs but who have good language, self help and social skills may have a more sophisticated representation of death and dying and the Author suggests that some people who have severe learning difficulties have strengths in these particular areas. Cathcart (1996) reported that some studies have suggested that the concept of death in adults with learning disabilities is similar to the development of the

concept of death in children, however this does not allow for the individual differences between people with SLD and regards them as a homogeneous group in terms of their strengths and weaknesses. As described previously, a number of factors are involved in an individual developing an understanding of this concept and this is also true for children with SLD.

Consideration of the feelings and conceptual understandings of others is dependent on a certain amount of interpretation, and this is particularly the case when working with children who may not have the vocabulary or reporting skills to describe their views and opinions accurately. Where a child or young person has severe learning difficulties, interpretation is also required and, because of the nature of their needs, the opportunities for people to recall their experiences in retrospect may also be limited.

Frude (1991) suggested that where death can be predicted, for example where somebody is elderly or very ill, the grief can be easier to cope with than in a sudden or unexpected loss. It could be argued however that for children, all losses would be viewed as sudden and unexpected because they are less able to make judgements about people's comparative ages or relating to the severity of different illnesses. This is likely to be particularly true of pupils with SLD whose social understanding and awareness may reflect that of a younger child. Staff from the school that had been involved with the working party provided an illustration of this, as some of the pupils had removed the dead child's work from the wall displays because they said that he was no longer a pupil of the school.

### **How do Children with Severe Learning Difficulties display grief?**

McLoughlin (1986) suggested that children with significant learning difficulties respond to bereavement and grieve in the same way as their peers who do not have learning difficulties, although the evidence base for this statement was not recorded. This view is not universal and has been disputed, for example see Morgan, (1985).

Oswin (1991) has written one of the few books in relation to this subject, which describes numerous case studies about her work in this area. This tends to focus, without exception on the negative experiences of people with learning difficulties following a bereavement. The language of the text is deliberately emotive and there is much supposition about the negative reactions of care staff towards bereaved individuals who have learning difficulties. This may have been the experiences of Oswin at the time of her writing, however it is also true to say that many care staff form close relationships with the young people with whom they work, and would be extremely sensitive and understanding if they had suffered a loss of this type.

Persaud and Persaud (2003) developed a workshop for adults with learning difficulties who had been bereaved. They described how many of the people involved had been encouraged to hide their distress and to 'not make a scene' following a death, and this has also been reported by other sources (Oswin 1991). The reverse situation could also be considered to be true however, as

people with SLD are often expected to display behaviours that would not be seen in same-age peers who do not share their difficulties. Extreme or unusual behaviours would therefore be viewed as being within the 'normal' continuum of behaviour for children with learning difficulties, whereas extreme behavioural reactions to bereavement in a young person who falls within the average range of ability might be considered culturally or socially inappropriate.

The majority of the literature in this area relates to the experiences of children who might be considered as being within the mainstream population. Section Four therefore provides an account of how children with severe learning difficulties might be affected by a significant bereavement or loss through integrating knowledge about children's responses to loss and knowledge of pupils with complex needs.

### **Integration of Theory, Research and Practice**

In considering the integration of theory, research and practice, the five objectives of the working party are revisited below. The literature did not help to provide a wide body of information about working with children who have SLD and who have experienced a bereavement. It was agreed however that general principles of working with children who are considered to be of 'normal' ability could be adapted to consider this particular group of pupils, when combined with the skills and expertise from within the working party.

### **To consider areas of bereavement and loss that are relevant to children with severe and complex learning difficulties**

Members of the working party agreed that any of the areas of bereavement and loss that might affect a 'mainstream' pupil would also be relevant to children with SLD. In addition to this, pupils with SLD might actually experience more losses than a child who does not have the same level of needs because of being removed from their peer group as part of the segregated educational system within this country, and also through being more likely to be supported through Social Care.

It was important for the group to state that the ways in which these particular children express their grief might be different to that of their same age peers who do not have learning difficulties. From the literature, an extensive list of emotional and behavioural responses by young people to bereavement and loss was

compiled. The working party considered each of these responses in turn to consider whether each behaviour could be observed within a pupil with SLD. Once this exercise had been completed, the information was then tabulated (see Appendix 2) and was summarised for use within the Information Leaflet for schools (see Appendix 3). It was acknowledged that not all children or young people would experience all of these emotions or behavioural changes and that some individuals might hide their feelings. However, this type of example was felt to be helpful to heighten awareness within school as to the possible range and intensity of feelings prompted by a significant loss.

**To develop a theoretical knowledge base of the effects of bereavement and loss within this cohort of pupils**

Research into feelings towards bereavement and loss would be considered a complex exercise if it was directed towards a representative sample of adults within the population, not least because the subjects of the study and the researchers might find this emotive area difficult to rationalise and discuss objectively. In looking to undertake this type of work with children, there are further dynamics to consider including the child's developmental stage and their ability to verbalise emotions and thoughts. For children and young people with learning difficulties, these complexities are heightened. A number of researchers have described the ways in which children at particular ages conceptualise death, including Brown (1999), who examined children's levels of understanding at pre-school level, Keystages 1 and 2 and adolescence.

It was agreed within the working party that even young, or developmentally delayed children had the capacity to grieve and mourn, and that children appear to experience the same type of mourning process as adults, which occurs in distinct phases. There has been much discussion as to how many stages characterise the grieving process, however three main phases appeared to be paramount and therefore for clarity, this description was adopted by the working party to support the production of the leaflet. These are summarised as follows (adapted from Brown 1999):

The *Protest Phase* describes the initial period after being told of a death. It tends to be a short phase of numbness, unreality and disbelief.

The *Disorganisation Phase* is a period of intense despair and pain as the bereaved individual understands that the death is a reality. This period can last for many months in adults, although there are some differences of opinion as the length of time that this stage might be observed in children. During this stage, individuals may be distressed by repetitive memories or wishes of having acted differently whilst the deceased was alive.

The *Reorganisation Phase* is a period of acceptance a reassessment for the bereaved. The individual now starts to look forward and develop a new normality, which does not involve the deceased being in their life.

A child's reaction at each of these phases is likely to depend on a number of factors, including their previous experiences of loss and the implications of the loss to them. Children's cognitive development will also play a part in their interpretation of the facts presented to them and how they respond to this information. Within the literature, children's responses to death were all based upon age related norms that were not appropriate for the cohort of pupils with SLD that were being considered by the working party. By compiling information from the literature and from expertise within the group, a developmental model for understanding the concept of death was developed that was not based upon age related norms (see Appendix 1). This was later included within the information leaflet for teachers to help assimilate their knowledge of how children within their care might understand this difficult concept. It is acknowledged that this model was produced through a wide review of the literature and not through direct observation or reporting, and this is an area that would be useful to explore if this exercise was to be repeated. The limitations of this however is that it would be extremely difficult to gather a 'pre' and 'post' bereavement cohort of pupils to observe for both practical and ethical reasons. Pupils with SLD often have such complex structures for communication that any observer would have to know the pupil extremely well to be able to comment upon changes within their personality or behaviour. The concept of Essential Lifestyle Planning is introduced later in

this section as a model for helping staff and families to understand the emotions experienced by a pupil with SLD. If this type of approach is adopted, it provides a baseline of typical behaviours for an individual pupil with then makes it easier for staff and families to monitor changes and communication of a young person with SLD through their behaviour.

**To elicit practical ideas and strategies for school staff after experiencing a death in the school**

“Without communication structures you are more likely to behave the way you feel”

Hewitt (1998)

Pupils with severe learning difficulties may have no language or lack the complex language structures and communication skills that allow them to express feelings or ask questions in the way that children without complex difficulties are able to. Hewitt argues that communication structures help individuals to cope with their emotions, therefore allowing, ‘a more balanced and ordered emotional life’. No evidence was found however to suggest that pupils with SLD are more likely to have emotional difficulties than a person who is considered to fall within the ‘average’ range of intelligence and therefore this opinion should be treated with some caution.

The difficulties that individuals with SLD may experience with communication, language, and cognitive skills mean that it is difficult those who are working with them to understand their needs and perceptions of life. Professionals do not know exactly how a young person with SLD who has been bereaved might feel and often can only seek to do so by interpreting observations of their actions. The concept of Essential Lifestyle Planning (Smull and Burke-Harrison 1991, cited by Sanderson 1998) is generally used for preverbal pupils and completed by those people who know them well in order to be able to describe their perceptions of how the individual is feeling, and what they are communicating. The plan helps professionals working with the child or young person to learn about the relationships that are important to the individual, what they do, and about significant aspects of their life. The difference of the ESP is that it focuses on the feelings of the individual pupil, rather than their acquired level of skills, and this idea might be helpful in thinking of supporting children with SLD who have experienced a bereavement.

In an ideal situation, all children with SLD would have an ESP, which would be created following a meeting of all the individuals who know the young person well. Each person in the meeting would have an opportunity to discuss their perceptions of how the pupil communicates, and this discussion could be structured with basic questions. Information about what the child enjoys doing to relax, what stimulates them, how they behave on a 'good' and on a 'bad' day, how they show that they are communicating, how they display that they are stressed and a range of other information could be recorded on the plan. This

would give carers the opportunity to understand the child more effectively on an emotional level and therefore to be able to monitor changes in the young persons emotions more effectively. If an incident occurred within the pupil's life that may cause a significant change in emotional arousal, such as a bereavement, it would be helpful to hold a meeting to discuss the observed changes since the ESP was written. Work could then be planned to support the young person at their most vulnerable times and to provide ongoing monitoring of changes in their behaviour. This was proposed by the working party as an appropriate model for all children with SLD and was received positively by staff working with children in the school for pupils with SLD who had generated the initial concern.

#### **To develop an information leaflet for teachers and school staff**

From the information gained by the working party, a guidance leaflet was developed by the group (see Appendix 3). It was not possible to include detailed information within the leaflet due to the space available and members of the working party wanted the leaflet to be succinct. It was decided therefore to reduce the number of objectives that the leaflet was going to fulfil. Out of the original six objectives, it was felt that it would be important to use a theoretical framework to describe the types of loss that a child may experience, how children with SLD might conceptualise death including the staged developmental model of understanding this concept, and how a child may react to a significant loss or bereavement. It was therefore not possible to include information about questions that the child may have or information about school policy, however during the presentation to the staff, these issues were discussed in detail.

The leaflet was targeted towards teachers within the special school who had initially requested support in developing their knowledge within this area, rather than for a wider audience. To ensure that the leaflet was clear and user friendly, it was given to colleagues within the Educational Psychology Service for feedback and these comments were then discussed and the leaflet was slightly adapted to include some organisations that could provide further support to the reader. By including the contact numbers of organisations that are able to offer further support, it was felt that individuals would be able to gain more information and support if they wished to do so.

**To provide guidance for policy writing in order that all staff members were aware of school based procedures for responding to the death of a member of the school community.**

Both Morgan (1985) and Brown (1999) argue for a curriculum in school that prepares children and young people for coping with losses in their lives, including death. As the working party had been established to provide strategies for staff in the event of a significant loss, it was also important to establish post-bereavement guidance for staff. The working party discussed the fact that talking about death is uncomfortable, not least because the conversation raises worries and concerns about individual's own mortality. It was also felt that it might also raise uncomfortable feelings for staff who had experienced their own losses. This reinforced the view that it would be important to plan for how the school should respond to a bereavement as staff would be more likely to feel confident in their

actions if they had a framework to work through at a time when they were perhaps feeling rather vulnerable.

During the presentation to school staff, guidance was provided in developing a policy document. It was suggested that a bereavement/loss policy should be divided into three sections, Curriculum, Short-term support and Longer Term Support. This guidance was summarised into a fact sheet (see Appendix 4) and the Deputy Head who had responsibility for Pastoral Care in school took charge of using this information to work on a school policy for coping with loss and bereavement in school.

### **Evaluation of the work**

The working party considered that after the planned three-month period, the initial objectives had been achieved. It was acknowledged that it had not been possible to develop a wide theoretical knowledge base within this area, although members felt positive that it had been possible to integrate personal knowledge, expertise and experience within a theoretical framework. The information leaflet for staff was warmly received, although not formally evaluated and it was suggested that this could be piloted in other schools in the future.

Staff in the management team expressed their thanks to the group for their work within the project and set targets within the school year for developing the bereavement policy and to discuss how some of the issues raised could be built into the curriculum.

### **Implications for future research**

There is clearly a need for further, high quality research to be conducted to explore the effects of bereavement and loss on children with severe learning difficulties. This is a neglected area within the field of child psychology and yet this information is crucial in helping to understand and support the needs of some of the most vulnerable young people within our society. The Author suggests that one reason for the lack of research that is conducted with children who have SLD is due to their lowered status and segregated position within our society, however research in this area might also be considered problematic due to methodological and ethical issues.

Techniques that are used to explore individual's experiences of bereavement or loss tend to focus on a case study or self-reporting techniques, using structured interviews or questionnaires. This may not be appropriate for individuals with SLD, particularly where they have difficulties through reporting information using language. Observations of young people with SLD who have been bereaved may also be problematic; not only for ethical and moral reasons, but also because a researcher who is unknown to the individual will not have developed a baseline of their pre-bereavement behaviour and therefore cannot make judgements based on before-and-after comparisons. Studies in this area are therefore likely to depend on the recall and interpretations of the families and care staff who know the bereaved individual and who can therefore report on changes in behaviour during the loss and mourning period.

The proposed six-stage developmental model for understanding the concept of death (see Appendix One) provides a starting point for individuals working with children who have experienced a bereavement. This can help families and professionals to develop an awareness about how the child or young person might be interpreting this information and to consequently support them throughout the process of mourning. Children displaying short-lived displays of anguish and who continue to ask for or seek out the individual who has died are therefore at the earlier stages of understanding the concept of death and may need reassurance that their own thoughts and behaviours are not responsible for causing the death. Children expressing fears of their own mortality and exhibiting risk-taking behaviours have a different understanding of death, which is placed at the later stages of the developmental model. These pupils will therefore require emotional support networks to discuss their anxieties. Exploring the use of the model over time will determine the effectiveness of this approach and heighten the need for further work in this area.

## **Conclusion**

There is little information available to professionals working with pupils who have severe or complex learning difficulties in relation to talking about loss and grief. Individuals may therefore be poorly prepared in dealing with a significant loss or death within the school community which is likely to create further anxiety at a time when staff may be feeling particularly vulnerable. There are ethical, practical and emotional reasons why there is likely to be so little research within this area. It is also suggested within this assignment that pupils with SLD have been assigned a lowered status that runs throughout society and that this could be a contributory factor to the lack of empirical evidence relating to the needs of pupils with SLD. This assignment argues for greater consideration into examining how significant life events might affect children and young people with SLD and also that more approaches should be developed to identify and measure the behaviours of pupils with SLD.

Although links can be made between the experiences of all children who experience bereavement and loss in that they are likely have similar emotions and pass through similar stages of grief, children with SLD are more likely to show their feelings through their behaviours than through language. It is acknowledged however that children with SLD cannot be considered to be similar in their personal strengths and weaknesses and that they should be viewed as individuals as any other child would be. It is suggested that schools are beginning to consider a more emotional curriculum alongside the academic curriculum and that this is an effective way to help children cope with anxieties.

*The effects of bereavement and loss on pupils with severe learning difficulties*

As an extension of this type of curriculum content, it is proposed that talking about loss and bereavement at school would be of benefit to many children, as all children experience some losses in their lives through normal developmental changes. Children with SLD may experience more losses than children without special educational needs and therefore it would appear to be even more important to prepare them for changes within their lives.

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Appendix 1: A Developmental Model for Understanding the Concept of Death

- STAGE 1: Characterised by separation anxiety, seeking the absent person. Attachments formed to primary caregiver. No real concept of death. Displays of anguish are shortlived.
- STAGE 2: In this stage, death is viewed as a temporary and reversible state, although there is some understanding that death is linked to separation. Individuals at this stage are not aware that everybody dies and in particular that they will die. Children or Young People at this stage may feel that it can be caused by magical thinking (for example because they wished their sibling dead after a fight). They may believe that their 'bad' behaviour has caused a death. Individuals who are at this stage may ask questions that can appear insensitive to adults who are unaware of the reasons for the questions.
- STAGE 3: Questions are also asked at stage 3, which is characterised by the person understanding that death is permanent. The child or young person does not think that they will die and may just relate the causes of death to those that they have witnessed on the television or in life.
- STAGE 4: The individual realises that everyone, including him or herself will die and may become anxious about this. Questions may become more specific in terms of asking familiar adults about when they will die and asking for clarification about euphemistic terms.
- STAGE 5: At stage 5, individuals may try to challenge death through risk taking behaviours. Questioning may relate to more abstract concepts such as life after death and ethical debates.
- STAGE 6: Stage 6 is difficult to define because there is no logical ending point to the concept of death, which may change for individuals throughout their lives. At this stage however, death is seen as part of the life cycle. Individuals may fear their own morbidity and the loss of others, particularly when they are reminded of this fact, but it is not a preoccupation for them. Generally individuals will have found ways to cope with this, perhaps through a religious belief system, or by organising practicalities of funerals, or organ donation.

Appendix 2: Feelings and observable behaviours that may be seen in children with SLD who have experienced loss

Feelings	Observable behaviours
Numbness Sadness Longing Depression Loneliness Feeling abandoned Powerless Frightened Cheated, that life is not fair Guilt Anger Anxiety about the well being of others Denial At fault Panic Withdrawal Hostile to the deceased Idealisation of the deceased Disbelief Rejection of former religious beliefs Separation anxiety Blame Embarrassment	Tearfulness Regressive behaviour Physical illness Poor appetite/eating disorders Sleep disturbance Enuresis Self harm Acting out behaviours Unsociable to others Lack of concern for self Shortened attention span Poorer performance in classwork Forgetfulness Assumption of deceased's mannerisms Aggression Denial School refusal Fantasies/hallucinations about the dead person Stealing Nail biting Difficulties in sustaining relationships Rejection of affection Breathlessness Obsessive rituals

**Appendix Three: Information Leaflet for Schools**

**Helping Children with**

**Learning Difficulties**

**Cope with**

**Bereavement and Loss**

*Guidance for staff working with pupils who have complex learning needs*

Types of loss that might be experienced

Any child may experience loss through changes in routine, changes in school staff, moving house, a family breakdown, or the death of a family member or pet. Some information is available from research about how children respond to these particular situations, although this generally relates to children who fall within the average range of development and therefore little is recorded in relation to the affects of bereavement and loss in children with more complex needs

How do children with learning difficulties conceptualise death?

McLoughlin (1986)\* suggested that children with significant and profound learning difficulties display similar responses to bereavement and loss as individuals without learning difficulties.

Publications that consider how children respond to bereavement and loss suggest that their understanding of the concept of death is broadly based upon the age of the child. In reality, a variety of factors affect the individual's understanding and reaction to death including their relationship with the dead person, their previous experiences of loss, the support networks available to them, and their personality type.

\* McLoughlin, I. (1986) Bereavement in the Mentally Handicapped British Journal of Hospital Medicine , 36(4) 256-6

**Developmental stages in understanding the concept of death**

Children and young people will also react to a significant bereavement or loss differently depending on their understanding of the concept of death. This is not always related to their chronological age and therefore a 'staged' model is suggested below:

STAGE 1: At this stage, individuals have no real concept of death and their anguish is short lived.

STAGE 2: Death is viewed as a temporary, reversible state, linked to a separation. Individuals may feel that somebody's death could be caused by their bad thoughts or behaviour.

STAGE 3: Death is viewed as permanent but not something that will happen to everyone.

STAGE 4: The individual realises that death is universal and may develop anxieties in relation to this knowledge.

STAGE 5: Individual's questions about death relate more to abstract concepts such as life after death.

STAGE 6: Death seen as part of the life cycle. Coping strategies may be developed for dealing with any uncomfortable feelings relating to anxieties about death and dying.

### How are children and young people affected by grief?

Grief describes how an individual responds to a loss or bereavement and in adults and children this is generally seen as having distinct phases. These are summarised below (adapted from Brown 1999\*).

#### **The Protest Phase**

After being told of a death people tend to experience a short phase of numbness, unreality and disbelief.

#### **The Disorganisation Phase**

A period of intense despair and pain as the bereaved person copes with understanding that the death is real. This period can last for many months in adults, although there are some differences of opinion as to how long this stage is seen in children.

#### **The Reorganisation Phase**

This is a period of acceptance a reassessment for the bereaved. The individual now starts to look forward and develop a new normality, which does not involve the deceased being in their life.

Brown, E. (1999) *Loss, Change and Grief, An Educational Perspective*. London, David Fulton Publishers

### Feelings and behaviours associated with mourning in children

Mourning relates to the feelings experienced after having been bereaved. Possible feelings include:

Numbness, sadness, longing, loneliness, abandonment, powerlessness, fear, guilt, anger, anxiety, denial, panic, and disbelief.

Behaviours relating to these feelings may include:

Tearfulness, regressive behaviour, physical illness, poor appetite, sleep disturbance, enuresis, self harm, acting out behaviours, shortened attention span, forgetfulness, assumption of deceased's mannerisms, aggression, rejection of affection, breathlessness, and obsessive rituals

Not all children or young people would experience all these emotions or behavioural changes and that some individuals might hide their feelings. Pupils with learning difficulties may lack the complex language structures and communication skills that allow them to express feelings or ask questions about bereavement and loss in the way that children without special needs are able to.

### How can I help?

It can be difficult for professionals working with young people with learning difficulties to understand their needs and perceptions of life and often they can only seek to do so by interpreting observations of actions and changes in pupil's behaviour.

By understanding that these behavioural changes are a natural part of the grieving process and in providing opportunities to display complex feelings within a safe context, staff can help to meet the child's needs following a bereavement or significant loss and to help them accept the difficult situation that they are faced with.

#### **Specialist resources**

Cooley, J and McGauran, F., (2003) *Talking Together About Death, A Bereavement Pack for People with Learning Disabilities*. Dover, Smallwood Publishing Ltd

Nagraj, R., and Moddia, B., (1995) *Bereavement and Loss in People with Learning Disabilities*. Oxford. Oxfordshire Learning Disabilities NHS Trust

#### **Other Organisations**

CRUSE Bereavement Care, (01494 722515)

Educational Psychology Service:  
01296 383219 (Aylesbury)  
01494 732187 (Amersham)

## Appendix Four: Developing a School Policy about Coping with Bereavement at School

### **Developing a School Policy in relation to Coping with Bereavement at School**

These guidelines are designed to prompt discussion and ideas within the context of your school.

A policy should aim to consider three main areas within school, *Curriculum, Short-term support and longer-term support*.

*Curriculum* relates to the everyday work in school that may prepare the children and young people for experiencing losses through discussion in science, religious studies and PSHE. In this context, preparation for life changes and 'small losses' will help staff to understand the pupils' reactions to change. This will enable them to discover ways to support the pupils in the event of a death or significant loss. It is important to share the content of this work with parents who may feel that this type of support is more appropriate to be raised within the home.

Specific techniques such as Essential Lifestyle Planning might be helpful to build a baseline of 'normal' behaviours for preverbal pupils that can be monitored and revised over time, but particularly in the event of a bereavement or significant life event.

*Short-term support* considers the procedures that could be put into place if somebody from within the school community died. This should include the following information within the policy:

- Who should break the news about a death?
- What exactly will the children be told?
- How will they be told? (As a class, individually etc)
- When will they be told?
- How will this information be communicated to parents and other staff?
- What questions might the children ask?
- What links will be made with the family of the deceased?
- Whether it is appropriate for staff to show their emotions to the children.

*Longer-term support* relates to the ongoing support of the pupils whilst they are working through the process of mourning. This might be through direct work with the pupil by referring them to appropriate professionals in the field, or in supporting school staff who have concerns about what a child is thinking and feeling. At this time, it is also important to consider individual the development needs for individual members of staff.

**Appendix Four: Continued**

Useful publications and Resources:

**Curriculum Resources**

Cooley, J and McGauran, F., (2003) Talking Together About Death, A Bereavement Pack for People with Learning Disabilities. Dover, Smallwood Publishing Ltd

**Short-Term and Longer-term Strategies**

Nagraj, R., and Moddia, B., (1995) Bereavement and Loss in People with Learning Disabilities. Oxford. Oxfordshire Learning Disabilities NHS Trust

Oswin, M (1991) *Am I Allowed to Cry* London. Souvenir Press. Chapter 6, 'Recommendations and Suggestions'

**Other Organisations**

CRUSE, Cruse House, 126 Sheen Road, Richmond, Surrey. (Also see local telephone directory for details)