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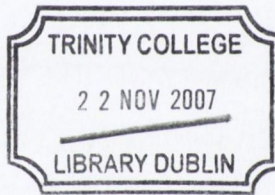
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*THESIS*  
*8237*

# **Bereavement and people with Intellectual Disabilities**

**Philip Charles Dodd**  
**M.B., B.Ch., B.A.O., M.Sc., M.R.C.Psych.**

**Submitted for consideration of a Doctorate in Medicine**

**University of Dublin, Trinity College.**

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## **Declaration**

This thesis has not been submitted as an exercise for a degree in this or any other University. I declare that the work in this thesis is entirely my own except where credited in the acknowledgements. I agree that the University may lend or copy this thesis upon request. All subjects involved in the study gave their consent freely.

*Philip Dodd.*

## **Definition**

For the purposes of this thesis, the term intellectual disability is defined as the presence of a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which starts before adulthood and has a lasting effect on development. However, the presence of low intelligence (IQ below 70) is not, of itself, a sufficient reason for deciding whether an individual requires health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need.

## **Publications**

In the course of preparation of this thesis, I have made a number of publications of portions of it's subject matter as follows:

### Publication in peer-reviewed journals

Dodd, P., Dowling, S., & Hollins S. (2005). A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities. *Journal of Intellectual Disability Research* 49, 537-543.

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### Abstracts/Oral Presentations at International Conferences

Dodd P., Guerin S., McEvoy J., Hillery J, Hollins S. (2004). A Study of Complicated Grief Symptoms in people with Intellectual Disabilities. *Journal of Intellectual Disability Research*, 48, 432.

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Dodd P., Mulvany F., Guerin S., Mulcahy M., Hillery J. (2004). The Assessment of Need: a study of individuals assessed as not needing intellectual disability services. *Journal of Intellectual Disability Research* 48, 487.

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Oral Presentations at International Conferences

Dodd P., Mulvany F., Mulcahy M., Hillery J. (2003). A Study of the characteristics of individuals with intellectual disabilities who are not attending intellectual disability services.

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# Summary

## Introduction

For most people, the loss of a loved one is a tragedy unequalled by any other. It affects every family and raises policy and logistic issues for the health and social service agencies of every community.

Currently, people with intellectual disabilities are living longer than previously and are experiencing more and varied relationships. However for most people with intellectual disabilities, they are looked after at home by relatives. As a result, the degree of attachment and dependence may become very strong. It is very clear that when these very close bonds are broken, by the death of the carer, it may prove catastrophic for the individual.

## *Research Hypotheses*

-There has been little systematic research carried out on the bereavement symptoms that people with intellectual disabilities experience in general; in particular little work has been done to distinguish so called 'normal' grief symptoms from more serious complicated grief symptoms.

-There is a lack of consensus on the best way to support individuals, in order to prepare them for inevitable bereavements. This is based on my own clinical experience, and my efforts to support bereaved individuals in the absence of evidence-based interventions. In addition, there is a wide range of support staff's knowledge and understanding of grief in people with intellectual disabilities, and how to best support individuals.

-In addition, because of limited resources, our specialist services for people with intellectual disabilities are passive in trying to engage individuals in services, who remain socially isolated and at risk of significant difficulties, should their family residential care break down. This hypothesis is based on my own clinical experience of trying to support bereaved individuals who have come to clinical attention for the first time, following the death of a parent, despite the individual having significant clinical and social needs well before the parental loss.

## **Method**

This thesis is made up of three studies, looking at each of the hypotheses above:

- a. A control study of complicated grief symptoms in bereaved people with intellectual disabilities; this study is designed to better understand more serious bereavement related symptoms.

- b. A national survey of the approach that service providers adopt to support bereaved individuals with intellectual disabilities and in addition, a questionnaire based study to examine carers knowledge and practise in supporting bereaved individuals;
- c. A multi-method study of a cohort of vulnerable individuals, recruited from the National Intellectual Disability Database, who are outside services. This study looks at how service providers understand, assess, monitor and support this group.

## **Results**

Bereaved people with intellectual disabilities experience some of the symptoms of complicated grief, as in the general population.

While individual service providers and carers appear to be providing good support to bereaved individuals, the support is *ad. hoc*, and not based on adequate training programmes, or agreed policies of service delivery. In addition, nationally, the assessment procedures to assess and support vulnerable adults with intellectual disabilities are inadequate.

## **Conclusions**

Further work is needed to refine the relevant symptoms of complicated grief in this population, with a view to informing the debate on including complicated grief as a distinct diagnosis. This will greatly assist informed assessment and treatment.

Service providers need to put in place evidence based policies and training packages for care staff, to best support bereaved individuals with intellectual disabilities.

Enhanced assessment and support practices need to be put in place nationally to support vulnerable adults and their families, who are out-of-service. This has implications on the way in which funds are provided centrally for services to this population, and should inform the provisions as laid out in the new Disability Act, 2005.

<b>Table of Contents</b>	<b>Page</b>
Title Page	1
Declaration	2
Publications	3
Acknowledgements	5
Summary	8
Table of Contents	12

## **Chapter 1**

### **Emotional, Psychiatric and Behavioural Responses to Bereavement in People with Intellectual Disabilities**

1.1 Grief in general	16
1.2 Pathological Grief Reaction	17
1.3 Grief in Intellectual Disability	20
1.4 Materials and Methods	24
1.5 Results	25
1.6 Research Challenges	31
1.7 Thesis Aims	33

## **Chapter 2**

### **A Study of Complicated Grief and people with intellectual disabilities**

2.1 Introduction	36
2.2 Aims	39
2.3 Method	40
2.4 Administered measures/Assessment Tools	42
2.5 Results	47
2.6 Discussion/ Conclusions	67

## Chapter 3

### Attitudes to Bereavement and Intellectual Disabilities in an Irish Context

3.1 Introduction	75
3.2 The Study	78
3.3 Materials	79
3.4 Results	81
3.5 Discussion/ Conclusions	89

## Chapter 4

### A Study of Service Refusers: Characteristics, assessment and understanding

4.1 Introduction	96
4.2 Aims	99
4.3 The Study	99
4.4 Part 1: Examination of the Characteristics on an out of service group from the National Intellectual Disability Database	100
4.5 Materials and Methods	100
4.6 Results	102
4.7 Conclusions	109
4.8 Part 2: A study of the assessment and support practices of service providers	111
4.9 Background	111
4.10 Materials and Methods	112
4.11 Results	114
4.12 Summary/ Discussion	124
4.13 Part 3: A Qualitative study of the understanding and attitudes of service providers and stakeholders	128
4.14 Introduction	128
4.15 Method	128
4.16 Results	131
4.17 Conclusions: Part 3 and overall study	139

## **Chapter 5**

<b>Conclusions: Main Findings</b>	<b>144</b>
-----------------------------------	------------

<b>References</b>	<b>151</b>
-------------------	------------

<b>Appendices</b>	<b>164</b>
-------------------	------------

<b>Appendices A: Appendices from Chapter 2</b>	<b>165</b>
--	------------

2.1: Bereavement History Questionnaire (Adapted)	166
2.2 Bereavement History Questionnaire (Control)	169
2.3: Complicated Grief Questionnaire for people with Intellectual Disabilities (Adapted)	170
2.4: Complicated Grief Questionnaire (Control)	176
2.5: Index of Social Competance	182

<b>Appendices B: Appendices from Chapter 3</b>	<b>186</b>
--	------------

3.1: Bereavement Questionnaire for Organisations	187
3.2: Bereavement Questionnaire for staff working with people with a learning disability	199

<b>Appendices C: Appendices from Chapter 4</b>	<b>202</b>
--	------------

4.1: Questionnaire for Key-Worker	203
4.2: Semi-Structured Interview Schedule	208
4.3: Coding Frame	210



# Chapter 1

## **Emotional, Psychiatric and Behavioural Responses to Bereavement in People with Intellectual Disabilities:**

Background literature review and research aims of thesis.

## 1.1 Grief in general

The life events blamed for causing an increase in psychiatric disorders that follow them (Brown & Harris, 1978) are in fact losses and there is good reason to believe that some bereavements endanger mental health (Parkes, 1972). Many of the investigators of the process of grief and bereavement in the general population have described stages in the normal grief process (Bowlby, 1980; Parkes, 1985; Pollock, 1987). However, as emphasised by DeVaul et al (1979), grief is not a linear process with concrete boundaries, but its staging is defined by overlapping clinical stages. Zisook & Schucter (1986) described a multidimensional appreciation of the effects of normal grief, examining cognitive and affective states, coping mechanisms, the continued relationship with the deceased, changes in functioning, changes in relationships, and alterations in identity.

The literature suggests that there is little agreement among authors regarding the time course of normal grief and bereavement. Parkes (1971), in his study of a group of London widows found that some elements of the process of grieving were still evident after 13 months. Many authors have found that several features of grief, particularly those related to attachment behaviours, continue for several years after the loss. It has been suggested that some aspects of grief work may never

end for a substantial proportion of otherwise normal bereaved individuals (Stroebe & Schut, 1999).

## **1.2 Pathological grief reaction**

The study of pathological grief is notable by its lack of clarity concerning definitions of normality and abnormality with numerous terms being adopted to describe pathological or traumatic bereavement responses: absent (Deutsch, 1937), distorted (Brown & Stoudemire, 1983), abnormal (Pasnau, Fawney, & Fawney, 1987), morbid (Sireling, Cohen & Marks, 1988), truncated (Widdison & Salisbury, 1990) atypical (Jacobs & Douglas, 1979) and traumatic (Prigerson et al., 1999) to name but a few.

Pathological grief reactions have been examined from a number of perspectives over the last century. The internalisation of lost objects and loss in general remain central in psychoanalytic theory. Freud, in his paper 'Mourning and Melancholia' (1917), noted similarities between mourning ('normal' grief) and melancholia ('pathological' grief), but also attempted to differentiate between them.

Deutsch (1937) examined 'absent grief', which she felt would ultimately be expressed in an alternative form, including repeated depressive

episodes. According to Klein (1940), individuals who do not successfully negotiate the depressive position in infantile development are more likely to develop pathological grief later in life. Lindemann (1944) reinforced the Freudian concept of 'grief work', in which the expression of affect was seen to help weaken the bonds to the deceased.

Bowlby (1970) integrated analytic and ethological concepts in developing attachment theory. He saw similarities between infants separated from their mothers and adults facing bereavement, and he conceptualised that grief was an extension of a general response to separation. Parkes (1972) applied the attachment model to his examination of the course of grief, and suggested three principal forms of pathological grief: inhibited grief, delayed grief and chronic grief.

Until recently, the literature appeared to be divided and unclear concerning the validity of the various syndromes of pathological grief (Middleton, 1993), in addition to the delineation of the overlap between pathological forms of grief and specific psychiatric disorders (Jacobs, 1993). According to DSM-IV (American Psychiatric Association, 1994), the only recognised complication of bereavement is depression.

Recent studies have shown that the symptoms of pathological grief are different to the symptoms of depression and anxiety (Bierhals et al., 1996), and have distinct clinical correlates from those associated with depression, including distinctive electroencephalogram sleep architecture (Mc Dermott et al., 1997). Distinctive relationships to the deceased have also been described in bereaved people explaining pathological grief (van Doorn et al., 1998). The evidence is growing that pathological grief is a syndrome distinct from other disorders, which needs specifically defined diagnostic criteria. A group of leading experts in reactions to loss and trauma, have formulated consensus diagnostic criteria (Prigerson et al, 1999) for 'traumatic grief' (a term used to acknowledge the fact that many symptoms of pathological grief resemble those of post-traumatic stress disorder). More recently this group have replaced the term 'traumatic grief' with 'complicated grief', and for the purposes of this thesis, the later term will be used. The authors agreed that the presence of certain marked symptoms of grief, persisting for more than two months, should be a critical factor in distinguishing between normal and pathological or traumatic grief. This is quite different to other studies that usually define pathological grief on the basis of the amount of time that has elapsed since the loss rather than the specific symptoms.

### 1.3 Grief in intellectual disability

While research into pathological forms of grief is at a relatively early stage of development in the general population, little work has been done to examine the effects of loss on people with intellectual disabilities. There has yet to be a systematic examination of the grieving process, and how it is affected by intellectual disabilities. Much of the recent literature firstly involves the debate concerning the ability of people with intellectual disabilities to grieve, and their concept of death, and secondly the effect that bereavement has on behaviour and mental health.

#### *The ability of people with intellectual disabilities to grieve*

Observational studies suggest that attachment theory may have an important place in the understanding of emotional problems in people with intellectual disabilities, and the difficulties many have in establishing relationships (Frankish, 1989, 1992; Clegg & Lansdall-Welfare, 1995; Esterhuyzen & Hollins, 1997; Hawes & Hollins, 2000). Currently people with intellectual disabilities are living longer than previously and are experiencing more and varied relationships both within their families and within the community at large. In many cases, they are looked after at home by relatives well into adulthood. When these bonds are broken, by

the death of the family carer, it may prove catastrophic for the individual. The death of a parent, particularly a sole surviving parent, can lead to additional associated losses for someone who has an intellectual disability. They may have to leave their home at short notice and go to emergency accommodation, from where it is not unusual for people to move four or five times in the year following a major bereavement (Oswin, 1991). These sometimes unexplained and often unexpected disruptions, which involve the loss of the life that has been led until now and all of the familiar details of it, can also lead to a loss of individuality, while the negotiation of new, often communal, environments can have the effect of making someone's disability appear worse. New carers may overlook the recent loss and assume that behaviours that are a reaction to it are signs of mental ill health rather than expressions of grief. Inappropriate 'treatment' of quite normal responses to loss can make a difficult situation worse (Bicknell et al, 1983). As Meyers (1980) states, in reference to responses to death 'as in most other aspects of their lives, individuals with mental retardation are more like everyone else than they are different'. Thus, the adaptation of attachment theory as a theory of grief and loss in people with intellectual disabilities seems justified.

It has been erroneously argued that people with intellectual disabilities, irrespective of their age, are incapable of comprehending the finality,

irreversibility, and inevitability of death (Speece & Brent, 1984). It has also been assumed that they are unable to form the emotional bonds and intimate interpersonal relationships that ultimately could culminate in feelings of personal loss and mourning (Deutsch, 1985; McDaniel, 1989) leading to a disenfranchised type of grief (Doka, 2002).

Of course, it seems likely that the degree of intellectual disability will affect an individual's ability to formulate abstract concepts, such as death (McLoughlin, 1986). Research suggests that the understanding of these concepts is more related to cognitive level as determined by Piagetian tasks, than to chronological age (Bihm & Elliott, 1982). It has also been shown that life experience acquired through aging enhances the ability of adults with intellectual disabilities to understand the meaning of mortality, as assessed on an understanding of the universality, irreversibility and inevitability of death (Lipe-Goodson & Goebel, 1983). Elderly individuals with intellectual disabilities appear to have acquired a more accurate conceptualisation of death than their younger counterparts have, with comparable cognitive abilities (Seltzer, 1989). Mc Evoy (1989) found that in his sample of adults with intellectual disabilities, there was a relative lack of understanding of aging and death as a natural part of the life-cycle, which may reflect the fact that some people with intellectual disabilities continue to be treated as children and are not encouraged to



act, speak or dress in age-appropriate ways. However, understanding the concept of death is not a prerequisite for experiencing the emotions associated with grieving. The absence of the person who has died is the tangible manifestation of their death, and people with intellectual disabilities recognise the absence of someone they love. They will grieve for this loss with or without comprehension of the abstract nature of death. Concepts of death have also been studied in the content of dreams of people with intellectual disabilities (Turner & Graffam, 1987); much of the dream content was similar to that reported by people without intellectual disabilities who have suffered a traumatic bereavement.

#### *The effects of bereavement on people with intellectual disabilities*

In the absence of a clear understanding of what constitutes a normal grief reaction in people with intellectual disabilities, and whether or how it differs from grief in other adults, our understanding of the effects of bereavement on these individuals is largely based upon the observation of behavioural change, or the development of psychiatric illness. Understanding and assessing the emotional states of people with intellectual disabilities in general, is in its infancy (Clark, Reed & Sturmey, 1991). As a result, the challenge to try to distinguish a 'normal' grief

reaction from an 'abnormal' one is even greater than in the general population.

#### **1.4 Materials and methods**

The author carried out a systematic review of the literature to examine the clinical effects of bereavement on people with intellectual disabilities. Items that were specifically looked for included peer-reviewed psychiatry, psychology, nursing and social work papers that described psychiatric, emotional or behavioural reactions to bereavement, published from 1966 to date. Potential articles for review were collected from Pre-Medline, Medline, Embase, Psyclit, Psychinfo, CINAHL, and the Cochrane Library. In addition published books and dissertation theses were examined. Altogether 67 articles were identified on the subject of bereavement and people with intellectual disabilities, of which 27 presented the results of original research with the stated aim of investigating psychiatric, emotional or behavioural reactions to bereavement. The majority of these articles were descriptive single case studies, seven studies employed qualitative or quantitative methodology, and only one study involved the use of a control group. The most significant of these studies are discussed in the text.

## 1.5 Results

### *Psychiatric Illness*

People with intellectual disabilities are particularly vulnerable to psychiatric illness. Actual estimates of psychiatric illness within this group have varied widely, due to methodological problems concerning diagnosis and classification. Overall prevalence rates range from 20%-70% (Corbett, 1979; Lund, 1985; Eaton & Menolascino, 1982; Bregman & Harris, 1996.) A recent diagnostic classification (the DC-LD) has been published (Royal College of Psychiatrists, 2001), for use with adults with intellectual disabilities, which is expected to help diagnosis and research. The relationship between life events, such as parental bereavement, and the development of psychiatric illness continues to be of great interest and various research findings are well documented (Brown and Harris, 1989). This is an under-researched area in people with intellectual disabilities (Nadarajah et al, 1995). However, it does seem reasonable to assume that this group is at least as vulnerable as the rest of the population to the effects of life events, especially as institutional living becomes less frequent

and the exposure to a wide range of experiences becomes part of living in the community (Ghaziuddin, 1988).

Day (1985) examined over 300 long stay hospital residents and over 200 new admissions to a psychiatric unit for people with intellectual disabilities, to carry out a hospital and community based study of psychiatric morbidity. He found a high incidence of 'reactive depression' and 'anxiety state' among the admission group (over 33 per cent), in which almost 50 per cent of these breakdowns were clearly precipitated by the death or serious illness of a family carer. He suggested that the onset of these psychiatric disorders might be viewed as 'bereavement reactions'. On a similar theme, McLoughlin (1987) described the case of an individual with moderate intellectual disabilities, who developed a severe depressive episode, with psychotic features, following the death of her father. He described the relationship between father and daughter as being ambivalent before the death and wondered whether this contributed to the individual's difficulties. Similar cases have been reported by Reid (1972), Hollins & Kloepfel (1989), and Sireling & Hollins (1999). A case of mania and a case of a schizophrenic episode, both precipitated by a bereavement have also been described (Singh I. et al., 1988; Yapa & Clarke, 1989). Stoddart et al. (2002) evaluated the effect of bereavement on a group of 21 individuals with intellectual disabilities, and

also evaluated the effect of group work on measures of anxiety, depression and knowledge of death. Scores for depression were significantly elevated following the bereavement, while scores for anxiety were much lower.

Hollins & Esterhuyzen (1997) carried out a systematic study of the reaction of people with intellectual disabilities to bereavement. They recruited adult subjects (n=50) from day centres, who had lost a parent in the preceding two years, and compared them to a non-bereaved matched control group. They used the informant-based version of the Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Matson, 1988) to assess for psychopathology possibly related to the grieving process. 21 participants were found to be 'case present' on at least one of the sub-scales of affective, anxiety or adjustment disorder, a score much higher than the control group, indicating the likely effect of bereavement on psychopathology scores. The authors point out that although increased symptoms of psychopathology were found, this does not automatically indicate pathological grief, since many of these symptoms form part of what we understand to be 'normal grief'. A follow up study was carried out with the bereaved group, approximately five years after the parent bereavement (Bonell-Pascual et al., 1999). The PIMRA was again used to assess for psychopathology. Of the 21 'cases'

described above, 18 no longer scored, the data suggesting an overall reduction in affective disorder and anxiety disorder symptoms since the initial study. However, other subjects scored as cases at follow-up, who had not done so at the initial assessment suggesting the possibility of a delayed grief reaction for these individuals.

### *Behaviour and Emotion*

Emerson (1977) explored the incidence of bereavement and the onset of marked behaviour and mood change in adults with intellectual disabilities. She found that 50 per cent of the individuals had experienced the loss of a close contact before the onset of the symptoms. She also reported that carers for the individuals had minimized the significance of the death, or misunderstood the reactions to it. Strachan (1981) interviewed care staff closest to adults with learning disabilities in an institutional setting. Despite reports from care staff of having observed a wide variety of responses to bereavement, a typical comment was 'no response to the death'. Strachan wondered whether this was due to carers' expectation of little response to bereavement by these adults, and that distress was undetected.

In the course of research at St. George's Hospital Medical School, interviews with both carers and bereaved people themselves have been carried out (Dowling et al., 2003). These interviews have again exposed the once common perception amongst carers, that people with intellectual disabilities have no response or merely a limited response to a death. However, this was broadly contradicted by the bereaved people themselves, who clearly expressed their sadness, distress and anxiety at their loss.

Harper & Wadsworth (1993) carried out 43 structured direct interviews with adults with moderate to severe intellectual disabilities, using the Iowa Loss Instrument, designed by the authors. They found 25 of the individuals questioned reported that at least one death was very disruptive to their lives, complaining of symptoms of anger, anxiety, confusion and discomfort thinking about the death. Eighteen of the individuals for whom the loss had occurred at least a year previous to the interview reported continuing problems in their lives including feelings of loneliness, anxiety, sadness and behaviour problems.

In the study by Hollins & Esterhuyzen (1997), behaviour was assessed for the bereaved group using the Aberrant Behaviour Checklist (ABC; Aman et al., 1985), and compared to the control group. Results showed a

significant increase in irritability, lethargy, inappropriate speech and hyperactivity in the bereaved group compared to the control group. At follow-up, the ABC was again administered to most of the bereaved group. In general behaviour was found to have deteriorated between the initial assessment, and the follow-up approximately five years after the reference bereavement, suggesting continued difficulties, possibly related to the bereavement.

Kitching (1987) described delayed grief in a single case study and suggested that grief is often delayed for people with intellectual disabilities, who may not initially understand the loss, but come to do so later, and then enter an atypical grieving process. Allison (1993) used short case vignettes to describe patterns of bereavement in people with autism and found failure to grieve, delayed grief, apparent failure to understand the irreversibility of death and uncertain or inappropriate responses to bereavement. People with autism often have a very limited number of close relationships and the loss of one of these may be catastrophic.



## 1.6 Research Challenges

There are significant difficulties associated with researching the effects of a significant life event, such as a bereavement, on the mental health of people with intellectual disabilities. Firstly people with intellectual disabilities are not a homogenous group: there are wide differences in experience, environment, personality, and ability. Secondly the well developed and validated grief scales that are used in the general population are frequently not appropriate for use in this population because of the complexity of the language and concepts used in them; examples include the Texas Revised Inventory of Grief (TRIG) (Faschingbauer, 1981), the Grief Experience Inventory (Sanders, Mauger & Strong, 1985) and the Inventory of Complicated Grief (Prigerson et al., 1995). Thirdly, interviewers may have to rely on the information provided by carers rather than the individuals themselves, as many have difficulties communicating the relevant information; this may greatly affect the reliability of any research conclusions. However, people with intellectual disabilities can often be reliable informants about their own emotional reactions to loss. In a study carried out in the U.K., interviews have been carried out with over 60 bereaved people with intellectual disabilities who all have different abilities and communication skills (Hollins & Dowling, 2002). The interviewees were all able to offer insight into their feelings

following their loss. They did this not just by talking but also by a variety of means, some using aids such as drawing, pictures, books or photographs, others through body language and changes in expression. Some people cried or rocked or clasped and unclasped their hands. What these research participants were 'saying' could be captured through qualitative methodologies, interviews and observation. In view of this experience, the lack of validated grief scales 'appropriate' to this population should not be regarded as an obstacle to further research.

Much work has been done to show that bereavement and loss (Hastings, 2004) has a distinct effect on the mental health of people with intellectual disabilities. Many studies have shown that symptoms of depression and anxiety increase, and behaviour changes following a bereavement. However it is still unclear whether these symptoms and changes in behaviour represent so-called 'normal' grief symptoms, or the more serious 'complicated grief' symptoms. As can be seen from the above review, there has not been a systematic large-scale study carried out to examine the nature, time-scale, severity and frequency of the symptoms of grief in people with intellectual disabilities. These symptoms need to be examined and described from a developmental perspective. This work is essential to improve the ability of families and carers to empathically and effectively support bereaved individuals.

## **1.7 Thesis Aims**

This thesis describes three distinct studies that were carried out by the author to examine a number of different research questions in the broad area of bereavement and people with intellectual disabilities. While little is known of the distinct symptom profile of bereaved individuals with intellectual disabilities, less is known of the way in which service providers assess the needs of, and support individuals who have been bereaved. This thesis attempts to address these deficits of knowledge.

Chapter 2 details a study that was carried out to look for the presence of complicated grief symptoms in people with intellectual disabilities, in addition to examining possible correlates with bereavement ritual experience. This study involved the adaptation and validation of a complicated grief scale.

Chapters 3 of this thesis, looks at service provider and carer responses to people with intellectual disabilities who have been bereaved. It is essential for professionals to effectively plan appropriate bereavement services and to have a clearer understanding of the characteristics of possible

high-risk groups with intellectual disabilities who develop significant bereavement difficulties, with a view to producing effective treatments.

This study was carried out in two stages: firstly a national survey of service providers was carried out, looking at the services and practices that are in place to support service users who have been bereaved; secondly a study was carried out examining the practises and knowledge of care-staff in supporting bereaved service users. A comparison study was made with a staff group from the U.K.

Chapter 4 describes a study that was carried out to look at the characteristics, assessment procedures and broad awareness of a group of people as listed on the National Intellectual Disability Database (N.I.D.D.), who represent a high risk for developing bereavement difficulties. This study involved assessing detailed information from the N.I.D.D, carrying out a questionnaire based study, as well as using qualitative type research methods.

## **Chapter 2**

**A Study of Complicated Grief and people with intellectual disabilities**

## 2.1 Introduction

As discussed in Chapter one, many studies have shown that symptoms of depression and anxiety increase, and behaviour changes following a bereavement. However we are still unclear whether these symptoms and changes in behaviour represent so-called 'normal' grief symptoms, or the more serious 'complicated grief' symptoms.

In January 1997, a group of experts in the field of bereavement, trauma and psychiatric nosology met and agreed on the development of diagnostic criteria for complicated grief. The panel used a three-step procedure to develop these diagnostic criteria (Prigerson et al., 1999). Firstly, studies relating to complicated grief were examined to determine how to best distinguish between normal and pathological grief. A two-month duration of symptoms was set as an appropriate marker of difficulty. Items to assess complicated grief symptoms were taken from existing psychopathology and grief symptom inventories (Frank, Prigerson, Shear & Reynolds, 1997).

Table 1. Diagnostic Criteria for Complicated Grief (Prigerson, 1995).

Criterion A. Separation Distress Symptoms

Person has experienced the death of a significant other and response involves 3 of the 4 following symptoms experienced at least daily or to a marked degree:

1. Intrusive thoughts about the deceased
2. Yearning for deceased
3. Searching for deceased
4. Excessive loneliness since the death

Criterion B. Traumatic Grief Symptoms

In response to the death, 6 of the following 11 symptoms experienced at least daily or to a marked degree:

1. Purposelessness, feelings of futility about future.
2. Subjective sense of numbness, detachment or absence of emotional responsiveness.
3. Difficulty acknowledging the death (disbelief).
4. Feeling life is empty or meaningless.
5. Feeling that part of oneself has died.
6. Shattered world view (lost sense of security, trust, control).
7. Assumes symptoms or harmful behaviours of, or related to, the deceased.
8. Excessive irritability, bitterness, or anger related to the death.
9. Avoidance of reminders of the loss.
10. Stunned, dazed, shocked by the loss.
11. Life is not fulfilling without the deceased.

Criterion C

Duration of disturbance (symptoms listed) is at least 6 months.

Criterion D

The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

As can be seen in the above table one, the symptoms are divided into symptoms of separation distress and traumatic distress as well as evidence of poor social and occupational performance. It was felt that symptoms of separation distress were at the core of complicated grief, relating to the idea that complicated grief is a form of an attachment difficulty as a

result of separation, relating to the work of Bowlby (1971). Traumatic distress symptoms represent bereavement specific manifestations of being traumatised by the death. The proposed traumatic distress symptoms included efforts to avoid reminders of the deceased, feelings of purposelessness about the future, a sense of numbness, feeling shocked and stunned, with difficulty acknowledging the death, feeling life is empty without the deceased, an altered sense of trust and security, in addition to anger over the death.

In the second step of the criteria development, the symptoms were tested empirically on a set of data of a previously carried out widowhood study (Zisook & Schuchter, 1991). Each symptom was evaluated to determine its ability to identify individuals who were considered to have a true case of complicated grief.

Thirdly, the analyses were re-run, omitting poor indicators of true complicated grief symptoms. These items were traumatic distress symptoms and included: 'frequent efforts to avoid reminders of the deceased', 'feeling stunned, dazed or shocked', and 'difficulty imagining a fulfilling life without the deceased'. Following on this work, efforts are being made to include complicated grief as a distinct mental disorder in DSM-V (Lichtenthal et al., 2004)



Referring to chapter one of this thesis, while we now accept that people with intellectual disabilities experience feelings of grief and sadness following a bereavement, (Dowling et al., 2003) and that their behaviour and mental health deteriorate (Hollins & Esterhuyzen, 1997), there is a lack of understanding of the types and characteristics of symptoms people with intellectual disabilities experience. To date, there is no study of complicated grief symptoms in this population. In addition, there is a lack of consensus on the optimal level of bereavement ritual involvement for people with intellectual disabilities after the death of a close relative. Although best practice would suggest that a high level of ritual involvement seems most appropriate and best illustrates the finality of death for the individual, it is clearly important for these rituals to be contextualized for the individual. Clearly previous ritual involvement, with appropriate death education would seem to be the best psychological preparation for the individual, though there is little evidence in the literature to support this approach.

## **2.2 Aims**

The aim of this study was to examine a population of individuals with intellectual disabilities, who had experienced a parent bereavement

within the previous two years, for the specific symptoms of complicated grief. This population was compared with an age-matched control population who had not been bereaved, in order to best illustrate the effect of the bereavement.

In addition, the bereavement history and the experience of bereavement rituals were examined. Any possible relationship between the experience of bereavement rituals and the possible development of complicated grief symptoms were examined

As this was the first study of complicated grief symptoms in people with intellectual disability, a carer-based assessment study was deemed the most appropriate.

## **2.3 Method**

### Sample

The study sample included the carers of all those individuals with diagnosed intellectual disability who had experienced a parent bereavement within a two-year time period prior to the study. As discussed previously, there is a lack of agreement regarding the length of a so-called 'normal' grief reaction, though it is generally accepted that

for most individuals, significant symptoms of grief have resolved within one to two years of the bereavement. In the study by Hollins & Esterhuyzen (1997), a two-year period was also chosen.

Our sample was recruited from two large Voluntary Service Providers to people with intellectual disability in Dublin, from both day and residential services. Index cases were identified from the electronic database held for each service user that also documents parent deaths. In addition, direct contact was made with senior staff in each service centre, in order to out-rule any cases not picked up on the database. For each index case, the key worker for the individual and one other care worker (who best knew the individual) were identified.

The carer of the control case was recruited from the same centre. The control case was matched for level of disability, gender and approximate age (within five years). Those with autistic spectrum disorders were excluded from the study, as well as those with low cognitive/adaptive ability: it was felt that the impairment of social interaction, or low cognitive ability, would make the carers' interpretation of symptoms very difficult.

## **2.4 Administered Measures/Assessment Tools**

### Bereavement History Questionnaire (Adapted):

This was adapted for the purposes of this study from the Bereavement History Questionnaire developed by Hollins & Esterhuyzen, (1997). This questionnaire covers areas relating to the level of contact with the deceased parent prior to the death, the circumstances of the breaking of the news, the level of support that the subject received both before and after the bereavement, and the level of participation in bereavement rituals. [See Appendices A, 2.1 for Bereavement History Questionnaire (Adapted)]

A Short Modified version was administered to the Control Group, to document that the control group had not experienced a parent bereavement within the previous two years [See Appendices A, 2.2 for Bereavement History Questionnaire (Control)]

## Complicated Grief Questionnaire for People with Intellectual Disabilities

### (C.G.Q)

This is a modified version of the Inventory of Complicated Grief for Children, developed by Prigerson in 1999. This questionnaire contains questions relating to all of the possible symptoms of complicated grief (both symptoms of traumatic grief and separation distress, as well as an indication of significant disturbance to social and occupational functioning), covering the broad diagnostic criteria for complicated grief. The questionnaire was designed for use by children themselves, and used age and developmentally appropriate language. This inventory contained all of the symptoms of complicated grief as originally examined by the expert panel, as described above, before the empirical tests of the symptoms were carried out. This was done to ensure that as wide range of complicated grief symptoms as possible were looked at in this population in the initial stage of study.

The questionnaire was modified so that carers were asked whether they observed potential symptoms of complicated grief in the clients that they were most familiar with. The original version for children was seen as

appropriate to modify for the purposes of this study, as much of the language used in the questionnaire effectively and clearly described the symptoms, and was readily adapted for use in this study.

While the purpose of the original questionnaire for children was designed to assess for the possible presence of a diagnosis of complicated grief (sufficient number of symptoms present to meet the diagnostic criteria), the modified questionnaire was designed to assess for the presence of any of the symptoms of complicated grief in this patient group.

[See Appendices A, 2.3 for Complicated Grief Questionnaire for People with Intellectual Disabilities- (C.G.Q)]

Complicated Grief Questionnaire for People with Intellectual Disabilities (Control Group) (C.G.Q-Control)

The Inventory of Complicated Grief for People with Intellectual Disabilities was further modified for use with the Control group. This questionnaire also contains questions looking for complicated grief-type symptoms, but not precipitated by a bereavement, but instead by short-term separation from a family member/key-worker. This was designed to illustrate the fact that the index case complicated grief symptoms are not just related to short-term separation from attachment figures.

[See Appendices A, 2.4 for Complicated Grief Questionnaire for people with Intellectual Disabilities (Control Group) (C.G.Q.-Control)].

### Index of Social Competence

The Index of Social Competence (McConkey & Walsh, 1982) is an assessment checklist covering 15 adaptive behaviour domains, used in surveys of service requirements. It contains four subscales of overall competence: Additional handicaps, Communication Skills, Self-Care, Community Skills.

It has been shown to be internally consistent and to discriminate between people on levels of ability (Mc Evoy & Dagnan, 1993). When completed, it categorises people as either 'low ability' or 'high ability'.

This checklist was administered, at the same time as the other measures, to ensure that all participants had similar ability levels and that there were no significant differences between the index and the control groups. Any individuals assessed as 'low ability' were not assessed any further for the purposes of this study.

This checklist was administered to both Index and Control groups.

[See Appendices A, 2.5 for Index of Social Competence].

### Basic Demographic Information

As part of the data collection, demographic information was collected on each client, such as age, gender, and current service profile. At no stage was the identity of the individual revealed.

### Description of Data Collection

All data was collected by the key investigator (P.D). The purpose of the study, format of the interview, length of time, etc, were explained to the carers before starting.

To facilitate the staff, interviews were carried out at the service centre. The key worker and other carer were interviewed separately, and were not permitted to discuss the case or possible answers. Apart from the Inventory of Complicated Grief for People with Intellectual Disabilities (Index and Control), the investigator filled out the questionnaires/checklists, based on the verbal answers of the carers. For the Complicated Grief questions, the questionnaire was explained to the carers, and they were referred to the information note at the beginning of



the questionnaires. Following this, the carers filled out answers themselves. The Investigator was available for questions, but carers were encouraged to answer the questions based on their own observations of the individuals, and without recourse to notes/files.

## **2.5 Results**

### Introduction

The design of the study included a number of analyses that were included to assess some of the psychometric properties of the C.G.Q. It was hypothesised that there would be a significant difference between the bereaved group and the control group on the C.G.Q.

### Demographic Information

Table two below reports the demographic details for the two groups. No significant differences existed between the groups on any of these variables. It should be noted that 16 of the control group had experienced a bereavement; however these deaths had occurred between four and 20 years previously (Mean = 8.68 yrs, S.D. = 4.33).

Table 2: Sample characteristics

Demographics	Group	Bereaved	Control
Gender*	Male	58.3% (21)	58.3% (21)
	Female	41.7% (17)	41.7% (17)
Age**	Mean	40.39	38.29
	SD	9.264	7.139
Service user attends a day service *		97.4% (37)	94.7% (36)
Service user is in residential care*		65.8% (25)	55.3% (21)

\* Chi-square tests revealed no significant differences on these variables

\*\*Independent samples t-test revealed no significant difference in age

### Index of Social Competence

All individuals in the study were identified as 'high ability' and no significant difference was found on level overall competency (see table 2 below). Also no significant differences were found between the groups on the four subscales (see table three below for a summary of the scores on the subscales and overall total

Table 3: Group comparisons on the scales of the Index of Social Competence Questionnaire.

Subscale	Group	Mean	SD	t <sub>obs</sub>	d.f.	Sig.
Total score for additional handicaps	Bereaved	3.53	.687	.705	68*	>0.05
	Control	3.47	.506			
Total score for communication skills	Bereaved	2.58	.889	.500	74	>0.05
	Control	2.71	.802			
Total score for self-care	Bereaved	6.50	1.109	.091	74	>0.05
	Control	7.03	1.533			
Total score for community skills	Bereaved	7.26	2.816	.297	74	>0.05
	Control	7.95	2.866			
Overall Competency	Bereaved	19.87	4.15	-1.32	74	>0.05
	Control	21.16	4.36			

\* No homogeneity of variance reported therefore d.f. adjusted

## Complicated Grief Questionnaire

### *Discriminant validity*

Following this, the two groups were compared on the C.G.Q. itself. An average C.G.Q. score was obtained by first calculating a total score, (across all questions answered) and then dividing this by the number of valid answers (e.g. where a valid response was given). The highest possible score on this scale is 4.7 (as some questions have a range of 0-4 and others 0-5). It should be noted that item 9 ('Believes the deceased is really dead') is reverse-scored, to account for a positive direction. The mean scores for the two groups are presented in table four and it is clear that a significant difference was found, with the bereaved group scoring significantly higher on the C.G.Q. scale. Higher scores are indicative of greater difficulty. The range of total scores for the bereaved group was 0 – 2.43.

Table 4: Group Comparison on the mean score of the Complicated Grief Questionnaire

Average score on	Group	Mean	SD	t <sub>obs</sub>	d.f.	Sig.
Complicated Grief Questionnaire	Bereaved	1.14	0.696	9.089	39*	<0.01
	Control	0.099	0.126			

- No homogeneity of variance reported therefore d.f. adjusted

### *Inter-rater reliability*

An assessment of inter-rater reliability of the C.G.Q. was carried out. Two key workers for each bereaved individual were asked to separately assess the individuals using the C.G.Q. and a Pearson's correlation was used to assess the relationship between the two sets of scores. A significant and very strong positive correlation of 0.965 (significant at  $p < 0.01$ ) was found between the two sets of scores, suggesting that almost 95% of the variance in the data is explained by the relationship between the different raters.

### *Internal Consistency*

The final assessment of the psychometric properties of the C.G.Q. used Cronbach's alpha to assess the internal consistency of the scale. Generally scores above 0.7 are considered to represent appropriate internal consistency and the analysis of the data collected revealed an alpha score of 0.9236 for the ratings by key-worker one (for both the bereaved and control groups) and 0.8890 for ratings by key-worker two (bereaved group only).

## Exploration of subscales within the C.G.Q.

As well as exploring the overall mean score of the C.G.Q., and the reliability of the scale as an overall measure of difficulty, the presence of possible subscales was also explored. Firstly, the researcher who initially developed the diagnostic criteria for complicated grief in the general population, Professor Holly Prigerson was contacted and asked if any of the symptoms required for a diagnosis of complicated grief had been refined. Indeed, the poor performance of a number of symptoms had led to their exclusion from the proposed complicated grief diagnostic criteria. Table five below reports the symptoms that are currently accepted as required in the process of making a diagnosis of complicated grief in the general population as described by Professor Prigerson (2004, 2006). As can be seen in table five, all of the symptoms of separation distress were retained, while some of the symptoms of traumatic grief were excluded. These suggested subscales were adopted and Cronbach's alpha was calculated. The separation distress subscale had an alpha of 0.8714, while the traumatic grief subscale had an alpha value of 0.8233. The item-total correlations were examined for each scale and only one item appeared problematic: when Item 9 ('Believes the deceased is really dead') was

removed from the traumatic grief sub-scale, the alpha value rose to 0.8569.

Table 5: Refined symptoms identified by Prigerson (2006).

<b>Separation Distress</b>	<b>Traumatic Grief</b>	<b>Items Excluded</b>
2. Gets upset when thinking about the deceased	3. Thinks the deceased will come through the door	12. Avoids things that remind them of the deceased <i>(Traumatic grief)</i>
4. Misses the deceased so much they cannot tolerate it	7. Feels guilty if they are having a good time	13. Reports hearing the deceased's voice <i>(Traumatic grief)</i>
5. Wishes the deceased were here to look after them	8. Feels angry about the deceased's death	14. Describes the feeling of seeing the deceased <i>(Traumatic grief)</i>
6. Wants to revisit places they used to go to with deceased	9. <i>Believes the deceased is dead</i>	21. Feels the deceased death was their fault <i>(Traumatic grief)</i>
18. Feels lonely since the death	10. Finds it hard to trust people since the death	23. Avoids talking about the deceased because it is painful <i>(Traumatic grief)</i>
22. Thinks about the deceased when wanting to think about other things	11. Finds it hard to feel close to people since the death	<b>Social/Occupational Disturbance (also excluded)</b>
	15. Finds it difficult to feel anything	1. Finds it hard to do normal activities
	16. Thinks its unfair that he/she is alive	20. Grief/sadness gets in the way of activities
	17. Feels envious of others who have not been bereaved	
	19. Feels insecure since the death	

The next analysis used to identify the most appropriate subscales was to identify those items that did not differentiate the bereaved and the control group. Chi-square analyses were used to identify the items in which there was a significant difference in the frequency of occurrence

of symptoms between the two groups. Table six below reports the results of this analysis and indicates those items where the frequency did not differ significantly. Seven items (items 3, 8,13, 14, 16, 17, 21) were found to show no difference in frequency between the bereaved and control groups. These items were removed and Cronbach's alpha was recalculated and found to be 0.9224. Remembering that this is a carer based study, it may well be that the items that revealed no difference between the bereaved and the control groups, may well represent symptoms that were too difficult for the carers to accurately observe and describe with any level of confidence. It is interesting to note that three of the items that were excluded by Prigerson (13,14,21), as detailed above, were also items that did not differentiate between the bereaved and control groups in the chi-square analysis.

Table 6: Results of Chi-square analyses\*\*

Item	Chi-square Result
1. Finds it hard to do normal activities	( $\chi^2 = 31.302$ , df = 4, $p < 0.01$ )
2. Gets upset when thinking about the deceased	( $\chi^2 = 42.723$ , df = 4, $p < 0.01$ )
3. Thinks the deceased will come through the door	( $\chi^2 = 8.952$ , df = 5, $p > 0.01$ )*
4. Misses the deceased so much they cannot tolerate it	( $\chi^2 = 13.571$ , df = 4, $p < 0.01$ )
5. Wishes the deceased were here to look after them	( $\chi^2 = 29.184$ , df = 5, $p < 0.01$ )
6. Wants to revisit places they used to go to with deceased	( $\chi^2 = 29.048$ , df = 5, $p < 0.01$ )
7. Feels guilty if they are having a good time	( $\chi^2 = 11.045$ , df = 2, $p < 0.01$ )
8. Feels angry about the deceased's death	( $\chi^2 = 10.862$ , df = 5, $p > 0.01$ )*
9. Believes the deceased is dead	( $\chi^2 = 17.576$ , df = 4, $p < 0.01$ )
10. Finds it hard to trust people since the death	( $\chi^2 = 17.267$ , df = 4, $p < 0.01$ )
11. Finds it hard to feel close to people since the death	( $\chi^2 = 16.603$ , df = 5, $p < 0.01$ )
12. Avoids things that remind them of the deceased	( $\chi^2 = 12.187$ , df = 3, $p < 0.01$ )
13. Reports hearing the deceased's voice	( $\chi^2 = 5.719$ , df = 3, $p > 0.01$ )*
14. Describes the feeling of seeing the deceased	( $\chi^2 = 6.514$ , df = 3, $p > 0.01$ )*
15. Finds it difficult to feel anything	( $\chi^2 = 21.176$ , df = 4, $p < 0.01$ )
16. Thinks its unfair that he/she is alive	( $\chi^2 = 5.586$ , df = 2, $p > 0.01$ )*
17. Feels envious of others who have not been bereaved	( $\chi^2 = 11.189$ , df = 4, $p > 0.01$ )*
18. Feels lonely since the death	( $\chi^2 = 44.697$ , df = 5, $p < 0.01$ )
19. Feels insecure since the death	( $\chi^2 = 26.078$ , df = 4, $p < 0.01$ )
20. Grief/sadness gets in the way of activities	( $\chi^2 = 19.884$ , df = 3, $p < 0.01$ )
21. Feels the deceased death was their fault	( $\chi^2 = 7.683$ , df = 4, $p > 0.01$ )*
22. Speaks about the deceased when talking about other things	( $\chi^2 = 15.728$ , df = 4, $p < 0.01$ )
23. Avoids talking about the deceased because it is painful	( $\chi^2 = 15.770$ , df = 4, $p < 0.01$ )

- No significant difference identified
- \*\* Alpha set to 0.01 due to number of tests being performed

Based on this analysis it was decided to use the overall scale, excluding those items that did not differentiate between the groups as described above, as well as the Prigerson subscales, again with the same items excluded. The reliability of the overall scale (less item 9, which continued to correlate poorly with the overall scale) was 0.9326. With regard to the actual symptoms, no changes needed to be made to the separation



distress subscale ( $\alpha = 0.8714$ ), while five further items (items 3,8,9,15,16) were removed from the traumatic grief subscale. The revised traumatic grief scale had a Cronbach's alpha of 0.8474. Overall, six symptoms have been excluded, based on this analysis (symptoms 3,8,9, 15,16,17), and the chi-squared analysis. Table seven below illustrates the remaining relevant symptoms, when the excluded Prigerson items and the excluded items from this study are removed.

Table 7 Symptom Sub-Scales following analysis (including those symptoms excluded by Prigerson)

<b>Separation Distress</b>	<b>Traumatic Grief</b>
2. Gets upset when thinking about the deceased	7. Feels guilty if they are having a good time
4. Misses the deceased so much they cannot tolerate it	10. Finds it hard to trust people since the death
5. Wishes the deceased were here to look after them	11. Finds it hard to feel close to people since the death
6. Wants to revisit places they used to go to with deceased	19. Feels insecure since the death
18. Feels lonely since the death	
22. Thinks about the deceased when wanting to think about other things	

Once these three scales had been decided on, scores were calculated and the bereaved and control groups were compared on these variables. Table eight below reports the findings of this analysis. As highlighted below, significant differences were identified between the

groups on all three scores, with the bereaved group scoring higher, but particularly for the separation distress symptoms.

Table 8: Group comparisons on the scales of the Complicated Grief Questionnaire.

Subscale	Group	Mean	SD	t <sub>obs</sub>	d.f.	Sig.
Overall C.G.Q. mean score	Bereaved	1.370	0.836	9.027	41*	<0.01
	Control	0.112	0.196			
Separation Distress mean score	Bereaved	1.925	1.032	9.847	44*	<0.01
	Control	0.191	0.334			
Traumatic Grief mean score	Bereaved	0.599	0.515	6.101	43*	<0.01
	Control	0.067	0.154			

\* No homogeneity of variance reported therefore d.f. adjusted

Clearly the separation distress symptoms proved to be the most consistent symptoms, and best differentiated between the bereaved and the control groups.

### *Factor Analysis*

An exploratory factor analysis was also carried out on all of the initial symptoms that were assessed. While the size of the current data set does not meet the 4:1 participant to item requirement for this procedure, it was felt that this analysis might provide some insights into the possible substructures within the C.G.Q. Factor analysis identified two subscales, which together accounted for 52.4% of the variance within the data. The breakdown of factors is included in Table nine below. Where items loaded

in both factors, the highest loading decided the final location of the item. Cronbach's alpha for factor 1 was found to be 0.9276, while factor 2 had an alpha value of 0.7542. This analysis supports the existence of subscales and the need for further study. However the poor participant to item ratio means that additional research will be necessary.

Table 9: Item distribution identified by factor analysis.

Item*	Factor 1	Factor 2
1. Finds it hard to do normal activities	.584	<b>.595</b>
2. Gets upset when thinking about the deceased	<b>.666</b>	.526
3. Thinks that the deceased will come through the door		<b>.778</b>
4. Seems to miss the deceased so much that they can't tolerate it	.293	<b>.657</b>
5. Wishes that the deceased were here to look after them	<b>.534</b>	.520
6. Wants to revisit places where they used to go with the deceased	<b>.601</b>	.351
7. Feels guilty if they are having a good time since the deceased passed away	<b>.615</b>	
8. Feels angry about the deceased's death	<b>.750</b>	
10. Is it hard for the client to trust people since the deceased passed away	<b>.835</b>	
11. Find it hard to care or feel close to people ever since the deceased passed away	<b>.842</b>	
12. Avoids things that remind them of the deceased	<b>.785</b>	
13. Reports hearing the deceased's voice speaking to them		<b>.595</b>
14. Describes the feeling of seeing the deceased in front of them		<b>.843</b>
15. Reports it difficult for them to feel anything	<b>.678</b>	
16. Thinks it is unfair that they are alive while the deceased is dead	<b>.548</b>	
17. Describes feeling envious of others who have not lost someone close to them	<b>.483</b>	
18. Feels lonely since the deceased died	<b>.719</b>	.456
19. Feel as safe since the deceased's death	<b>.821</b>	.350
20. Grief or sadness gets in the way of them doing things at work or home	<b>.698</b>	.258
21. Reports feeling that the deceased's death was their fault	<b>.400</b>	
22. Says that they are thinking about the deceased even when they want to talk about other things	<b>.701</b>	
23. Avoids talking about the deceased because it is too painful	<b>.734</b>	

\* Item 9 did not appear in the factor analysis

It is interesting to note that three of the items that were excluded by Prigerson (13,14,21) were also items that did not differentiate between the bereaved and control groups in our factor analysis. There was a certain

level of similarity between the Prigerson items and the factor analysis; however due to the poor participant-to-item ratio this analysis, these findings are theoretically weak.

#### Occurrence of C.G.Q. symptoms among bereaved group

One of the main aims of the study was to identify the frequency of symptoms of complicated grief among adults who had been bereaved. Table 10 below summarises the frequency of response for each symptom among the bereaved group.

Table 10: Occurrence of symptoms among bereaved group

Symptom	Never – Rarely	Sometimes – Always
1. Finds it hard to do normal activities	58.3% (21)	39.5% (15)*
2. Gets upset when thinking about the deceased	36.8% (14)	63.2% (24)
3. Thinks the deceased will come through the door	86.8% (33)	13.2% (5)
4. Misses the deceased so much they cannot tolerate it	76.3% (29)	13.7% (9)
5. Wishes the deceased were here to look after them	36.8% (14)	63.2% (24)
6. Wants to revisit places they used to go to with deceased	54.1% (20)	39.5% (15)*
7. Feels guilty if they are having a good time	77.8% (28)	18.4% (7)*
8. Feels angry about the deceased's death	65.8% (25)	34.2% (13)
9. Believes the deceased is dead	2.6% (1)	94.8% (37)*
10. Finds it hard to trust people since the death	63.1% (24)	36.9% (14)
11. Finds it hard to feel close to people since the death	68.4% (26)	28.9% (11)*
12. Avoids things that remind them of the deceased	78.9% (30)	21.1% (8)
13. Reports hearing the deceased's voice	92.1% (35)	5.3% (2)*
14. Describes the feeling of seeing the deceased	92.1% (35)	7.9% (3)
15. Finds it difficult to feel anything	65.8% (25)	23.7% (9)*
16. Thinks its unfair that he/she is alive	76.3% (29)	18.5% (7)*
17. Feels envious of others who have not been bereaved	81.6% (31)	15.8% (6)*
18. Feels lonely since the death	26.3% (10)	73.7% (28)
19. Feels insecure since the death	50.0% (19)	50.0% (19)
20. Grief/sadness gets in the way of activities	60.5% (23)	39.5% (15)
21. Feels the deceased death was their fault	86.8% (33)	10.5% (4)*
22. Speaks about the deceased when talking about other things	68.4% (26)	31.4% (12)
23. Avoids talking about the deceased because it is painful	68.4% (26)	31.4% (12)

\* Remaining percentage represents missing data/ not possible to answer response

In addition to this calculation, the number of symptoms on which each individual scored within the clinical range (i.e. 'sometimes-always') was calculated. The number of symptoms among the bereaved group ranged between 0 and 17 (out of a possible total of 23) and 12 participants (31.6%) within the clinical range on ten or more of the symptoms. The

number of symptoms among the control group ranged from 0 to 2, with 86.8% (n =33) reporting no symptoms.

### Bereavement History

The bereavement history of the bereaved group was also explored as part of the study. In keeping with the design of the study, all of the service users had lost a parent, with 42.1% (16) losing a father and 57.9% (22) losing a mother. 44.7% (n =17) had experienced a previous bereavement in the family, with 13.2% (n = 2) having lost a member of their immediate family. Looking at the most recent parental bereavement, in almost two thirds of the cases (63.2% n = 24), the parent had passed away in hospital, and the service user was aware of the illness in slightly more cases (68.4%, n = 26). In addition, while the service user was involved in caring for the person in only four cases (10.5%), in almost two-thirds of the cases (65.8% n = 25) the service user had visited the parent in hospital and in 21 cases (84.0%) the service user had visited their parent at least weekly.

In relation to discussing the death with the service user, this happened in over half the cases (55.3% n = 21) and the most usual people to be involved in this discussion were staff or staff and family members together. Table 11 below reports the frequency with which service users were

involved in various aspects of bereavement rituals. Finally, staff members reported that very few of the service users had received bereavement counselling following the death (n = 6, 15.8%).

Table 11: Involvement of service users in funeral rituals

Activity	Yes
Service user was involved in saying goodbye	73.7% (28)
Service user was involved in visiting the body	71.1% (27)
Service user was involved in preparing for the funeral	71.1% (27)
Service user was involved in talking about the deceased	86.8% (33)
Service user was involved in attending the funeral	94.7% (36)
Service user was involved in attending the wake	76.3% (29)
Service user was involved in looking at photographs	89.5% (34)
Service user was involved in attending the months mind	68.4% (26)

In addition to the descriptive analysis as described above, an index of involvement in the bereavement was created. Table 12 below reports the twelve items initially identified as possible items in a 'Bereavement Involvement Index' (B.I.I.). The internal reliability of this scale was found to be 0.8687, with no problematic items highlighted.

Table 12: Items initially included in the Bereavement Involvement Index

Items included in the Bereavement Involvement Index
Client aware of the person's illness
Client involved in caring for the person during their illness
Person's death discussed with the client
Client visited the person whilst in hospital
Client involved in 'saying goodbye'
Client involved in visiting the body
Client involved in preparing for the funeral
Client involved in talking about the deceased
Client involved in attending the funeral
Client involved in attending the 'wake'
Client involved in looking at photographs
Client involved in attending the 'months mind'

However it was felt that this scale included both events that preceded the death (e.g. visiting the person while ill) and events that followed the event (attending the funeral). Therefore a factor analysis was completed to see if two subscales could be extracted. The analysis was run with two factors requested and the resulting model was found to explain 59% of the variance in the data (see Table 13 below for the two-factor structure)

Table 13: Factor structure of the B.I.I.

<b>Bereavement Involvement Items</b>	<b>Factor 1</b>	<b>Factor 2</b>
Client involved in attending the 'months mind'	<b>.845</b>	
Client involved in preparing for the funeral	<b>.793</b>	.360
Client involved in attending the 'wake'	<b>.752</b>	
Client involved in talking about the deceased	<b>.739</b>	
Client involved in looking at photographs	<b>.739</b>	
Client involved in 'saying goodbye'	<b>.540</b>	.499
Client involved in visiting the body	<b>.492</b>	.671
Client involved in attending the funeral	<b>.428</b>	
Client visited the person whilst in hospital		<b>.956</b>
Client aware of the person's illness		<b>.935</b>
Person's death discussed with the client		<b>.799</b>
Client involved in caring for the person during their illness		



Where items loaded in both factors, the highest loading decided the final location of the item. Looking at the items in each factor, it is evident that events that occurred before the death seemed to cluster in factor 2, whilst events that took place after the death seemed to cluster in factor 1. The item 'client involved in visiting the body' loaded more strongly in factor 2, so it was decided that it was an experience more appropriate to factor 1, which seemed to mainly consist of events that followed the bereavement. In factor 2, the item 'was involved in caring for the person' did not appear in the analysis as the factor loading fell below the preset cut off of 0.3. Overall Factor 1 was found to have an internal reliability score of 0.8637, while Factor 2 had an internal reliability of 0.9157. As with previous scales, average scores were calculated to take into account the number of questions validly answered in the scale.

#### The relationship between bereavement history and scores on C.G.Q.

Six scales were used in this analysis. The first was the overall Bereavement Involvement Index (B.I.I.), along with the two subscales of post-death involvement (B.I.I.-POST), factor 1 above, and pre-death involvement (B.I.I.-PRE), factor 2 above. For all three scales higher scores are indicative of more involvement. The other scales were the overall Complicated Grief

score (C.G.Q.), along with the two subscales of Separation Distress (S.D.) and Traumatic Grief (TG). For these scales, higher scores are indicative of greater difficulty.

Using Spearman's Rho correlations (as the B.I.I. could not be assumed to be normally distributed), a significant positive correlation was found between the S.D. subscale and the B.I.I. ( $r = 0.363$ ,  $p = 0.015$ ). This represents a low-moderate relationship. Significant correlations were not found for B.I.I. and overall C.G.Q. ( $r = 0.270$ ,  $p = 0.055$ ) or for the B.I.I. and the T.G. subscale ( $r = 0.066$ ,  $p = 0.351$ ).

The next scale to be considered was the B.I.I.-PRE scale, but no significant correlations were identified with overall C.G.Q. ( $r = -0.108$ ,  $p = 0.266$ ), S.D. ( $r = 0.030$ ,  $p = 0.430$ ) or T.G. ( $r = -0.193$ ,  $p = 0.129$ ). However significant correlations were identified between B.I.I.-POST and overall C.G.Q. ( $r = 0.507$ ,  $p = 0.001$ ), B.I.I.-POST and S.D. ( $r = 0.542$ ,  $p = 0.000$ ), and between B.I.I.-POST and T.G. ( $r = 0.292$ ,  $p = 0.042$ ).

Following this, linear regression was used to examine whether the significant relationships identified above were predictive, i.e. that bereavement involvement was a predictor of complicated grief. Overall C.G.Q. correlated with B.I.I.-POST, with the prediction model found as

significant ( $F = 8.728$ ,  $d.f. = 1,34$ ;  $p = 0.006$ ), suggesting that greater involvement in bereavement rituals, following the death, predicted higher scores on C.G.Q. However the adjusted r-square value, which represents the percentage variance in the dependent variable (separation distress) accounted for by the predictor (involvement), was 0.181, suggesting that less than 20% of the variance in S.D. scores is accounted for by B.I.I. scores. This indicates that other factors are involved in level of overall difficulty.

Correlations were also found between S.D. and both B.I.I. and B.I.I.-POST; therefore both levels of B.I.I. were included as possible predictors.

However only B.I.I.-POST was included in the prediction model, which was both significant ( $F = 16.773$ ,  $d.f. = 1,34$ ;  $p = 0.000$ ), and accounted for just over 30% of the variance in the data (adjusted r-squared value = 0.311).

Again this suggests that other factors are involved in predicting separation distress.

#### Relationship between C.G.Q. scores and other aspects of bereavement history

In addition to correlation and regression analysis, a number of specific variables were identified for use as independent variables in an examination of C.G.Q. scores. The first variable was whether there had

been an opportunity to discuss the death prior to the event, and thus perhaps prepare the individual for the event. As reported above, this had happened in just over half of the cases (55.3%  $n = 21$ ). However no significant differences were found between these two groups on scores of overall complicated grief (C.G.Q.:  $t = -0.202$ ;  $d.f. = 25$ ;  $p > 0.05$ ), separation distress (S.D.:  $t = 0.632$ ;  $d.f. = 36$ ;  $p > 0.05$ ), or traumatic grief (T.G.:  $t = -1.048$ ;  $d.f. = 36$ ;  $p > 0.05$ ).

Also considered was whether the individual had experienced a previous bereavement, which occurred for 44.7% ( $n = 17$ ) individuals. However no significant differences were found between those who had experienced a previous bereavement, compared to those who had not, on scores of overall complicated grief (C.G.Q.:  $t = -1.603$ ;  $d.f. = 36$ ;  $p > 0.05$ ), separation distress (S.D.:  $t = -1.437$ ;  $d.f. = 36$ ;  $p > 0.05$ ), or traumatic grief (T.G.:  $t = -1.4518$ ;  $d.f. = 36$ ;  $p > 0.05$ ).

In addition, differences in the type of parent bereavement (mother or father) were examined. Again no significant differences were found between these two groups on scores of overall complicated grief (C.G.Q.:  $t = 0.325$ ;  $d.f. = 36$ ;  $p > 0.05$ ), separation distress (S.D.:  $t = 0.138$ ;  $d.f. = 36$ ;  $p > 0.05$ ), or traumatic grief (T.G.;  $t = 0.947$ ;  $d.f. = 36$ ;  $p > 0.05$ ).

Finally, the rated quality of the relationship with the deceased was assessed as a possible influencing factor. Key workers had indicated the quality of the relationship (from their perspective) and their responses were categorised as poor/minimal, good, and very good. Table 14 below reports the frequencies for each group and the mean scores on the three scales, along with the findings of three. one-way non-repeated Analysis of Variance (ANOVA) tests. However, no significant differences were found.

Table 14: Descriptives and ANOVA outcomes for quality of relationship analysis

Group	% (n)	C.G.Q.	S.D.	T.G.
Poor/minimal relationship	23.7 (9)	1.45 (1.08)	1.86 (1.30)	0.69 (0.63)
Good relationship	34.2% (13)	1.29 (0.82)	1.86 (1.04)	0.52 (0.52)
Very good relationship	36.8% (14)	1.32 (0.77)	1.95 (0.97)	0.59 (0.49)
ANOVA Outcome		F = 0.094; df = 2,33; p>0.05)	F = 0.030; df = 2,33; p>0.05)	F = 0.267; df = 2,33; p>0.05)

## 2.6 Discussion/Conclusions

### *Summary of Results*

As far as the researcher is aware, this is the first study of complicated grief symptoms in people with intellectual disabilities. As discussed in chapter

one, the evidence is there to show that bereavement and loss have a distinct effect on the mental health of people with intellectual disabilities. Many studies have shown that symptoms of depression and anxiety increase, and behaviour changes following a bereavement. However it is unclear whether these symptoms and changes in behaviour represent so-called 'normal' grief symptoms, or the more serious 'complicated grief' symptoms.

This carer-based control study has shown that bereaved individuals with intellectual disabilities can and do experience complicated grief symptoms, following the death of a parent. 31.6% of the bereaved group experienced ten or more clinically apparent symptoms.

The study involved the development of an adapted C.G.Q. to assess for the presence of complicated grief symptoms in a bereaved cohort of individuals. The C.G.Q. has been shown to have good face validity and, based on the results, the researcher is confident that when used with a population of people with intellectual disability, the C.G.Q. is an internally consistent scale, which effectively distinguishes between individuals who have experienced a bereavement and those that have not. In addition, it can be used consistently by two staff, rating the same individual, separately. In other words, it has good discriminant and internal validity.

It has also been possible to rationalise the number of relevant complicated grief symptoms for this population, which broadly reflects the rationalisation of symptoms that has occurred in studies that were carried out in the general population. A total of six symptoms of traumatic grief failed to adequately distinguish between the bereaved and the control groups, while all of the symptoms of separation distress were distinguishable. Therefore there is good evidence to suggest that symptoms of separation distress are experienced more consistently in this population, when compared to the traumatic grief symptoms. This is in keeping with the understanding, as developed by Bowlby (1970), that grief is an extension of a general response to separation, where an attachment has been broken. This innate response best explains the ability of people with intellectual disabilities to grieve, often much more than expectations, when cognitive ability is narrowly considered. It is clear that the reduced number of symptoms, rationalized by both Prigerson and the analyses of this study, have produced a set of symptoms that need to be tested again on a sample of bereaved individuals in order to improve validity.

This study also gathered information on the bereavement related experiences of individuals both before and after their parent's bereavement. There was a high level of awareness of the approaching

death, in most cases, and there was a high level of bereavement ritual involvement after the death. These findings are very much in keeping with that which is reported in the studies as described in chapter three of this thesis.

An effort was made to ascertain whether bereavement related experiences predicted whether an individual went on to develop complicated grief symptoms. A positive correlation was found between those individuals who were very involved in bereavement rituals after the death (seeing the body, attending the funeral etc) and the development of complicated grief symptoms and, more so, separation distress symptoms. On the surface this would seem to be at odds with the commonly understood practise of maximizing involvement in bereavement rituals to help the individual understand the finality of death etc. However, remembering that the post-bereavement ritual involvement accounted for 30% of the variance in separation distress symptoms, clearly other factors are involved in predicting this unexpected finding. The important point here is the context of the ritual involvement: if the bereaved individual was very involved in rituals for the first time in their life, then it is likely that this involvement may prove to strengthen the separation distress type symptoms. The analysis does not indicate that these individuals will necessarily go on to experience significant



complicated grief problems; all that can be said is that individuals who were involved in an increased number of post-death bereavement rituals, experienced a higher level of separation distress and complicated grief symptoms. This may have implications for the way in which we support bereaved individuals. While involvement in bereavement rituals is important, previous exposure to, and understanding of, these rituals is clearly important. It may well be that, before recommending a bereaved individual be involved in all of the bereavement rituals, a bereavement ritual history may need to be taken; those with little previous ritual involvement may be less distressed by being involved in rituals commonly regarded as less traumatic (eg. avoiding seeing the dead body or seeing the coffin lowered in to the ground). Of course, decisions regarding this can only be made on an individual basis.

### *Methodological Issues*

An important strength of this study lies in the fact that it is based on a well-matched comparison group. However, it still remains a carer-based study. All of the information gathered was based on the observations of carers. In addition, the study was retrospective, depending on the observation skills and memory of the individual's key worker. However, only staff that

knew the individual very well were chosen, and the level of agreement between the key-worker and the other carer was very high.

The study was retrospective, and concerned symptoms that were associated with a bereavement that might have taken place up to two years previously; therefore some symptoms may not have presented, while others may have resolved, while still being clinically relevant.

There is no diagnostic gold standard for complicated grief in the general population, so the issue of diagnostic validity could not be attempted.

Of course, this study only looked at the experience of high functioning adults with intellectual disabilities. It does little to advance our understanding of the experiences people with more severe intellectual disabilities following a bereavement.

### *Suggested Future Research*

Sufficient information has been collected in this study to suggest that a study involving direct interviews with bereaved people with intellectual disabilities is warranted. A replication of this study, with all of the initially proposed symptoms of complicated grief would be of benefit. In addition more detailed information about previous bereavement history and the quality of bereavement ritual involvement, in particular, could be collected. Following this, a prospective longitudinal study of complicated

grief symptoms would be indicated with symptom assessments at three or six month intervals. This may expose the time, following a bereavement, when an individual with intellectual disabilities is most vulnerable. The prospective study could be linked with a randomised control trial of a bereavement education package for both individuals and carers, prior to any significant bereavement; this would have the aim of definitively showing the positive mental health benefits of bereavement education for this population.

## **CHAPTER 3**

### **Attitudes to Bereavement and Intellectual Disabilities in an Irish Context**

### 3.1 Introduction

It is now well accepted that participation in mourning rituals helps convey the finality of death and facilitates adaptation to loss and the resolution of grief (Cathcart, 1995; Read, 1999; Worden, 1991,1996). Indeed, exclusion as an attempt to try to protect the individual from possible emotional discomfort may, in fact, place the individual at a higher risk of developing significant subsequent emotional discomfort (MacHale & Carey, 2002; Hollins & Esterhuyzen, 1997; Seltzer, 1985). However, the preparation that a person with intellectual disabilities receives for the impending death of a care-giving relative is often minimal. Frequently information about a caregiver's illness is withheld, time or privacy to grieve denied and the individual excluded from funeral and other grieving rituals (Ghaziuddin, 1988; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Raji, Hollins & Drinnan, 2003; Oswin, 1991).

Exclusion from cultural rituals associated with death may be as a result of carer's lack of knowledge of the bereavement and grief processes of people with intellectual disabilities (Murray, McKenzie & Quigley, 2000). Caregivers may hold inaccurate beliefs, or lack knowledge of the ability of people with intellectual disabilities to grieve. For example, there is a common assumption that people with intellectual disabilities have little or no awareness of death or the grieving process (Kloeppel & Hollins, 1989);

research suggests otherwise (Bihm & Elliott, 1982; McEvoy, 1989, 2002).

Caregivers may believe it better to distract grieving individuals until they forget about the deceased (Deutsch, 1985), and frequently fail to associate behaviour change with recent bereavement (Strachan, 1981; Hollins & Esterhuyzen, 1997).

Recent evidence suggests that many of these beliefs and attitudes may be changing (Murray, Mc Kenzie & Quigley, 2000). Murray et al. (2000) carried out a questionnaire based study and reported that staff knowledge of the grieving process of individuals with intellectual disabilities was good, as was their awareness of the emotional and behavioural impact of death. Generally staff were confident to support individuals through the grieving process, particularly staff that had previously supported bereaved individuals.

In many parts of Western Europe, there have been dramatic changes in the way death is treated by society, and also in the beliefs surrounding death and dying (Howard & Jupp, 1999; Aries, 1991; Elias, 1985). In Ireland, many of the older rituals associated with death are still common (Power, 1993), including seeing the dressed dead body and saying goodbye (family) and attending the funeral mass or service (wider community). Although the position of religion is clearly changing in Irish

society, attendance at funerals is still seen as an important sign of support to bereaved individuals and a religious element to death and bereavement is still expected (Van Doorslaer & Keegan, 2001).

Therefore, the experience of death and bereavement for people with intellectual disabilities in Ireland may be somewhat different to that in other countries where research has taken place. Indeed, there is some evidence that the Irish population are conversant with grief issues and appreciate the benefits of death education (McGovern & Barry, 2000), although whether these attitudes transfer to supporting people with intellectual disabilities has yet to be demonstrated.

The extent and nature of staff reactions to bereaved individuals with intellectual disabilities may vary widely and can be dependent on their attitudes and experiences of coping with death, their belief systems, their education and training, and also cultural and societal factors. This chapter presents a descriptive study in two parts, examining attitudes to death and bereavement within services and organisations providing services to people with intellectual disabilities within the Republic of Ireland. The aim of the study was to examine organisational, management and front-line care staff attitudes and practises regarding bereavement and people with intellectual disabilities.

### **3.2 The study**

This study used a mixed method approach to explore organisational and staff practices and attitudes to the issue of bereavement and people with intellectual disabilities. Quantitative multiple choice and Likert-scale questions were combined with more qualitative open-ended questions to ensure that both patterns of response and unexpected themes were identifiable. The study involved two parts, each allowing a different perspective to be considered. In the first part of the study, a national survey of service and organisational approaches to bereavement and intellectual disabilities was carried out. The aim was to examine the type of experience people with intellectual disabilities have, following bereavement, and to assess levels of staff training and support as perceived by senior managers.

The second part of this study aimed to replicate Murray et al's (2000) investigation, this time using a staff group working in the Republic of Ireland. The aims of this part of the study were to assess staff knowledge and understanding of the grieving process of individuals with intellectual disabilities in an Irish context, and to report on any differences between the U.K. and Irish staff groups.



### 3.3 Materials

Two questionnaires were employed in the study. The first questionnaire was designed to examine views on the overall organisational attitude and support for the bereaved person with an intellectual disability and organisational policies on bereavement and commitment to staff training in the area. The questions set were based on feedback from attendees at an in-service educational workshop on bereavement. In line with the mixed method approach, both multiple choice and open-ended questions were used to explore a number of key areas. These were identified as:

- Service information
- Guidelines around bereavement
- Available training and resources
- Process of informing the service user of bereavement
- Supports available to service users
- Supports available to staff
- Funerals, month's mind, annual anniversaries.

The 'month's mind' is a religious ceremony held in memory of the dead person, one month after their death. It is an important traditional ritual in Irish Catholic families and remains common practice (Van Doorslaer & Keegan, 2001).

This questionnaire was sent by post to all the chief executives and clinical directors of 40 organisations providing a wide range of services to people with intellectual disabilities, throughout the Republic of Ireland. The organisations that were chosen represented the vast majority of service providers in Ireland, were evenly distributed throughout the country, and were representative of the range of service providers that is in place. Full approval of the local Ethics Committees was obtained.

[See Appendices B, 3.1 for Bereavement Questionnaire for Organisations].

The second questionnaire used in this study was identical to that used by Murray, et al., (2000) in their UK study. As in the previous questionnaire, both quantitative and qualitative components were contained in this questionnaire, examining staff knowledge of the bereavement process, in addition to enquiring about staff confidence in providing death education and in supporting bereaved individuals. Background information concerning age, gender, and years of experience working in intellectual disability services was also collected.

This questionnaire was distributed to 93 care staff working in centres providing services to adults with intellectual disabilities within one health board area. The centres approached provided residential, day and

training services, in both an urban and rural setting. Questionnaires were filled out voluntarily, and all participants were assured of anonymity, and were asked to return the completed questionnaires within a specified time. Ethical approval for the study was obtained. [See Appendices B, 3.2 for Bereavement Questionnaire for staff working with people with a learning disability (Murray et al., 2001)].

### **3.4 Results**

The results of both questionnaires were analysed separately using SPSS (Version 8.1). Frequency analyses were used to identify patterns in the responses to multiple choice and Likert-scale questions. In addition content analysis was used to identify the main themes emerging from responses to open-ended questions. Finally chi-squared tests were used to identify any significant differences between the present study and U.K. study (Murray et al., 2000). Alpha was set at 0.05 for all statistical analyses.

#### A. Service Response

Of the 40 questionnaires distributed to service agencies, 17 were returned (response rate = 42.5%). This sample was well geographically distributed throughout the country, with good urban and rural representation.

### *(1) Experience of Bereavement*

All 17 organisations reported that the person with an intellectual disability was always informed of the death of their relative or associate and in the vast majority of cases (82%, n = 14), this was done in discussion and agreement with family where possible. Fourteen (82%) organisations reported that service users always attended family funerals. Three indicated that service users attended sometimes, citing family wishes as the only reason for non-attendance. Fourteen (82%) reported attendance at the funeral of other service users. Six organisations (32%) frequently support service user attendance at the funerals of staff members, and 6 (32%) sometimes. Ten (59%) of the services surveyed, reported that the months mind mass was attended by most service users, and 4 (23%) reported service users as sometimes attending the month's mind. Eleven services (65%) reported that the annual anniversary mass for deceased family members was attended by service users.

Regarding bereavement support following the death of a family member, 13 services (77%) indicated that time was set aside for staff to specifically support clients following the death. In the case of the death of another service user, 15 services (88%) indicated that time was set aside for staff to support the bereaved. When asked about specific bereavement

supports, 10 (59%) services responded, indicating a variety of activities, including specialist bereavement counselling, cognitive therapy, group bereavement work, and the use of simple bereavement resources including books and videos.

## *(2) Staff Training and Support*

For the purposes of the Questionnaire, staff 'Guidelines on Bereavement' were described as any uniform or service-wide instruction regarding bereavement. Only one service reported having a formal written policy on bereavement, while 13 (77%) described an unwritten/understood code or culture of practise, primarily communicated to staff during in-service training or initial job induction.

Fifteen (88%) services reported that they explicitly encouraged staff to undertake training in bereavement work. In addition 7 (41%) services provided specific in-house training courses for staff and 14 (82%) routinely provided financial support for attendance at national or international bereavement courses. All of the respondents stated their awareness of the need for on-going training of staff in this area, and expressed commitment to providing this.

## B. Direct Care Staff Response

Of the 93 questionnaires distributed, 60 were returned, representing a 64.5% response rate. Table 1 below reports the characteristics of this group.

Table 1. Characteristics of care staff

Gender	8% (n = 5) male	92% (n = 55) female
Age	62% (n = 37) under 40 years	38% (n = 23) 41-60 years
Nature of role	18% (n = 11) nurses	82% (n = 49) care staff
Years experience	68% (n = 41) 10 yrs or less	32% (n = 19) 11 yrs plus

### *(1) The grieving process.*

Thirty-four respondents (58%) indicated that the normal grieving process for the general population would take 1-2 years. Thirteen (22%) said that it would take 6 months to a year, and 3 (5%) felt that it would take less than 6 months. One staff member felt that it would take up to one month. Eight respondents (14%) understood that the process would take over 2 years. When asked about the grieving process for people with intellectual disabilities, 35 (64%) respondents said that it would take the same length

of time as for the general population, while 20 (36%) felt that the process would last longer.

Fifty-one (85%) people felt that some individuals with intellectual disabilities do not understand the concept of death. The remainder (13%) indicated that this was not the case, while only one person did not know. Only 3 people (5%) believed that only those individuals with sufficient intellectually ability are able to grieve adequately. The remainder (95%) believed that this was untrue.

Responses to the open-ended question " What are the most common reactions of someone with an intellectual disability to a bereavement?" were examined and the key categories were extracted. These are outlined in Table 2 and it is clear that, in the experience of care staff, emotional and behavioural reactions predominate.

Table 2. Most commonly cited reactions of people with intellectual disabilities to bereavement

<b>Reaction</b>	<b>Example</b>	<b>Number*</b>	<b>Percentage</b>
Emotional	Sadness, crying, depression, anger, fear, shock	26	43
Behavioural	Self Injurious Behaviour, withdrawn, attention seeking	15	25
Physical	Illness	2	3
Cognitive	Confusion	7	12
Depends on other factors	Depends on level of intellectual disability & relationship to deceased, each person's reaction is individual	6	10

\* Most staff gave more than one response

## *(2) Providing help*

Fifty-nine (98%) of the respondents felt that people with intellectual disabilities should be taught about the concept of death, while only 1 (2%) felt that they should not. Forty-two (70%) believed that people with intellectual disabilities were able to grieve adequately when supported appropriately, while 10 (17%) believed they could not. Thirty-five (58%) of the respondents said that they had previously worked with an individual with an intellectual disability who had experienced a bereavement. Table 3 illustrates responses to the different approaches identified as being helpful to bereaved individuals with intellectual disabilities.



Table 3. Number and percentage of respondents rating each approach as always, sometimes or never helpful to bereaved people with an intellectual disability.

<b>Supportive action</b>	<b>Always</b>		<b>Sometimes</b>		<b>Never</b>	
	<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>
Being told about the death	50	86	8	14	0	0
Viewing the body	15	29	35	67	2	3
Attending the funeral	40	69	18	31	0	0
Visiting the grave	40	70	17	30	0	0
Counselling	33	60	22	40	0	0
Behaviour modification	7	19	27	75	2	6
Medication	1	2	29	64	15	33

It can be seen from the table that direct care staff were very much in favour of informing the person about the death, having the person view the body, attend the funeral and visit the grave. Staff were also in favour of the availability of counselling, and nearly two-thirds agreed that counselling should always be available following bereavement.

Additional comments included six requests for staff training and three requests for counselling and support specifically for people with an intellectual disability. Five people stressed the individuality of people with intellectual disabilities and the need to guard against generalised approaches; one person requested a protocol on bereavement; one person commented that people with intellectual disabilities were not

included enough in mourning rituals and one person stated that they felt they would be unable to counsel service users following a bereavement.

### *(3) Staff group comparison*

A series of Chi square tests were conducted on seven of the responses of the Irish staff group and data from the Murray et al., (2000) UK study. With regard to grief rituals, Irish staff were more inclined to “always encourage” viewing the body ( $\chi^2 = 17.77$ , d.f. 2,  $p < 0.001$ ), funeral attendance ( $\chi^2 = 4.08$ , d.f. 1,  $p < 0.05$ ), and visiting the grave ( $\chi^2 = 7.95$ , d.f. 1,  $p < 0.01$ ) when compared to their UK counterparts. In addition, differences were found between the groups regarding forms of intervention. Irish staff were more inclined to “always” consider counselling ( $\chi^2 = 5.14$ , d.f. 1,  $p < 0.05$ ), and behaviour modification ( $\chi^2 = 8.25$ , d.f. 2,  $p < 0.05$ ), while the UK staff appeared to be more favourable towards the use of medication ( $\chi^2 = 11.9$ , d.f. 2,  $p < 0.01$ ).

There were no significant differences (using t-tests) in relation to confidence in supporting a bereaved person. In addition, no significant relationship was found between confidence in supporting a bereaved client and experience of working in intellectual disability services.

### 3.5 Discussion & Conclusions

The results from this study suggest that, in Ireland, attitudes are generally positive towards supporting people with intellectual disabilities who have been bereaved. There is good understanding of the needs of bereaved individuals, and there appears to be commitment to delivering supports. In addition, there is a high level of participation by bereaved individuals with intellectual disabilities in grief rituals, reflecting the general high level of participation in such rituals by the general public in Ireland (Van Doorslaer & Keegan, 2001). From the early part of the twentieth century, much of the care for people with intellectual disabilities in Ireland was provided by the various religious orders (Hillery, 1993). Since then services have undergone much change. However, the high level of participation in grief rituals that we have found may be, in part, due to the historical influence of the religious orders. Therefore, the concern expressed in other studies (Oswin, 1991; Hollins & Esterhuyzen, 1997; Raji, Hollins & Drinnan, 2003; Harper & Wadsworth, 1993) at the low level of involvement in grief rituals may not apply to the same degree in the Irish context.

Further evidence for a positive attitude to inclusion in rituals can be found in the second part of the study examining direct care staff attitudes. The results are similar to those of Murray et al. (2000) with the majority of staff

(98%) agreeing that people with intellectual disabilities should receive death education. However a higher percentage of Irish staff (81% compared to 67% in the UK sample) believed that people with intellectual disabilities could grieve when supported appropriately. Irish staff gave similar responses to their UK counterparts regarding the reactions of people with intellectual disabilities to experiencing a bereavement; however they did not mention the possibility of aggressive or challenging behaviour or mental health sequelae. It must be remembered that an over-reliance on 'emotional' expressions of bereavement may deny some grieving individuals much needed support who may not express their grief in an overt 'emotional' way.

Some differences did emerge regarding helpful approaches following bereavement with Irish staff much more inclined to recommend viewing the body, funeral attendance and visiting the grave. It would appear that Irish staff were very much against the use of medication, whereas U.K. staff were less favourable towards the use of behaviour modification. Interestingly, despite the high profile afforded to funerals and ritual in Irish society, the Irish staff group, in contrast to their UK counterparts, had less actual experience of supporting people following bereavement. However, such experience or length of service did not correlate with confidence in teaching or supporting people with intellectual disabilities

following a death. This may indicate insufficient continuous training for staff, who, despite their experience, lack confidence.

The present study also highlights some important challenges for staff development and training in Ireland, not least the need to build confidence in Irish staff in supporting people with intellectual disabilities through the grieving process. While the expression of positive attitudes is encouraging, there may be a need to develop a greater flexibility of viewpoint regarding appropriate supports for people following bereavement. For example, it may not 'always' be appropriate for the person with intellectual disabilities to view the body and the use of medication may be required in some instances. Moreover, in some instances, an over reliance on counselling, at the expense of positive life style changes after bereavement may simply serve to pathologise further the grief responses of people with intellectual disabilities. The move from a caring interventionist model (Hillery, 1993) towards supportive responses based on developing equality of relationships, self determination and knowledge of the individual must be kept central in future training initiatives and service planning.

Despite the fact that only one service had a formal written policy on bereavement, a high rate of attendance and involvement of individuals

with intellectual disabilities in grief rituals was reported by managers and staff and contrasts with recent U.K. research highlighting the continued exclusion of people with intellectual disabilities from funerals and other mourning rituals (Raji, Hollins, & Drinnan, 2003). However, the policy gap is a worrying finding in light of the cultural and societal changes affecting services in Ireland. The advent of a performance culture with the need for clinical governance and quality assurance necessitates services to formalise their guidelines on bereavement and grief. This is needed to ensure equity of service and quality outcomes while, at the same time, maintaining flexibility and respecting the individual needs of bereaved clients.

The present study had a number of limitations. First, the response for the service-based questionnaire was disappointing, and the direct care staff questionnaire only sampled staff in one geographical area. Second, there may be a potential bias in both sets of respondents who were willing to return their questionnaires as they may have been better informed about, and committed to, bereavement issues. The direct care staff questionnaire used categorical questions to assess participants' self-reported experiences of this issue and these questions were then analysed as individual items. As there was no attempt made to measure a theoretical construct in the typical sense, standard concerns around the

psychometric properties of scales do not apply. However face validity is met by the agreement of the authors on the suitability of the items, and it is supported by the finding that both studies report similar responses in different settings, and from different sets of respondents. In addition these results are in keeping with previous Irish-based studies on death issues (McGovern & Barry, 2000). Despite these limitations the study demonstrates consensus between service planners and policy makers and direct care staff. Such consensus is encouraging and offers a basis for further development of appropriate supports to bereaved person with intellectual disabilities.

While the findings of this study are generally positive, it should not be assumed that the outcome of bereavement for people with intellectual disabilities in Ireland is any different to any other country. Indeed a recent study of bereaved Irish people with intellectual disabilities (MacHale & Carey, 2001) suggests similar psychiatric and behavioural outcomes to other studies following bereavement (Hollins & Esterhuyzen, 1997). Moreover, attendance at grief rituals is only one aspect of bereavement support and may only be of emotional benefit if the individual understands the meaning of the ritual. The importance of death education for people with intellectual disabilities has previously been described (Yanok & Beifus, 1993). Further research is advisable to assess

the current level of death education being provided, and its impact on coping following a bereavement. Within Ireland, the development of culturally sensitive individualised support needs to be addressed and in addition, attention to staff training and policy development on grief and bereavement is worthy of further consideration.



## **Chapter 4**

**A Study of Service Refusers: Characteristics, assessment and understanding.**

## **4.1 Introduction**

### *Clinical Context*

As in the general population, people with intellectual disabilities can develop mental health problems following significant life events (Ghaziuddin, 1988). Specifically parent bereavement has been shown to be associated with the development of significant psychopathology and behavioural difficulties (Esterhuyzen & Hollins, 1997).

Also, parent bereavement for an individual with intellectual disabilities can also be associated with losses such as the family home, the loss of a familiar day placement or job, the loss of a familiar community, and can end with emergency residential placement (Esterhuyzen & Hollins, 1997; Oswin, 1991).

In addition, because many individuals with intellectual disabilities usually live with parents much longer than those with normal cognitive development, frequently living at home into their thirties and forties, the life events associated with a parent bereavement clearly must have a catastrophic effect on the individual, especially if they have limited experience living away from the family home, or if their level of

vocational training or socialisation is only confined to the family home setting.

Therefore, individuals with intellectual disabilities, living at home with elderly parents, with limited contact with specific intellectual disability respite, residential or day services, must represent a high-risk group in the development of mental health difficulties, specifically after a parent bereavement. They represent a putative high-risk group in the development of complicated grief symptoms.

Not all families who care for adults with intellectual disabilities seek available services in their community, a group often described as service-refusers. In addition, due to limited resources, there are individuals on waiting lists for services. Individuals in these two groups, who remain outside services, represent a vulnerable group of people for the reasons as outlined above.

#### *National Intellectual Disability Database*

Comprehensive recording of the prevalence of intellectual disability began in Ireland in 1974 with a nation-wide census, which was followed up in 1981 (Mulcahy and Ennis, 1976; Mulcahy and Reynolds, 1984). The experience with local registers in the intervening years led to the establishment in 1995 of a National Intellectual Disability Database

(N.I.D.D.), which is primarily used for the planning, funding and management of services.

The Database incorporates three main pieces of information: demographic details, current service provision, and future service requirements.

The Database was established on the basis of collecting minimum information with maximum accuracy and contains information on all of those individuals with intellectual disabilities who are assessed as being in receipt of, or in need of, appropriate specialised intellectual disability health and social services in Ireland.

The operational structure of the database involves the annual completion of the database form, reporting on each individual, done by local service providers. This usually involves community care workers, public health nurses, school principals etc., filling out the database form on an annual basis, on the understanding that the individual filling out the form is well acquainted with the individual, and assesses need on an annual basis at least. This information is supplied to the regional Health Board, forming a regional database, which on a twice-yearly basis is transferred to the N.I.D.D.

## **4.2 Aims**

This chapter describes a three-part study that used the N.I.D.D. as a focus, to access data on a representative sample of individuals who are outside services. As described above, these individuals represent a high-risk group in developing bereavement and mental health difficulties, if left unsupported.

This study was carried out with a view to better understanding the magnitude and characteristics of, and assessment procedures carried out on, these individuals. In addition, efforts were made to document the views, understanding and opinions of key stakeholders in intellectual disability services in Ireland with regard to these individuals.

## **4.3 The Study**

There are 3 parts to this study:

Part 1: Examination of the characteristics of a putative high-risk group on the N.I.D.D.

Part 2: A study of the assessment procedures used by service providers to collect information on a representative sample of this group.

Part 3: A study, using qualitative research methods of the understanding and attitudes of key service providers and stakeholders towards this out-of-service group.

#### **4.4 Part 1: Examination of the characteristics of an out of service group from the N.I.D.D.**

#### **4.5 Materials and Method: Part 1**

The N.I.D.D. is compiled from regional databases from each health board. The regional databases are written in a database language called Clarion. The Health Research Board, on behalf of the Department of Health and Children receive a file (.dat file) from each of these Clarion databases. At national level, each file (.dat file) is imported into an empty version of the Clarion database, converted to a new file (a .dbf file) and opened in S.P.S.S. (version 11.0 was used in this study). Therefore the N.I.D.D. is an S.P.S.S. file compiled from .dat files received from the health boards.

For the purposes of this study, the sample was made up those individuals, over the age of 30 years, living with family members, with moderate, severe or profound intellectual disabilities who were either

receiving no services (neither day or residential services), but waiting for services, or those described as having 'no current service requirements'.

The geographical distribution, demographic information, and residential circumstances of the above individuals were examined and compared by age, gender and level of intellectual disability.

The above sample was identified and a select cases statement was constructed that matched the desired criteria as above.

The entire population as contained on the N.I.D.D. was included, from which the relevant sample was taken. However, for the purposes of this study, data from the largest region, the Eastern Region, was excluded for reasons of unreliable data regarding service provision. Data for the years 1996 and 2001 was examined and compared.

#### 4.6 Results: Part 1

a. Day Services	15386	57.7%
b. 5 or 7 day residential services	7619	28.6%
c. Resident in psychiatric hospitals	677	2.5%
d. Residential support services only	206	0.8%
e. Receiving no service (Waiting list)	515	1.9%
f. No current service requirements	2265	8.5%
g. Total	26668	100%

Table 1. Overall National level of Service Provision, N.I.D.D. 2001.

Table 1 above, taken from the N.I.D.D., lists the overall number of individuals accessing specialist services in Ireland for the year 2001. As highlighted, 515 (1.9%) are listed as 'receiving no service', while 2265 (8.5%) are listed as having 'no current service requirements'. Taken together, 2780 (10.4%) individuals are outside services.

Looking at the group outside services in more detail, the number of adults as described on the N.I.D.D., outside the Eastern Region, over the age of 30 years, living at home with family, not attending any services, with moderate, severe or profound intellectual disability was found to be 394 (i.e. n=394). This represented 7.5% of all of those



individuals, over the age of 30, with moderate, severe or profound intellectual disability (total was 5281) in the same region.

Looking at the gender of the sample, 225 (57.1%) were male, while 169 (42.9%) were female. This reflects the general trend on the Database regarding the gender of individuals.

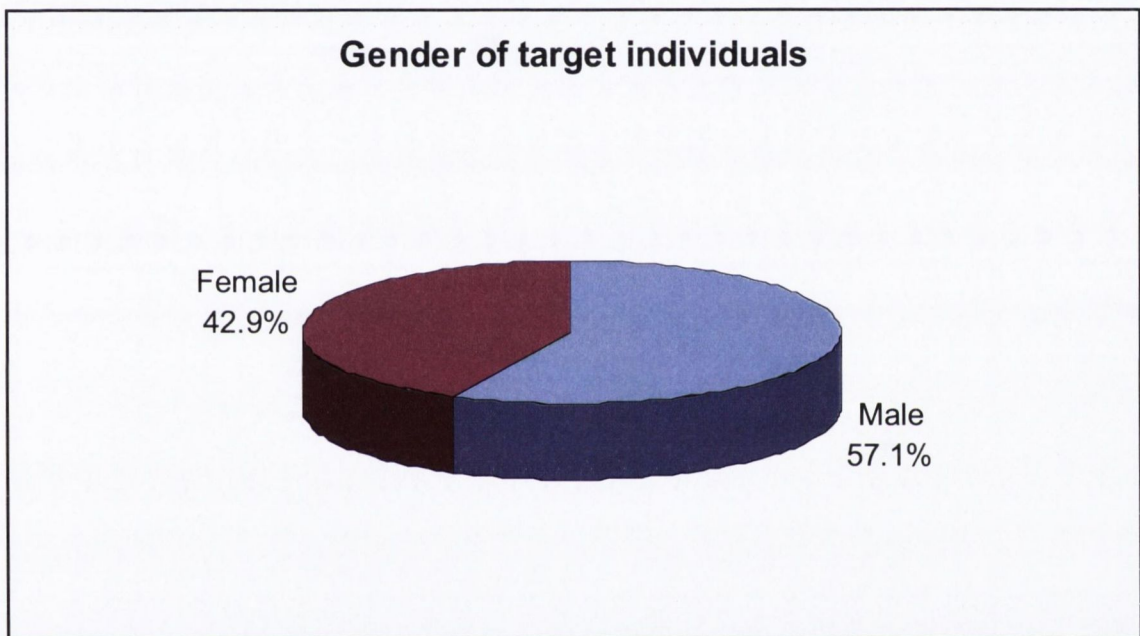


Figure 1

The age profile of the sample is shown below in table 2 and figure 2.

**Table 2: Age profile of sample:**

30-39 yrs =	109 =	27.7%
40-49 yrs =	112 =	28.4%
50-59 yrs =	101 =	25.6%
60-69 yrs =	41 =	10.4%
70-79 yrs =	26 =	6.6%
Over 80 yrs =	5 =	1.3%

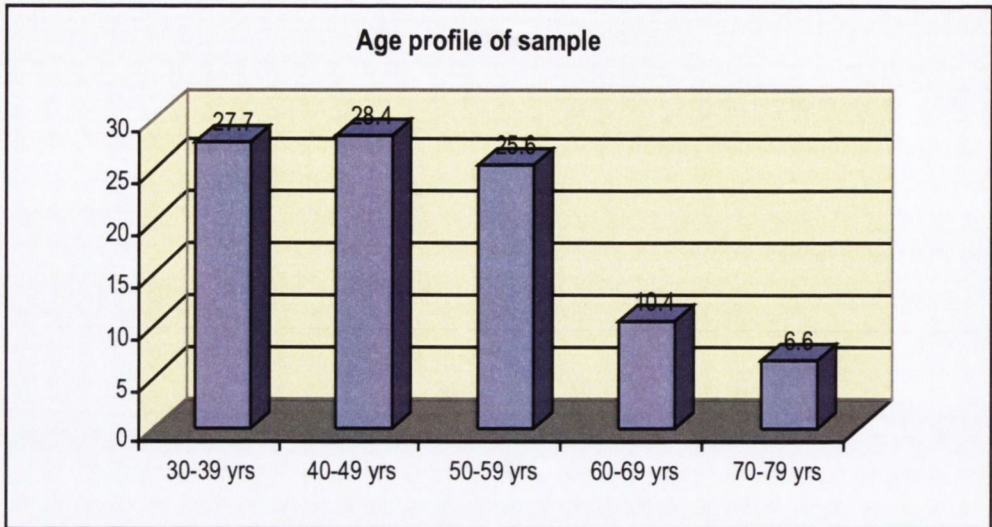


Figure 2

As can be seen above (figure 2), most individuals were aged between 30 and 60 years. However, there is a clear spread of age distribution, and over 16% of the sample were over 60 and under 80 years.

As in the Database in general, most individuals (327 individuals [83%]) had a moderate intellectual disability, 58 (14.7%), severe intellectual disability and nine (2.3%), profound intellectual disability.

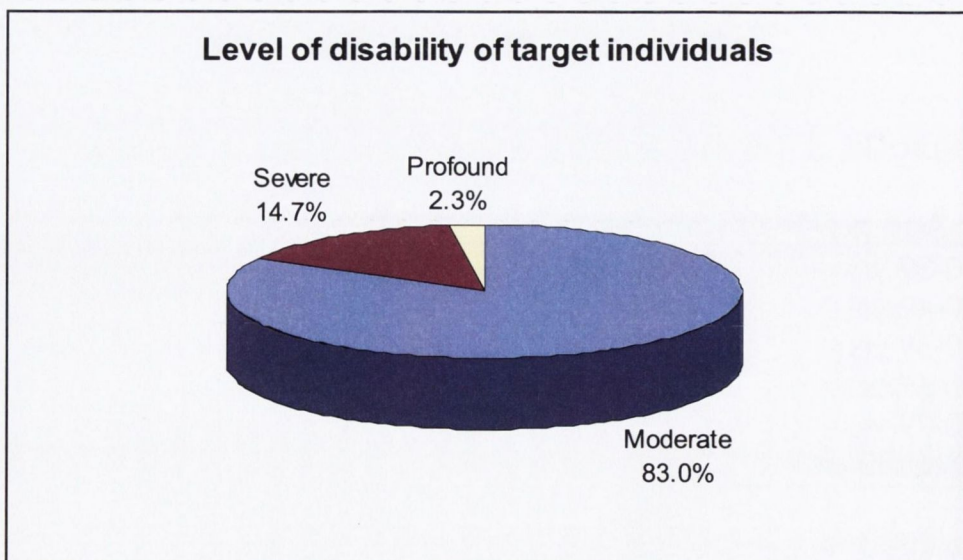


Figure 3

Turning now to the residential status of the sample, as reported on the Database, as expected, most individuals lived with one or both of their parents. 100 individuals (25.4%) were living with both parents, 118 (29.9%) living with one parent. 141 (35.8%) were living with a sibling while 30 (7.6%) were living with another relative. 5 (1.3%) individuals were reported to be living with non-relatives. These results are illustrated in Figure 4.

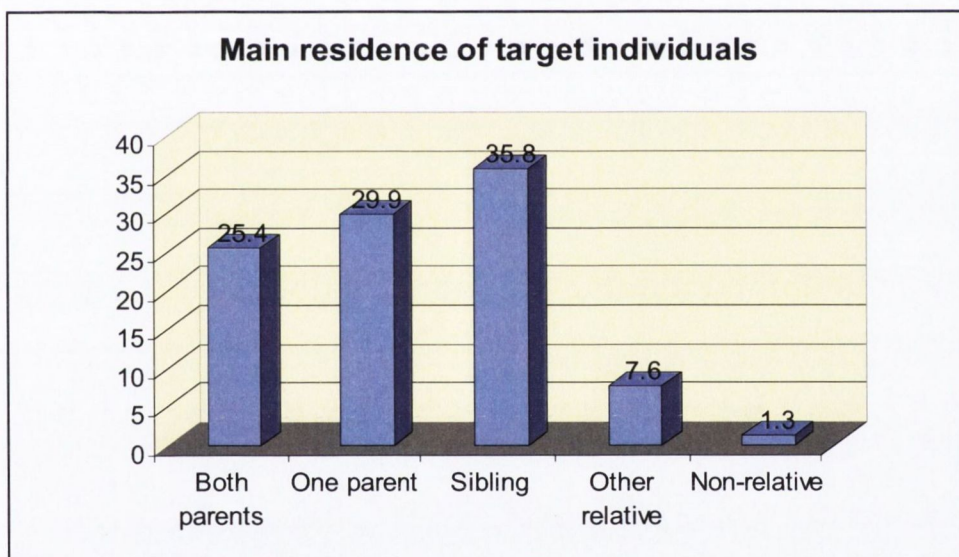


Figure 4

Looking at residential status, using different parameters, gives a better understanding of where these individuals were living, taking into account the age range, the level of disability, and the relationship of primary carer, of the individuals in the sample.

Looking firstly at the age profile, below are frequency and percentage tables of residential settings (Tables 3 & 4).

Clearly, as individuals grow older, they are more likely to live with either one parent or a sibling. Also worth noting is the large number in the sample over the age of 40 years, living at home with one parent (78, (20%) while overall 30% of individuals live with just one parent, while 65% of individuals live with just one parent or sibling. These findings are illustrated in Tables 3 & 4, and figure 5.

**Table 3: Main residence by age profile of sample (frequencies):**

<b>Residence</b>	<b>Age groups</b>					
	30-39 yrs	40-49 yrs	50-59 yrs	60-69 yrs	70-79 yrs	80 yrs plus
Both parents	57	31	8	3	1	0
One parent	40	47	29	1	1	0
Sibling	10	26	53	32	18	2
Other relative	2	6	10	5	4	3
Non-relative	0	2	1	0	2	0
Total	109	112	101	41	26	5

**Table 4: Main residence by age profile of sample (percentages):**

<b>Residence</b>	<b>Age groups</b>					
	30-39 yrs	40-49 yrs	50-59 yrs	60-69 yrs	70-79 yrs	80 yrs plus
Both parents	52.3	27.7	7.8	7.3	3.9	0
One parent	36.7	41.9	28.9	2.4	3.9	0
Sibling	9.2	23.2	52.5	78.1	69.2	40
Other relative	1.8	5.4	9.9	12.2	15.4	60
Non-relative	0	1.8	0.9	0	7.6	0
Total	100	100	100	100	100	100

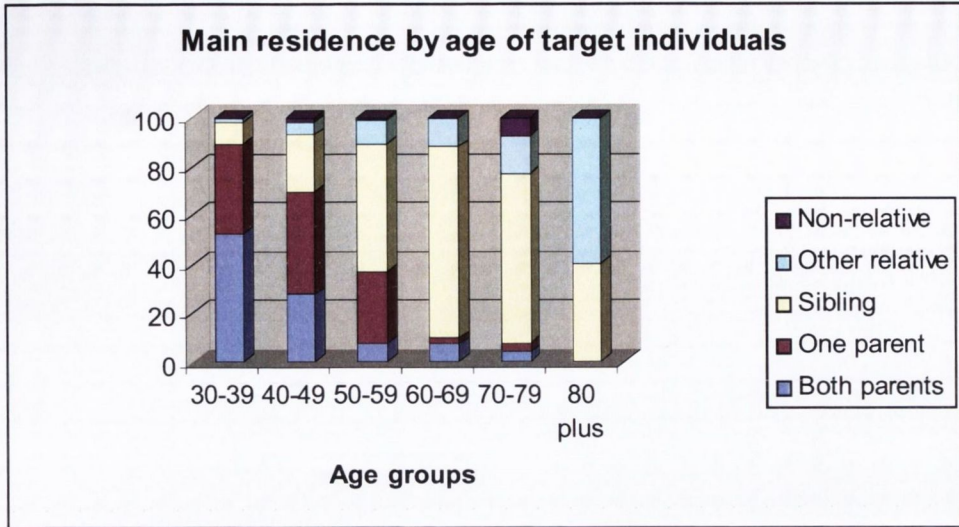


Figure 5

When level of disability is assessed, the majority living at home with both parents have a moderate intellectual disability (79, 24.2%). However, a significant number of individuals with severe and profound intellectual disability live at home with family, including a single parent (63 or 19.3% individuals living with either parents or siblings). (See tables 5 and 6 below)

**Table 5: Main residence by level of disability of sample (frequencies):**

Residence	Level of disability		
	Moderate	Severe	Profound
Both parents	79	19	2
One parent	102	14	2
Sibling	115	22	4
Other relative	26	3	1
Non-relative	5	0	0
Total	327	58	9

**Table 6: Main residence by level of disability of target individuals (percentages):**

<b>Residence</b>	<b>Level of disability</b>		
	Moderate	Severe	Profound
Both parents	24.2	32.8	22.2
One parent	31.2	24.1	22.2
Sibling	35.2	37.9	44.5
Other relative	7.9	5.2	11.1
Non-relative	1.5	0	0
Total	327	58	9

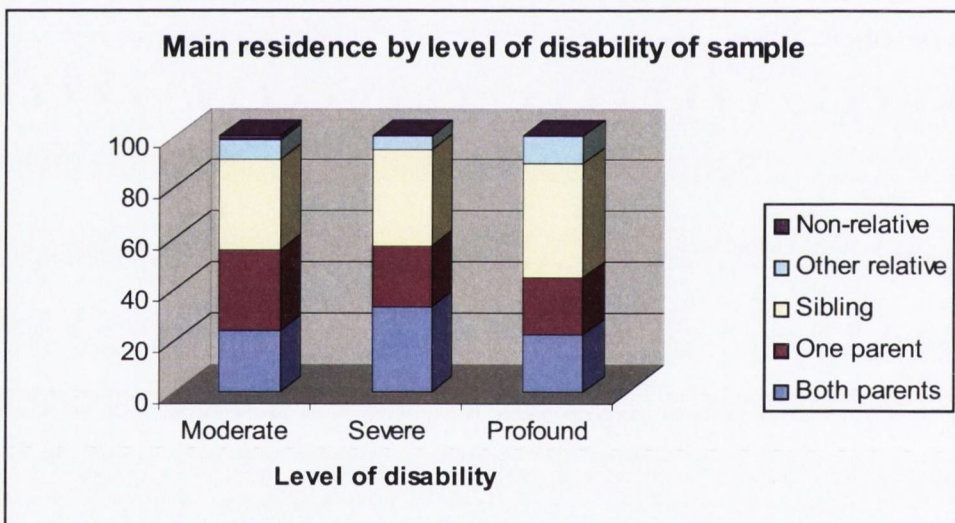


Figure 6

Figure six above illustrates the fact that the individuals in the sample were found to live in broadly similar settings, irrespective of their level of intellectual disability.

## Results from N.I.D.D. for the year 1996

Looking at the same sample from the 1996 database, the sample was larger at 527 (n=527). This represented 8.3% of the entire group as described by the database, that were 30 years and over (total was 7217).

With regard to the progression of this sample into services over time, the individuals identified in 1996 were followed to 2001. Of the sample from 1996, a total of 260 (66%) of these individuals were still outside services in 2001, with 134 (44%) new cases present on the 2001 database. In other words, 66% of the sample as described on the 2001 database, have been present on the database since 1996, and are still outside services, indicating that the sample is a relatively stagnant sample, with little evidence of active engagement in services.

### **4.7 Conclusions: Part 1**

As can be seen by the above analysis, those individuals with intellectual disability, who are over the age of 30 years, and are listed on the N.I.D.D. as outside services (either on a waiting list, or deemed as not needing services), represent 7.5% of all of those with a similar level of intellectual disability, living outside the Eastern region. Two thirds of this group have been awaiting or outside services for at least five

years. 20% of the sample are over 40 years and are living with only one parent, illustrating the residential vulnerability of this group. Should this precarious residential setting break down, these individuals have no experience of accessing services. Therefore, if other members of the family are not in a position to provide ongoing residential care, these individuals will have to be placed in emergency respite residential services. Therefore not only will the individual have to deal with the loss of a parent, but also the loss of the family home, community, and may end up living with many different people in a respite residential setting. It is not surprising that many individuals experience serious behavioural and mental health difficulties under these circumstances.



## **4.8 Part 2: A Study of the assessment and support practices of service providers.**

### **4.9 Background**

The above study has exposed the magnitude, demographic profile and current residential circumstances of those people as described on the N.I.D.D., who are either awaiting services, or are described as having 'no current service requirements'. This group remains very vulnerable, should their residential placement break down suddenly. For those people who are awaiting services, it is probably fair to say that service providers are familiar with their needs, are likely to have had a multi-disciplinary assessment, and are awaiting the most appropriate services based on need. Of the service group who are described as having no service needs ('no current service requirement'), it is unclear what type of assessment has been carried out. In addition, given the parameters of the sample that were looked at in part one, all of these individuals were over the age of 30 years, were living at home with family, and have an intellectual disability that is either moderate, severe or profound in severity. Therefore it is likely that these individuals definitely have needs- either social, psychological or medical. The question is: what type of assessment procedure was carried out with these individuals to inform the decision that they have no service needs?

This part of the study aims to look at the assessment procedure, as carried out by health board officials, with a sample of those individuals as listed on the N.I.D.D. as having no service needs. This will provide a better understanding of the reliability of this classification, and whether the classification is likely to be a reflection of true clinical need.

#### **4.10 Method**

##### *Sample*

Identification was made of the key-workers of all of those individuals listed on the N.I.D.D., for the year 2003, as having 'no current service requirements', living outside the Eastern region, over the age of 30 years, with a moderate, severe or profound intellectual disability, and listed as living at home with family. This sample was chosen to best represent the most vulnerable individuals that are most likely to experience significant psychological distress should their residential setting break down. In 2003, there were 88 people on the database matching these criteria. This represents 14.8% of all of those individuals described on the Database, outside the Eastern Region, who are understood to have no service requirements. (See Table 1 for level of service provision for year 2001; this table illustrates the categories of service provision as listed on the N.I.D.D., from which the above sample was taken, for data returned for 2003).

## *Materials*

A structured questionnaire was designed for this study, to be completed by the key-worker who returned the annual information on the individual to the N.I.D.D. [See Appendices C, 4.1 for Questionnaire for Key Worker]. The questionnaire contained quantitative multiple-choice and likert-scale questions, as well as more qualitative open-ended questions, to ensure that both patterns of response and unexpected themes were identifiable.

The questions that were set enquired about the assessment process as carried out by the key-worker, seeking information on the nature and frequency of contacts with the individual, the reason for these contacts, who attended the assessment and whether the key-worker agreed with the decision not to access services. The content of the questions were set following informal discussions with public health nurses, who usually do return assessment information on people with intellectual disabilities to the N.I.D.D., and following study of the information contained in part one of this study.

## *Method*

Permission to carry out this study was received from the National Intellectual Disability Database Committee, and the project was coordinated with the assistance of the Health Research Board, who manage the database. The co-operation of the Directors of Disability Services in each of the relevant Health Board regions was sought, and the questionnaires were sent to the key-workers that had returned the information on the sample individuals for the year 2003 (this study was carried out in late 2004). In keeping with the practise of the N.I.D.D., the Personal Identification Numbers (P.I.N.) of the individuals were used at all times, to protect confidentiality. After an appropriate time lapse, the questionnaires were re-sent to the key-workers who had not returned the questionnaires, in order to optimise response rate.

### **4.11 Results**

#### *Response Rates*

Initially, 88 individuals were identified on the database and questionnaires were sent out to their key-workers, and 72 of these returned, giving an 81.8% response rate. However following analysis of

the returned questionnaires, it was discovered that 16 of the surveys related to individuals under the age of 30 years and therefore were not valid participants. Two other participants were in receipt of full-time care in other settings and a third had emigrated. As such, only 69 valid participants were contacted and 53 returned questionnaires, giving an adjusted response rate of 76.8%

#### *Incomplete returns*

Of 53 valid returned, 10 (18.9%) were returned incomplete. Where reasons were given for incomplete data, they included the fact that the key-worker had no contact with the individual ( $n = 4$ ), or for reasons of staff turnover or sick leave ( $n = 3$ ). In two further cases, the key - worker indicated that the individuals in question were well looked after at home, but no other information was given.

Based on the exclusion of invalid cases and incomplete data returned, the final analyses were carried out on 43 cases, which represents a 62.3% response rate.

### *Demographic information*

There were 32 males (74.4%) and 11 females (25.6%). This represents a higher proportion of males when compared to the overall gender distribution as described on the N.I.D.D. (Approx. 60:40;M: F).

40 individuals (93%) had a moderate intellectual disability, while 3 (7%) had a severe intellectual disability.

The mean age was 47.9 (S.D. = 10.7). The youngest was 30.1 years, the oldest was 68.9 years.

### *Key-Workers contact with Target Individuals/Families*

#### *Time: With Individual*

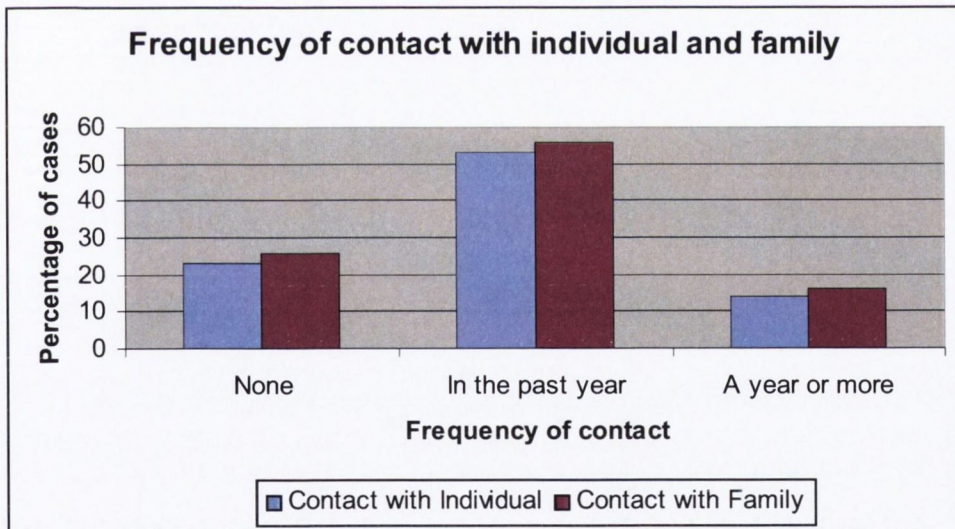
The mean time since the key-workers had any form of contact with the target individual was 5.3 months (S.D. =7.3) [Minimum =0, Maximum =37]. In four cases, no information was given for this question.

In 10 cases (23.3% of responses), there had been no contact with the individual and in 6 cases (14.0%) the last contact was 12 months or more before the time of data collection

*Time: With Family*

The mean time since the key-worker had any contact with the family of the target individual was 5.2 months (S.D. = 8.4) [Minimum = 0, Maximum = 37.0].

In 11 cases (25.6% of responses), there had been no contact with the individual's family, and in 7 cases (16.3%) the last contact was 12 months or more before the time of data collection. Figure six below illustrates much of this information as a bar chart.



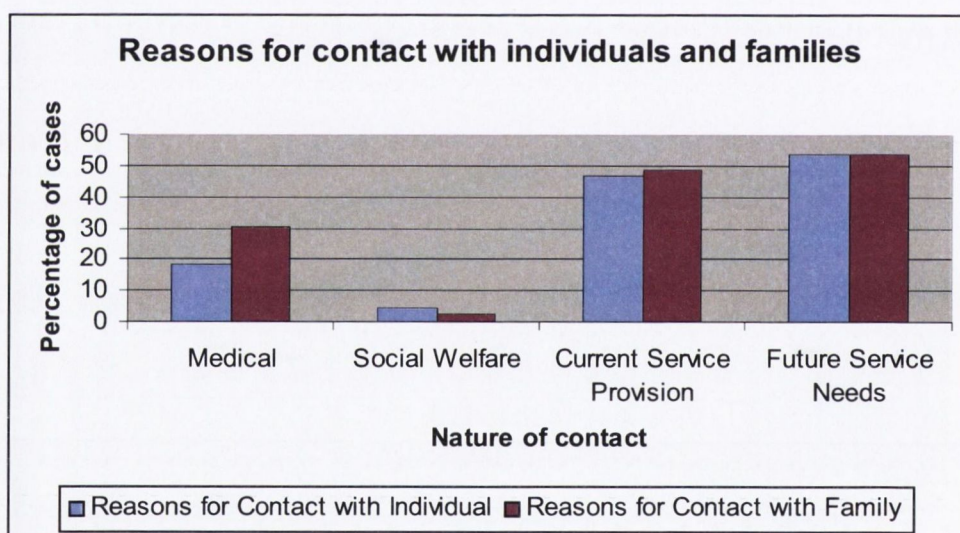
**Figure 6.**

*(2) Reason for Contact*

The key-workers were asked for the main reason for contact, and were given the options: medical reasons, social welfare reasons, to assess current service need, and to assess future service requirements.

The bar chart (figure 7) below illustrates the results of this question (there were some multiple answers).

It can be assumed that four individuals (8.5%) had no contact with key-workers in relation to any of these issues as no response was ticked. In 12 cases (25.5%) there was no contact in relation to the assessment of current or future service provision (i.e. there was either no contact, or the contact was in relation to medical or social welfare issues only).



**Figure 7.**

When asked about the reasons for the most recent contact with target individual (including multiple contacts), six individuals (14.0%) had no contact with services in relation to any of these issues (e.g. no response was ticked). In 14 cases (32.6%), there was no contact in relation to the planning of current or future service provision (e.g. there was either no



contact or if there was, it was in relation to medical or social welfare reasons only).

When asked about the reasons for the most recent contact with the target individual's family (including multiple contacts), one family (2.3%) had no contact with services in relation to any of these issues (e.g. no response was ticked) while in 13 cases (30.2%), there was no contact in relation to the planning of current or future service provision (e.g. there was either no contact or it was in relation to medical issues or social welfare only).

Table 7 below summarises much of this information. The high number of key-workers who returned 'no response' is somewhat surprising, together with the fact that medical and social welfare needs seem to be assessed infrequently. This would suggest that the assessments that do take place, happen yearly at most, and would seem somewhat superficial in nature.

**Table 7. Frequency of, and reasons for, contact with individual or family over the past two years** (including multiple contacts).

Reason for contact	Never	Once a year or more	No response
Medical needs	30.2% (13)	37.2% (16)	32.6% (14)
Social welfare needs	41.9% (18)	2.3% (1)	55.8% (24)
Current service provision	7.0% (3)	76.7% (33)	16.3% (7)
Future service provision	11.6% (5)	67.4% (29)	21% (9)

## Decision Making

When asked about the people who were involved in the decision not to access specialist services for the individual, only 8 (18.6%) of the individuals themselves were involved in the decision-making process. Siblings were involved in the majority of the decisions (23, 53.5%), closely followed by parents (21, 48.8%). Looking across the categories, at least one member of family was involved in the decision-making process in almost all cases (93%,  $n = 40$ ). These results are illustrated in figure 8 below.

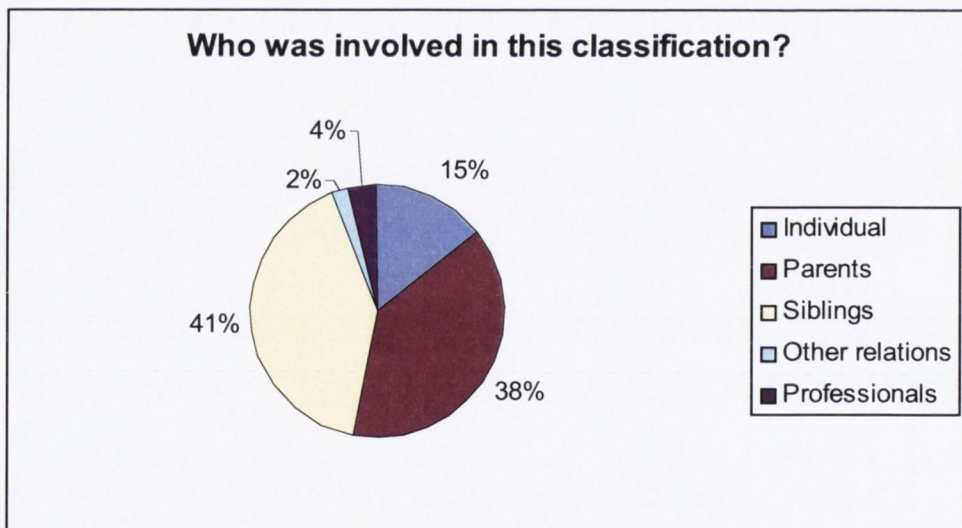


Figure 8

## Key-Workers' Opinion

When the key-workers were asked whether they agreed that the individual had no current service needs, 26 (60% of valid responses)

indicated that they agreed, while 12 individuals said that they disagreed (28%). Participants were asked to support their opinion with free-text comments.

In five cases (12%), the data was missing, but the key-workers gave comments to explain, mainly consisting of comments indicating that they had no opinion.

When key-workers reported that they agreed with the decision, this was based on the view that family were providing a satisfactory level of care, as demonstrated by the following quotes:

- “The person has a hectic day schedule during the day at his sister's house. His sister involves him in the working of the farm as well as going to social activities with family members. The person appears very happy with the current situation”
- “Very supportive family. Four adult sisters care for him and they say that between them they will always look after him”.

For the key-workers who hadn't actually assessed the individuals themselves, the following quotes illustrated the position:

- “This person's mother has indicated that services are not required. I am not personally familiar with this individual.”

- “I am not familiar with this person. However family have expressed opinion that this person does not currently need or will require services”

When key-workers disagreed with the decision to refuse specialist services, they usually commented that the individual would benefit from increased socialization and stimulation. Others commented on the fact that the individuals themselves did not want to access services, or that services were currently not accessible because of rural location.

#### *Perceptions of Involvement in services*

Key-workers were asked if the individual had ever been involved in specialized services, and 30.2% (n = 13) had been in the past. When asked about the reasons for the individual ceasing service use, most responded that the family stopped the individual attending because of exploitation (n=2), too strenuous for the individual (n=3), exploitation (n=2), or reason unknown (n=4). The other reasons included the fact that no suitable services were available or the individual was refusing to attend.

When asked about the reasons given by families for, not availing of services, most families indicated that they felt the individual was happy

to remain at home, or where generic community services were utilized. Others indicated that families were not offered services, or that services were not available. More particular reasons are described by the following quotes:

- “The cultural influences of being Jamaican (mother's ethnicity) is possibly a factor here. Both mother and son enjoy a good relationship and have established a way of coping that excludes services”.
- “Family are elderly. Have coped with out intervention for years. Feel that they can continue to manage independently. Lack of knowledge of services has caused apprehension. Fear of split of family unit”.
- “Mother considers her son as not being appropriate for a day service and thinks that he wouldn't be happy in a service”.
- “No institution able to cope. Public Health Nurse calls to provide equipment”.

When asked about efforts to engage the family to utilise services, 11 key-workers (25.6%) reported that nothing had been done. Most others indicated that families were informed about, and encouraged to attend, services. Of course, where services were not available, the key-

workers reported that they would inform relevant families if the services were created (n=5).

#### **4.12 Summary/Discussion**

The strength of this study lies in the fact that the sample examined was based on returns to the N.I.D.D. It is fair to say that the Database has information on almost all individuals in the State, who have a moderate, severe or profound intellectual disability. Therefore there is a high level of confidence that the sample chosen is highly representative, coming from both rural and urban settings. In addition, the study was able to take advantage of the key-worker system of assessment and data return, ensuring that the information that was returned was as accurate as possible.

It is clear from this study that many individuals on this Database have had inadequate assessments of clinical need, and indeed remain in a very vulnerable clinical position. The study raises concerns about the quality of the data returned on the individuals. Many of the key workers who return the information are Public Health Nurses, who have many other demands on their working time; data collecting for the Database must represent a very small part of their responsibilities. However, their

role is so important in engaging vulnerable people in services, as well as assessing the safety of individuals on an ongoing basis.

In addition, there did not seem to be a structured assessment procedure in place, with reliable recording. There was also evidence of deficits in staff training. All in all, more resources need to be put in place to enhance assessment procedures.

A number of individuals were not personally assessed for service need, yet decisions were made, sometimes not even with family contact, on service needs. Clearly this is an unsatisfactory situation. People with intellectual disabilities frequently do not have the capacity to consent to, or refuse services. Best practice would suggest that maximising information, and involving family in service decisions would, for the most part, avoid people being forced into services to protect their welfare. These situations are *in extremis*, and rare. However, if individuals remain in a socially isolated setting, living with a single parent, with little option for family to take over care after the lone parent dies, services need to be more assertive in linking with families, in order to prevent the emergency residential placements that can lead on to complicated grief reactions, and mental health difficulties. Some of the provisions of the new Disability Act (2005) may provide a framework for improved assessment procedures for all people with intellectual disabilities. Clearly people outside services have most to gain from these assessments.

While people have a right to choose or refuse services, it is very important that families and individuals are given adequate and appropriate information about services. A recent study by Giles (2001) exposed the fact that many elderly carers and adults with intellectual disabilities usually avoid discussing future care planning; however when given the opportunity through the project, carers and adults with intellectual disabilities were usually keen to discuss the future and engage in discussing care options.

There are many other contributing factors as to why families and individuals refuse services. An Irish study on service refusal (O'Callaghan et al., 1992) revealed a number of discriminant variables that were associated with service refusal:

- Family perceptions: many families do not perceive the available services as relevant to the adult that they are looking after; much of this resistance was based on the stigma of accepting services, as well as former institutional setting of services.
- Reality constraints: the services were not convenient, with simple travel difficulties. This point was echoed in a number of responses in this study.
- Less time an individual spent in school was associated with an increased level of service refusal; the earlier a family became involved in services, the less likely the family were to refuse services subsequently.



In many ways a more assertive service is needed, similar to the model of Assertive Outreach, and the earlier Case Management approach that has developed in generic and intellectual disability mental health services (Hassiotis et al., 2003).

### **4.13 Part 3: A qualitative study of understanding and attitudes of service providers and stakeholders.**

#### **4.14 Introduction**

While the above study revealed many shortcomings in the assessment of need process for this service group, it is unclear whether these weaknesses are based at local level, or whether they reflect the realities of policy deficit.

In order to improve our understanding of the broader national context of the way in which this service group is understood, assessed and provided for, the researcher carried out a study using qualitative research methods including individual and group interviews.

#### **4.15 Method**

##### *Participants*

A numbers of key stakeholders in the area of service planning, development and advocacy were targeted in this study, in order to try to ascertain the level of understanding that these stakeholders have for this service group; in addition questions were set to look for any specific

initiatives that are in place to try to engage this group of people in services.

The Directors of Disability Services of six of the former Health Boards were interviewed, in addition to members of senior management of agencies such as the National Federation of Voluntary Bodies, the National Disability Authority, and the National Association of People with an Intellectual Disability in Ireland (N.A.M.H.I.). It was felt that the level of understanding that these agencies have for the characteristics, needs, requirements and vulnerabilities of this service group was representative of the level of understanding in general.

### *Interview Design*

A semi-structured interview was designed for this study [See Appendices C, 4.2 for a copy of the Semi-Structured Interview Schedule]. Questions were set around three main areas of interest: Firstly, questions regarding the classification of this service group were set, including enquiries about the implications of the classification for the individual, the family and the organisation. Secondly, questions were posed regarding the response that the services make to accurately assess the needs of these individuals, and whether a specific policy is in place regarding these assessments. Thirdly, the implications of this service group on future service provision were

explored, and interviewees were asked about other challenging service groups within intellectual disability services. Many of the questions set were based on findings from the questionnaire study as described above.

### *Procedure*

A focus group was convened with four of the Health Board officials, while individual telephone interviews were carried out with the remainder of the participants. The interview procedure was explained and all interviews and the focus group were tape-recorded and a transcript was generated from each session. The same researcher carried out all interviews.

### *Analysis*

Content analysis was used to develop a coding frame for frequency analysis. In order to ensure the reliability of the classification of text, two coders (P.D. & S.G.) worked independently to review the transcripts and identify mutually exclusive categories of themes. Following this, the transcripts were coded by both researchers, and only units of text where consensus was reached were included in the coding frame. Using this coding frame, a frequency analysis of themes and ideas was carried out. [See Appendices C, 4.3 for Coding Frame].

## 4.16 Results

<b>Section 1: Understanding of classification</b>	<b>No. of Comments</b>
Individuals who do not currently need services	1
Individuals whose needs are met by family/careers	4
Individuals whose needs are not met by services available	4
Individuals who will have needs later on	6

Table 8.

### *Understanding of Classification*

The first issue explored, as part of the interviews and focus group was the participants' understanding of the classification of 'no current service requirement' as described on the N.I.D.D. Analysis of the transcripts identified four general themes in the participants' responses (see table 8 above). The first, and least common of these, was that these were individuals who simply did not require specialist intellectual disability services at this time. The fact that the majority of the participants gave a more involved definition highlights that this service group is one that does have a need for services, but not at this point in time. A supporting theme, which was reported by four participants, was that this group had needs which were not being met by the specialist services currently available. This issue is highlighted by a participant who reported, *"these people have requirements, but they are not within the services that we currently have...and they are not down as having future requirements, so they are, in a sense, hidden"*. Another

understanding of the classification, which occurred with the same frequency (n = 4) was that these individuals' needs are currently being met by their family, as illustrated by, *"someone who has a disability, who is obviously being supported by family and at the present time doesn't have a requirement for a service or a support from outside the family"*. However the most frequently described understanding (n = 6) was that this group represented individuals who will have future service needs, for example after the death of a primary carer. Some of the issues relating to this theme are highlighted by one participant who reported, *"people in this category would obviously have potential service requirements-this would be our experience that a very stable situation can become an acute situation quite quickly when something happens the primary carer....Mum either dies or has a serious illness and what was a stable situation then becomes acute-an emergency-and the services have to react"*.

<b><u>Section 2: Implications of this classification</u></b>	No. of comments
<u>Resource implications</u>	4
<u>Implications of accuracy of figures on database</u>	4
<u>Implications of those not on the database</u>	3
<u>Impact of these cases on waiting lists</u>	5
<u>Implications for formal/informal planning</u>	6

Table 9.

*Implications of this classification*

Participants were asked for their thoughts on the implications of this group for both current and future service provision. The overall impression from the interviews was that many of the individuals in this service group frequently end up requiring emergency services, both day and residential service. Three participants expressed concern about individuals that were not on the N.I.D.D. who, from time to time appear needing emergency residential services, adding to the resource implications of the 'no current service requirement' group in question. This led some participants (n=4) to question the accuracy of the Database as demonstrated by one individual saying *"If someone comes to us in an emergency situation, regardless of what the Database says, or doesn't say, we have to provide services"* Four participants clearly described the significant resource implications of this group, evident by this quote: *"most of them do emerge very much as a high support need"*. The whole nature of emergency service provision for this service group was at the centre of five participants' views regarding the impact on the existing waiting lists for residential

services; for example, one participant reported: “For our agencies then, there's queue jumping-they may have their own priorities in terms of who is next in when a respite bed becomes available, when all of a sudden they are landed with this person who they know nothing about as they may have had little or no contact with the service”. All of this led six participants to acknowledge the significant implications that all of this has on formal and informal service planning.

<b><u>Section 3: Implications for the family</u></b>	No. of Comments
<u>Concerns around lack of knowledge of services/database</u>	3
<u>Can cause family difficulty</u>	1
<u>Importance of financial benefits</u>	5
<u>Stigma associated with accessing services</u>	1
<u>Recognition that the family has made a choice</u>	3

Table 10.

### *Implications for the family*

The participants were also asked about the implications of this classification for the family. One of the predominant themes discussed (n=5) at this point related to the financial support families received for caring for their son/daughter/sibling and the extent to which they may rely on this support, with one participant reporting “you would be surprised at the number of families who rely on the allowances etc. that



a person with a disability is entitled to for income support." Some of the participants felt that the reliance on this support might influence a family's decision to involve their son/daughter/sibling in services. Some (n=3) acknowledged the fact that many families were refusing services, had made this choice and that society should respect this; this idea is reflected by the quote: "we don't have the right to interfere, we don't have the right to go in and say-dictate-how people should live their lives". Others wondered whether families were adequately assessed and educated about services (n=3): "many older families have very low expectations of services....they don't know the services are much better than before...we are probably not good at doing that education piece with older families." A single participant described a possible family scenario, where parents and siblings were differing on the need for specialist services for their family member.

<b><u>Section 4: Implications for the individual</u></b>	No. of Comments
<u>Issues of advocacy and consent</u>	6
<u>Impact of breakdown of the home placement</u>	5
<u>Issues relating to lack of exposure to services</u>	4
<u>Concern about the safety of home care</u>	3
<u>Appropriateness of the new setting</u>	3
<u>Situation is working for the individual</u>	2

Table 11.

*Implications for the Individual*

Considering the possible implications for the individual remaining outside services, six of the participants raised the complicated issue of

consent and advocacy. Many were concerned that decisions on service refusal were being made by family members on behalf of the potential service user. Regarding consent, the following illustrates a view: *"the presumption is there by the family that the current support that they offer is satisfactory for the individual- but maybe the individual has other expectations.....does the person with the disability have full informed choice?"* Many were aware of the impact on the individual when the family placement breaks down (n=5), especially if the individual has had no exposure to services (n=4): *"if it is a tragic situation involving the death of a mother, there's already enough trauma and now the person with the disability is trying to cope with the trauma and grief, and is now looking at a whole new set of people and a whole new set of circumstances"*. Another participant described the impact on the individual, describing how *"everything changes and [it] can happen over night ... everything they have known ... someone who is going through a massive amount of change very quickly and who may not be able to deal with that."*

Some expressed concern at the appropriateness of the new service setting (n=3) for an individual who's family placement has suddenly broken down: *" but people may end up being put in a private nursing home if there is an emergency-and with the Health Board, they may end up in a psychiatric hospital"*. Others expressed concern at the safety of the home setting (n=3): *" Some families may have an agenda,*

might have reason for saying 'No-our Mary doesn't have any current service requirement', because this may allow an abusive situation to continue".

Of course, there may be few implications for the individual who may be happy in the family setting as observed by two participants: "Some people...don't need anything that comes out of the specialist services"

<b><u>Section 5: Policy relating to this group</u></b>	No. of Comments
<u>Exists at a local level</u>	3
<u>No policy at national level</u>	4
<u>There is a policy at national level</u>	1
<u>Policies are typically informal</u>	3
<u>Reference to the impact of new legislation</u>	3
<u>Issues of financial allocation</u>	4

Table 12.

*Policy relating to this group*

Overall the interviews suggest that there is no clear national policy regarding the assessment and case management of people with significant intellectual disability (n=4), who are not in receipt of specialist services. However of the policies that do exist, the participants described them as informal (n=3) and local (n=3), as illustrated by one individual who said: " We [health board] wouldn't have a policy....well, we have a weak policy, but we would have a practice of regular contact with annual review so people would be

contacted.”, while another participant said regarding a policy of assessment, “it would definitely be local”, and another said, regarding this service group: “ well they are obviously aren't being considered at national level...we are not resourced to provide the contact that is required”.

Three participants felt that some of the provisions of the new Disability Act may provide a framework for the adequate assessment of this group, while four individuals felt that the current system of resource allocation did not lend itself to the assessment and follow-up of people who are not in receipt of services.

<b><u>Section 6: Other challenging groups</u></b>	No. of Comments
<u>Autism</u>	4
<u>Challenging behaviour</u>	4
<u>Older groups, issues of dementia/Alzheimer's</u>	2
<u>ADHD</u>	1
<u>Individuals with a mild disability</u>	4
<b><u>Section 7: Other issues</u></b>	
<u>Benefits of having a database</u>	2
<u>Need for flexibility in resource allocation</u>	3
<u>This group are not homogenous</u>	1
<u>Need to integrate other databases</u>	2

Table 13.

#### *Other areas of concern*

The participants were asked to volunteer their views regarding other service groups that were presenting a challenge to service provision

and development. As expected, autism (n=4), challenging behaviour (n=4), individuals with mild intellectual disability (n=4), dementia (n=2) and A.D.H.D. (n=1) were mentioned.

With regard to other relevant opinions, three participants particularly emphasised the need for a more flexible approach to resource allocation; this would enable service groups who do not fall tidily into a service category of funding, to still receive a service. Two individuals talked about the benefits of having the N.I.D.D., while two other people discussed the benefits of integrating the information held on other databases such as the National Physical and Sensory Disability Database with the N.I.D.D.

#### **4.17 Discussion: Part 3 and overall study**

Part three of this study, using qualitative research methods, clearly enriches the findings of the other two parts. The individuals who took part in this study included six Directors of Disability Services of the former Health Boards (there were seven Health Boards, as well as the Eastern Regional Health Authority; data from the Eastern Region was excluded from this study); these senior managers were responsible for the disability services in the areas from which the sample was taken in parts one and two of this study. Therefore, the opinions gathered in the course of the interviews were directly referring to the sample of this study. The other participants represented the views of voluntary service

providers, (The National Federation of Voluntary Bodies), the main national family and carer organisation (N.A.M.H.I.), as well as the state agency for disability policy development and research (the National Disability Authority).

It should be noted that while these are the views of a small group, Sim's (1998) principle of theoretical generalisability argues that "the data gained from a particular study provides theoretical insights which possess a sufficient degree of generality or universality, to allow their projection to other contexts or situations, which are comparable to that of the original study.

In general, the participants views and understanding of this service group reflected much of what was evident from part two of this study. The participants were well aware that many of these individuals have future service needs, that often present suddenly, usually following the death of the primary carer. Participants were also aware of the serious impact a sudden breakdown in family residential care could have on the individual, including potential mental health difficulties.

Much of the discussion was taken up with the difficulties in providing resources to this group, based on the current system of resource allocation; resources are provided to individuals if they are in receipt of day or residential services: otherwise, no funds are available to provide

anything other than an annual assessment. As was evident in part two of this study, in many cases the annual assessment didn't take place. Another consequence of the poor assessment and follow up of this service group was the effect a sudden breakdown in residential care can have on other individuals who are known to the services, and are on the waiting list. The emergency placement of individuals from the study sample has the effect of taking resources and possible residential placements from those on the waiting list. Therefore neither service group receives an appropriate service.

The observation that some families may refuse services as a way of protecting welfare payments has serious implications for the welfare of the individual. Of course, this study in no way represents the views of families. However, in order for any progress to be made to introduce services to individuals in these circumstances, the system of payments of disability benefits would have to be changed. While participants pointed out this phenomenon, there was no suggestion that any efforts were being made to remedy this situation.

The need for families and individuals to be educated about the need for contact with services was articulated. Indeed the issue of families making decisions for individuals and the difficulties with consent to services was also understood. This was very much in keeping with the observation from part two of this study which showed that in many

cases, the decision to refuse services was often made without any contact with the individual, or in some cases, their family. Clearly the rights of the individual, and the family, to be educated about the benefits of accessing services are not being addressed.

Regarding a policy on assessing and managing these individuals, it was clear that there was a huge deficit: in keeping with findings in part two, assessment practises and follow up seems very ad hoc. From the interviews, there was no evidence of any plans to advance a policy of practise. Of course the provisions of the new Disability Act, 2005 may remedy this situation, a point made by a number of respondents. Indeed the findings of this study may be very beneficial to the authorities in the practical enactment of the Disability Act, in providing background information and factual evidence of assessment and service deficits. The provision from the Act, of a mandatory assessment of need for all people with disabilities, including intellectual disabilities, will clearly provide a framework for the adequate assessment of vulnerable individuals and their families. For service refusers, the potential mental health difficulties for individuals whose family residential settings suddenly break down, can be explained, with a view to avoiding potential complicated grief problems for individuals. In this way, individuals, and their families, can make an informed decision to either accept or refuse services. At the same time, service providers can make a proper assessment of whether the welfare of the



individual with intellectual disabilities is being properly catered for by families.

# Chapter 5

Conclusions: Main Findings-Future Directions

This thesis has been made up of three distinct research studies and a literature review. Each study looked at a different research question in the broad area of bereavement in people with intellectual disabilities. Each chapter has ended with a detailed discussion of the findings and implications of the study, and these will not be replicated here. Instead the main contributions that this thesis has offered to the understanding of bereavement will be outlined.

Chapter 1 described a comprehensive literature review of the behavioural changes that have been described in people with intellectual disabilities, following a bereavement. Only one control-based study was found and described. The literature was found to offer little understanding of the difference between so called "normal" grief symptoms, and the more clinically disabling complicated grief symptoms in this population. This, of course, means that our understanding of how this group of people experience grief is very limited, and possible symptoms of complicated grief may be missed, or misattributed to environmental, medical, psychiatric or other factors.

With this in mind, chapter 2 outlined a control-based study of complicated grief symptoms in a population of individuals who had experienced a parent bereavement up to two years prior to the study. This study

involved the adaptation and validation of a complicated grief scale, and showed that people with intellectual disabilities commonly experience complicated grief symptoms, following the death of a parent. This study showed that separation distress type symptoms occurred much more frequently than traumatic grief symptoms. Further work is needed to refine the relevant symptoms of complicated grief in this population, with a view to informing the debate on including complicated grief as a distinct diagnosis. A positive correlation was found between those individuals who were very involved in bereavement rituals after the death and the development of complicated grief symptoms and, more so, separation distress symptoms. This is a surprising finding, which goes against the common practice of encouraging as much ritual involvement as possible, with a view to clearly illustrating the finality of death to the individual. It may well be that sudden exposure to all forms of bereavement ritual, without previous exposure or contextual understanding, may precipitate complicated grief symptoms for these individuals. This finding may have implications in the way in which carers and clinicians support bereaved individuals.

This study highlights the need to research the symptoms of complicated grief from a number of different perspectives:

*a. Risk Factors*

This study showed some relationships between the experience of bereavement rituals, and the subsequent development of symptoms. The study design did not expose any relationship between the type of relationship that the bereaved individual had with the parent before the death, the other life events that took place close to the time of the death, and the development of symptoms, the characteristics of the actual death (i.e. sudden, gradual etc.). A more detailed study, involving direct interviews with bereaved individuals is needed to explore these probable relationships. This will inform services on how to best prevent mental health difficulties after a bereavement, by being aware of the risk factors, and putting measures in place to best avoid them.

*b. Clinical course and outcome*

As in the general population, it is unclear how long symptoms of complicated grief are relevant for the individual. Indeed, it is likely that bereavement related depressive illness may also co-exist in some individuals with complicated grief symptoms. The incidence of co-morbid psychiatric illness and its influence on outcome needs to be looked at.

*c. Response to assessment and treatment*

Clearly the response to treatment for any condition is so dependent on the detail and rigour of the assessment. As the treatment of choice for complicated grief is based on psychotherapeutic methods, the need to distinguish these symptoms from other similar clinical presentations is very important, especially considering the impact of the intellectual disability on the presentation of the symptoms.

*d. Death Education*

As people with intellectual disabilities have more varied and enriched lives, their involvement in bereavement rituals seems more and more accepted practice (as illustrated in chapter 3). However, if these rituals are experienced without an understanding of the death, involvement in rituals may become counterproductive. The relationship between an individual's understanding of death, prior experience of bereavement rituals, and the subsequent experience of bereavement needs to be researched. The author is involved in a study looking at the delivery of a bereavement and death education programme, for individuals, staff and families. It is envisaged that this research will develop into a study looking at the effects that this training has on the experience of bereavement, the development of

complicated grief symptoms and the effect the training has on an individual's understanding of the concept of death.

Chapter 3 illustrated a mixed method study examining service and organizational approaches in supporting bereaved people with intellectual disabilities. Little formal training or policies on supporting individuals were found. This policy gap is a worrying finding in light of the cultural and societal changes affecting services in Ireland. The advent of a performance culture with the need for clinical governance and quality assurance necessitates services to formalise their guidelines on bereavement and grief. This is needed to ensure equity of service and quality outcomes while, at the same time, maintaining flexibility and respecting the individual needs of bereaved clients.

In addition a comparison study was carried out looking at staff knowledge and understanding of the grieving process; the findings were compared to a carer group working in the United Kingdom. Cultural differences in the experience and knowledge of carers were found, indicating the importance of local research to best inform the design of training packages.

Chapter 4 used the National Intellectual Disability Database to access information on a proposed vulnerable population, at risk of developing

complicated grief symptoms. The assessment of need procedure as carried out by the statutory agencies, with responsibility for service provision, was examined. Deficits in the process of assessing and attracting individuals to specialist services were uncovered. In many cases, individuals were not personally seen or assessed, yet decisions on their service needs were made. A study, using qualitative methods, of key personnel in the planning and provision of services for people with intellectual disabilities was also carried out. Regarding a policy on assessing and managing these individuals, it was clear that there was a huge deficit: assessment practises and follow up were presented as very *ad hoc*. From the interviews, there was no evidence of any plans to advance a policy of practise. Of course the provisions of the new Disability Act, 2005 may remedy this situation. Indeed the findings of this study may be helpful to the authorities in the practical enactment of the Disability Act, in providing background information and factual evidence of assessment and service deficits. The provision from the Act, of a mandatory assessment of need for all people with disabilities, including intellectual disabilities, will clearly provide a framework for the adequate assessment of vulnerable individuals and their families.



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# Appendices

# Appendices A

Appendices from Chapter 2



## Appendix 2.1: Bereavement History Questionnaire (Adapted)

### Bereavement History Questionnaire

(Adapted from Bereavement Questionnaire, Hollins S. & Esterhuyzen A. (1997). Bereavement and Grief in Adults with learning disabilities. British Journal of Psychiatry, 174, 67-74.)

Date of Completion..... Code.....

Questionnaire completed by.....

(to be filled out by key worker/carer well known to client)

---

(1) How long have you been working with your client?

<1 year      1-2 years      2-3 years      3-4 years      >4 years  
Months..... (Please circle answer)

(2) Relationship of deceased to client: \_\_\_\_\_

(3) Date of death: \_\_\_\_\_

(4) Cause of death if known \_\_\_\_\_

(5) Cremation or burial (Please circle correct answer)

(6) Was cremation or burial attended?

Yes      No      (Please circle)

(7) Has client been to any other burial or cremation before?

Yes      No      (Please circle)

Please give

details: \_\_\_\_\_

---

(8) Please give dates (approx.) of other important bereavements

(parents/siblings) \_\_\_\_\_

---

(9) What was the quality of your client's relationship with the deceased person? (eg. close, dependent, conflicted, ambivalent)

---

(10) Where was your client when the person died? \_\_\_\_\_

(11) Where did the deceased die?

Home                      Hospital                      Other (please specify) \_\_\_\_\_  
(Please circle)

(12) How long was he/she ill? \_\_\_\_\_

(13) Was your client aware of the person's illness?

Yes                      No

(Please circle)

If 'yes', at what point the person's illness was your client informed? \_\_\_\_\_

(14) Was your client involved in caring for the person during their illness?

Yes                      No

(Please circle)

Please give details \_\_\_\_\_

(15) Did your client visit the person whilst in hospital?

Yes                      No

If Yes, how often?

Daily                      Weekly                      Monthly                      Other (please specify) \_\_\_\_\_  
(Please circle)

(16) Was it possible for the person's death to be discussed with your client prior to the death?

Yes                      No                      By whom? \_\_\_\_\_  
(Please circle)

Please give some details \_\_\_\_\_  
\_\_\_\_\_

(17) How was your client told about the death?

(Who broke the news? How was it done? What words were used? Where and when were they told?) \_\_\_\_\_  
\_\_\_\_\_

(18) How did your client initially respond to the news of the death?

---

---

---

(19) Was your client involved in the following grieving rituals?

Saying 'goodbye'	Yes	No
Visiting the body	Yes	No
Preparing for the funeral	Yes	No
Talking about the deceased	Yes	No
Attending the funeral	Yes	No
Attending the 'wake'	Yes	No
Looking at photographs	Yes	No
Attending the 'months mind'	Yes	No

(20) Has your client had any bereavement counselling?

Yes                                  No

Please give  
details \_\_\_\_\_

---

(21) Who does your client live with?

Parent                  Sibling                  Other. Please specify: \_\_\_\_\_

(Please circle)

(22) If different, who did client live with before the bereavement?

Parent                  Sibling                  Other \_\_\_\_\_

(Please circle)

## Appendix 2.2: Bereavement History Questionnaire (Control)

### Bereavement History Questionnaire (Control Version)

(Adapted from Bereavement Questionnaire, Hollins S. & Esterhuyzen A. (1997). Bereavement and Grief in Adults with learning disabilities. *British Journal of Psychiatry*, 174, 67-74.)

Date of Completion.....

Code.....

Questionnaire completed by.....

(to be filled out by key worker/carer well known to client)

.....

(1) How long have you been working with your client?

<1 year

1-2 years

2-3 years

3-4 years

>4 years

Months.....

(Please circle answer)

(2) Please give dates (approx.) of other important bereavements  
(parents/siblings) \_\_\_\_\_  
\_\_\_\_\_

(3) Has your client been to any burial or cremation before?

Yes

No

(Please circle)

Please give

details: \_\_\_\_\_  
\_\_\_\_\_

(4) Has your client ever had any bereavement counselling?

Yes

No

Please give

details \_\_\_\_\_  
\_\_\_\_\_

(5) Who does your client live with?

Parent

Sibling

Other. Please specify: \_\_\_\_\_

(Please circle)

**Appendix 2.3:** Complicated Grief Questionnaire for people with Intellectual Disabilities (Adapted)

**Inventory of Complicated Grief (Modified form for Carers of Bereaved Individuals with Learning Disabilities).**

(Modified version of the Inventory of Complicated Grief for Children)

The following questions refer to difficulties that some clients experience following the death of a loved one.

For the purposes of this questionnaire, your client must have suffered the bereavement of one of their parents within the last 2 years, and you must know them well.

Please tick the answer that best describes how you think your client has been feeling over the last month. Your answers should be based on what your client **says** as well as your own assessment of how you think your client is **feeling**.

Please fill in the first name of the deceased parent of your client in the blanks provided.

.....

**1** How often does your client find it hard to do normal activities because he/she is thinking so much about \_\_\_\_\_

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (Daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**2** How often does your client get upset when thinking about memories of \_\_\_\_\_?

- Never
- Almost never (less than once a month)
- Rarely (Monthly)
- Sometimes (Weekly)
- Often (Daily)
- Always (Several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**3** How often does your client keep thinking that \_\_\_\_\_ will come through the door?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**4** How often does your client seem to miss \_\_\_\_\_ so much that he/she can't tolerate it?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**5** How often does your client wish that \_\_\_\_\_ were here to look after or visit them?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**6** How often does your client want to revisit places where he/she used to go with \_\_\_\_\_?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**7** How often do you think that your client feels guilty if he/she is having a good time since \_\_\_\_\_ died?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**8** How often do you think that your client feels angry about \_\_\_\_\_'s death?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**9** Do you think that your client really believes that \_\_\_\_\_ is dead?

- Not at all
- A little
- Somewhat
- A lot
- Completely
- Not possible to answer
- If so, why? \_\_\_\_\_

**10** Do you think it has been hard for your client to trust people ever since \_\_\_\_\_ died?

- No difficulty trusting others
- A slight sense of difficulty trusting others
- Some sense of difficulty trusting others
- A marked sense of difficulty trusting others
- A strong sense of difficulty trusting others
- Not possible to answer
- If so, why? \_\_\_\_\_

**11** Do you think that your client has found it hard to care or feel close to people ever since \_\_\_\_\_ died?

- No difficulty feeling close to others
- Slight difficulty feeling close to others
- Some difficulty feeling close to others
- Marked difficulty feeling close to others
- Very difficult feeling close to others
- Not possible to answer
- If so, why? \_\_\_\_\_

**12** How often does your client avoid things (pictures, clothes, places, things) that remind him/her of \_\_\_\_\_?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**13** How often does your client report hearing \_\_\_\_\_'s voice, speaking to him/her?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**14** How often does your client describe the feeling of seeing \_\_\_\_\_ in front of him/her?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**15** How often does your client report it difficult for him/her to feel anything?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (Daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**16** Does your client think that it is unfair he/she is still alive, while \_\_\_\_\_ is dead?

- No sense of guilt over surviving the deceased
- A slight sense of guilt
- Some sense
- A marked sense
- A strong sense
- Not possible to answer
- If so, why? \_\_\_\_\_



**17** How often does your client describe feeling envious of others who have NOT lost someone close?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**18** How often do you think that your client feels lonely since \_\_\_\_\_ died?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**19** Do you think that your client feels as safe since \_\_\_\_\_'s death?

- No change in feelings of security
- A slight sense of insecurity
- Some sense of insecurity
- A marked sense of insecurity
- A strong sense of insecurity
- Not possible to answer
- If so, why? \_\_\_\_\_

**20** Do you think that your client's grief or sadness gets in the way of him/her doing things at work/home/ with family or friends?

- No problems in doing things
- A slight problem in doing things
- Some problems in doing things
- Marked problems in doing things
- Completely unable to do things
- Not possible to answer
- If so, why? \_\_\_\_\_

**21** How often does your client report feeling that \_\_\_\_\_'s death was his/her fault?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**22** How often does your client say that he/she is thinking about \_\_\_\_\_, even when he/she wants to think about other things?

Never

Almost never (less than once a month)

Rarely (monthly)

Sometimes (weekly)

Often (daily)

Always (several times a day)

Not possible to answer

If so, why? \_\_\_\_\_

**23** How often does your client avoid talking about \_\_\_\_\_, because it is too painful?

Never

Almost never (less than once a month)

Rarely (monthly)

Sometimes (weekly)

Often (daily)

Always (several times a day)

Not possible to answer

If so, why? \_\_\_\_\_

---

*Thank you for completing this questionnaire!*

## Appendix 2.4: Complicated Grief Questionnaire (Control)

### Inventory of Complicated Grief (Control Version)

The following questions relate to symptoms and feelings that some people with learning disabilities experience from time to time.

The questions asked relate to symptoms/feelings that your client may experience when separated/apart from their parent/s, friends, brothers or sisters for any significant period of time (more than a month.)

Please tick the answer that best describes how you think your client has been feeling as a result of the separation. Your answers should be based on what your client **says** as well as your own assessment of how you think your client is **feeling**.

The blanks refer to the name of the person that your client is separated from.

.....

1 How often does your client find it hard to do normal activities because he/she is thinking so much about \_\_\_\_\_ ?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (Daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

2 How often does your client get upset when thinking about \_\_\_\_\_ ?

- Never
- Almost never (less than once a month)
- Rarely (Monthly)
- Sometimes (Weekly)
- Often (Daily)
- Always (Several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**3** How often does your client keep thinking that \_\_\_\_\_ will come through the door?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**4** How often does your client seem to miss \_\_\_\_\_ so much that he/she can't tolerate it?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**5** How often does your client wish that \_\_\_\_\_ were here to look after or visit them?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**6** How often does your client want to revisit places where he/she usually goes with \_\_\_\_\_?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**7** How often do you think that your client feels guilty if he/she is having a good time since \_\_\_\_\_ went away?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**8** How often do you think that your client feels angry about \_\_\_\_\_ going away?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**9** Do you think that your client really believes that \_\_\_\_\_ is away?

- Not at all
- A little
- Somewhat
- A lot
- Completely
- Not possible to answer
- If so, why? \_\_\_\_\_

**10** Do you think it has been hard for your client to trust people ever since \_\_\_\_\_ went away?

- No difficulty trusting others
- A slight sense of difficulty trusting others
- Some sense of difficulty trusting others
- A marked sense of difficulty trusting others
- A strong sense of difficulty trusting others
- Not possible to answer
- If so, why? \_\_\_\_\_

**11** Do you think that your client has found it hard to care or feel close to people ever since \_\_\_\_\_ went away?

- No difficulty feeling close to others
- Slight difficulty feeling close to others
- Some difficulty feeling close to others
- Marked difficulty feeling close to others
- Very difficult feeling close to others
- Not possible to answer
- If so, why? \_\_\_\_\_

**12** How often does your client avoid things (pictures, clothes, places, things) that remind him/her of \_\_\_\_\_?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**13** How often does your client report hearing \_\_\_\_\_'s voice, speaking to him/her, even though he/she is away?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**14** How often does your client describe the feeling of seeing \_\_\_\_\_ in front of him/her, even though he/she is away?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**15** How often does your client report it difficult for him/her to feel anything?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (Daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**16** Does your client think that it is unfair he/she is still here, while \_\_\_\_\_ is away?

- No sense of guilt of being here
- A slight sense of guilt
- Some sense
- A marked sense
- A strong sense
- Not possible to answer
- If so, why? \_\_\_\_\_

**17** How often does your client describe feeling envious of others who are not separated from someone close?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- plf so, why? \_\_\_\_\_

**18** How often do you think that your client feels lonely since \_\_\_\_\_ went away?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**19** Do you think that your client feels as safe since \_\_\_\_\_ went away?

- No change in feelings of security
- A slight sense of insecurity
- Some sense of insecurity
- A marked sense of insecurity
- A strong sense of insecurity
- Not possible to answer
- If so, why? \_\_\_\_\_

**20** Do you think that your client's sadness or distress at being separated gets in the way of him/her doing things at work/home/ with family or friends?

- No problems in doing things
- A slight problem in doing things
- Some problems in doing things
- Marked problems in doing things
- Completely unable to do things
- Not possible to answer
- If so, why? \_\_\_\_\_

**21** How often does your client report feeling that \_\_\_\_\_ going away was his/her fault?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**22** How often does your client say that he/she is thinking about \_\_\_\_\_, even when he/she wants to think about other things?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

**23** How often does your client avoid talking about \_\_\_\_\_, because it is too painful?

- Never
- Almost never (less than once a month)
- Rarely (monthly)
- Sometimes (weekly)
- Often (daily)
- Always (several times a day)
- Not possible to answer
- If so, why? \_\_\_\_\_

---

*Thank you for completing this questionnaire!*



**Appendix 2.5:** Index of Social Competance (Mc. Conkey & Walsh, 1982)

**INDEX OF SOCIAL COMPETENCE (Walsh & McConkey, 1982)**

Insert in the box the number of the item describing the individual's best level of functioning.

***Additional Handicaps***

VISION

1. Normal vision (include glasses)
2. Partial sight – problems in mobility
3. Blind for all practical purposes

1

HEARING

1. Hearing normal (include deafness in one ear)
2. Partial hearing; hearing aid prescribed
3. Profoundly deaf – only residual hearing

2

EPILEPSY

1. No fits – no medication
2. Has or had fits; taking medication to control fits; not real problem at present
3. Has or had fits; taking medication to control fits; recurring problem at present

3

1+2+3

***Communication Skills***

INSTRUCTIONS

1. Can remember to carry out a sequence of instructions e.g. a shopping list or directions to a place
2. Can remember instructions and carry them out later, e.g. a message from work
3. Follows a simple instruction which can be carried out there and then - 'switch on the light'
4. No response when talked to, except to own name

4

COMMUNICATION

1. Speaks well – intelligible to all; uses appropriate language; able to give accurate information
2. Some difficulty in speaking – lack of clarity or fluency (e.g. may tend to stammer), but language appropriate
3. Difficulty in speech – only intelligible to those who know him/her well
4. No speech – relies on gestures if attempting to communicate

5

4+5

## Self-Care Skills

### EATING

1. Feeds self and manage all activities at table with no problem 6
2. Feeds self can manage most activities (e.g. cutting meat) but needs some guidance/help
3. Feeds self competently but needs help in seasoning foods, cutting meat etc.
4. Needs to be fed or if left alone is a messy feeder

### PERSONAL NEEDS

1. Can look after his/her personal needs *completely independently* - cleanliness, toilet, dressing and chooses appropriate clothes 7
2. Generally looks after personal needs but requires checking and reminding
3. Has to be helped to wash, dress etc.
4. Dependent on other persons for all personal needs

### WALKING ABILITY

1. Able to walk, run and climb stairs with no difficulty 8
2. Able to walk fair distances (around ¼ mile) but finds running and climbing stairs difficult
3. Can walk only short distances; tires easily
4. Unable to walk alone

### USE OF HANDS

1. Fully competent use of hands and fingers – can hit nail with hammer, thread needle, use tin-opener 9
2. Manages most day-to-day activities involving hands, doing up buttons, using knife and fork, ties shoelaces
3. Slow and rather clumsy in using hands but manages some day-to-day activities
4. Only capable of very basic hand skills or not at all

### AROUND THE HOUSE

1. Capable of doing most jobs around the house without supervision - makes bed, washes and dries dishes, cleans floor, etc. 10
2. Attempts most jobs but needs supervision and help to complete the job properly
3. Able to do simple repetitive jobs – setting the table, dries dishes
4. Attempts these simple jobs but cannot do them properly
5. Unable to do any household jobs

## PREPARING FOOD

- |  |                                     |
|--|-------------------------------------|
| 1. Can prepare an adequate variety of meals without supervision  | 11                                  |
| 2. Prepares simple hot food without supervision – makes eggs, warm soups                                     | <input type="checkbox"/>            |
| 3. Makes up food which does not require cooking or with which he/she is familiar – cereals, teas, sandwiches | 6+7+8+9+10+11                       |
| 4. With supervision, can prepare simple foods  |                                     |
| 5. Needs all food prepared for him/her   | <input checked="" type="checkbox"/> |

## READING

- |  |                          |
|--|--------------------------|
| 1. Can read and follow a series of written instructions, e.g. directions on a packet of food, recipes, etc.    | 12                       |
| 2. Can read and act appropriately to signs giving directions in shops or in the street                         | <input type="checkbox"/> |
| 3. Recognize own name written down   |                          |
| 4. Recognize and pick out around six different labels on tins and boxes of food, e.g. cereals, washing powders |                          |
| 5. Unable to recognize any writing   |                          |

## WRITING

- |  |                          |
|--|--------------------------|
| 1. Can write short notes, e.g. shopping lists  | 13                       |
| 2. Can write own name and address without help | <input type="checkbox"/> |
| 3. Writes full name without help               |                          |
| 4. Writes name and address from copy           |                          |
| 5. Unable to write                             |                          |

## TIME

- |   |                          |
|---|--------------------------|
| 1. Regularly uses watch or clock to check timing of activities, e.g. when a friend might call         | 14                       |
| 2. Tells time in hours and minutes, with clock or watch   | <input type="checkbox"/> |
| 3. Knows what hour it is by the clock   |                          |
| 4. Shows by behaviour that he/she can anticipate some events of the day, e.g. start of T.V. programme |                          |
| 5. Seems to have no idea of time  |                          |

## MONEY

- |  |                                     |
|--|-------------------------------------|
| 1. Able to use money responsibly – no difficulty in coping with everyday money transactions; giving right amount and checking change | 15                                  |
| 2. Can select the amount of money appropriate to stated price of article   | <input type="checkbox"/>            |
| 3. Estimates roughly what different amounts might buy, e.g. if given 50p has some idea of what he/she could get for that             | 12+13+14+15                         |
| 4. Picks out coins by name, e.g. 50p, 10p etc  |                                     |
| 5. No understanding of money   | <input checked="" type="checkbox"/> |

SUMMARY CHART

Shade the appropriate box on the chart according to the totals for each section of the index

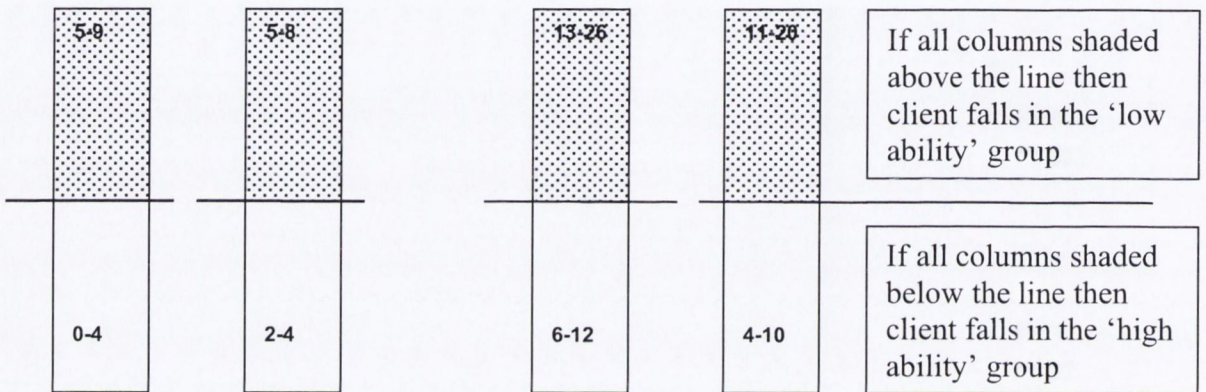
Additional  
Handicaps

Communication  
Skills

Self Care  
Skills

Community  
Skills

SCORES



# Appendices B

Appendices from Chapter 3

**Appendix 3.1:** Bereavement Questionnaire for Organisations

***Guidelines around Bereavement***

***Service Information***

**1. Does your service cater for people with:**

- |                               |     |                          |           |                          |
|-------------------------------|-----|--------------------------|-----------|--------------------------|
| Mild Learning Disability?     | Yes | <input type="checkbox"/> | Sometimes | <input type="checkbox"/> |
| No                            |     | <input type="checkbox"/> |           |                          |
| Moderate Learning Disability? | Yes | <input type="checkbox"/> | Sometimes | <input type="checkbox"/> |
| No                            |     | <input type="checkbox"/> |           |                          |
| Profound Learning Disability? | Yes | <input type="checkbox"/> | Sometimes | <input type="checkbox"/> |
| No                            |     | <input type="checkbox"/> |           |                          |
| Severe Learning Disability?   | Yes | <input type="checkbox"/> | Sometimes | <input type="checkbox"/> |
| No                            |     | <input type="checkbox"/> |           |                          |

**2. What age groups do you work with?**

- |                                |     |                          |           |                          |
|--------------------------------|-----|--------------------------|-----------|--------------------------|
| 0 – 4 years (pre-school age)   | Yes | <input type="checkbox"/> | Sometimes | <input type="checkbox"/> |
| No                             |     | <input type="checkbox"/> |           |                          |
| 5 – 17 years (school age)      | Yes | <input type="checkbox"/> | Sometimes | <input type="checkbox"/> |
| No                             |     | <input type="checkbox"/> |           |                          |
| 18 – 50 years (adult age)      | Yes | <input type="checkbox"/> | Sometimes | <input type="checkbox"/> |
| No                             |     | <input type="checkbox"/> |           |                          |
| Over 50 years of age (old age) | Yes | <input type="checkbox"/> | Sometimes | <input type="checkbox"/> |
| No                             |     | <input type="checkbox"/> |           |                          |

**3. What type of service do you provide?**

- |                        |     |                          |    |                          |
|------------------------|-----|--------------------------|----|--------------------------|
| Day Service            | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| Residential Service    | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| Respite Service        | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| Other (please specify) |     |                          |    |                          |

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**4. Approximately how many service users does your service cater for?**

---

## Guidelines around Bereavement

For the purposes of this survey, 'guidelines' are any form of uniform / service-wide instruction in the area of procedures for dealing with bereavement. Guidelines can refer to a variety of practices, including a written policy or a service-wide code of practice that is not documented but is understood by staff to be the 'way things are done around here'.

**5. In your opinion, how important is it to have guidelines for dealing with bereavement?**

Essential       Important       Unimportant   
 Unnecessary

**6. Are there guidelines in your service on how to respond to the needs of a service user who is bereaved?**

Formal written policy	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Understood code of practice	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Other (please give details)		

\_\_\_\_\_

\_\_\_\_\_

*If 'No' to all please go to Question 8*

**7. Are these guidelines communicated to staff through:**

Induction to the job	Yes <input type="checkbox"/>	No <input type="checkbox"/>
In-service training	Yes <input type="checkbox"/>	No <input type="checkbox"/>
External training	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Informal discussions with a designated support person ( <i>chaplain personnel, social worker, psychologist</i> )	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Informal discussions with other colleagues	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Other (please specify)

\_\_\_\_\_

\_\_\_\_\_

**8. Has your service experienced the following scenarios?**

The death of a service users family member	Yes <input type="checkbox"/>	No <input type="checkbox"/>
The death of a service user	Yes <input type="checkbox"/>	No <input type="checkbox"/>
The death of a staff member	Yes <input type="checkbox"/>	No <input type="checkbox"/>

The next four sections of the questionnaire are concerned with the current practice of your service in the area of bereavement. The three scenarios outlined above i.e. a family death, the death of a service user and the death of a staff member are examined separately in each section.

If you have answered 'No' to one of the scenarios above, you are not required to complete the questions specific to that scenario in the sections below, please leave them blank. If you have answered 'No' to all scenarios above, please proceed to question 15 (Anniversaries).

**Current Practice: Informing the Service User of a Bereavement**

9. In general, who informs the service user of:

a) the death of a family member?

	Yes	Sometimes	No
Staff specifically trained in bereavement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff directly caring for the service user	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____			

b) the death of another service user?

	Yes	Sometimes	No
Staff specifically trained in bereavement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff directly caring for the service user	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____			

c) the death of a staff member?

	Yes	Sometimes	No
Staff specifically trained in bereavement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff directly caring for the service user	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____			

10. Is the family consulted in deciding who should inform the service user of:

a) the death of a family member	Yes	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	No	<input type="checkbox"/>
b) death of another service user	Yes	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	No	<input type="checkbox"/>
c) the death of a staff member	Yes	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	No	<input type="checkbox"/>



**Current Practice: Supports available**

11. Are the following supports available to service users:

*a) in the case of a family bereavement?*

	Yes	Sometimes	No
Is time set aside for staff to support them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is specific staff designated to support them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is there space available for support meetings to take place in privacy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are there specific techniques used to help them express their feelings?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If Sometimes or No – why not?	
Such support not needed	Resources not available
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

*(Please describe any specific techniques used to help them express their feelings)* \_\_\_\_\_

*b) in the case of the death of another service user?*

	Yes	Sometimes	No
Is time set aside for staff to support them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is specific staff designated to support them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is there space available for support meetings to take place in privacy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are there specific techniques used to help them express their feelings?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If Sometimes or No – why not?	
Such support not needed	Resources not available
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

*(Please describe any specific techniques used to help them express their feelings)* \_\_\_\_\_

*c) in the case of the death of a staff member?*

	Yes	Sometimes	No	If Sometimes or No – why not?	
				Such support not needed	Resources not available
Is time set aside for staff to support them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is specific staff designated to support them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is there space available for support meetings to take place in privacy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are there specific techniques used to help them express their feelings?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*(Please describe any specific techniques used to help them express their feelings)* \_\_\_\_\_

**12. Please describe any other ways in which the needs and wishes of the service user are supported.**

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13. Are the following supports available for staff when a service user dies?

	Yes	Sometimes	No
Is time set aside for group discussion of the loss?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is time allocated for access to individual counselling, if required?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other support service (please specify) _____			
_____			
_____			

14. Are the following supports available for staff when a staff member dies?

	Yes	Sometimes	No
Is time set aside for group discussion of the loss?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is time allocated for access to individual counselling, if required?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other support service (please specify) _____			
_____			
_____			

***Current Practice: Funerals***

15. Attendance at the funeral of:

*a) a family member*

	Yes	Sometimes	No
Do service users attend family funerals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does a member of staff accompany the service user to family funerals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is the family consulted in deciding on the attendance of the service user?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the case of the service user not attending the funeral, is this due to:

	Yes	Sometimes	No
Family wishes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of resources for staff to accompany	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____			
_____			

**b) another service user**

**Yes**      **Sometimes**

- |  |                          |                          |
|--|--------------------------|--------------------------|
| Do service users attend the funeral of another service user?               | <input type="checkbox"/> | <input type="checkbox"/> |
| Does a member of staff accompany the service user to these funerals?       | <input type="checkbox"/> | <input type="checkbox"/> |
| Is the family consulted in deciding on the attendance of the service user? | <input type="checkbox"/> | <input type="checkbox"/> |

**In the case of the service user not attending the funeral, is this due to:**

**Yes**      **Sometimes**

- |  |                          |                          |
|--|--------------------------|--------------------------|
| Family wishes                            | <input type="checkbox"/> | <input type="checkbox"/> |
| Lack of resources for staff to accompany | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (please specify)                   |                          |                          |
- 
- 

**c) a staff member**

**Yes**      **Sometimes**

- |  |                          |                          |
|--|--------------------------|--------------------------|
| Do service users attend the funeral of a staff member?                     | <input type="checkbox"/> | <input type="checkbox"/> |
| Does a member of staff accompany the service user to these funerals?       | <input type="checkbox"/> | <input type="checkbox"/> |
| Is the family consulted in deciding on the attendance of the service user? | <input type="checkbox"/> | <input type="checkbox"/> |

**In the case of the service user not attending the funeral, is this due to:**

**Yes**      **Sometimes**

- |  |                          |                          |
|--|--------------------------|--------------------------|
| Family wishes                            | <input type="checkbox"/> | <input type="checkbox"/> |
| Lack of resources for staff to accompany | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (please specify)                   |                          |                          |
- 
- 
- 

***Current Practice: 'Months Mind'***

**16. Attendance at the 'Months Mind' of:**

**a) a family member**

**Yes**      **Sometimes**

- |  |                          |                          |
|--|--------------------------|--------------------------|
| Do service users attend family 'months minds'?                             | <input type="checkbox"/> | <input type="checkbox"/> |
| Does a member of staff accompany service users to family 'months minds'?   | <input type="checkbox"/> | <input type="checkbox"/> |
| Is the family consulted in deciding on the attendance of the service user? | <input type="checkbox"/> | <input type="checkbox"/> |

**In the case of the service user not attending the ‘months mind’, is this due to:**

	Yes	Sometimes	No
Family wishes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of resources for staff to accompany	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)			

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***b) another service user***

	Yes	Sometimes	No
Do service users attend the ‘months minds’ of another service user?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does a member of staff accompany service users to these ‘months minds’?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is the family consulted in deciding on the attendance of the service user?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**In the case of the service user not attending the ‘months mind’, is this due to:**

	Yes	Sometimes	No
Family wishes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of resources for staff to accompany	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)			

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***c) a staff member***

	Yes	Sometimes	No
Do service users attend the ‘months minds’ of a staff member?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does a member of staff accompany service users to these ‘months minds’?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is the family consulted in deciding on the attendance of the service user?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**In the case of the service user not attending the ‘months mind’, is this due to:**

	Yes	Sometimes	No
Family wishes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of resources for staff to accompany	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)			

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***Current Practice: Annual Anniversaries***

**17. Attendance at the annual anniversary of:**

***a) a family member***

	Yes	Sometimes
Does the service user attend the anniversary (e.g. mass or other commemoration)?	<input type="checkbox"/>	<input type="checkbox"/>
Does a member of staff accompany the service user to the anniversary?	<input type="checkbox"/>	<input type="checkbox"/>
Is the family consulted in deciding on the attendance of the service user?	<input type="checkbox"/>	<input type="checkbox"/>

**In the case of the service user not attending the anniversary, is this due to:**

	Yes	Sometimes
Family wishes	<input type="checkbox"/>	<input type="checkbox"/>
Lack of resources for staff to accompany	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)		

---



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***b) another service user***

	Yes	Sometimes
Does the service user attend the anniversary (e.g. mass or other commemoration)?	<input type="checkbox"/>	<input type="checkbox"/>
Does a member of staff accompany the service user to the anniversary?	<input type="checkbox"/>	<input type="checkbox"/>
Is the family consulted in deciding on the attendance of the service user?	<input type="checkbox"/>	<input type="checkbox"/>

**In the case of the service user not attending the anniversary, is this due to:**

	Yes	Sometimes
Family wishes	<input type="checkbox"/>	<input type="checkbox"/>
Lack of resources for staff to accompany	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)		

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**c) a staff member**

	Yes	Sometimes	No
Does the service user attend the anniversary (e.g. mass or other commemoration)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does a member of staff accompany the service user to the anniversary?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is the family consulted in deciding on the attendance of the service user?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**In the case of the service user not attending the anniversary, is this due to:**

	Yes	Sometimes	No
Family wishes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of resources for staff to accompany	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)			

***Training & Resources Available***

**18. Do you encourage your staff to undertake training in the area of bereavement?**

Yes  Yes, but only specific staff  No

**19. With regard to your staff attending training courses in the area of bereavement:**

Has your service provided courses in this area? Yes  No   
Have any of your staff accessed courses in this area independently?  
Yes  No   
Has your service financially supported attendance for courses? Yes  No

**20. Does your staff have access to reference material in the area of bereavement?**

Yes  (e.g. books, journals, reference packs/folders)  
No

If Yes, please indicate the type of material available.

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21. **Would you like your staff to be formally trained in the area of bereavement?**

- Yes     Yes, but only specific staff   
 No

22. **Would a formal training course in this area be beneficial to your service?**

- Of great benefit       Of some benefit       Of little benefit   
 Of no benefit

23. **What would you like to see included in a programme on bereavement?**

- |   |                              |
|---|------------------------------|
| Education on the bereavement process  | Yes <input type="checkbox"/> |
| Education on how people with learning disability present during bereavement | <input type="checkbox"/>     |
| Training in supporting people with learning disabilities during bereavement | <input type="checkbox"/>     |
| Facilitating the family in supporting their learning disabled family member | <input type="checkbox"/>     |

**Suggestions of other topics to be included in a programme on bereavement:**

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**Appendix 3.2: Bereavement Questionnaire for staff working with people with a learning disability (Murray et al., 2001)**

MURRAY ET AL.: CARE STAFF AND THE GRIEVING PROCESS

**Appendix: bereavement questionnaire for staff working with people with a learning disability**

Please answer the following questions in the spaces provided, or by ticking boxes where appropriate.

Place of work:

Age:

Sex:

Religion:

Years of experience working with people with a learning disability:

- 1 Have you ever worked with someone with a learning disability who was bereaved?

Yes  No

- 2 Do you believe in?  
(please tick)

God   
The soul   
Life after death   
Reincarnation   
None of the above

- 3 How long do you think the normal grieving process takes?  
(please tick)

Up to 1 month   
1 to 6 months   
6 months to 1 year   
1 to 2 years   
Over 2 years

- 4 How long is the grieving process for people with a learning disability?  
(please tick)

Shorter   
Same   
Longer

- 5 What are the most common reactions of someone with a learning disability to a bereavement?

6 Which of the following can be helpful to a person with a learning disability who has suffered a bereavement?  
(please tick)

	Always	Sometimes	Never
Being told about the death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Viewing the body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attending the funeral	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Visiting the grave	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour modification	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7 All people with a learning disability are able to grieve adequately if supported.  
(please tick)

True   
False

8 People with a learning disability should be taught about death.  
(please tick)

True   
False

9 Some people with a learning disability do not understand the concept of death.  
(please tick)

True   
False

10 Only people who are sufficiently intellectually able can grieve adequately.  
(please tick)

True   
False

11 How confident do you feel about counselling someone with a learning disability who has experienced a bereavement?  
(please indicate with a cross on the scale that represents your view)

—|—————|  
No confidence Totally confident

- 12 How confident do you feel about teaching people with a learning disability about death?  
(please indicate with a cross on the scale that represents your view)

|-----|  
No confidence Totally confident

- 13 Do you believe that once you have completed appropriate training you should be involved in bereavement counselling?

Yes  No

- 14 Have you any further comments?

# Appendices C

Appendices from Chapter 4

**Appendix 4.1:** Questionnaire for Key-Worker

**PIN:**       

**NAME:**        \_\_\_\_\_

**KEYWORKER NAME:**        \_\_\_\_\_

**PROFILE OF INDIVIDUAL**

1. Gender: M  F       2. Level of intellectual disability: \_\_\_\_\_
3. Actual age: \_\_\_\_\_      4. Health Board: \_\_\_\_\_
5. Community Care Area: \_\_\_\_\_

**CONTACT WITH SERVICES**

6. When was the last time you had contact with the individual named on the cover sheet?  
 Month: \_\_\_\_\_ Year \_\_\_\_\_ [e.g. May 2002]

7. In what capacity did this contact occur [tick all that apply]?
- Medical needs       Social welfare needs   
 Current service needs\*       Future service needs\*

8. When was the last time you had contact with this individual's family members (parent(s), sibling(s), other relative(s))?  
 Month: \_\_\_\_\_ Year \_\_\_\_\_ [e.g. May 2002]

9. In what capacity did this contact occur [tick all that apply]?
- Medical needs       Social welfare needs   
 Current service needs       Future service needs

10. In the past two years, how often have you had contact with this individual and/or their family members in relation to each of the following [for each item please tick the box that applies]?

	Never	Once a year	3-4 times a year	Once a month	More than once a month
Medical needs (e.g. dressings)					
Social Welfare needs (e.g. benefits)					
Current service needs					
Future service needs					

**INVOLVEMENT IN SERVICE PLANNING**

In June 2003 this individual is classified on the National Intellectual Disability Database as not currently being in receipt of specialised health services relating to his/her intellectual disability and not having any immediate requirement for such services.

11. Was this individual ever in receipt of specialised health services in the past?  
 Yes  No

**12.** If yes, briefly outline the services accessed and the reason for termination.

**13.** Who was involved in reaching this classification [tick all that apply]?

- |            |                          |                       |  |
|------------|--------------------------|-----------------------|--|
| Individual | <input type="checkbox"/> | Other relative(s)     | <input type="checkbox"/>                             |
| Parent(s)  | <input type="checkbox"/> | Self                  | <input type="checkbox"/>                             |
| Sibling(s) | <input type="checkbox"/> | Other professional(s) | <input type="checkbox"/> (specify disciplines) _____ |

**14.** In your opinion is this classification appropriate to the individual's needs?

- Yes  No

Please explain:

**15.** In your opinion would this person benefit from access to specialised health services?

- Yes  No

Please explain (indicating services that might be of benefit):



16. What in your opinion are the primary reasons why this family does not avail of services?

17. What in your opinion could be done to engage this family in services?

**IF NO FAMILY MEMBER WAS INVOLVED PLEASE GO TO SECTION HEADED 'NO FAMILY INVOLVEMENT' (Q20-23)**

**Family involvement**

18. If family (individual, parent(s), sibling(s), other relative(s)) were involved, what was the level of agreement with the classification please [for each family member tick the level of agreement that applies]?

	In full agreement	In partial agreement	Not in agreement	Not involved
Individual				
Parent(s)				
Sibling(s)				
Other relative(s)				

19. Briefly outline key areas of disagreement.

**IF THE FAMILY WAS INVOLVED, YOUR INPUT TO THIS QUESTIONNAIRE IS NOW COMPLETE. THANK YOU FOR COMPLETING THE QUESTIONNAIRE AND PLEASE RETURN IT TO YOUR LOCAL HEALTH BOARD IN THE ENVELOPE PROVIDED.**

**No family involvement**

**20.** If family (individual, parent(s), sibling(s), other relative(s)) were not involved in reaching this classification, were efforts made to engage with them in deciding on specialised health service needs?

Yes  No

**21.** If yes, briefly outline the methods used and the outcome.

**22.** In your opinion, are there other methods which should be considered in involving this family in the service planning process in the future?

**23.** What in your opinion are the primary reasons why this family does not engage in service planning?

**YOUR INPUT TO THIS QUESTIONNAIRE IS NOW COMPLETE. THANK YOU FOR COMPLETING THE QUESTIONNAIRE. PLEASE RETURN IT TO YOUR LOCAL HEALTH BOARD IN THE ENVELOPE PROVIDED.**

## **Appendix 4.2: Semi-Structured Interview Schedule**

### **HRB Database Study: Proposed Interview Schedule**

Directors of Health Board Disability Services (n = 6) and key others (n = 3)

#### **General instructions:**

How contact made with interviewee

Nature of study

Reason for contact with this particular interviewee

Proposed length of interview

Inclusion criteria = 30 years plus, moderate/severe/profound disability, living at home

Recording issues = Tape recording

Ethically = Anonymous, all identifying information is removed in final report (reports and academic publications)

Are they happy to continue?

#### **Classification**

What is your understanding of the classification 'No current service requirement'?

How many people within this area classified in this way?

Remind re inclusion criteria

How does this impact on the priority of this group?

What are the implications of this classification for national service provision?

Is it being considered at a national level (clarify HB or DoH)?

What are the implications of this classification for your organisations?

Staff issues

General resources

Residential issues

What are the implications of this classification for the family of the registered individual?

Prompts

What are the implications of this classification for the registered individual?

## Prompts

### **Service response/practices**

Is there a policy/specific practice in place within this organisation to manage contact with these individuals and their families?

If yes: What are the main features of this practice?

Who is responsible?

What is the context for this practice?

What are the main benefits of having such a policy?

What are the main challenges of having such a policy?

What changes would you like to see in this policy/practice?

What would be the resource implications of such a policy?

Staff and financial

Are these issues part of your service plan?

If no: Would your service/organisation benefit from a defined policy/practice?

What would be the main benefits of having such a policy?

What would be the main challenges of having such a policy?

What would be the resource implications of such a policy?

Staff and financial

Are these issues part of your service plan?

### **Future service provision**

What the implications of this classification for the development of future services?

Have the recent changes in resource allocation had an impact on service provision for this group?                      If yes: how?                      If no: Any plans to?

Apart from this group, are there any other classifications on the database that may represent a challenge to service providers in the ID area?

### **Any other comments or questions?**

## **Close and thanks**

## **Appendix 4.3: Coding Frame**

### **Coding frame for HRB Database Analysis**

#### **Section 1: Understanding of Classification**

- A. Individuals who do not currently need services
- B. Individuals whose needs are met by the family/carers
- C. Individuals whose needs are not met by the services available
- D. Individuals who will have needs later on (death of carer)

#### **Section 2: Implications of this classification**

- A. Resource allocation (including emergency placement, no staff for follow-up)
- B. Accuracy of figures
- C. What about others who are not on the database
- D. Impact on waiting list (emergency cases skipping ahead)
- E. Informal future planning around this group

#### **Section 3: Perceptions of policy for this group**

- A. Not at national level
- B. Typically informal
- C. Impact of the new legislation (needs assessment)

#### **Section 4: Implications for the family**

- A. Concern that the family needs supports
- B. Concern around lack of knowledge of services and the database
- C. Can cause family conflict (differing views of need)
- D. Family reluctant to lose financial benefits
- E. Stigma of accessing services (younger vs older parents)

#### **Section 5: Implications for the individual**

- A. Advocacy/Consent (who decides for the individual)
- B. Impact of breakdown of home placement
- C. Lack of exposure to services, no transition
- D. Safety of home care situation

#### **Section 6: Other challenging groups**

- A. Those not receiving appropriate care
- B. Autism
- C. Challenging behaviour
- D. Older groups (dementia/alzheimers)
- E. ADHD
- F. Individuals with mild disability

#### **Section 7: Other issues**

- A. Benefits of having a database
- B. Need for flexibility in resource allocation
- C. Not a homogenous group – need to explore why individuals are classified as such
- D. Need to integrate ID and Physical/Sensory databases