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# **Bereavement and Disability: Implications for the Therapeutic Encounter**

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Thesis submitted in fulfilment of the requirements for  
the degree Doctor of Psychology

City University  
Department of Psychology  
December 2009

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## **Declaration**

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Elizabeth Kliman

## Abstract

This portfolio is presented in four parts: an overview, a research study, a client study and a critical literature review.

**Overview:** The first part introduces the portfolio and the overarching themes of bereavement and of disability. It introduces the researcher and the motivation behind this portfolio.

**Research Study:** This study explores the therapeutic relationship in bereavement counselling for clients with learning disabilities. Specifically, it addresses the impact upon the therapist of the work with the client as well as broader systemic issues. It examines the therapeutic relationship and suggests a six-stage model for effective bereavement counselling for individuals with learning disabilities.

Following a pilot study involving two participants, ten participants were interviewed using a semi-structured interview; seven of these were counsellors and three, counselling psychologists with varying levels of experience and theoretical orientations. Interviews were transcribed and analysed using grounded theory, according to the methodology of Glaser and Strauss (1967,1998). Questions were modified as new themes emerged from the data. A core category of *Challenge* emerged. This spanned a wide range of issues, all of which could be challenging for the client, therapist and others in the system and which interacted with and impacted on each other. Strategies for overcoming these challenges and achieving a feeling of success and 'energy' were explored. Interpretations of these findings are proposed and suggestions for future research are made

**Critical Literature Review:** This focuses on outcome research in order to examine the effectiveness of psychotherapeutic interventions for clients with learning disabilities who have been bereaved. It is argued that, although the outcome research, which is presented, indicates that bereavement counselling can be effective for this client group, there is a need for further rigorous exploration in order to provide an evidence base of the most effective interventions for clients with varying degrees of learning disabilities and experiences of bereavement.

**Client Study:** This study re-examines my work with a client with a physical disability. Sexuality has been viewed similarly in clients with physical and intellectual disabilities reflecting society's double taboo against sexuality and disability. This parallels the rest of the portfolio which examines the double taboo experienced of both learning disabilities and bereavement. I reflect on the anxieties and difficulties this raised for me both professionally, as a trainee, and the challenges this work placed on my personal values, suggesting that disability leads to anxieties in therapists, particularly when combined with another challenge to our worldview.. I describe how I used a Cognitive Behavioural approach to work with a male client who presented with social anxiety and sexual difficulties. The client study describes how I worked with him to overcome the above obstacles to form a successful and effective therapeutic relationship.

## SECTION A: Preface

### 1.1 Overview

The central theme of this portfolio is examining issues in bereavement and disability, which occur for clients, therapists and the therapeutic relationship. This is an interest, which has developed over time and is reflected in many areas of my therapeutic work. Counselling psychologists often see clients who might be considered as different or are stigmatised by the rest of the society in which we live, whether this is due to a disability, mental illness, or anything else that is contrary to societal norms (Hinshaw & Cicchetti, 2000). Thus, topics such as death are also considered threatening. It is argued that society, afraid of becoming damaged, singles out those with illness or disability to project their own insecurities onto. It builds up a taboo against speaking of subjects which may cause emotional discomfort and employs strategies of denial which maintain these (Wilson, 2003, Conboy-Hill, 1992). Thus, some individuals can be marginalised by wider society and it is our job as counselling psychologists to be non-judgemental and offer these individuals the core conditions of unconditional positive regard, empathic understanding and congruence (Rogers, 1952), to accept the individual for who he or she is and form a therapeutic relationship with them.

Working with individuals with learning disabilities for the past twelve years, I became interested in their role in society and the prejudices which society often holds regarding people with disabilities. I found that many individuals were judged based on their behaviour. In many cases, it was not recognised that these individuals had a voice, which needed to be heard, or emotions that needed to be attended to.

I also came to realise that bereavement brings its own taboo in addition to the disability (Oswin, 1991). To my surprise, training in the need to support clients through grief work did little to change the perceptions of staff. 'Challenging behaviour' of a recently bereaved client was just that, she was considered to be 'acting up' to 'get attention' and grief was not considered as a motivation. In fact,

when carrying out grief work with her, I was told it was 'unnecessary'. It was clear that staff working with people with learning disabilities, and I myself, do hold some of the prejudices of the society of which we are a part of, despite having chosen to work with disabled individuals.

Reading *Voices of the Voiceless* (Hawkins, 2002) was inspirational for me as it not only gave people with learning disabilities a voice, but also emphasised their value and respect. Description of the experiences of counsellors and the sense of isolation they felt in their work was something with which I could identify. However, it appeared that the book was not only giving clients a voice, but that the counsellors who worked with them also needed to be heard.

Taking a placement in a learning disability service, I found that, although clients, were referred for a variety of difficulties, often bereavement or loss lay at the core of these and emerged in therapy. I found there was little guidance on how to work as a counsellor with people with learning disabilities who had been bereaved and led to my review of the effectiveness of different approaches to this work. I then became interested in the process of bereavement counselling for people with learning disabilities and wondered whether an understanding of the process, which professionals use, might be useful in order to give those new to the field more confidence. However, it was interesting that it was not the process of bereavement counselling which was pertinent for counsellors but rather a complex pattern of disability, bereavement and society's perceptions of these on both themselves and their clients.

I have found that it is not only in working with people with learning disabilities that societal taboos and expectations become activated. I describe work with a client with physical disabilities. It was evident that sexuality is perceived in a similar manner in the physically and the learning disabled. Thus, a physically disabled man must contend with the double taboo against disability and sexuality, which is similar to the double taboo, which people with learning disabilities face, of their disability and of bereavement. Society projects its deficiencies onto the disabled and therefore denies that they can experience pain, of death or the enjoyment, of sex because to admit these would mean recognising the feelings of those who are

the containers of society's deficiencies and would throw this role into doubt. This feeling may also occur when our own personal values or schemas are challenged, which I reflect upon in the client study.

With the awareness that our culture and society not only contribute to who we are as individuals but to how we interact with others, I would like to introduce the researcher: I am a thirty-year-old British Orthodox Jewish woman from a middle class background. As can be seen above, I have worked in the learning disability field for a long while and feel passionately about this. Writing this thesis and compiling the portfolio has led me to think about my role in society both as an individual and as someone who will shortly be qualified as a psychologist. It has led me to reflect and think back on both my current and previous work and to recognise the development of my self-awareness over the length of the course.

## **1.2 Section B: Research**

As discussed above people with learning disabilities have often been stigmatised by society and, from birth, are often considered a loss to society. Bereavement has the potential to be a great deal more traumatic for individuals with a learning disability who have been shown to have a delayed grasp on the meaning and finality of death in comparison to other adults (Harper & Wandsworth, 1993). Due to societal taboos, the existence of emotions of the learning disabled client and their grief are often denied which can lead to disenfranchised grief (Doka, 2002; Read, 2006). A number of other factors also complicate this as will be discussed. Perhaps due to this stigma, there has been little training for counsellors wishing to work in this field.

The research section examines the process of bereavement counselling for clients who have learning disabilities and the manner in which it impacts upon therapists. This research indicates that people with learning disabilities are more likely to have traumatic experiences that associated with bereavement. Working with these clients is challenging, has a significant impact on therapist and is also influenced by a therapist's own anxieties. However, the therapeutic relationship was important for effective work and therapists found that a sense of hope was often

generated as a result of supporting clients to work through their grief. The research will also examine why this was not necessarily the case for clients with severe learning disabilities.

### **1.3 Section C: Professional Component**

The next item in the portfolio is a client study. In this, I re-examine my work with a client in light of the client's disabilities, the societal taboos against disability and sexuality, which I shared, and the personal impact of the work. I reflect on the anxieties and difficulties this raised for me both professionally, as a trainee in counselling psychology, and the challenges this work placed on my personal values. I describe how I used a Cognitive Behavioural approach to work with a male client with social anxiety who also presented with sexual difficulties. It explores how we worked together in order for the client to overcome his difficulties and the effects on the therapeutic relationship of our perceptions, personal schemata, and values absorbed from the surrounding society.

### **1.4: Section D: Critical Literature Review**

The portfolio concludes with a literature review. This focuses on outcome research of the effectiveness of psychotherapeutic interventions for people with learning disabilities who have been bereaved. There has traditionally been little recognition of the grief of people with learning disabilities and their need for counselling has often gone unacknowledged. Although recently there has been some interest in psychotherapeutic work with people with learning disabilities, there have been few studies on the effectiveness of bereavement interventions for these clients. It will be argued that, although the outcome research that is presented indicates that bereavement counselling can be effective for this client group, there is a need for research to be carried out more rigorously in order to provide an evidence base of the most effective interventions for clients with varying degrees of learning disabilities and experiences of bereavement.

## **1.5 Summary and Conclusion**

I have found the process of conducting research, reviewing the literature and reflecting on my client work to have strengthened my personal and professional development. I hope that by examining the topics of disability, bereavement and sexuality, which are often neglected by others, I might generate an interest in these areas. It is hoped that this may lead to a greater awareness of these issues, improve therapeutic practice, provide support for therapists and identify further training needs, in addition to generating questions for future research. I hope that reading this thesis might lead others to become as inspired as I was when conducting this research.

## **1.6 Terms Used**

Throughout this portfolio, the terms counsellor, therapist, therapy and counselling have been used interchangeably. These terms are not used to suggest the theoretical orientation of practitioners but rather as a descriptive word for the generic field of counselling.

## **SECTION B: Research**

### **Bereavement Counselling for Adults with learning Disabilities: Implications for the Therapist and the Therapeutic Relationship**

# Chapter 1: Literature Review

## 1.1 Introduction

Death and loss are universal experiences, which we must all go through at some point in our lives. However, many people with a learning disability have been denied the right to grieve and their losses have often gone unrecognised or been considered unimportant. It was often believed that these individuals were incapable of understanding death and that they did not have any reaction to grief or loss. On this basis they were often not informed of the death of someone significant and were excluded from rituals surrounding the death. Similarly, their emotional needs surrounding this loss also went unacknowledged, even by the psychological or therapeutic community. They were also viewed as incapable of benefiting from counselling interventions. However, in the last forty years, there has been a growing recognition of these needs, along with attempts to develop counselling interventions for people with learning disabilities. Although a large number of people with learning disabilities appear to have unresolved difficulties around bereavement, provision for bereavement counselling lags behind that of the rest of the population.

This literature review will explore the concept of disability, the effects that disability and other losses have on the learning disabled individual, and their ability to understand death and, ultimately, to grieve. It will then go on to look at the provision of psychotherapy for people with learning disabilities and, more specifically, for grief therapy; its success; and how it might be made more accessible to people with learning disabilities.

## 1.2 Defining Learning Disability

There are numerous terms to describe an individual who has limited intellectual functioning, with some debate about which term would be most appropriate. I have chosen to use the term most favoured in the United Kingdom, learning disabilities. This commonly refers to individuals who have an IQ of less than 70. It can be

subdivided into those who have a moderate learning disability, with an IQ of around 50 or 55 to 70, whilst an IQ below 50 or 55 is considered to be severe or profound learning disability (Emerson, Hatton, Bromley and Caine, 2000).

### **1.3 Models of Disability in Counselling**

The manner in which disability is viewed influences the perception of the disabled individual in the eyes of the wider society in which they live.

This has a bearing on how the disabled person perceives themselves and is treated by others and, in turn, can impact on a counselling relationship, which, in essence, can be considered as a microcosm of societal experience. Two models of disability will be examined here, the medical model which is the most commonly held by society, and a social model from which therapists might attempt to view disability and to practice.

#### **1.3.1 The (bio)medical model of disability**

This model is the most commonly held view of disability, being backed by the authority and stature of the medical profession. According to this model, the disability is considered to lie within the individual. Thus, according to this model, disability is seen as a medical problem or defect in an individual.

*“We think it is so obvious as to be beyond serious dispute that disablement is a characteristic of a defective person, someone who is functionally limited ... someone who is neither whole nor healthy, fit nor flourishing, someone who is biologically inferior or subnormal. The essence of disablement, in this view, is that there are things wrong with people with disabilities”.* (Bickenbach, 1993, p. 61).

This approach runs the risk of dehumanising an individual (Longmore, 1995) and, in turn, influences the perception of the person with a disability who may realise that, despite their own talents and abilities, they belong to an inferior group of people. Thus, medicalising and individualising the disability ignores issues of social justice (Smart & Smart, 2006). The society in which counselling has evolved is one in which people with disabilities are segregated and marginalised (Barnes, 1991). This has influenced the expectations of physically disabled people seeking

counselling who may expect others to hold the belief that they should invest less in a life with a disability (McCarthy, 2003). It is likely that there is a similar effect for people with learning disabilities, yet there is little research on this (Szivos & Griffiths 1990).

### **1.3.2 The social model of disability**

The social model of disability was developed in the UK in the 1970s and was a reaction against the medical model. It differentiated between social and political, and bodily aspects of disability. According to this model, it is not an objective disability, which disables an individual, but rather society itself that disables individuals from functioning as equal members of a society organised and constructed by and for non-disabled people. It views the disabled as having experienced exclusion and prejudice. The social model of disability seeks to remove barriers in society, such as attitudes, institutions, language and culture, and the philosophy and delivery of support services, which 'disable' individuals, aiming to increase the independence and choice of the disabled. It seeks to change the views of disability in society so that people are no longer discriminated against but, rather, are accepted by society (Oliver, 1990, 1996). As opposed to a medical model which often leads to feelings of guilt and shame for the individual's perceived deficiency, the social model of disability "*engenders self-confidence and pride*" (Swain, Griffiths & Heyman, 2003). According to this model, a disabling society would be responsible for increased psychological problems or distress amongst the disabled. Research suggests that many counsellors of people with a physical disability believed that, if taken out of this disabling environment, an individual's need for counselling would be greatly reduced (Oliver, 1995).

Schneider (2006) describes that, with the rise of the disability rights movement, the focus on interventions for disability has now moved from solving the problem of disability that lies within individuals to environmental interventions. Thus, changes to the environment, will result in differences to the experience of disability for the individual. The International Classification of Functioning, Disability and Health, published by the World Health Organisation (2001) thus defines disability as the interaction between the factors internal to individual (sex, age, education, skill

level, coping style, personality) and those environmental factors external to the individual. This is known as a biopsychosocial model of disability. Thus, disability is now seen not as an unchanging aspect of an individual, but rather, as complex and constantly changing with the environment. The environment consists of everything that makes up the world external to the individual, that is, attitudes of society to disability; the physical world, such as accessibility, assistive technology and the level of distractions and the social environment and its organisation, e.g. policies, societal norms and services. The disabilities movement has focuses on the development of a greater understanding of how people become oppressed and barriers which prevent full participation and equality in society.

A social model of disability can be seen in action on a society wide scale in the South Africa. The constitution, which was written after the abolition of apartheid, in 1996 defines disability very clearly and stresses the importance of eliminating discrimination based on disability. It aims to create an accessible society, which enables the fullest participation by all citizens, in all aspects of life. Schwartz and Schneider (2006) mention that one of the main features of this way of thinking is that there are no clear cut off points between the disabled and non-disabled, rather

*“disability is a fluid and changing category, and what causes disability is the interaction between the person and the environment” (p.234-5).*

To this end, a governmental department was formed which mainstreams and integrates disability issues within government and society (Matsebula, Schneider & Watermeyer, 2006). South Africa has an Integrated National Disability Strategy (1997) which views disability as a human rights issue emphasising the attitudinal and physical barriers presented by society, which prevent disabled people from participating in society. In fact, a report written by The South African Human Rights Commission (2000) stated that prejudice was the greatest disability faced by disabled individuals.

According to the social model, it is apparent that people with learning disabilities are affected by society’s perception of their role within society . Unlike in South Africa, the government in the United Kingdom has yet to adopt the social model as

core to its belief system. Although disability rights are important, many lack understanding of the disabling influence of society itself.

Many members of society would be expected to share a biased, medicalised view of the disabled individual. This might, in turn, influence the therapeutic relationship between the able-bodied counsellor and the disabled client.

#### **1.4 Learning Disabilities and Society in the United Kingdom – a brief overview**

Prior to the 1950s, it was accepted that people with learning disabilities would fare better living in institutions. This was as much to protect the members of the public as it was for the individuals' own benefit, and was based on principles of the eugenics movement. This was reflected in the terms used to describe individuals with learning disabilities such as “mental deficiency” and “mental sub-normality”. Indeed, legislation, the Mental Deficiency Act, which encouraged their ‘detention’ in such institutions remained in force until 1959.

During the 1960s and 70s the Normalisation movement (Wolfsenberger, 1972) led to growing public recognition for the rights of the learning disabled and resulted in the publication of a government White Paper, *Better Services for the Mentally Handicapped*, in 1971. This recognised a need for individuals with learning disabilities to live “as normal a life” as possible, within the community and marked a move from institutional care to care in the community. However, people with learning disabilities have since faced a number of barriers in accessing services in the community. They often experienced difficulties in accessing the treatment they needed with their needs going unrecognised by health care staff or carers who have little experience of working with people with limited communication. Thus, health outcomes for people with learning disabilities were found to be poorer than the rest of the population (Department of Health 1999).

The recent publication of the government White Paper, *Valuing People* (2001) had an expectation of “*all local agencies providing help to people with learning disabilities*” (p.25). Under this a

*“person with a learning disability who has a mental illness should therefore expect to be able to access services and be treated in the same way as anyone else.” (p.66).*

However, although the White Paper describes guidelines for inclusion of people with learning disabilities in mainstream services for both physical and mental health, it is not clear whether bereavement would fall under either of these categories. It is certainly more likely that if a bereavement is identified an attempt might be made to include that individual in a mainstream service. The question remains if their need for counselling is identified and referred on.

In a report produced by The Tuesday Group (2003), a group of service users with learning disabilities identified a need to receive information about treatments such as counselling and to have access to a counsellor or psychologist, providing the same access to services and treatment as anyone else, *“who have experience and training about people with learning disabilities”* (p.17). Therefore it appears that inclusion is important for people with learning disabilities, provided that the professional is able to understand the client and their needs. Conboy-Hill (1992) advocated that individuals with learning disabilities should have access to ordinary counselling services but acknowledged that counsellors in these services are not *“geared to our clients’ needs”*.

## **1.5 Bereavement - Grieving and Grief Models**

Freud (1915, 1917) was one of the first to introduce the concept of ‘mourning’ to describe the behavioural and emotional reactions to a significant death. Since then, a number of theorists have attempted to define, categorise and describe the experience of grief. As a result there are many terms used to describe the grieving process. The terms used here will be defined as follows: bereavement is the state of having experienced a loss (Rando, 1995) whilst grief is the reaction to it.

Grief is actually a complex series of responses which goes well beyond the emotional realm (Rando, 1993), into the cognitive, social, affective, behavioural (Rando, 1995, Worden, 2002) and spiritual spheres (Cook & Dworkin, 1992). Mourning refers to the active processes of coping with bereavement and grief

(Rando, 1995). Although there appears to be a consensus that mourning involves some kind of integration of the loss experience (Corr, Nabe & Corr, 2000; DeSpelder & Strickland, 2002; Rando, 1995), the exact nature of both the processes involved, and the optimal outcome of this integration, are areas of considerable controversy (e.g., Wortman & Silver, 2001).

A number of factors impact on the manner in which bereavement affects an individual. These include personality traits, cultural background, and developmental level of the bereaved, as well as the nature of the relationship with the deceased, mode of death, availability of social support, and previous and concurrent stressors (DeSpelder & Strickland, 2002; Corr et al., 2000; Worden, 2002).

Rando (1993) has suggested that the expression of grief (i.e. the involuntary and passive reaction to bereavement) is not sufficient "*to come to successful accommodation of a loss*" (p. 219). Thus, encouraging the expression of grief is important but is often insufficient to enable moving on from, and coping with, the grief; counsellors must also guide clients through the active process of mourning (Servaty-Seib, 2004).

Mourning has been conceptualised as either a number of stages or tasks which must be completed in order for successful grieving, or, more recently, as an interactive ongoing process. There are numerous models each with their own strengths and limitations (e.g. Kubler-Ross, 1970; Parkes, 1972; Bowlby, 1980; Raphael, 1983). It is not possible to review all of these here, therefore three popular models will be discussed below.

Worden (1996, 2002) conceptualised the process of mourning into four tasks which must be achieved: to accept the reality of the loss, to work through the pain of grief, to adjust to an environment in which the deceased is missing, and to emotionally relocate the deceased and move on with life. Worden's work was an important development in the understanding of the process of coping adaptively with bereavement as each task is clearly defined in an action-oriented manner (Stroebe and Schut, 2001). Rando (1993, 1995) similarly identified six "R"

processes of mourning: i. recognize the loss, ii. react to the separation, iii. recollect and re-experience the deceased and the relationship, iv. relinquish the old attachments to the deceased and the old assumptive world, v. readjust to move adaptively into the new world without forgetting the old, and vi. reinvest. The proponents of these models have argued that they are not to be viewed in a linear fashion; it is possible that these elements can and do exist simultaneously and are revisited over time (Worden, 2002; Rando, 1995). According to these models, grief is seen as having an end point when these tasks had been achieved.

One of the more recent theories of grieving has recognised that difficulties with bereavement commonly does not just involve one stressor, but rather stressors are multiple and diverse. Therefore the dual process model of coping (Stroebe & Schut, 1999, 2001) is a stressor-specific model of coping with bereavement. Stroebe and Schut classified these stressors into two types: loss oriented versus restoration oriented. The model suggests that successful oscillation between these two types of coping processes is essential for adaptive coping. This enabled the dilemma of the mourning process to be expressed: the need to move on with life versus the desire to remain connected to the deceased (DeSpelder & Strickland, 2002). This also recognises the fact that grief is an ongoing process which each individual goes through in their own time. In successful grieving, the past might often still remain important to the individual but the way they relate to it might change (Silverman, 1986). Complicated grief, either chronic or inhibited, can be explained by an absence of either restorative or loss-oriented coping (Stroebe & Schut, 1999).

### **1.5.1 Models of Attachment and loss**

Attachment theory suggests that human infants are biologically predisposed to bond with primary caregivers. These attachment relationships occur throughout life with other people who become emotionally important. Even in adulthood, people will experience distress when separated from the attachment figure unexpectedly (Bowlby, 1969; Shaver & Tancredy, 2001). The attachment relationship which an infant has with its caregivers influences the way in which he or she forms, maintains and breaks future relationships (Bowlby, 1969; Stroebe, 2002).

Attachment styles with the caregiver in infancy are paralleled in the grief reactions of an individual, and some styles of interaction might lead to increased vulnerability for difficulties in grieving (Fraley & Shaver, 1999; Parkes, 2001; Shaver & Tancredy, 2001). According to an attachment perspective (Bowlby, 1980), therefore, recovery would necessitate the maintenance of a secure attachment bond with the deceased whilst recognising that they are no longer there to provide physical comfort and care (Fraley & Shaver, 1999). People with learning disabilities often have complexities in the attachment relationship and possibly have an increased likelihood of insecure attachments (Blackman, 2003) which can lead to difficulties in coping with distress (Parkes, 1991) and to complications in their grief reactions.

However, although models are useful for conceptualising grief, it is important to remember that mourning is a multi-faceted and individual process in which the bereaved individual integrates the deceased into their lives, whilst concurrently establishing their role in the present. Often the bond with the deceased is retained as part of a healthy way of coping with the loss (Klass, Silverman & Nickman, 1996).

### **1.5.2 Complicated grieving**

Researchers have struggled to provide a definition for the difference between grief that is overcome in which the individual returns to their previous way of functioning, and that in which the individual appears incapable of returning to the level of emotional functioning prior to the bereavement. Grief has previously been defined as 'pathological' (Freud, 1917; Parkes & Weiss, 1983) or abnormal (Worden, 1982) if it was viewed as particularly strong or was experienced for a long time, or, on the other hand, the individual did not appear to grieve at all or grieved only for a short time. These definitions were based on societal norms (Blackman, 2003; Loconto & Jones-Pruett, 2008).

More recently, difficulties in grieving have been conceptualised as 'complicated' grief or mourning. Although there remains no definition, which is accepted for complicated grief (Prigerson et al., 1995), it is commonly seen to focus on the difficulties an individual, has in coping with past grief in the present time.

Individuals may seem to become 'stuck' and unable to move forwards in the grieving process (Cutcliffe, 2004) and have difficulties in forming new relationships. Complications in grief are often linked to having had a complex relationship with the deceased. This is often relevant to the relationships that people with learning disabilities have and the social environment surrounding them (Blackman, 2003). Complicated grief reactions are often associated with a sense of pervasive hopelessness (Prigerson et al., 1995; Stroebe & Stroebe, 2000).

## **1.6 Attachment and loss in learning disability**

Loss is significant for every individual and lies at the core of many experiences, with its emotional impact disturbing the routines of everyday life (Clements & Henry, 2001; Clements et al., 2003). A person experiences loss from his very first experience of existence in this world, the loss of leaving the womb.

The birth of a child with a learning disability can disturb the family unit and ultimately mean a loss for the family who may grieve for the 'perfect' child they have 'lost' (Bicknell, 1983). Whilst they attempt to understand and make sense of their child's difficulties, they may not be able to contain the emotions and projections of their infant (Hodges, 2003). As a result of these emotions, bonding with the child may be interrupted and may impact on the child which can lead to further guilt on the parents' behalf of being imperfect (Clements, Focht-New & Faulkner, 2004) and which can, again, impact on the child. Winnicott (1965) described how a mother's face mirrors the way she feels towards the infant; through the love which is communicated in this manner, the infant views himself as perfect and loved. The mother of a disabled child may experience varying responses to the child, feelings of love and acceptance on one hand and rejection on the other. Sinason (1992) proposed that if a child is unwanted:

*"it sees a different message in its mother's eyes. There is no gleaming light or twinkle that says you are loveable; there is coldness hurt, shame fear or anger".*

This can be true even in parental relationships which are not rejecting of the learning disabled child: a mother of a child born with Down's Syndrome remarked:

*“I’m not sure that I can hide from her how upset I feel at times, my fears for the future, even though I do really love her.” (Hodges, 2003, p.36).*

Thus the child with a learning disability might pick up a sense of being unwanted, a loss to their family. This is often reinforced through psychological and medical testing and the comments of parents and others of their lack of physical and intellectual abilities. They may begin to integrate these negative beliefs into their sense of self and they may then begin to grieve the loss of their positive sense of self (Clements et al, 2004).

In addition to this, many individuals with learning disabilities live apart from their families, in residential care or supported living projects. This separation from their families is also a loss, which can often be traumatic. Adults with a learning disability may find it difficult to understand the loss of daily contact with their family members and family rituals, which previously governed their lives. For some, this results in a continual grieving process in which they are constantly seeking to be restored to the parental home, particularly if the move occurred without any explanation (Clements et al, 2004).

Individuals with learning disabilities living in the community also form attachments to their key workers and friends. However, they might not be informed of the death of friends (Oswin, 1991). They may experience further loss from the frequent departure of members of staff or key workers to whom they are close and who may leave suddenly, without providing any explanation to the disabled individual. This loss may be even felt on a daily basis between staff shifts as:

*“an important part of the staff’s role is the development of therapeutic relationships”. However, staff members arrive at work without notice and “disappear” routinely, allowing no transition time for the individuals living in the home. With each change in staff comes the change in each staff person’s therapeutic style and expectation of the individuals they work with, creating a sense of anxiety” (Clements et al, 2004, p.805).*

According to attachment theory (Bowlby, 1956), both loss and mourning are experienced from an individual's earliest attachment experiences. The infant must separate and differentiate itself from the caregiver, which involves the development of limits. This allows for the development of the infant's ego and its

own sense of identity or individuation. The individual mourns the loss of the close attachment to the caregiver on the way to developing autonomy. Each loss results in grief, which the individual will react to by entering the mourning process. Shaver & Trancredy (2001) argue that

*“parts of the brain involved in separation-protest behaviour evolved before mammals had the capacity to understand death and its permanence; thus for certain parts of the grief response there is no difference between extended separation and loss.”(p.69).*

Therefore, it would seem that an individual with a learning disability who has a limited concept of death would experience the same reactions as they would to separation anxiety, those of searching and protesting. Mourning can be viewed as a method of psychological repair (Kauffman, 2005). If one is to believe this, the very foundation of the Self is through a process of losses and of mourning. People with learning disabilities pass through the same stages of development as others, yet the process through these might prove to be more complicated. This might be made increasingly so if there is no support for or understanding of the states of mourning through which they inevitably must pass.

### **1.7 Can people with a learning disability grasp the concept of death?**

There is a common misconception that people with learning disabilities are unable to understand the concept of death and, by extension, grief. This belief has often been quite wide ranging, being held by parents, carers or health care providers (Moddia & Chung, 1995; Read, 2001). It is suggested that this is due to being treated like children until well into adulthood. In fact, there has been only a limited amount of research carried out on how people with learning disabilities experience the death of someone close to them (Luchterhand and Murphy, 1998). However, people with learning disabilities are more likely to have complications with their bereavement, which may mean that some intervention is needed from a professional.

Comprehension of the concept of death in thanatology research has been defined by the two key concepts of irreversibility and non-functionality. Kauffman (2005) believes that most people with mild or moderate learning disabilities have the

ability to understand both concepts, moreover, *“the firmness of this grasp does not appear to be less than that of other humans”* (p.17). This has also been shown in research (Harper & Wandsworth, 1993). In cases where it appears that individuals lack this understanding, Kauffman (2005) posits that this is normally due to our miscomprehension of their, limited, use of language. Additionally, denial, which is part of the normal grieving process, may be interpreted as a lack of comprehension of the irreversibility of death. In fact, without some understanding of the concept of irreversibility, the mourning process would not begin at all, as without the realisation of a permanent loss there would be no reason to mourn (Kauffman, 2005). It is this recognition of the loss of a caregiver which can bring about the sadness of bereavement (Shaver & Trancredy, 2001).

It has been shown that children develop an increasingly sophisticated understanding of death as they age, which is consistent with their movement through the different stages of cognitive development as defined by Piaget (Piaget & Annett, 1959). The level of Piagetian cognitive development has also been seen to determine the complexity of the understanding of death in individuals with a learning disability (Bihm & Elliot, 1982; Sternlicht, 1980). Individuals who had reached the concrete stage of operations had a more accurate grasp on death than those who were in the pre-operational stage. Another study found that understanding of death in people with learning disabilities depended on chronological age to a greater extent than intellectual level (Lipe-Goodson & Goebel, 1983). Nevertheless, whatever their level of cognitive ability, individuals with a learning disability are able to recognise and be distressed by loss of a significant individual in their lives (Conboy- Hill, 1992, Harper & Wandsworth, 1993). In fact research suggests that these reactions to bereavement appeared to be the same as in other people (Carder, 1987). Indeed, Sinason (1992) quotes Stokes' (1987) distinction between 'cognitive intelligence' and 'emotional intelligence'. Despite their evident limitations in cognitive abilities, the 'emotional intelligence', that is the ability to understand and perceive the complex nature of emotions, is often preserved in the learning disabled individual. The responses of individuals of varying abilities to losses of friends, relatives, and even pets, have been documented in many case studies (e.g. Kloeppe & Hollins, 1989; Kitching, 1987). However, the difficulty often lies in reactions to loss being displayed

behaviourally, rather than verbally, which is often not interpreted as grief reaction by support staff. It has also been suggested that where people with learning disabilities have delayed reactions to other things, their reaction to loss might also be delayed (Blackman, 2003).

People with learning disabilities have been found to have a limited understanding of death and ageing as part of the natural life-cycle (McEnvoy, 1989). Blackman (2003) suggests that the more dependent a person with learning disabilities is, the slower the development of their 'ego', the part of people which is their sense of self. This might mean it is not capable of the work of mourning and therefore will use "*some mechanism of narcissistic self-protection to circumvent the process*" (Worden, 1996 p.70).

A symbolic interactionist perspective sees individuals as having many 'selves', or the meaning which they attach to every individual and object they interact with. When a significant other dies, an individual needs to act out a different self. However, people with learning disabilities often have difficulty accessing these different selves. They commonly have less social interaction and therefore develop fewer selves to choose from. When one person is lost, the impact on their daily life is much greater as they may find it harder to understand the world, being limited to continuing to act out a self which is not matched by the deceased to act towards or with (Loconto & Jones- Pruett, 2008). Thus, social isolation plays a large part in the grief of the learning disabled.

People with learning disabilities are not only capable of understanding the concept of death, but they have requested a greater knowledge and understanding of death to help them through bereavement. Cresswell and Tuffrey-Wijne (2008) encouraged an individual with a learning disability to express his thoughts about his mother's death from cancer. He was not informed of her illness before she died:

*"I still regret it now. She never told me that she was dying. I don't think she really wanted me to know what was going on. ....she could have told me afterwards. She wanted to protect me. Of course, things like that are upsetting, but it's definitely better to know. It would have made it a lot easier if she had told me, because when she started getting even worse,..... my mum didn't even want me anywhere near her. She used to really be in a bad mood*

*all the time, she use to shout at me, it was horrible. And of course I didn't understand why!"*

Richard West (2006), who has a learning disability was made aware that father was suffering from cancer and that it was likely that he would die, reported:

*"if someone had talked to me it would have been easier to find out what was going on... when he died, the nurse didn't tell me I could see his body. I didn't get to say goodbye to my dad."*

Whilst, for Pat Charlesworth (2006), knowledge of her father's illness and prognosis helped her to deal with his death. Irene Tuffrey -Wijne (2006) argues that people with learning disabilities should receive the same information as others but with the additional aid of pictures or photographs to make this more understandable. People with learning disabilities will commonly have difficulty with standard information leaflets and have limited access to other sources of information such as the internet. Thus, it appears that it is not necessary the case that it is the individual with a learning disability who is incapable of understanding the concept of death, but rather, that it is too painful for the individuals supporting and surrounding the person to discuss death with them or to accept that they can understand.

## **1.8 Recognition of the Grief of the Learning Disabled**

Despite the development of theories of grief and bereavement, and efforts to change the attitudes of society to include people with learning disabilities, until recently the grief of people with learning disabilities had been all but ignored (Oswin, 1991). Tuffrey -Wijne (2002) talks of a 'conspiracy of silence' whereby professionals, family and friends are afraid to talk about illness or death in front of an ill patient with learning disabilities, often using arguments such as 'he won't understand' or 'the truth is too upsetting. Conboy- Hill (1992) remarks that "*it is unclear why this should be*" (p.151) but suggests a possible explanation. Firstly, death is a topic which is taboo. People prefer to avoid talking about it, using euphemisms to refer to it. Terms such as 'gone to sleep' or 'passed on' do nothing to suggest the permanency of death. Learning disability is also often something which is a difficult topic for people to deal with. Psychodynamically, the learning

disabled individual is the 'damaged' and 'disabled' one who becomes, in effect, a representation of feelings of hatred or disability. Family members then project all of these feelings on to the disabled individual. Wider society is also responsible for doing this, projecting onto the population who represent 'disability' all their own feelings of disability, inadequacy, ugliness and insecurity (Hodges, 2003). Thus people with learning disabilities who are bereaved may be facing a 'double taboo' (Oswin, 1991). If society was aware of the psychological and emotional pain which people with a learning disability experience, they would be forced to recognise their own weaknesses. Thus in response to the emotional discomfort caused by these taboos, society has developed strategies of denial. People have developed sophisticated excuses for this denial, such as people with learning disabilities being 'different' and having a lack of comprehension of death or not experiencing, the same range of emotions. This allows society, including parents, carers and other professionals, to ignore the grief of people with learning disabilities.

### **1.9 Typical Grief Reactions of People with Learning Disabilities**

People with learning disabilities often do not grieve in the same manner as others. Their grief regularly differs in intensity or duration (Parkes, 2006; Summers & Witts, 2003). They are frequently seen as experiencing 'complicated grief' and grieving can be delayed. These individuals often have limited communication skills and their grief reactions may either not be recognised at all or misinterpreted. In those with more limited communication abilities, grief is commonly indicated through changes in behaviour or presenting symptoms (Bicknell, 1983; Clements, Focht-New & Faulkner, 2004; Oswin, 1991). It is often difficult and confusing to ascertain the cause of these changes (Focht-New, 1996) and they may not be recognised as grief responses, leading to a failure in identification of complicated grieving and further emotional and developmental difficulties (Clements et al, 2004). People with learning disabilities may also react to grief by 'regressing' through incontinence or a lack of daily hygiene (Clements et al, 2004; Marston & Clark, 1999; Conboy-Hill, 1992). Many people with learning disabilities who display sudden emotional and behavioural difficulties have recently been bereaved of someone close to them and these difficulties can persist for some time after the

bereavement (Emerson, 1977; Bonell-Pascual et al, 1999). The grieving process typically lasts longer for people with learning disabilities than in the rest of the population (Clements et al, 2004; Marston & Clark, 1999). Additionally, an examination of psychotherapeutic groups for people with learning disabilities found that amongst the emotions which were most commonly articulated were those of loss, separation, sadness, abandonment and rejection (Jones & Bonnar 1996), indicating that not only do these individuals experience these emotions, but they may not have the opportunity to express or address these in other settings.

### **1.10 Support following bereavement**

People with learning disabilities typically receive little, misleading or confusing information about death (Oswin, 1991). In addition individuals are often not informed of the death until a substantial time after, precluding attendance at funerals or participation in other family mourning rituals (Oswin, 1991; Deutsch, 1984; Kloppel & Hollins, 1989) and are frequently denied time or privacy to grieve (Oswin, 1991, 1992). These are all ways in which an individual is able to accept what happened to them and begin to grieve (Blackman, 2003). Not being informed of a death immediately can increase disenfranchisement and may result in complicated grief (Read, 2006). Even when the grief is recognised, families and carers are often unsure of how to support the individual (Cathcart, 1995).

People with learning disabilities typically receive little, if any, support with, or direction for, their grief (Crick, 1988). In fact *“for many years, people with a disability have had forgotten deaths, forgotten grief and have often become forgotten people when it comes to meaningful support over the death of a loved one”* (Read, 1997, p.5). They may also have little understanding or experience in working through the emotions typically experienced following bereavement. This may mean that they have a *“delayed and ineffective grieving process”* (Clements, Focht-New & Faulkner, 2004, p.805). By not recognising or tackling this grief, another loss is created, the loss of the grieving process. *“The individual may be left to grieve in the shadow of the loss and in the darkness of the lack of education, support, and guidance.”* (Clements et al, 2004, p.800). It can be compared to that of children whose *“feelings about loss can often become buried”* (Lendrum &

Syme, 1992, p.144), becoming delayed and eventually resulting in complicated patterns of behaviour.

### **1.11 Emotional needs of people with a learning disability**

Although there have been a number of improvements in the physical environment for people with learning disabilities, individuals often remain socially isolated (Dagnan, Look, Ruddick & Jones, 1995). A recent study found that only thirty per cent had a friend who was not either learning disabled, part of their family, or paid to care for them. (Hester Adrian Research Centre, 1999). This means that their lives are often marked by loneliness, isolation, fear and apathy (Sullivan, Vitello & Foster, 1988). Even people with profound learning disabilities experience stressful emotions, although they might not be able to communicate these (Chaney 1996). In fact, rather than needing less intervention as they are less aware of their emotional states, research suggests that the opposite is true. People with learning disabilities suffer a higher amount of emotional difficulties compared to those without disabilities (Arthur, 2003; Ramirez & Kratochwill 1997; Cohen, 1985; Wenz-Gross & Siperstein, 1996).

### **1.12 Complicated Grief and People with learning disabilities**

Bereavement and loss are common features at some point in the lives of most individuals. Individuals with a learning disability, however, may experience a proportionally greater number of losses, or cumulative loss *“beginning with others’ perceptions of their value. Therefore, the death of a loved one may compound the interpretation of and response to the loss, as it is piled atop a lifetime of losses and devaluing experiences”* (Clements et al, 2004, p.805). Individuals may be more likely to lose contact with friends if they or their friends are moved to different homes. People with learning disabilities who live with parents often experience multiple losses in close succession which may necessitate an immediate move into residential care e.g. the loss of their home (Wandsworth & Harper, 1991). Individuals with learning disabilities also tend to have limited social networks (Robertson et al, 2001). A lack of social support has been found to be a risk factor for complications in bereavement and the need for bereavement therapy amongst

the wider population (Stroebe & Schut, 2001). In some cases, bereavement may mean the loss of the main carer whom they relied upon for emotional support and who understood their communication (Kitching, 1997; Hollins and Sireling, 1991).

The death of a parent can be met with ambivalence. Feelings of pain and sadness at the loss are often accompanied by more disturbing feelings of anger at being abandoned or unconsciously wishing for the parent's death, possibly accompanied by guilt over these distasteful wishes. Individuals with learning disabilities are commonly reported to often have feelings of abandonment and rejection at the death of a parent. These are often associated with a relationship characterised by dependency and ambivalence (Kaufman, 1994) and can lead to complications in the grieving. Being raised with non disabled parents in a 'normal' world can lead to a sense of self loss, that is, a loss of self- esteem and self-concept. Parents might cause their child narcissistic injury through their reactions to their disabled child. This can lead to feelings of dehumanisation and shame, which can create a self-concept that is filled with losses, pervading the sense of identity of the individual. Thus, *"the mourning process over the loss of a loved one may be complicated by the vulnerabilities caused to the mentally retarded person's sense of self-worth."* (Kauffman, 1994). Envy and rage may be directed towards the deceased parent who was 'normal' and who, through their very normality, caused these injuries to the self.

Conboy-Hill (1992) suggests that challenging behaviour which occurs subsequent to a loss indicates the distress of the individual in response to a loss they deem to be significant. Like any other individual, the person with a learning disability may simply need their loss to be acknowledged through listening and support, which may be of crucial importance to their ability to adjust to the loss. Therefore it seems reasonable that factors above, such as the lack of social support and the isolation of people with learning disabilities, difficulties in attachments with their parents and compounded losses can contribute to the development of complicated grief. This combination *"makes the mentally handicapped person particularly vulnerable to the uncertainties and insecurities normally associated with the death of a loved one"* (Kloepfel & Hollins, 1989, p.34). This occurs to a greater frequency in people with a learning disability than in the wider community (Hollins & Esterhuzen, 1997;

Bonnel-Pascall et al, 1999). The attachment of the individual to the deceased may also be important. People with learning disabilities may have very different relationships with their parents from the rest of the population. They may have idealised them, perhaps as a result of dependency and helplessness if cared for by them. Alternatively, they may have viewed parents as being rejecting. Thus, there may be a number of complex underlying emotions which clients cannot accept, leading to complications with their grief (Conboy-Hill,1992), leading to a number of factors which complicate the grieving of the learning disabled. The question is whether these emotional needs are recognised and met.

### **1.13 Addressing the Emotional Needs of People with Learning Disabilities**

A focus on the promotion of independent living and responses to challenging behaviour has allowed us to all but neglect the emotional needs of people with learning disabilities (Read, 1997). In fact, their emotional needs are often not recognised by the staff who support them, particularly if they have difficulties in communication. Research showed that staff were unable to recognise behaviours which were linked with sadness and had received no explicit training on the expression and understanding of emotions (Clark, Reed & Sturmey, 1991). It appears that people with learning disabilities living in the community may actually have a more stressful life than people without a disability. A higher rate of neurotic disorder has been found in people with learning disabilities than in the rest of the population (Day, 1985). It was suggested that this was related to experiencing the death of a caregiver.

In fact, some have even gone as far as to say that this client group has been one of the most overlooked for provision of appropriate mental health services and in research into therapeutic techniques. Research has indicated a lack of knowledge (Lindsay et al. 1994) and even neglect of the emotional needs of these individuals (Black, Cullen & Novaco, 1997; Davis, Judd & Hermann, 1997). One would expect psychology to have aimed to identify and meet the emotional requirements of people with learning disabilities, yet this has been surprisingly absent (Hollins &

Evered 1990; Garber 1991; Wagner 1991; Jones & Bonnar, 1996; Wenz-Gross & Siperstein 1996).

### **1.14 Are People with learning disabilities receiving counselling?**

Until recently counselling was not recognised as a useful intervention with this client group, with a focus instead on either medication or behaviour therapy (Crick, 1998; Elliott, 1995). A search of the literature indicated (Gallagher, 2002) a “*remarkable lack of literature on counselling adults with learning difficulties. In books on intellectual disability, there is often no mention of counselling. If there is, it is assumed to be for parents rather than the intellectually disabled person*” (p.206). It was found that counsellors often held the belief that, in order to offer counselling to people with learning disabilities, a counsellor must possess “*special techniques or superhuman skills*”(ibid. p.206). This might be expected to be proportionally greater for bereavement which in itself is a taboo subject.

Historically there has been a lack of resources for bereavement counselling for people with learning disabilities and, in fact, in the provision of psychotherapy and psychoanalysis in general (Sinason, 1992; O’Driscoll, 2000). Work with individuals with a learning disability has been treated with ‘*therapeutic disdain*’ (Arthur, 2003, p.25) and therapists can even be considered to have discriminated against these individuals and to be reluctant to work psychotherapeutically with them (Reiss, Levithan & McNally, 1982).

It is likely that reluctance to engage in this work has its roots in some of the proponents of major psychotherapeutic theories. Many of these believed that therapeutic work with people with learning disabilities was impossible. Freud (1904) stated that analysis could only be used with those who were “educable” whilst Rogers (1951) suggested that therapeutic work should not be done with individuals of limited intellectual ability and Morgan (1950) posited that such work would not be necessary as they do not experience mental conflicts. It has been suggested that psychotherapy was not effective in terms of time or money and, indeed, that research into this area would be a waste of time (Gardner, 1967) and even as late as 1998 it was remarked that there was a lack of research on “*the*

*nature of emotion and response to treatment*” in people with learning disabilities (Lindsay and Olley, 1998, p.250). As a result, the use of direct therapeutic interventions was not considered, rather behavioural work was, and indeed still continues to be, endorsed. This can be seen to apply across the board to all therapeutic orientations; psychodynamic (Bender, 1993), psychoanalytic (Beail, 1998) and cognitive-behavioural psychotherapy (Dagnan & Chadwick, 1997).

The needs for the provision of psychotherapy to people with learning disabilities have been recognised by some (Clements et al, 2004). Psychotherapeutic work with people with learning disabilities was largely pioneered in America in the 1940s but it was not until the late 1970s that psychotherapy was considered with these clients in the UK (Sinason, 1992). Since then some practitioners have tried to draw attention to the importance of psychotherapeutic work with people with learning disabilities (e.g. Gunzberg, 1973; Spensley; 1985; Frankish 1989). Bicknell (1983) argues that this work is particularly necessary for problems in the areas of loss, grieving, mourning, bonding and attachment, which have often been ignored.

#### **1.14.1 Current provision**

Blackman (2003) related that for people with learning disabilities living in the United Kingdom, there are often a number of ‘*barriers*’ (p82) to accessing counselling services, one of which was that counsellors within generic bereavement counselling services or working at G.P. surgeries have a lack of training and experience in, or appropriate supervision for, working with people with learning disabilities. In addition to this, counselling provision at G.P. surgeries is often time-limited to a few sessions, whereas people with learning disabilities may need longer treatment than is funded. Counsellors may be afraid to offer counselling to individuals with a label of ‘learning disability’ although they may have treated clients on a similar ability level who did not have the label (Gallagher, 2002). There are services available from a specialist learning disability team although there are few counsellors working in the field. As Blackman (2003) remarks, referrals to learning disability teams often continue to result in referrals to either psychiatrists or clinical psychologists with a focus on treating challenging behaviours through medication or a brief course of cognitive behaviour therapy. Indeed, professionals

continue to recommend behavioural treatments for people with learning disabilities who have mental health problems (Alford & Locke, 1984; Dorn & Prout, 1993). This, of course, would not address their emotional needs.

It appears that this lack of psychotherapeutic interventions is not confined to the United Kingdom; this is also the consensus of researchers in the United States (Hurley, Pfadt, Tomasulo & Gardner, 1996; Mansell & Sobsey, 2001). In a review of the literature on psychotherapy for people who have learning disabilities in 2000, it was concluded that psychologists should have a greater awareness of the use of psychotherapy to treat people with learning disabilities (Butz, Bowling, & Bliss, 2000). Conboy- Hill suggests that:

*“for therapists already skilled in their own methodology it is a matter of adjustment and the understanding that mental handicap does not translate into ‘inaccessible’, ‘incomprehensible’ or ‘different species’ but boils down to a set of variations on a theme whose major feature is intellectual limitation” (p. 158).*

The government White Paper, Valuing People (2001), urged services to be more inclusive of people with learning disabilities, yet without the requisite experience of counsellors in this field (Blackman,2003) this might be impossible.

### **1.15 The challenges of working psychotherapeutically with people with learning disabilities**

Working in a psychotherapeutic manner with people with learning disabilities presents many challenges. People who have limited communication may find verbally-based talking therapies to be difficult (Strohnmer & Prout, 2004). Counsellors may need to adapt their practice to incorporate non-verbal and creative methods of working with clients with learning disabilities in order to facilitate the exploration of their grief in a way which is meaningful to them.

Due to limitations in their intellectual functioning, clients might find also it difficult to comprehend some of the emotions which bereavement evokes, such as guilt, or cognitive labels such as denial or acceptance (Conboy-Hill, 1992), and have a

limited vocabulary with which to express their emotions. Thus, initial work must be carried out to develop terms to express these. In the therapeutic relationship with people with learning disabilities client and counsellor expectations be very different, particularly as people with learning disabilities are often free of the same social inhibitions as the therapist (Conboy-Hill, 1992) and it is important for a therapist to be open to this. These individuals commonly find it difficult to remain in a therapeutic session for an entire fifty minutes. Conboy-Hill (1992) offers a useful technique to overcome this, labelled 'Quit while You're Winning' in which the therapist assesses when the individual has reached their limit of engaging in the session and then terminates it before the client feels they have had too much.

### **1.16 Effective Counselling for Individuals with learning disabilities**

Therapists must tailor their interventions to be appropriate for the level of linguistic and cognitive development of a client. Most clients with mild or moderate learning disabilities will function at Piaget's concrete stage of operations (Dougherty & Moran, 1983). However the focus of most therapeutic techniques would need the acquisition of formal cognitive operations and these may often require adaptation, with a need to focus on more concrete issues which clients can easily relate to. This may necessitate being more directive in sessions and using more 'activities', rather than just talking, such as role-plays and modelling (Prout & Strohmer, 1995). Additionally, the counsellor is encouraged to be aware of both verbal and non-verbal methods in which the client is communicating and to allow the client to set the pace (Blackman, 2003). They may need to consult with others as to the client's means of communication but general guidelines would be to simplify the language used, supporting it with signs or symbols if necessary, discussing fewer concepts per session or using exaggerated facial expressions or displaying higher levels of affect (Prout & Strohmer, 1995; Blackman, 2003). These serve as ways of adapting therapeutic techniques used with adults. Another option may be to use techniques used with children and adolescents, although it is important to consider the need for normalisation (Wolfsenberger, 1972) and be careful to respect the client's status as an adult and not to treat them in a child like fashion (Prout & Strohmer, 1995).

There are a variety of techniques which can be used as a concrete method of expressing feelings or thoughts. These might include drawing pictures, painting, poetry or stories (Blackman, 2000, 2002; Read 1999), whilst puppets and dolls can aid the recounting of a story or the communication of painful events (Blackman, 2003). Other examples are the creation of family trees, artwork, life story work, photographs, memory books, drama or poetry (O'Hara & Sperlinger, 1977; Read, 1999). These allow self-expression (Rothenberg, 1994; Loconto & Jones-Pruett, 2008) and allow for the grief of people with learning disabilities to be recognised or enfranchised, and facilitate the grieving process (Read, 1999). Books such as *When Dad Died* and *When Mum Died* (Hollins & Sireling, 1989) or *Understanding Death and Dying* (Cathcart, 1994) describe and explain the finality of death and associated rituals as well as common emotional reactions to death in a manner which is easily understood for people with learning disabilities and can be used in counselling to aid understanding about death.

A symbolic-interactionist perspective views these tools as means to develop alternate 'selves' or viewpoints which can aid with recovery from grief (Loconto & Jones-Pruett, 2008).

### **1.17 Efficacy of Psychotherapy for People with Learning Disabilities**

The effectiveness which has been demonstrated from cognitive behavioural therapy with individuals has challenged the notion that people with learning disabilities can only benefit from simple behavioural interventions. However, there remains limited research in this area (Lindsay & Olley 1998).

Since the majority of therapeutic or psychological interventions tailored to people with learning disabilities have been in providing skills training and behavioural modification, little attention has been given to bereavement and loss (Kauffman, 1994). There has been little empiric investigation of the outcomes and effectiveness of bereavement counselling interventions for people with learning disabilities (Stoddart et al, 2002; Summers and Witts, 2003; Read, 1996) with Summers and Witts (2003) calling for more research to be carried out to evaluate different interventions.

Research has indicated the efficacy of loss and bereavement interventions for people with learning disabilities using a number of therapeutic orientations. This has mainly focused on case studies (Summers & Witts, 2003; Elliott, 1995; Kitching, 1987; Gault, 2003). However there have been some research outcome studies for individual therapeutic work (e.g. Dowling, Hubert, White & Hollins, 2006) for group therapeutic work (Stoddart, Burke & Temple, 2002) and death educational and therapeutic groups (Yanok & Beifus, 1993; Read, Papakosta-Harvey & Bower, 2000; Mappin & Hanlon, 2005; Szivos & Griffiths, 1990). Although there were methodological difficulties with many of these studies, they show clear indication that it is possible not only for people with learning disabilities to understand grief but also to benefit from therapeutic work to help them through the grieving process.

It is unlikely that there will ever be enough counsellors to provide support for each individual with learning disabilities who is bereaved. Therefore many professionals offer training and consultation to care staff who support these individuals (Reed, 1997). Research suggests that this intervention facilitates emotional development, improves relationships between staff and service users, reduces problematic behaviours associated with grieving and helps improve quality of life (Arthur, 1999).

### **1.18 Bereavement and the Counselling Relationship in Learning Disabilities**

The challenges inherent in counselling people with learning disabilities combined with the need to constantly adapt ways of working for people with learning disabilities can make the counselling process more difficult for the counsellor (Hawkins, 2002). People with learning disabilities have often been dehumanised; offering grief counselling is one way in which to recognise the person with a learning disability as an individual, a person with needs and emotions, and to connect with them on an often profound level:

*“Relating to another’s grief is profoundly humanising. Recognising clients’ grief and experiencing their loss in the care giving relationship humanises the client, the relationship and the caregiver. With a group such as the mentally retarded, whose humanity is already disenfranchised, mourning their grief opens and nourishes the common human bond”* (Kauffman, 1994, p. 258).

This suggests that there may be an opportunity for a unique therapeutic relationship with this client group following bereavement. Shaver & Trancredy (2001) suggest that people with learning disabilities are more prone to separation anxiety following a loss. Thus, the development of a secure attachment within the therapeutic relationship may be uniquely important in work with people with a learning disability.

### **1.19 The Effect of Bereavement Counselling on the Counsellor**

There is a limited amount of research on the effects of counselling adults with learning disabilities, on the counsellor. Hodges (2003) pointed out the importance of recognising *“the demands of this kind of work”* on the counsellor. Hodges explains that counselling others may lead an individual to consider their own losses, which may be overcome by supervision and personal therapy. Yet there may also be different and greater demands made of the counsellor working with this client group. A focus group of bereavement counsellors working with this client group identified an arduous aspect to the work (Read 2001). Although concrete methods are often used in counselling sessions, these all need to be talked through and may include the need to frequently repeat words and phrases to check understanding and communication. Counsellors must also continuously encourage the client to reflect on personal situations.

There appears to be an absence of literature concerning the manner in which bereavement counselling specifically with this client group might impact on counsellors. However, there is some research on bereavement counselling amongst the wider population. The need for self care amongst bereavement counsellors has been noted. Due to the complex nature of emotions surrounding grief and loss there can be a tendency for the counsellor to take on the moods and feelings of the bereaved; their frustration, anger, guilt, helplessness, sadness and

anxiety which can result in a 'bereavement overload' (Kastenbaum, 1969; Sanders, 1989). If the counsellor feels a need to rescue the bereaved individual, they might be tempted to do the grief work *for* their client which is likely to ultimately be unsuccessful and may leave the counsellor feeling ineffective and overburdened. In addition to this, bereavement work commonly leads to the reawakening of losses which the counsellor has previously experienced (Sanders, 1989). It seems likely that these factors would also impact on bereavement work with people with learning disabilities. In combination with the other challenges that face the therapist in their work with people with learning disabilities it is likely that the work will present some significant challenges for the counsellor.

## **1.20 Motivation for this research**

In the United Kingdom, the provision of psychological and therapeutic services by the National Health Service is increasingly judged on evidence-based practice (Roth & Fonagy, 1996). This evidence is limited for interventions for people with learning disabilities (Beail & Warden, 1996) and perhaps all the more so for bereavement interventions for this population. It is hoped that forming a picture of the practice of, and obstacles to, successful therapy following bereavement will go towards providing some guidance for others entering the field, particularly as they may have received limited training in the area. It would also contribute towards the evidence base, providing clues as to the effectiveness of various possible interventions and providing guidance on effective use of available resources. As Arthur (2003) states, studies into psychotherapeutic treatment of people with learning disabilities

*“are important not just for the evidence they provide about effectiveness, but also because they describe the emotional experiences and difficulties of people with learning disabilities from this different perspective” (p.27).*

The need for research on bereavement in people with learning disabilities is especially evident, as it has been noted that people with learning disabilities suffer a similar or even greater extent of emotional distress when compared to the wider population and therefore can be seen to have the same, if not greater, emotional needs. In addition to this, a number of factors might serve to make grieving more complicated for people with learning disabilities. Learning disability is intrinsically

bound up with the theme of loss, and throughout development this might result in a series of compounded losses of the development of the self, abilities, and milestones. Added to this are possible difficulties in the attachment process, losses of independence, a family home, or care staff. Additionally many people with learning disabilities have little understanding of death or grieving, may be excluded from family death rituals and often receive little, if any, social or other support in the grieving process. The higher incidence of complicated grief in people with learning disabilities is likely to mean that there is a greater need amongst this population for intervention from a professional.

Some differences in process in psychotherapy with the learning disabled have been noted, yet there seems to be an absence of research as to the manner in which bereavement issues might have a significant impact on this. Conboy-Hill (1992) pointed out that counsellors often do not know how to work with individuals with learning disabilities, and there is a need to develop more flexible and adaptable approaches (Read et al, 1999). It has been observed that bereavement counselling interventions have been successful when counsellors received only two days training in working with individuals with a learning disability (Dowling et al, 2006). Beail and McNally (2006) refer to the absence of a clear account of the practice of psychodynamic psychotherapy with people with learning disabilities. This also appears to be lacking from the practice of bereavement counselling in general for adults with learning disabilities, with counsellors reporting a lack of formal guidance for working with this client group (Read, 2001).

Working with loss ultimately has an impact on the therapist. In bereavement work with people with learning disabilities, the compounded losses, together with issues of working with a client with a disability may combine to have a unique impact on the therapist. As Hodges (2003) remarked, counselling provides a space where the individual with a learning disability can talk about and consider together the feelings which bereavement can bring to the fore. She highlights this as a *“necessary and important aspect of work with this client group”* (p.95) yet it is also important to be aware *“of the demands of this kind of work on the counsellor”*. Counselling others may lead an individual to consider their own losses, which may impact on their work. A counsellor’s ability to respond effectively to grief is

dependent on their self-understanding, yet counsellors are often unaware of the extent to which attitudes towards death limit their abilities as therapists to respond to it (Hartley, 1980). There may also be different and greater demands made of the counsellor working with this client group. Counsellors have found a number of difficulties in the process of counselling in general with these clients.

Counsellors may have a unique take on both the process of counselling and the impact it may have on the counsellor. A greater recognition of the experiences of counsellors working with this client group may both lead counsellors to examine their own practice and mean that counsellors in this field feel less isolated in their practice (Hawkins, 2002).

It has been stated that:

*“very little is known about the professional practices of psychologists who serving people with mental retardation”* (Jacobson & Ackerman, 1989, p.33.).

Although there has been a great deal of research in the nearly twenty years since they wrote this, it still holds true that although

*“the professional literature provides extensive examples and demonstrations of specific intervention strategies and recommendations for practice [it is] very general in focus with respect to the actual practices of clinicians”* (Jacobson & Ackerman, 1989, p.33).

It was hoped that this research would allow for the development of a model of therapeutic practice with adults with learning disabilities who have been bereaved. In addition, this study aims to provide an insight into the inner world of people with learning disabilities, following bereavement through the eyes of their partner in the process, the therapist, who is able to witness, interpret and guide their client through the experience. This relationship also inevitably has an impact on the therapist, which has often gone unrecognised for work with this group of clients. In this study, therapists will be given an opportunity to express both their successes and frustrations in this work, to reflect upon its challenges and rewards, which might act as a guideline for counsellors entering the field and may highlight areas of training needed.

### **1.2.1 Research questions**

To Summarise; this study initially set out with a number of aims:

- Are there any factors or features in the process of therapy with clients with learning disabilities, who have been bereaved, which differ from the approach taken for a grief intervention with a client without a learning disability?
- What does the process of successful bereavement counselling for individuals with learning disabilities include and is this process different dependent on the severity of the disability?
- How are resources and aids for therapy used effectively?

As the research progressed; the focus changed as new questions emerged from the data. Participants described the successes and frustrations of bereavement counselling in clients with a learning disability. These questions are detailed below:

- Does this work place any specific demands on therapists? If so, what are these demands and how are they addressed?
- What motivates therapists to enter and remain in this field of work?
- Is further training is necessary to meet therapists and clients needs in this area?

## Chapter 2: Methodology

### 2.1 Introduction: the rationale for adopting a qualitative research paradigm

A qualitative methodology using semi structured interviews was chosen for this study, which explores process in counselling bereaved adults with learning disabilities, the impact of this work on counsellors, and the impact of counsellors own experience on their practice.

Qualitative research can be viewed as '*a process of systematic inquiry into the meanings that people employ to make sense of and guide their actions*' (McLeod, 1999, p.117). A qualitative method enables the participants' views to be heard in all their complexity, and to uncover the meaning they attach to these and to the way in which they perceive and interact with their own reality. McLeod (2003) argued that giving the client 'a voice' allows their experiences and life stories to be documented. This can be viewed as particularly important for this group of counsellors who are working with what is, essentially, a group which is considered socially undesirable and whose needs are often neglected. This would refer to individuals with learning disabilities and is often amplified by another taboo, that of death (Oswin, 1991). In this climate, the counsellor themselves might feel isolated by their peers and looked down upon for working with this group (Hawkins, 2002).

Qualitative research is not a unified activity (Strauss & Corbin, 1998) and, thus there is no single correct qualitative method (Parker, 1998). However the aims of the present research were to develop a rich understanding of the experiences of counsellors, the impact of this on the process of counselling within the session, and details of the particular aspects of process which were considered to be important in the therapy room. By informing the practice of counsellors entering the field and by providing an insight into the experiences of these counsellors, it was hoped that some support might be offered in this, often challenging, field. The challenges can come from a variety of different areas, as will be shown in the analysis, including the clients themselves and their families or carers, as well as

other professionals. Qualitative enquiry is an appropriate tool as participants are seen as individuals who co-create their worlds (Lincoln and Guba, 1985), adding meaning to it through their own actions and interpretations. In fact, participants in this study often had a good idea of aspects of their own practice which were useful to others, and thus this approach could enable them to be co-creators in the research. They were also empowered by gaining the opportunity to have a voice, given that the research was aimed toward benefiting practice in the field.

## **2.2 Choice of Methodology; adopting a grounded theory approach**

The qualitative research method chosen for this study is grounded theory which has been said to be developed to such an extent that it is 'currently the most comprehensive qualitative research methodology available' (Haig,1995). Moreover, a grounded theory approach was considered to be the best fit to the research question which aimed to discover the particular techniques and skills which could be successfully used to facilitate process in counselling bereaved adults with learning disabilities. This would enable the development of a theory to explain the aspects of process which contribute to a successful outcome for both the client and counsellor and perhaps to discover and explicate the interplay of both the client and therapist in this process. It would enable the researcher to gain an understanding of the impact of the work on the therapists as well as the impact of the therapists' own skills and particular experiences on their work. By listening to what these therapists say and looking at how they behave with their clients I could attempt, as Rennie (2006) suggests, to understand their world.

The popularity of grounded theory can be attributed to its ability to bridge the gap which is often observed between clinical practice and academic research. Such a disparity holds a danger of leading to academic research which has little relevance to clinical practice and which may be difficult to apply (McLeod, 1994).

Limited research has been carried out into bereavement counselling of people with learning disabilities. The existing research has focused mainly on the outcomes of counselling or therapy whilst aspects of process have been neglected. A grounded theory approach would lead to the collection of rich data which, it is hoped, will inform the practice of newcomers to this field as well as being a springboard to

identify the further training needs of existing practitioners. This should inform evidence - based practice, which is particularly important for psychologists as scientist practitioners. Grounded theory has been seen as a

*"robust method for the generation of a form of practical knowledge that is best suited to making a contribution to the efficient and humane functioning of ...health and social welfare"*(McLeod, 2006, p. 79).

### **2.2.1 The development of Grounded Theory**

At the beginning of the 1960s the scientific method of research was seen as one which was based on replicable experiments, logically deduced concepts and hypotheses which were either proven or disproven by research. However, by the mid 1960s, qualitative methods of research had gained some popularity in social research. These challenged the positivist notions of quantitative research, which was previously viewed as the *only* scientific method. These positivist quantitative methods emphasized objectivity, with an unbiased and passive researcher who collected and observed data, yet did not create it, and research which was easily quantifiable and had replicable designs. Quantitative researchers viewed qualitative research as anecdotal, impressionistic, unsystematic and biased and, where qualitative research was accepted, it was valued only as a foundation for the development of quantitative techniques. Qualitative research, on the other hand, focused on the understanding and interpretation of participants' meanings.

The publication of Glaser and Strauss's (1967) book, *The Discovery of Grounded Theory*, led to a revolution in the development of qualitative research (McLeod, 2003). It adhered to qualitative principles by rejecting the ideas held by quantitative researchers that research was a deductive process designed to prove initial hypotheses. They viewed the process of research in an inductive, 'bottom up' manner, in which the researcher is able to cast aside their own preconceptions of the topic in order that the theory will be based or 'grounded' in, the data (Glaser and Strauss, 1967). As such, this answered the quantitative critics of the qualitative approach, and challenged the notions that qualitative research methods were impressionistic and unsystematic, could not generate true theory and were useful only as a method to generate quantitative theory. This was achieved through

the use of systematic strategies of enquiry in order to develop explanatory theoretical frameworks which would provide abstract, conceptual understandings of the area to be researched (Charmaz, 2006).

This also challenged thoughts that theory and research must remain separate and brought about a change in the manner that qualitative research was carried out. Previously the study of qualitative research methods required long periods of study with researchers, which concentrated mainly on qualitative methods of data collection. However, there was a lack of consistency in the analysis of such data. Glaser and Strauss' guidelines made analysis of qualitative research more accessible for all researchers and allowed a focus on analysis rather than merely being descriptive of the data. Grounded theory has now become one of the most widely used analytic strategies (Bryman, 2001) and is currently thriving with its success attributed to its robustness and flexibility (McLeod, 1999).

Although Glaser and Strauss proposed the grounded theory method of research, they did not claim to present a prescriptive method of how to carry out research. They stressed that grounded theory should use a constant comparative methodology (Glaser & Strauss, 1967) in which incidents in the data are compared with other incidents for similarities and differences. This should address '*the context of discovery*', which had been previously repressed by the exclusive focus on '*the context of justification*'. However, although this marked a turning point in qualitative analysis, it was quite vague and left the methodology open to interpretation and to differences in the manner of its application. As a result, many different versions of grounded theory emerged. Its authors themselves came from differing traditions. Glaser came from a background of positivist social research at Columbia University where he was involved in quantitative survey methods. This influenced his desire to codify qualitative data and to form theories which grounded concepts in data. On the other hand, Strauss was from the symbolic interactionist school at the University of Chicago. This was characterized by pragmatism and field research. With its major focus on how people create their own reality, it emphasized that all social interactions are interpretative. Both Strauss and Glaser taught their methods of grounded theory separately, yet it was not until 1990 when Anselm Strauss published a book with Juliet Corbin that it

was revealed how different the approaches of Strauss and Glaser really were. This book marked a split in their opinions of the way in which grounded theory should be developed. Although they agree on many key methods of conducting grounded theory, there are significant differences.

One of the key differences between Glaser's and Strauss' interpretations of grounded theory is, that whereas Glaser states that the process of coding is combining "*the analyst's scholarly knowledge and his research knowledge of the substantive field*" (Glaser 1978, p.70) (i.e. according to an implicit background theoretical knowledge, Strauss and Corbin encourage the use of a specific theoretical framework based on an understanding of human action), Strauss and Corbin (1990, 1998) posit that there is a reality which must be interpreted and that description is only one of the bases of forming a theory. They focused on the development of a systematic method for the collection and analysis of data to enable theory to be developed. However, Glaser (1992) remained loyal to his conception of grounded theory in which it was seen as a method of discovery where categories *emerged* from the data. He believed that with Strauss and Corbin's use of concepts such as "*axial coding*" and "*coding paradigms*" researchers would "*force*" categories on the data too early on in the process instead of allowing the categories to "*emerge*" (p.31).

It has been argued that Strauss and Corbin's version of grounded theory is too prescriptive. However a prescriptive method encourages analytic rigidity; on the other hand, in order for grounded theory to keep its potential for generating new theories, the method must be flexible enough to respond to the data as in the original version (Melia, 1996).

There has been some debate as to the direction which grounded theory has taken in reference to a positivist or constructivist epistemological stance. Glaser and Strauss (1967) originally defined grounded theory as "*involving the discovery of theory from data*" (p.1). Both "discovery" and "emergence" of data imply the existence of pre-existing concepts which are merely exposed by the researcher. Thus, Glaser and Strauss (1967) suggest that researchers are capable of recognizing their own perspectives, whilst being able to avoid the imposition of their own categories and meaning onto the data. This would indicate that incidents

create their own representations which are clearly visible to researchers.

Accordingly, the researcher has been compared to “*a midwife who delivers the fully formed baby*” (Willig, 2001). This view has been linked with a positive epistemology (Pidgeon & Henwood, 1998).

However, recent research (Madill, Jordan & Shirley, 2000) found that different researchers, given the same data set to analyse, emerged with different categories. In fact, a closer examination of Glaser and Strauss’s (1967) work may even appear to support this conclusion. They state that a researcher’s perspective can have such an impact on data that different researchers analysing data may develop alternative theories. They considered this to be acceptable as long as all theories were grounded in the data. However, if Glaser and Strauss did believe this to be true, it is likely to have epistemological implications as it would mean that the data is not objective, but rather the researcher may be playing a part in interpreting the data (Rennie, 2006).

Charmaz (1990, 2000, 2006) stresses the importance of the *construction* of grounded theory. Her theory was based on a social constructivist model, which posits that there is *no* objective world to be observed. Individuals are not objective scientific observers for whom theory emerges from the data. Both participants and researchers construct their own reality as a part of the world around them. Thus, their own experiences and interactions with participants, and research practices influence the data and its analysis. As such, grounded theory, according to this approach, offers an interpretative representation of observed phenomena and not an exact picture of it. However such constructivist criticism of the original method of grounded theory can be said to neglect a focus on Glaser and Strauss’ (1967) original criteria for judging the quality of a theory and thus to jeopardise the validity of a grounded theory i.e. to be grounded in the data.

### **2.2.2 Validity in GT research – the realist/ constructivist debate**

An ontological or epistemological realist perspective implies that there is an objective world which is unaffected by an individual’s perceptions or interpretations

of it. Human beings are, to some extent, able to view this reality, enabling them to collect reliable and often unbiased information about the world. In this way theories can be validated. However, limitations of human knowledge mean that the ultimate truth regarding reality can never be fully verified. Nevertheless, the idea of truth remains, thus allowing theories to be discovered which give some insight into the actual world (Packard & Polifroni, 1992; Schumacher & Gortner, 1992).

Three main realist epistemologies have been identified: naïve, scientific and critical (Madill 2000). A naïve realism insists that the world is observable and is as it appears to be, ignoring the social and psychological aspects of human life. A critical realist approach argues that the way in which people 'perceive facts, especially in the social realm, depends partly on our beliefs and expectations' (Bunge, 1993) and therefore indicates a belief that knowledge is subjective (Madill et al., 2000). Somewhere in between the two comes scientific realism which sees the scientific method as being able to observe reality, yet also having some flaws.

On the other hand, there are a number of researchers who reject the notion of realism, adopting non realist positions which claim that it is not possible for truth to be related to an external reality (Kirkham, 1995). A naïve realist position which would assume that the world is completely observable, ignoring social and psychological contributions, does not seem plausible. On the other hand some non-realist approaches have been criticised for being based on unexplored realist assumptions. A radical realist position and to some extent a constructivist approach, can be seen as having questionable validity as it would mean that any research produced would only have relevance as a construction of the researcher. This would mean that results can never be generalised as any data is only based on the researcher's interpretations and nothing more. Results would have very little ability to be generalised to, or even a misleading impact on clinical practice (Lomborg & Kirkevold, 2003).

As stated earlier, the original version of grounded theory was unclear in its epistemological origins and this was particularly the case with the notion of realism. Annells (1997) labelled Glaser and Strauss' (1967) original formulation of grounded theory as 'critical realist' and 'modified objectivist' with Corbin and

Strauss' reformulation being termed 'relativist' and 'subjectivist'. However Charmaz (2000) asserts that they are both based on positivist philosophical stances as they both '*endorse a realist ontology and positivist epistemology, albeit with some sharp differences*' (p.513). Her opinion is that Strauss and Corbin move into post positivism as they have the same basis as Glaser and Strauss' original work yet also recognise their participants' interpretation of reality. However Strauss and Corbin's position remains ambiguous as they appear to waver between objectivist and constructivist (Charmaz, 2000). Indeed, MacDonald & Schrieber (2001) believe that Strauss and Corbin's methodology would allow a researcher to find support for any perspective they choose, whether this be realist or constructivist.

Lomborg & Kirkevold (2003), point out that although Strauss and Corbin (1998) imply a nonrealist position, stating that theories are limited to the historical era they occur in and that the truth of theories can never be fully established, this does not necessarily rule out a realist position which '*assumes ... the existence of a reality that is – at least partly – independent of human consciousness*' (p. 194).

In Glaser and Strauss' (1967) original work the authors provided a number of guidelines for judging the quality and validity of a theory. In doing this, they used the concepts fit, work, relevance and modifiability. Fit was defined as categories which are 'discovered', emerging from the data rather than from a pre-stated theory. The theory would then 'fit' observed situations. By 'work', they intended that theories would enable predictions, explanations and interpretations to be made with 'relevance' to the area they were claiming to explain and focusing on the core dilemmas and processes. The theory should also have 'modifiability', as new data emerged, and should be able to change and produce qualifications to the theory (Glaser & Strauss, 1967; Glaser, 1978). These criteria can all be grouped under the first of 'fit' (Lomborg & Kirkevold, 2003). Glaser saw 'fit' as the strength of the grounded theory approach, emphasising that it is 'what is', and not what should, could or ought to be (Glaser, 1999). Lomborg & Kirkevold (2003) believe that Strauss and Corbin also value the notion of 'fit'. However as 'fit' is concerned with correspondence to the real observed world this would seem to imply a realist position.

Charmaz (2000) and MacDonald & Schreiber (2001) view reality as a man-made construction. This can be seen as a relativist position as they draw upon constructions without any external references. This then places the concept of 'fit,' and with it the validity of any theory, into jeopardy as it cannot be seen as something which is consistent with reality. They therefore substituted the terms 'congruence', 'consistency' and 'preservation' for 'fit', yet as Lomborg & Kirkevold (2003) assert, without more explanation these distinctions are unhelpful.

Let us examine the origins of grounded theory. Grounded theory is based on symbolic interactionism. The founder of symbolic interactionism, Blumer (1986) believed that, for empirical science to be valid, there must be an objective, observable world in which reality exists, although this reality may not necessarily be observed in any given study. Theorists such as Charmaz side with a social constructivist approach which implies that reality is constructed in such a manner as there are no true, objective facts. However this would then mean that, if truth cannot be relied on, there would be no framework in which research such as grounded theories could be validated and then applied to practice (Schumacher & Gortner, 1992; Stajduhar, Balneaves & Thorne, 2001).

Searle (1995) is a philosopher who holds ontologically and epistemologically realist perspectives. He proposed a theory which recognises that people construct their social reality yet there remains a reality outside of these definitions and an admission that these are also not all that exist. Therefore according to Seale (1995) social reality is dynamic and social facts are not always recognised, yet social constructions do have a basis in reality. This is consistent with Blumer who believes that a social reality has the ability to 'resist and talk back'. Therefore symbolic interactionism can be viewed as being underpinned by a realist philosophy, 'thereby salvaging grounded theory from the nonrealist social constructivist erosion of its epistemological foundations' (Lomborg & Kirkevold, 2003, p. 198). This would then also mean that truth and validity can be applied to the evaluation of the practice of grounded theory. A valid theory would therefore be one which is consistent with the observed data in the area under study (the social reality) which is validated by reality and can be judged using Glaser and Strauss' (1967) concept of 'fit' (Lomborg & Kirkevold, 2003). An important point which

Lomborg & Kirkevold (2003) make regarding this is, that, although a number of theoretical interpretations can be made, only certain theories will 'fit' the phenomena which is being studied. This can be seen as an answer to Charmaz' (2000) remarks that a researcher chooses which theoretical interpretations to use based on their own constructions.

The addition of Glaser and Strauss' (1967) principles of *work*, *relevance* and *modifiability* will enable the validity of any theories developed in this research to be established. Relevance and workability will be important if the theory is to have an effective application in the field of counselling psychology. Modifiability will enable the theory to be flexible and adapt to challenges from any further data which might come to light. This present work will be validated against these standards.

### **2.2.3 Selection of an approach to analysis**

The approach selected was that of Strauss and Corbin (1998) as they provide clear guidelines for carrying out grounded theory research, yet their stance does not serve to reject positivist assumptions, nor does it suggest a total acceptance of social constructivism. It is in accordance with Seale's (1995) identification of social reality, recognizing the voice of participants whilst still valuing the notion of a 'fit'. This places value on external validation of research. The realist philosophical approach will enable me to listen to the voice, to participants' experience and perceptions of the impact of their work, yet to take their accounts of their practice as recounted by them as a reflection of a true reality.

### **2.2.4 Reflexivity**

When using a qualitative methodology, one should take "*methodological precautions*" (Coolican, 2004, p.235) in order for the reader to have an awareness of how the researcher's stance might influence their interpretations of the research. Strauss and Corbin (1998) recognized that complete objectivity is impossible and that when undertaking any piece of research, qualitative, or even quantitative, there is some aspect of subjectivity. They define objectivity in

qualitative research as the ability to give participants a voice through listening to their viewpoint. This implies a good understanding of participants. However, researchers' understanding is often based on the values, training, culture, and experiences that they bring with them, which might be quite different from those of the participants in the research (Bresler, 1995; Cheek, 1996). Reinhartz (1983) urged researchers to state their own attitudes and values in any piece of research.

Glaser and Strauss recommend some techniques for increasing awareness of bias and to attempt to control for its interference in the analysis but it is a fine line to do this whilst still retaining sensitivity to the data. They recognise that researchers, as much as we may try, "*cannot completely divorce ourselves from who we are or what we know*". Our insights into data are produced from existing theories that we, as individuals, carry with us. According to Dey (1993) having an open mind does not mean that we should not use our existing knowledge of theory when we analyse data but rather the question should be *how* we use this knowledge. In recognition of this, I acknowledge that my own knowledge and experience may influence me. I have worked in the field of learning disabilities for over twelve years in a variety of settings and roles, which included bereavement work. Glaser and Strauss recognise that such professional experience can increase sensitivity as it allows a researcher to enter the field of enquiry more rapidly with no time wasted in achieving an awareness of the surroundings and events. However, this professional knowledge may also hinder the researcher's perceptions.

My interest in this research stems from my own experience as a trainee counselling psychologist working in this area. Although I had benefited from a short training course in bereavement in people with learning disabilities, this had not been a part of my training as a counselling psychologist. I was also interested to learn from my counsellor colleagues that they felt their counselling courses had not equipped them for this either but rather they had to 'learn on the job'. As a trainee on placement, I specifically felt this lack of guidance in the limited reading on the area and had found that, although there were some resources there did not appear to be enough consensus and guidance on their use or the best approach to take. I found that if not for my previous experience of working with people with learning disabilities; I would not feel comfortable providing this service. Additionally, I found that for many clients who were referred for other difficulties, an unresolved

bereavement often lay at the heart of their difficulties. This had often not been recognized by professionals but had often been viewed in terms of 'challenging behaviour', a phrase which learning disability services often seem to use with startling regularity to explain any difficulties a service user may be attempting to communicate.

In addition to this, I have recently experienced the pain of losing a parent. My support networks and family have played a large part in being able to successfully cope with this. It brought me to reflect on how I might have coped with this if I had been excluded from death rituals, had limited support or understanding from those around me or if my grief reactions had merely been seen as strange or challenging behaviour which I would need to be 'jollied out of' (Blackman, 2003) if they were acknowledged at all. This, unfortunately has been the case for some of my clients.

Glaser and Strauss recognise that these personal experiences provide not only an understanding of the area, but also a comparative base for asking questions on the topic. I found that most of the initial questions in the semi structured interviews stemmed from an interest based on my own personal experience, although they also explored areas in which there were gaps in the literature. However, I also found that, at times, my experiences have led me to attempt to force my own hypotheses onto the data with this even influencing further questioning which I engaged in during an interview and which became evident during initial analysis of one transcript. This has led me to stand back and ask myself 'what is going on here?' to constantly question if my thinking is fitting the data accurately (Strauss and Corbin, 1998).

Throughout this research, I have aimed to be aware of my own knowledge and experiences and the need to use the guidelines recommended by Glaser and Strauss (1998) in order to take these into account to benefit and not compromise the analysis.

## 2.3 Examination of the Literature

In Glaser and Strauss' original version of grounded theory, the researcher was expected to steer clear of literature in the area in order to avoid being influenced by it. It was expected that it might blind one to realizing new perspectives. However since I had both previously reviewed some research and have worked in the area, I already have a familiarity with some of the literature. Strauss and Corbin (1998) recognise that, as professionals, many researchers would have some prior familiarity with the literature. They maintained that some knowledge of the literature was not an obstacle; rather the researcher had to be careful not to be so immersed in the literature that their thought was constrained by it. In fact Strauss and Corbin merely request that, rather than attempting to ignore the influence of their prior knowledge on analyses, the researcher retains reflexivity to identify and recognise their own knowledge and its contribution to their outlook. Strauss and Corbin were thus able to interweave literature throughout the process of evolved grounded theory as another voice contributing to the researcher's theoretical reconstruction. In the same way that Strauss and Corbin have viewed the use of techniques to increase theoretical sensitivity, the literature is able to provide examples of similar phenomena that can "*stimulate our thinking about properties or dimensions that we can then use to examine the data in front of us*" (Strauss & Corbin, 1998). Moreover, McLeod (1994) believes that knowledge of the literature can make the researcher even more sensitive to some dimensions of meaning.

## 2.4 Sampling and Participants

Adverts were posted on the MHID (the Mental Health and Intellectual Disabilities) email forum published by The Estia Centre (estia@kcl.ac.uk) and in Learning Disability Today to recruit participants. Participants were also recruited through a process of 'snowballing' where one counsellor suggested others who might be interested in participating. In qualitative research, participants are selected on the basis of their theoretical significance rather than in accordance with rules of randomised or stratified sampling (Strauss & Corbin, 1998). A sample of counsellors was required who would be able to provide rich data through giving accounts of the therapeutic process and their experiences of working with bereaved adults with learning disabilities. After beginning to code the interviews, it

soon became clear that experienced counsellors and therapists would likely provide the richest data regarding process. However, I also wished to generate an account of difficulties and dilemmas and its impact on process across the spectrum of development as a counsellor. It was hoped that this would highlight any areas of training which were necessary or lacking in the eyes of participants. These were areas which the more experienced counsellors might not recall. Therefore, attempts were made to sample counsellors with varying degrees of experience in the field, ranging from counsellors in the first year following training to those who were more experienced in the field. Participants were from various voluntary services for people with learning disabilities across Britain. Permission for participation in the study was obtained from the services for which participants worked.

## **2.5 Participants**

In addition to the two pilot interviewees, ten people were interviewed. Three of these were male and the remaining seven female. However, in order to protect the confidentiality of participants, all participants will be referred to as male throughout the rest of this study. Participants' details such as sex, theoretical orientation, members of accrediting bodies and training are listed in table 2, below. Details have not been reported for each individual, but rather an overview of all participants is provided, in order to protect confidentiality. Three participants were counselling psychologists and the remaining seven were counsellors. Participants came from different theoretical orientations; five were person-centred, three used a psychodynamic approach (2 of these also practiced creative arts or drama), one used a CBT orientation and the other; either CBT or person-centred. Four participants were accredited for their professional practice by the British Association of Counselling and Psychotherapy (BACP), three were accredited through the United Kingdom Council for Psychotherapy (UKCP) and three by the British Psychological Society (BPS). They also had differing levels of experience. One participant had recently qualified as a counsellor, one had worked as a counsellor for some time but had recently started to work within the learning disability sector; whilst the others had more experience both as a counsellor and in work with learning disabilities. As can be seen from the table below (table 1.) some

had either prior experience of working with people with learning disabilities before beginning their counselling training, whilst others had prior counselling experience before taking up work with clients with learning disabilities.

<b>Prior Experience</b>	<b>0-4 years</b>	<b>5-9 years</b>	<b>10 years +</b>	<b>TOTAL</b>
Counselling with learning disabilities	4	2	4	<b>10</b>
Experience of counselling	4	2	3	<b>9</b>
Prior Experience with Learning Disabilities	0	1	3	<b>4</b>
<b>TOTAL</b>	<b>8</b>	<b>5</b>	<b>10</b>	

*Table 1: Table to show experience of participants*

	<b>Number of Participants</b>
<b>Theoretical orientation</b>	
Person centered	5
psychodynamic	3
CBT	1
CBT & person centered	1
<b>Sex</b>	
Male	3
Female	7
<b>Training</b>	
Counselling Psychologist	3
Counsellor/ psychotherapist	7
<b>Accreditation</b>	
BACP	4
UKCP	3
BPS	3

*Table 2: Table to show Sex, preferred theoretical orientation ,training and accrediting body of participants.*

## **2.6 Measures**

A semi-structured interview schedule was developed (see Appendix C). The questions chosen to guide the interview were selected following critical reflection on the subject of inquiry and were guided by familiarity with the research, together with discussion with colleagues who were counsellors working in the field and with my research supervisor. A semi-structured interview enabled the researcher to guide the interview along the topic of investigation but also allowed each participant enough scope to fully express their own experiences, thoughts and feelings and how they made sense of these. The semi-structured interview was found to be a particularly useful technique in this research as it was exploratory. It allowed my initial questions to be modified by the participants' responses which allowed the investigation of any particularly interesting or significant areas which surfaced (Smith and Osborn, 2003). Questions were open and quite general so as not to lead participants but to discover themes and concepts relevant to each individual. Prompts were used if necessary to allow a further exploration of the area or to aid participants who had difficulty or did not understand the question.

After each interview, the data was coded and, following this, the questions were examined and revised in order to explore areas of importance raised by the participants (see appendix D for an example). Each interview lasted approximately one hour.

In order to check the validity of the generated theory, a version of respondent validation (Henwood & Pidgeon, 1995) was applied. The transcript and the theory generated from the collected data was returned to each participant following coding, inviting their comments both on the accuracy of the transcripts and of the appropriateness of the codes. Some participants added to the analysis by suggesting further dimensions which were indicated by their responses. As areas of interest emerged from the data, further questions were devised and asked to new and existing participants.

## **2.7 Selection of interview technique**

The semi-structured interview technique was chosen as a method to deal with the complex and sensitive material that I expected would be raised as counsellors discussed the background and their own motivations and experiences of working with a client group with learning disabilities who are bereaved. It was expected that interviews would provide an opportunity for the participants to become immersed in the topic, allowing sensitive questions to be introduced at appropriate points in the interview (McLeod, 1999).

The interview technique may be seen as an unusual technique to uncover process in the counselling sessions, however, what I was trying to establish was the impact of counsellors' experiences on, not only the development of process, but also on their interpretations and experiences of it. Use of a semi-structured interview would allow them to develop an account of their practice and experiences in a personal manner. In fact, the way in which they chose to use the interview was as much an expression of themselves as the actual content of the interview itself and uncovered previously undiscovered aspects of their experience. It also did uncover process issues which the counsellors believed to be particularly important to their practice and, by familiarising themselves with client notes previous to this, the experience was brought back to them.

## **2.8 Design of interview**

Initially, questions were constructed to form a two-part interview. The first part focused on the process when counselling clients with learning disabilities, one with a mild learning disability and one with a more severe disability. The second part focused on the counsellors' own training and experiences. Pilot interviews were carried out with two trainee psychotherapists who had some experience of offering bereavement counselling interventions for clients with learning disabilities, one in a private practice and one who had worked in a voluntary organisation. The subsequent interviews and analyses revealed that some of the questions were unclear and did not lead to the type of data I was hoping to collect. They were also judged as too long by the participants and, as inexperienced therapists, they found it quite difficult to answer questions regarding process. Additionally, following

analysis of these, it was clear that if I were to discover the impact of experiences on the counsellors' practice, the interview schedule would need to be reversed in order to ask relevant questions and generate richer data, assisting participants to describe their practice initially and to ask for accounts of the process with their clients towards the latter part of the interview. This would also enable questions to be asked to facilitate the exploration of any interesting aspects of their experiences and the relation of these to their practice. It also highlighted the need for myself, as a novice interviewer, to practice the interview schedule as this can improve the flow of the interview (McLeod 1999). This was particularly important in a semi structured interview and enabled me to have the flexibility to ask questions when the interviewee raised the topics.

As this was a grounded theory study, interview transcripts were analysed after each interview, line by line. using open coding. Changes were then made to questions or prompts, as necessary, in order to focus on aspects which were felt to be of particular importance, or which I wished to explore further.

## **2.9 Procedure**

Participants were initially contacted by telephone and email. An information sheet explaining the nature and rationale of the research, confidentiality issues, anonymity and the right to withdraw was sent to each participant prior to their participation, via email. It also requested that they bring to mind two examples of clients with whom they had worked, suggesting a reading of any notes taken regarding these clients. The information sheet made it explicit that the confidentiality of all clients would be protected. Participants were asked to abide by this by not mentioning the names or identifying details of the client whom they were speaking about. The need to maintain this confidentiality was stressed again at the interview.

Interviews were arranged according to each participant's preference, either at the participant's place of work, in which case private office space was reserved, or in a private room in their home. At the time of meeting the participant, the participant

was reminded of the rationale for the research. Confidentiality for both their information and that of their clients was reiterated and their anonymity and rights to withdraw were explained. Participants were assured that all audio recordings, transcriptions and analyses would be identified by number only and kept in a locked and secure location or on a password protected computer, in the case of digital, electronic recordings. They were also informed that all recordings would be destroyed once the research was completed. Participants were asked to sign a consent form (Appendix B).

Interviews lasted approximately 60 minutes but if participants had more information to add and wished to carry on with the interview, this was encouraged and some interviews lasted up to 90 or 100 minutes. The process of the interview is described more fully below.

The interview was audio recorded and transcribed verbatim. The process of transcribing interviews involved not only recording the words of participants but taking note of any inflections or subtle intonations in their voices, or any pauses or hesitations in speech which indicated thought processes and possible indications of expressions of difficulty or discomfort with the work they were describing.

During and following the interview, notes were made on the manner of the participants during the interview e.g. facial expressions or body language where this was considered significant to the content of the interview.

Participants were asked how they were feeling following the interview and were offered a debrief. As all participants were receiving regular clinical supervision for their work it was suggested that any pertinent issues were discussed with their supervisors. However, I was aware that many individuals only received this supervision on a monthly basis and I therefore provided a list of organisations which would offer free help or advice, or personal counselling should the interview have brought up any personal issues for participants.

### **2.9.1 The interview:**

A semi-structured interview was used in order to gain a sense of the experiences of participants; factors which might influence the counselling relationship or process and the impact of this work on them, to include both its challenges and rewards.

Initially, the interview was more open and exploratory but, as the interviews progressed, and data was analysed, more questions were added in order to investigate areas which were revealed to be rich in data, in a process of *theoretical sampling*.

Participants were asked to think of a client with whom they had finished a process of bereavement counselling. Initially, participants were directed to give the client a pseudonym. I established the age and gender of the client, their level of learning disability and ability at communication. It was hoped that this would enable the identification of any age or gender differences in the counselling process. The level of learning disability was established as it was expected that work with an individual with a mild learning disability would be very different from that of someone with a more profound disability, in light of both their intellectual functioning and communication. Participants were asked to describe approximately when the bereavement occurred and any knowledge of the level of support the client received both prior and subsequent to the bereavement as I was interested in how this might affect the impact the bereavement had on a client and, as a result on the counselling relationship and the counsellor. However, it emerged that often their clients had experienced multiple losses which mainly lay in the past. They commonly were not referred for bereavement issues and referrers did not mention the level of support provided following bereavement. Therefore participants rarely knew these facts. Thus, this aspect of the research was deemphasised.

Participants were encouraged to give a narrative account of their practice with each client, sequentially, from beginning to end, stating the number of counselling sessions which were provided and the approximate duration of each session. During this narrative account, they were asked to focus on any materials specific to working with individuals with learning disabilities or aids for communication that were used both within and across sessions And how these were used.

## 2.10 Analytic strategy

Firstly, the data collection process consisted of gathering rich data through the semi-structured interviews. These were transcribed and prepared as individual transcripts with each line numbered accordingly. To begin the analysis all transcripts were analysed line by line using an open coding process. This encouraged the full emergence of the data (Pidgeon & Henwood, 1992). This was written on individual index cards. Each theme identified was initially given its own index card e.g. 'communication' and the title was written on the top of the card.

As additional transcripts were analysed, they were written onto the same card if it was identified that they had the same theme. If there were additional themes, then these were given their own cards. This enabled the researcher to identify any similarities and differences in the process and participant's experiences. Continuations of the same theme were given the same number followed by a sequential letter of the alphabet e.g. 17, a, b, & c are all on the theme of communication. At times these cards were then sorted into themes which were deemed to be governing them in order to help the researcher to think about the overarching themes. These were then examined using memos. Diagrams were drawn to explore the relationship between memos and enable the emergence of themes and categories. Examples of the development of memos and diagrams are provided in appendices E and F.

This study used the constant comparative method, grounded theory (Glaser and Strauss, 1967, Strauss and Corbin, 1990) to examine interviews. Grounded theory allows an 'inductive theory to be constructed through the systematic collection, analysis and conceptualization of data on a particular phenomenon' (Charmaz, 2003). It starts with general concepts and questions around the research area or 'sensitizing concepts' (Blumer, 1986). These indicate the ideas that will be pursued and specific areas of or questions to ask on the topic. These ideas then become a 'point of departure' (Charmaz, 2003) from which new ideas are developed. Data was thus analysed in light of information given by each participant, and the questions continually revised to focus the analysis on to different and more specific

areas. Early analyses through open coding allowed themes to emerge which influenced the questions which were asked to future participants, concepts were identified and their characteristics and dimensions were discovered in the data (Strauss and Corbin, 1998). Axial coding brought together the data that was pulled apart during the initial stages of coding. It related the identified categories to their sub- categories and began to establish more clear-cut and comprehensive explanations of the phenomena. Lastly, a process of selective coding was engaged in which the overarching categories were refined and incorporated to create a theory that was specifically 'grounded' in the data.

As categories began to emerge from the data, constant comparative analysis was used to continually check and alter if necessary the groupings of categories. Data analysis therefore was an ongoing process which allowed for the testing of any emergent theory which developed from the data. Data collection and data analysis were carried out in parallel as data from the first interviews were collected, information was analysed until for some themes a 'saturation' of information was reached i.e. when similar relationships repeatedly emerged from the data and were validated in further interviews (Strauss and Corbin, 1990). However, due to time constraints not all themes were explored to saturation. Writing memos and continual theoretical sampling enabled data to be gathered to develop the emerging theory.

The aims of the present study were initially to explore the process of bereavement counselling for adults with learning disabilities through the eyes of the counsellor. As the study progressed, a theme began to emerge that it was the participant's own particular experiences and not just the model of counselling adopted or any particular techniques used, which played a part in the process of counselling and in their counselling style. The study therefore turned to a greater focus on the exploration of the counsellor's own experiences and the impact upon them of counselling clients with learning disabilities.

## 2.11 Ethical Considerations

This project was approved by the ethics committee of City University (see appendix A). Ethical safeguards and considerations of this study were formulated according to the ethical guidelines of The British Psychological Society (2006) who state four ethical principles: respect, competence, responsibility and integrity. Two of these, respect and responsibility, are directly applicable to my research.

*Respect:* The very fact that I was asking individuals to participate in my research indicated that I valued their 'knowledge, insight, experience and expertise'. Allowing them to have a voice and consulting with them on their contributions to the research, showed respect, which, as will be further discussed, is often perceived as lacking, due to working with an often undervalued client group. Their privacy was respected by maintaining their anonymity. Participants were given information on the nature of the study which enabled them to give their informed consent to participate. The right to withdraw was made clear to participants, in the event of which, their data would be destroyed. Additionally, all participants were provided with information on the research study and any questions which they had were promptly answered in order that they had a clear understanding of the nature of the study.

*Responsibility:* Researchers have an ethical and social responsibility to make research interesting and meaningful for participants in a manner that promotes the concept of research in the eyes of the public (McLeod, 1999). Therefore, I was careful not only in the design of the research interview but also in my follow-up. Providing the participants with the analysed transcripts not only allowed them to contribute to the research through respondent verification, but also ensured that they were able to view their positive contribution to research in the area in which they practised. This demonstrated my interest and positive regard of their information, which I considered so important that they were provided with an opportunity to review their contributions, the interpretations of the researcher and to add any further insights.

Counsellors who participated were asked to change the details of their clients so that they would not be easily recognised. They were also cautioned not to reveal

the name or identifying details of clients in order to protect the client's confidentiality. However, as there are only a limited number of counsellors who work with bereaved adults with learning disabilities outside the NHS, the use of a qualitative research method can mean that, although anonymous, the participant still may be recognised by other counsellors, particularly as they were offering personal reflections. This might be also relevant for the clients these counsellors are describing. If the entire process of their counselling is described in detail perhaps the identity of the client might become obvious even though their name is concealed from the researcher and might therefore present a breach of confidentiality. To overcome this I did not interview counsellors who work in services in which I myself have been employed and thus might know the clients described. Counsellors working in different areas where the researcher was unlikely to know their clients were selected instead. However, if I were to think that I recognised some details of a client, the narrative interview would be concluded immediately and only the personal semi-structured interview would be used. When writing up the research, any details regarding individual clients were concealed. No details of participants, nor the service they work for, were disclosed in any written reports, rather they were anonymised. For the purposes of this research all participants were referred to as male. All mention of specific evidence of the expertise of participants was removed. However, when representing an individual's views it is recognised that at least the participating counsellors might recognise themselves. Therefore attention was also paid to the use of special care and sensitivity when writing up the research.

Interviews required participants to think about issues which might make counselling individuals with a learning disability difficult. When discussing a difficult issue using an unstructured interview unexpected self-disclosure may occur and thus invalidate the informed consent by evoking and disclosing painful personal issues (Cieurzo & Kietel, 1999). If such a situation had occurred, the interview would have been moved on to gather information and the painful issue would have been discussed at the end as part of a debrief, with the tape recorder turned off (Fassinger, 2005). Participants were debriefed following the study and details of free counselling services were provided.



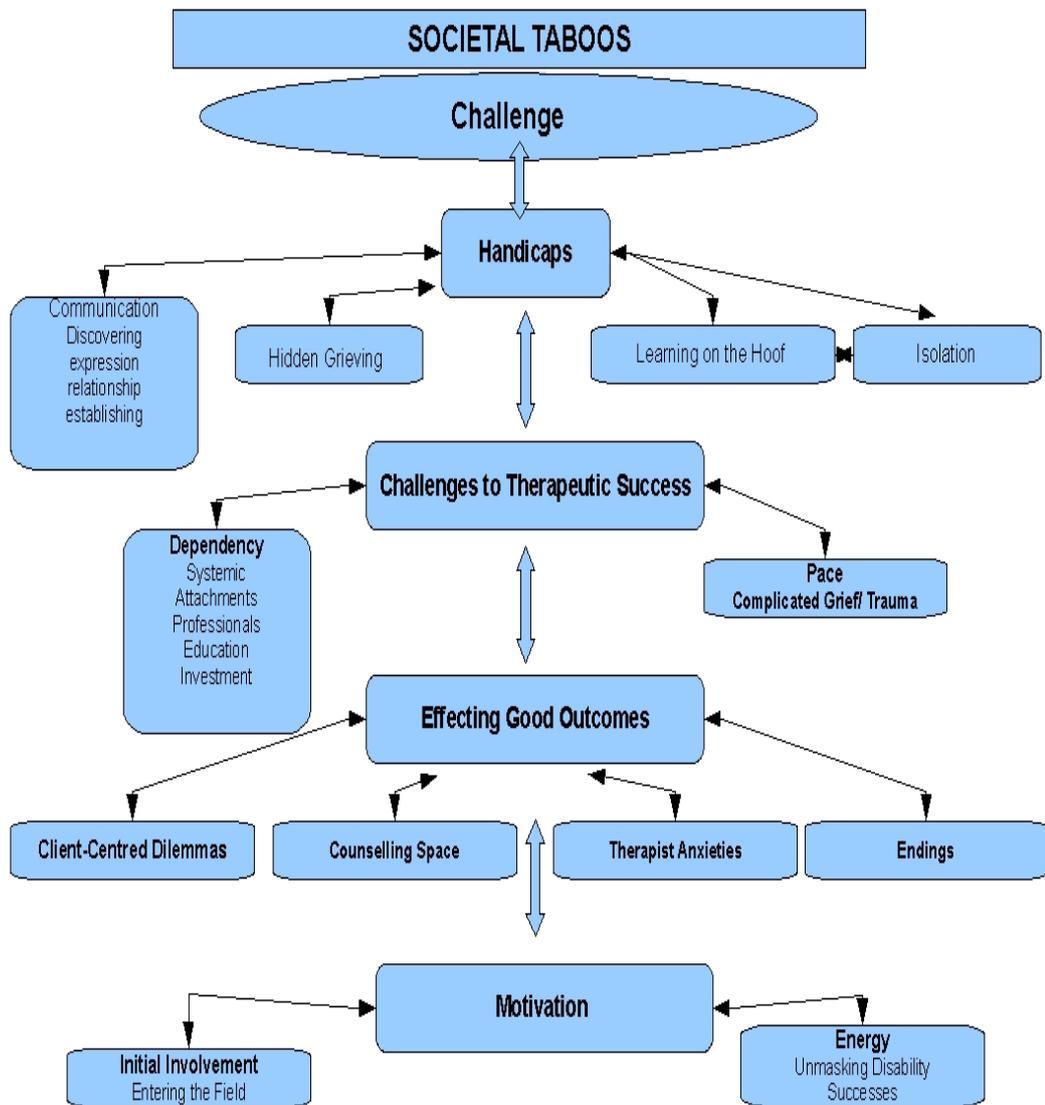
## Chapter 3: Analysis

### Introduction

In carrying out this research, I was interested in the process of bereavement counselling with people with learning disabilities. However, whilst some details regarding the process were revealed, a number of other themes began to emerge from the data. Due to the nature of this grounded theory analysis and the need to remain true to the data, I then explored and developed the other themes which emerged. Although these themes were related to process, the data revealed much more about the effect of doing this work and its impact on the counsellors who practice it.

In this analysis section, I will examine the categories, which emerged from the data. The results include quotations from interviews with participants, which both enables the participants' voices to be heard and 'grounds' the analysis in the data. Quotations from the interviews with participants are written in italics and are numbered to indicate the participant number and the point in the interview from which they were taken. For example, (01:07:03-06) is a reference to participant one, the seventh page of the transcript, lines three to six.

The category, which emerged as most important from the analysis, was *Challenge*. Within this category are a number of subcategories. These define counsellors' motivations for entering the field, qualities they deem essential, the counselling process and the counselling relationship. A theme, which ran through this, was that of the expectations and beliefs of the society of which both the client and counsellor are part. This challenged and impacted on both the client and counsellor.



*Figure 1: Diagram to show the Category of Challenge*

## Challenge

Challenge emerged as a central theme, which encapsulated the experiences of therapists providing bereavement counselling to people with learning disabilities. Participants saw their work as challenging. These challenges permeated every stage of the therapeutic process, from the referral, to establishing the therapeutic process, to their anxieties about the work, through to ending therapy. However, the counsellors were equally able to describe the skills they used to overcome many of these difficulties and revealed the factors which facilitated success in a seemingly

daunting task. The realisation that they could carry out successful therapeutic work which brought benefit and hope to clients often brought about an energy and enthusiasm for the work. The overall category of Challenge can best be described using subcategories. The five main sub-categories revealed were Process; Handicaps in Establishing the Foundation for Therapeutic Work; Challenges to Therapeutic Success; Effecting Good Outcomes, and Motivations.

Whilst it is not possible to entirely separate the therapeutic process from the impact this has on the therapist, for the purpose of this analysis, the first section will examine stages in the process of offering bereavement counselling to adults with learning disabilities.

### 3.1 Process

Participants were able to identify the ways in which they typically worked with clients with learning disabilities who were referred for bereavement difficulties.

A pattern emerged as participants of different theoretical orientations described the same basic steps which they used in therapy with this client group and reflected on their importance in a similar manner. These steps do not necessarily need to occur in a sequential fashion but were deemed to be necessary for effective bereavement therapy for individuals with a learning disability.

**Stage 1:** The majority of participants believed that the initial stage for this work was to make contact with the support network surrounding their client. Although only some participants reported doing this, others attributed the failure of therapy to the lack of involvement of the support network.

*I think that my role, sometimes, is to educate the referrers ... about the importance of the therapy ... Occasionally I've had to write letters to managers or sort of do some sort of written contract with the people who are wanting the service (07:03:01-03).*

Therapists might seek to establish an official “pre-therapy meeting” (03:07:15) with a client and carers in order to establish the parameters of therapeutic

sessions. Involving support networks involves some education as to the significance of the therapeutic work and obtaining some commitment to support clients to attend.

[The client is] *normally accompanied by someone else. It is up to the client whether they come in with them or not. They can do, because it helps sometimes for them to explain what the problem is (06:03:02-06).*

Therapists might ask the service supporting the client for a support worker to accompany the client, at least in the first few sessions. The client will be given a choice as to whether they are present or absent in the room although the former can be preferable, at least initially, in order to facilitate communication with, and serve as “*interpreters*” for the counsellor.

Involvement of support networks is common and improves understanding of the therapeutic intervention, thereby increasing commitment to support clients in attending sessions and can also, at least initially, facilitate communication and knowledge of previous events in the client’s life.

**Stage 2:** All therapists, despite their theoretical orientation, believed that the first step to successful therapy is to build up a trusting relationship and endorsed Rogers’ (1951) core therapeutic conditions.

*Of course I use Rogers’ core conditions.... It’s based very much on the relationship; the relationship really is the focus. Because, I do believe that if you haven’t got a therapeutic relationship, then you are not really going to get very far with anything else (08:4:56).*

*Most counselling ... the basis of it is the core conditions ... that’s part of ... forming a [good] relationship with your client ... being, genuine, being sincere and ... being non- judgemental ... particularly with someone with a learning disability it’s very important not to judge them (02:07:14).*

The non-judgemental aspect of the therapeutic relationship was found to be particularly important by all participants as they believed this group of clients were often “*marginalised*” by others and their lives “*are quite unimaginable to me and so I can’t have a sense of what it might be [like]*”. The therapeutic relationship is

important as it might be the first time the client with a learning disability has actually been listened to:

*often that people talk at them rather than actually listen (03:02:06-07)*

The relationship serves to provide a therapeutic and contained space for feelings accompanying grief.

*Providing a place to express feelings that maybe are seemingly unacceptable outside of the counselling session ... angry feelings or sad feelings or all the messy feelings (07: 09:09-11).*

Thus, such a relationship is not only possible to establish with a client with learning disabilities but is essential to bring about therapeutic change. However,

*the more learning disabled somebody is the longer that process will take as well (07: 08:16).*

Participants believed that the therapeutic relationship takes longer to establish in direct proportion to the severity of the learning disability. Thus another aspect of this stage is to enable therapeutic conditions such as acceptance and unconditional positive regard of the client to begin to influence the client's perception of self.

*Society's disabling ... the first six months or year of working with people with learning disability is when you start to see that stuff falling away ...that's very exciting, actually to begin to see somebody ... to be able to reflect ... and think and recognize that actually they have thoughts that are valuable (07:6:17).*

Society's perceptions of the learning disabled can add an additional disability, a secondary handicap (Sinason,1992), to the client which makes their learning disability appear to be more severe. The therapeutic relationship provides a space in which to combat this, as well as a space in which to address the client's experiences and feelings around their grief.

**Stage 3:** The third stage in the development of therapy is to establish the level of comprehension of the concept of death, as something which seems so basic may often be lacking for a person with a learning disability.

*I realised when I was talking to her ... that her understanding of that was ... a terrible tragedy that they happened to die, but under normal circumstances people would live forever ... it just suddenly sort of hit me that ... she didn't really understand that everybody dies ... she wasn't making that assumption or she hadn't drawn that conclusion ... which seemed unbelievable (08:12:20).*

Participants pointed out that, “just checking out the concept of death understanding that people have and checking how much of the information they've been given they understand” (07: 05:04) can involve a great deal of work and is not something which can be taken on face value from the words which clients use.

*finding out what a person actually means by the words they use, you know it's quite easy to take on face value, the sophisticated level of language.... If you probe a little bit ... around something somebody says, ... you find out that maybe they don't quite understand (03:06:22-25- 07:02).*

It is important not to treat people with learning disabilities generically as:

*People can be bombarded with information ... from textbooks ... about people with learning disabilities and bereavement but I think it's important to look at their individual needs and what their developmental level is and to gauge what information you give, to suit that developmental need [in order to] work with them at that level. (03:06:07-11).*

Taking time to assess and work at the developmental level of the individual will ensure that they understand and are fully involved in the intervention although this can be “a tricky area”. However, although some clients had a satisfactory understanding of death, it might be expressed in ways which are different from people without a learning disability and might be misunderstood as dysfunctional by the people around them.

*He believes that his mother is an angel ... he was diagnosed as being schizophrenic at one point, which I don't think is really accurate, ...he has talked about seeing ghosts and thinks that his mother is an angel. ... I don't*

*think that has been too far away from how somebody without a learning disability might in fact have experienced (08:25:07).*

Although, at the first glance, this behaviour might look abnormal, it often has a useful function which therapists need to respect as an expression of grieving and of processing that grief, rather than pathologising or attempting to eliminate it.

Establishing the extent of comprehension around death in clients is essential to bereavement work; any education which is needed should be specifically tailored with the developmental needs of the specific client in mind. Therapists should ensure that reactions to death are not pathologised but rather the underlying meanings of behaviour should be determined.

**Stage 4:** As will be detailed later, many participants found that their clients had experienced additional traumas linked to their bereavement. Therefore accurate assessment of clients is important and, if trauma is present, this would be the next stage in working with clients, rather than beginning with a focus on the bereavement itself.

*Successful bereavement work is ... normalising what's happening and also assessing maybe what's not normal and what might be the sign of something more complex underneath. So it might be to do with unresolved loss in the past or some other type of trauma that has been triggered (03: 04:16-22).*

**Stage 5** After having established all the preliminary work, therapists were then able to finally work through the grief with their clients in order

*“to normalise grief in that there are certain stages that people go through and they aren't necessary in a linear stage” (03: 04:18-20).*

This might be achieved by working:

*through those sorts of Worden's bereavement tasks with them. You know, remembering, talking and remembering. Remembering happy things, sometimes remembering things that aren't so happy, other things like that (03: -6: 12-15)*

This consisted of either overcoming the tasks or stages of grief, depending on the grief model used, as it would in any other client who was bereaved.

However, for people with learning disabilities it was recognised that there may still be a need for this some time after the bereavement as they often had not achieved any of the tasks of grieving.

*something that ... I have noticed ... that people will have had a bereavement,... 12 years ago or something like that and ... they tend to be in exactly the same place with it ... they haven't ... got ... acceptance of it perhaps and reinvesting the energy elsewhere, as it were. (08:16:22-17:04).*

The final task of grief models is to be able to *relocate* the relationship with the deceased and *internalise* it and to finally be able to *reinvest the energy elsewhere* in order to move on from bereavements which they might have experienced and never worked through independently. The goal of therapy would be:

*not feeling ... there's no connection anymore with the person that died, ... helping that person ... relocate and internalise relationship and helping people develop strategies to continue that ... [and] also recognizing some of the qualities they have within them perhaps of their family member who's died, so those kind of, you know, creating links (07:09:12-18).*

### **3.1.1 Summary: Process**

To summarise; the stages of successful bereavement work with clients with learning disabilities were found to be: working with the system surrounding the client, establishing a trusting therapeutic relationship, assessing the comprehension of death, working with trauma associated with bereavements and, only once these initial stages have been completed, working through the stages of grief. This differs from the manner in which one might expect a typical bereavement intervention to progress as it emerged that when counselling people with learning disabilities, the complicated nature of their grieving process and limitations in education and understanding necessitated initial, preparatory stages before beginning what would typically be thought of as bereavement work. Although the work of all participants was different, particularly as they worked from a number of different theoretical orientations, working through these five stages was found to

be a recurrent and successful pattern for effective therapy with people with learning disabilities in order to overcome difficulties surrounding the bereavement process.

### **3.2. Handicaps in establishing the foundation for therapeutic work**

It was found that in work with people with a learning disability, i.e. a 'mental handicap', there were a number of handicaps for the counselling process itself. People with learning disabilities have often been discriminated against by the attitudes of society. This has implications for the acknowledgement of a client's grief and the referral process. It also affects the integrity of the counselling space and the manner in which therapists working with this population may be viewed. In addition, aspects of the disability can also act as initial handicaps in therapy, for example in establishing a means of effective communication. Factors within the therapist may cause additional handicaps to the process such as the level of their training and the difficulties this may present and feelings of isolation in their work. These themes then form the four sub-categories of the theme Handicaps in Establishing the Foundation for therapeutic Work, which are: Hidden grieving, Communication, Learning on the Hoof and Isolation.

#### **3.2.1 Hidden Grieving**

It appears to be common for clients with learning disabilities to have suffered grief silently. It might often go unrecognised that their difficulties stem from their grief. Many participants reported that often the client was referred for another reason when bereavement was at the heart of their difficulties. In the words of one participant:

*What people are referred for doesn't mean that the other people referred don't have [difficulties with] grief or loss (08.11:22).*

Consequently, one of the preliminary challenges of working in this field, compared to other fields, was establishing the presenting problem of the clients, particularly as clients often found it hard to communicate this themselves. Thus, it can be a challenge merely to receive a referral for bereavement as often these issues:

*haven't been recognised by people ... I think that's terribly common (07:07:09).*

Therefore, unlike bereavement work within other groups, therapists working with people with learning disabilities must face an initial hurdle of working to define the exact nature of their client's presenting problems. It is likely that difficulties which a client is experiencing may stem from bereavements and grief which have gone unacknowledged, yet which underlie the difficulties which are now being displayed by the client either behaviourally or emotionally. Thus, this work can be more difficult than work with other clients, as the therapist often must look beyond the referral, using their experience and knowledge to discover hidden grief and support clients to explore and communicate this.

### **3.2.2 Communication**

One of the major challenges and frustrations particular to work with people with learning disabilities appears to be the difficulty of communication. This obstacle often crops up from the first instance of working with a client when, in order for any therapeutic work to take place, it becomes necessary to establish and negotiate a mutual means of communication.

#### **3.2.2.1 Discovering a means of communication**

The development of a common means of communication with a client may involve some searching and adaptations for both parties until they have negotiated a means to communicate.

*Obviously it depends if someone's got a language difficulty ... erm or a speech problem or what have you, because then I am looking much more for sort, sort of finding a communication ... mutual communication (03:03:14-18).*

The nature of this communication depends very much on the clients' abilities. It would be assessed on an individual basis, with non-verbal communication aids used as necessary.

A mutual method of communication might involve verbal communication or a

combination of verbal communication and non-verbal materials depending on the participant's training and experience. This ranged from the use of pre- printed expression pictures, books, and use of the written word to art, symbolic play, or drama.

However, particularly for the more experienced therapists, this means of communication might change over time. Therapists with more substantial experience in working with people with learning disabilities were less reliant on aids to communication and were able to trust in the client's ability to communicate either through using speech or through non-verbal cues of their choice, such as body language.

A pattern emerged of therapists who were new to working with people with learning disabilities often wishing to use non-verbal methods of communication alongside verbal methods, even for clients with mild learning disabilities. They described feeling anxious if the clients were unwilling to use these, whereas many more experienced therapists viewed the use of communication aids as an *obstacle* to their practice. They found it beneficial to just “*be there*”, to be fully present in the room in order to “*hear*” verbal and non-verbal communications.

*I think you have to be able to listen, uh, in a creative way, really, not just with your ears, but you have to really observe what's going on for that person and really attend to them (07:12:14-16).*

Novice therapists, on the other hand, described a need or an expectation to use communication aids with their clients and either explicitly reported feeling uncomfortable if they did not want to use these aids or implied this was the case:

*Er, ... no.. he didn't want to use any [of the suggested communication aids] (01: 04:06).*

For both participants who were new to the area, they were unable to accept that clients did not wish to use the communication aids offered and persisted in presenting them to their clients:

*Uh, she-she wasn't madly keen ... she wasn't madly keen on any-anything*

*that sort of where she'd have to draw or, umm, even though I sort of did try and get her ... you know, I said, you know, "It would be quite nice if you could do some drawing and we, you know, can express how you feel on paper," (06:25:22-26:02).*

Thus, it appeared that a mutual means of communication would be established with a client based on their level of ability. However there was a difference in approach of inexperienced and experienced therapists, with a preference seen amongst novices for the use of non-verbal communication aids which aided their own confidence in working. On the other hand, therapists with more experience tended to hold more confidence in the therapeutic relationship to bring about change, reporting that communication aids could actually get in the way of forming a therapeutic relationship. They had less anxiety about communication and were more comfortable with using the manner in which the client wished to communicate.

### **3.2.2.2 Clients' expression and understanding**

Despite searching out some common ground for communication, clients may often still have a very limited range of communication, at least initially;

*There may be very little that the person is able to bring to the session and talk to us about. (07:11:03-04).*

This can be in terms of an inability to communicate the content of their thoughts as above. However, this may not be due to only a functional inability to communicate but also due to the client's own expectations of the willingness of others to attend to their communications.

*He hadn't been used to being listened to for long periods of time so he doesn't have any expectation that people are going to, so he floats off from subjects quite often. (07:13:22-14:01).*

Thus, a client's lack of expectation of a connection with the listener almost makes it impossible for anyone to be able to listen and make sense of the communication. One participant described working with a client who attempted to compensate for

others' lack of interest in his communications outside of the therapeutic setting through adopting a social role of a clown. This inhibited the progress of sessions.

*... kind of like distract everyone and-and, uh, clown... it always seems to happen when someone's saying something that's a bit uncomfortable or difficult. (07:17:13).*

Due to their expectations of not being valued by the listener, clients may find that a therapeutic relationship comes as a challenge to their own way of relating to people without a disability,

*that would ... impact on the therapeutic relationship in that ... people are often, umm, expecting to be treated, ... told ... what to do or ... have things explained to them rather than being ... asked what they feel or what they think. (09:12:06-09).*

This reveals a disparity between the therapists' and clients' initial expectations of therapy, with clients expecting to be the recipients of advice or instruction, whereas the therapist has been trained to listen to a client's thoughts and feelings. Thus the therapeutic relationship is at risk of damage if this disparity is not addressed by the therapist. Such differing expectations were found to be a source of frustration to all participants. However, some seemed almost resigned to this, having an expectation that, if asked what they wished to discuss, their clients would:

*sort of look at you in a slightly bemused fashion and say, "Well, I don't know." (08:23:03).*

Thus, for some therapists, the clients' expectations of being unable to express their thoughts and feelings had become incorporated as part of their own expectations of the therapeutic process.

Communication difficulties may, in fact, be due to a difference in the expectations which clients and therapists bring to therapy, with the client often not expecting to be heard, but rather to be instructed, and with the therapist expecting to listen. Therapists realised that these issues were important and must be addressed as an initial stage of therapy, although some had become resigned to these differences in expectations.

### **3.2.2.3 The effects of communication difficulties on the therapeutic relationship**

Participants found that difficulties related to communication had a significant impact on the therapeutic process, often leading to frustration for both therapist and client.

*I didn't always understand her ... I had to keep asking her to repeat what she was saying, I didn't always understand her ... so that was kind of, umm, a bit difficult at times...it must have been quite frustrating for her as well. (02:10:13-22).*

As can be seen from the apparent frustrations of the above participant, at his difficulty in understanding this client, a lack of comprehension of their clients proved to be almost threatening for therapists who specialised in working with people with learning disabilities as it seemed to point to their own failures in managing the mere process of enabling their clients to communicate.

*I would try to talk to him about this, umm, he was challenging and I wasn't sure how well I was understood or received by him ... Umm ... and I don't know how successful it was because after a while the staff reported he was saying that he didn't want to come.... What I was doing- I was often a bit 'by the seat of my pants' really with him trying to work out, "What am I going to do here? How is this helpful?" and ... I wasn't sure how successful that was. I think people with more severe learning difficulties generate more anxiety concerning you and me.... and I have an anxiety about how we're going to communicate. How- how will it be received? (04: 20: 13-21:14).*

It emerged that, if communication was perceived to be difficult by the therapist, the therapist's anxiety increased. These anxieties appeared to be on two levels; one was as described above, a threat to their own therapeutic abilities and the other, a fear of rupture in the therapeutic relationship. Many participants believed that, if they constantly needed to clarify what the client was saying, the client would come to believe that the therapist could not understand them and become frustrated, with the implication that they would eventually disengage from the therapy.

*If I hadn't been able to get the... [words which the client was trying to communicate] for a really long time, it would have been very frustrating for*

*both of us (07: 16:14-15).*

This led to a dilemma, whether to be congruent and constantly clarify the meanings of words or phrases which were unclear or to allow the client to carry on without a complete understanding of what he or she was attempting to communicate.

*I think one of the things that was really challenging about working with him was that he was so difficult to understand and you have to really tune in, umm, to the way that he said things. But even then, you'd have to take a fairly random guess...it was a bit of a gamble... I have done this before and sometimes it doesn't work. (07:16:02-05).*

*The way she was speaking was, umm, quite mumbled and I didn't always understand her ... I had to keep asking her to repeat what she*

*was saying. ...so that was kind of, umm, a bit difficult at times. (06:10:12-26)*

In any event, the presence of communication difficulties means that it takes a great deal of time and effort merely to tease out the meaning of verbal communication, before any therapeutic work can take place. Often this raised a number of concerns for therapists; the information clients were communicating was clearly important to them, but addressing their lack of comprehension posed a number of difficulties. This might then lead to frustrations, a fear of failure and be perceived as a threat to their own abilities, yet a lack of understanding could also lead to worries of rupturing the therapeutic relationship.

#### **3.2.2.4 Establishing a means of communication**

Although experience can make the process of negotiating a means of communication easier, even having a great deal of experience in working with people with learning disabilities does not mean that it becomes easier to understand communication of clients who have difficulty in producing verbal communications. One participant described being quite frustrated with the difficulties inherent in working with clients with severe learning disabilities:

*How do you work with somebody who's got a vocabulary of 15 words? [Slight pause] How do you-? How-? Those are challenges. How do you work with someone who refuses to sit down, spends the whole time pacing around, needs to go out every 15 minutes? You know, these are all challenges. Umm, and the conventional psychotherapy training doesn't prepare you for that (04:10:14).*

One can see the frustration in the way that this participant expresses himself.

*Some people with learning disabilities can throw up technical challenges. How do you work with someone who's non-verbal? (04:10:11-12).*

This frustration was echoed by a number of participants, although mostly indirectly. The frustration appears to be linked to participants lacking a means of evaluating how well clients have received their communications which means they are unable to gauge the success of the therapeutic outcome.

#### **3.2.2.5 Communication: Summary**

Communication is the essence of a talking therapy. Difficulties in communication were seen to challenge the therapeutic process from the first instance of contact

with a client when therapists are challenged to use their experience and knowledge to discover grief which can often be hidden underneath a different referral. A mutual means of communication must then be established. Communication is something which must be negotiated between therapist and client. It was evident that difficulties in communication could be a source of anxiety for both inexperienced and experienced therapists. An inability to communicate particularly concerned participants who attributed it to their own deficiencies or linked it to fears of a therapeutic rupture. A disparity between the expectations of client and therapist from therapy can make it difficult to communicate and can also be a source of frustration for both parties. Even experienced therapists found that limitations in communication meant that they could lack a means of evaluating the outcome of their input. However, therapists with a greater degree of experience in working with clients with learning disabilities were more likely to be able to rely on the effectiveness of the therapeutic relationship alone, non-verbal cues and the medium of communication which the client wished to use rather than to attempt to use augmented methods of communication as a matter of course. Thus, discovering and perusing a mutual means of communication was challenging for both novice and experienced counsellors and for their clients:

*It must have been quite frustrating for her as well. But I wasn't understanding her (06:10:19-22).*

### **3.2.3 Learning on the Hoof**

Many participants, irrespective of theoretical background, had not received adequate, or in some cases, any, training in working with people with learning disabilities as part of their professional qualification as a counsellor or counselling psychologist.

*there was very little, uh, teaching [on the participant's counselling psychology course] really as to how you would work differently in the learning disabilities setting (08:08:08).*

Four participants worked in the learning disability field before beginning their counselling/psychology training. Many participants who were new to this field

described that their initial inspiration in working with people with learning disabilities came from their course tutors.

*One of the tutors who was like a mentor to me ... and in a way she inspired me to doing this type of work with people with learning disabilities.... I think that she was like a key sort of ... person and encouraged me (03:03:01-07).*

In addition to this, all participants, whatever their background, described being inspired by a supervisor to pursue this work and receiving some training from them.

*I was fortunate that one of my supervisors...had an interest in learning disability (04:10:20).*

Only one participant had received “special training”. This was provided by an agency specialising in bereavement work during a move to offer an inclusive service to people with learning disabilities.

*I've found the training ... that we had ... very helpful ... just discussions that ... we'd have about ... how you ... talk to a learning disabled person and you make things very clear and very precise (06:29:14-15)*

Despite this lack of specialist training for most participants, their initial therapeutic training equipped them with the tools which formed a crucial foundation for their work with people with learning disabilities. This was true for participants of all orientations.

A therapist from a person-centred background related:

*I think it [counselling training] helped, particularly in the person centred approach because of the Core Conditions (02:07:04).*

Good counselling training was seen to be the key to effective work with people with learning disabilities. It was important to treating and responding to people as individuals.

*in any therapy training you need to learn the basics. [Psychodynamic] psychotherapy is ... what I'm really interested in so- the basics of- of that model ... just ... building an understanding of that, which you can use in your work with learning disabilities. [The] most important thing is to have ... a good training. Which, you know, at the moment, we don't have the training*

*for people with learning disabilities (04:11:10-19).*

Once having developed the skills, participants found these could be adapted for work with people with learning disabilities. All participants found that they needed to make some adaptations to the use of their therapeutic model in order to be effective for people with a learning disability.

*Therapeutic skills ... you can then adapt and apply them in learning disabilities (08:03:02).*

Interestingly, one participant believed that, in order to be able to adapt his work for people with learning disabilities, it was essential to maintain therapeutic skills by working with people without a disability.

*I do some ... just a very little amount of work with normal, not disabled people ... to maintain some balance ... trying to hold on to those therapeutic skills, umm, and, you know, constantly develop those therapeutic skills so that you can then adapt and apply them in learning disabilities is—is quite important. (08:02:18).*

This participant found that constantly adapting therapy for people with learning disabilities would lead to a loss of focus of those skills without also being engaged in work with people without disabilities.

Skills were acquired “*on the hoof*” in a seemingly random and unstructured manner once they had started work with people with learning disabilities. Participants were forced to take any opportunities to pick up what they could from colleagues and supervisors.

*You sort of learn ‘on the hoof’, really. You know, you get colleagues around who know about it [adaptations to make when working with people with learning disabilities] (04:11:22-23).*

An additional challenge for therapists was trying to conceptualise differences in process when working with people with learning disabilities and having the mental agility required to adapt their work in light of this.

*You get supervisors which help you think about it and that can be a*

*challenge, as well (04:12:02-03).*

Good supervision can help therapists to conceptualise these differences, however, for participants, even the examination and conceptualizing of these differences proved a challenge.

*Emotionally they [people with learning disabilities] may be much the same as anybody else but in terms of..memory and being able to..absorb it in a conceptual way .It takes more..work..for that to happen (09:07:09-15).*

Participants found that therapy with people with learning disabilities required greater mental effort in order to identify in which areas their clients had processing deficits and to adapt the work accordingly. Although therapeutic training provided a basis to understand relationships, dynamics and process issues, most therapists had no specific training in adapting their work for people with learning disabilities. These skills were picked up inconsistently, leaving therapists feeling unprepared and challenged by the mental effort involved in the work. Often people became interested in this work through tutors or supervisors who were inspiring and supportive, yet many therapists reported that the process of supervision itself required more mental effort as they adapted theories and practice to their work which could often be more complex than work with another client group.

### **3.2.4 Isolation**

According to the social model of disability, individuals with learning disabilities are viewed in the context of their environment, a society which disables them and views them as different and, as a result, they are often isolated from the rest of society. The data revealed that this was reflected in the experiences of therapists working with these clients due to the fact that there are:

*“not a lot of counsellors and psychotherapists who do work with people with learning disabilities, so we are quite few and far between” (03: 05: 22-23).*

Thus, working with people with learning disabilities often felt quite “*isolating*”. Interestingly this appears to reflect the sense of isolation, which counsellors view in their clients, who:

*are very isolated, really, and lonely and they don't have those intimate relationships ... where they might just even reminisce with other people [about] a person who died.(07:05:18-21).*

*Like any minority group they are sort of marginalised (03:05:12).*

Additionally, this marginalisation of the clients had implications for the manner in which the therapist and his or her work were viewed:

*when I did my ...training and I was the only person who was interested in people with learning disabilities ...I sometimes talk about them. I often have a feeling that people were a bit bored. They're not as interested as when I worked in a psychiatric hospital. (04:02:16-19).*

This, in turn, influenced therapists' perceptions of their own work. This could lead them, in some way, to feel stigmatised themselves, often reporting a lack of interest from other counsellors.

*[Counselling people with learning disabilities is] an area [which] people outside of learning disability may- maybe perceive as boring or not interesting ... not therapeutically helpful (04:02:03-07).*

The manner in which society views clients with learning disability appears to be reflected in the manner in which people view the work of counsellors in the field. The perception of an inability to work effectively with this client group or of them not warranting as much attention appears to have an impact on the (lack of) training available to counsellors in the field. The limited number of colleagues and their peer support, in turn, inhibits counsellors' ability to reflect on their work with peers who understand their work. This reflects the experience of their clients who often have a limited circle of support, and suggests that society rejects and marginalises, not just those with learning disabilities, but also those who have chosen to work with and advocate on their behalf.

### **3.2.5 Summary: Handicaps in establishing the foundation for therapeutic work**

To summarise, counsellors reported experiencing a number of handicaps associated with the provision of bereavement counselling to people with a learning

disability. Initially, therapists must often face the first hurdle when a client is referred to them. A client's grief may have been silent, overlooked or denied and therapists often are forced to use their skills and experience to look beyond a referral and support clients to explore and communicate their grief. Communication is another difficulty mentioned by all participants, which places a number of handicaps in the way of effective therapy both for the client and therapist. There is often a disparity evident between clients' and therapists' expectations of therapy and one hurdle is often in establishing the basis for a therapeutic relationship. Many clients have difficulties in communicating verbally and counsellors must overcome this, working with their clients to establish a mutual means of communication. Difficulties in communication could lead to a lack of a means of evaluating the outcome of therapeutic input, to fears of a therapeutic rupture and may be attributed by the therapist to their own deficiencies. However, as experience increased so did a greater reliance on the therapeutic relationship to bring about change, rather than communication aids.

Counsellors, psychotherapists and counselling psychologists typically do not receive training in work with adults with learning disabilities. Although their basic training in therapeutic skills provides a good foundation, they must acquire specific skills as they progress in the field. They often have to work harder in order to continually adapt therapeutic techniques and to conceptualise the therapeutic process. Thus, although supported by supervisors, this work proved to be harder requiring greater mental effort to adapt their work. Some participants were struck by the disinterest of other colleagues in their work and reported a paucity of peers in the learning disability field. The "isolation" by wider society of this "minority" client group appeared to also seek to reject marginalise and isolate their therapists who shared this experience, to some extent, with their clients.

### **3.3 Challenges to Therapeutic Success**

A number of variables challenged therapeutic success. The theme of Dependency consisted of the following subcategories: Systemic factors, Attachments, Professional Views on Dependence, Educating Others and Investment. Whilst the

theme of the Pace of Therapy had subcategories: related to the Pace and Complicated Grieving or trauma.

### **3.3.1 Dependency**

There appears to be a complex pattern of dependency in the therapeutic relationship when counselling adults with learning disabilities. The client with a learning disability is often more dependent than other clients on the system surrounding them and on the therapist. On the other hand, therapists are dependent on their clients and the system, which they are a part of, to achieve a successful outcome. A successful outcome was seen to be of crucial importance due to the perceived vulnerability of the client with a learning disability who, not only is seen as vulnerable, but also as having limited ability to re-access therapy.

#### **3.3.1.1 Systemic Factors**

Participants suggested that systemic factors influenced the therapeutic relationship with people with learning disabilities to a different extent than they did with other clients. This could lead to a premature ending to therapy.

Attendance at counselling sessions for clients with learning disabilities often depends on the beliefs that others who play a part in the client's life, hold about it. Commenting on a client who sporadically attended sessions due to beliefs about counselling held by his mother, one participant reported:

*he lived with his mother, his mother would say to him, this was after about 7 or 8 months, "You've had enough now. You know that's- you don't need any more. You shouldn't be going this long."... You know, he was keen to carry on, umm, so it had become a battle for him and to get him to- to come. He was then torn between wanting to come and wanting to please his mother and- so I felt there was a premature end..[This left the counsellor feeling] very frustrated...[it was] energy sapping (04:18:01-19).*

This participant felt as if he was almost in a "battle" with the mother of this client just for the client to attend therapeutic sessions due to her beliefs in the usefulness of the intervention. Results indicated that therapy can be affected by the client's family, their carers or other professionals, all claiming to have an interest in their well-being. Sometimes it can seem as if the therapist must fight for

the clients' rights to therapy, which takes further exertion and causes further tension.

According to participants, this is often due to beliefs of other professionals that a therapeutic relationship will lead to dependence on the therapist.

*[The client] was looking forward to seeing me very much .....The manager [of the client's residential home ] was saying that he ...was pleased with the work that I had done with this guy ....but he thought that it was then time for a change...for somebody different [The manager thought it was a] dependency issue...it was a bit upsetting really. It was a bit like, well what's wrong with my work. (02:13: 06).*

The very fact that other professionals are removing a client from a therapist, who has been working well with them, can bring a mix of emotions as indicated in the above excerpt, in which the participant took this as an implicit criticism which was "upsetting".

Thus, the system can impact on the therapy due to beliefs of family or other professionals who have the power to influence whether the client will attend sessions, regardless of the therapeutic relationship with or the wishes of the client themselves. This can lead to a number of emotions being experienced by the therapist.

### **3.3.1.2 Attachments**

Difficulties in attachment were characteristic of participants' clients' relationships with others, particularly the deceased.

*She desperately wanted to be loved by her mother and-and her mother rejected her, really—completely rejected her. .... after her mother died, then that kind of escalated the whole thing (06:27:12-20).*

*In learning disabilities sometimes the increased dependence can, I think, be a factor which makes the loss of a loved family member all the more difficult (08:24 - 40-42).*

Some participants described how the disability led to differences in the manner in which parents formed an attachment bond with the client, whilst other talked of clients who were dependent on the attachment figure.

Difficulties in attachment were seen as affecting the therapeutic relationship and were something which participants believed important to attend to in the therapeutic relationship.

*Attachment and communication ... make it often much harder for someone with a learning disability to cope within their... own resources when they're bereaved. So, to me, it just seems just incredibly important area to attend to, really. (07:02:17-22)*

Participants suggested that difficulties in attachment would often not be resolved until clients were able to become 'dependent' on a therapist, by "building up a relationship [with the therapist] where there's an attachment" (04:11:14). This would be a secure, accepting attachment, in which the client could process their grief. In this case, dependence is seen as a positive trait. Attachments could have been problematic for clients because either they may have been rejected for having a disability or they may have had a dependency on their carer due to their disability. A number of participants believed that an important factor in their therapy was seen as addressing and attending to these attachment issues.

### **3.3.1.3 Professional views on dependence**

Participants believed that, when they developed a strong attachment and a good therapeutic relationship with their client, other professionals viewed this as a dependence on the therapist and, in turn, came to view therapy in a negative light.

*Because lots of professionals have views about counselling and how long someone should be going for counselling and I think there's ultimately like a cultural thing, we're against long term attachments ... people don't like the idea of dependency, even though all of us are dependent on someone- on our family members, our partner ... people with learning disabilities may not have those.(04:19:11-16).*

The above quote indicated a strong feeling which was noted amongst all participants, that clients with learning disabilities often lack a place to interact with or be supported by peers or family on an equal basis. Counsellors felt that they could provide a space where clients can express "difficult feelings" (01:03:12) which, individuals with learning disabilities often feel unable to or discouraged from expressing:

*because people maybe don't think that they understand or that they are going to get too upset; so lets not talk about it, basically (06: 04:06).*

When therapists have established a trusting relationship with a client, they could begin to address some of these feelings.

*one of the privileges we can have as therapists, is that using that relationship, a trusting relationship, we can say sometimes, difficult things. We can be with someone and express difficult feelings, which a lot of people 'back away from'. And we're doing it in a supportive way, and I hate this word, but it's almost like 'healing' ..... maybe more strong, uncomfortable feelings, which they may have about their family members, which they don't feel able to verbalise (03:25:1-5).*

Although the views of other professionals may be that dependence on the therapeutic relationship is something which is negative, once a trusting relationship has been established, therapists can support the client to face difficult feelings. This can be said to mirror the attachment relationship with the deceased and the tacking of any attachment related difficulties can be achieved through this therapeutic relationship. All therapists interviewed placed a great value on the therapeutic relationship, viewing it as essential to their role. For others to challenge this as a negative dependence, therefore, stands against the goals of therapy and thwarts the success of a therapist.

#### **3.3.1.4. Educating Others**

Therapeutic work is often more effective if it includes education of others in the support network in addition to one-to-one client work. Some participants held the belief that involvement of the support networks was essential, whilst for others this was an unfortunate obstacle. No matter which attitude they held, by their nature, clients with learning disabilities are not completely independent from their support networks.

*I think that my role, sometimes, is to educate the referrers, you know about the importance of the therapy and ... the need to be able to get here ... especially if clients have to be brought. Occasionally I've had to write letters to managers or sort of do some sort of written contract with the people who are wanting the service that they are going to be able to support the client in*

*getting here and ... we can't be cancelling just because they have a trip to the local café ... there is ignorance around the type of work that I do but partly it's up ... to me to try and understand the importance of it and the importance of people being able to come regularly.... I think I do quite a bit of PR work around the service. (03: 07:22- 08: 08).*

Often, allied professionals are ignorant of the requirements of counselling. Some participants believed that, part of their responsibility in taking on the role of counsellor to a client was to educate others in the client's support network. Greater involvement with these support networks appears to indicate a better outcome for clients, enabling greater engagement in sessions.

Rather than merely preventing infractions of the therapeutic process, it emerged that if the therapist initiates contact with the support network, it may actually aid the therapeutic process. Support workers may act as “*interpreters*” of a client's communications in initial sessions or may “*help bring in some bits of the story that the person's not able to bring on their own....to get things started*” (04:11:22). This can also serve to reduce other professionals' perceptions regarding dependence on the therapist.

The involvement of others can mean that others are able to provide the right environment to facilitate a process of healthy grieving and prevent the need for further intervention later. It might be possible to manage recent bereavements through interventions aimed at training the team of carers in supporting clients through tasks or stages of bereavement.

*I'm also, umm, mindful, you know, that ... bereavement at all is a painful process, is an actual process ... it's about encouraging people who support them to, umm, recognize that process, and—and support the person going naturally through that process rather than trying to over- pathologise it ... trying to draw out the significance of a bereavement and then support other people who are working with the client (08:09:17).*

In this manner, the difficulties of attachments can be resolved by developing a greater supportive relationship for the service users.

Attachment difficulties can be mediated through use of the therapeutic relationship, fostering dependence on a therapist. Dependence is an important part of the therapy, which can feel threatening to other professionals, whilst these

professionals are also threatening to the therapist. Educating other professionals may actually resolve the threat of dependence on the therapist by empowering other professionals to recognise and work with the process of bereavement.

### **3.3.1.5. Investment**

Counsellors viewed their involvement in the lives of clients with learning disabilities as having a unique importance. They were all aware of social issues surrounding them and understood their vulnerability. This gave their jobs purpose or *social importance*. However, this also meant that the recovery of clients was of greater importance to them. The very self-esteem of counsellors appeared to be dependent on this recovery.

It appeared to be of utmost importance for therapists that some of the discoveries resulting from work, which they did in counselling sessions, had an impact on the daily life of clients.

*I just hope that some of that ... 'cause I've been working with him now, but some of that's managed to go out back in the world with him (07:19:04).*

All participants seemed to be very invested in both the success and the importance of their work. They were not sure of the effectiveness of their interventions, which would only be proven when their clients went back out into the world and use them. Participants were very aware that their clients may not have another opportunity to receive interventions.

*But without—without a [counselling] psychologist who's prepared to—to do that work over a longer period of time and provide that frame, you know, that person would probably never really get the opportunity to—to, umm, to work with those issues because they're so—so sensitive (08: 18:21).*

The length of time of the intervention and the amount of their investment in clients was important for all participants. There was an acceptance that the therapeutic process would often take more time and commitment with a client with a learning disability. There appeared to be an assumption by some participants that therapy needed to be completed by themselves, whilst others attributed great significance

to their work with staff. For both of these groups, there appeared to be an assumption that it was their responsibility to be successful.

### **3.3.1.6 Summary: dependency**

To summarise; the category of *Dependency* represented a complex number of factors which the client, therapist or the therapy are dependent on. Factors involved in the system surrounding both the client and the therapist mean that the therapy itself, in addition to the client's attendance, are dependent on the views and reactions of family or other professionals, sometimes regardless of the views of the client. A number of attachment issues also need to be addressed and attended to. These attachment difficulties may be overcome through the therapeutic relationship; however this might be challenged by other professionals as a negative dependence on the therapist, affecting the potential for success. Educating other professionals might resolve this perceived threat through empowering them to recognise and work with the process of bereavement. Participants recognised that therapy with clients with learning disabilities might require a greater investment of both time and resources; however, they may be at risk of over investing in the relationship to the extent where their success as a therapist becomes dependent on the success of their work with their often vulnerable and dependent clients.

### **3.3.2 Pace of therapy**

Participants specifically mentioned that the process of counselling with people with learning disabilities, following bereavement, was often protracted, with progress in therapy being "very slow" (08: 18:22). Therapy typically might take longer than with clients without a disability, meaning that in order for the therapy to be effective, more sessions would need to be offered to the client.

*Some people, especially with complex needs, they do need longer work (03: 07:18).*

The more learning disabled the client is, the longer the process of therapy typically lasts in order to gradually address some of their "complex needs". The slow progress of this work is often marked by a therapeutic process, which can appear

almost circular, with the client constantly backtracking to areas which had previously been addressed. Several respondents noted this seemingly repetitive pattern to therapy. It appeared to be necessary for clients to repeat the material in order for therapy to be effective.

*Sometimes ... things would be repeated quite a lot ... sort of going over-over and over, uh, the same thing.... I don't know if it was sometimes that they hadn't remembered that they had been speaking about this particular thing or whether they just felt that they had to go over and over it. And it was almost like this problem could not get resolved. (06: 13:04-15).*

This repetition can prove to be frustrating for the therapist who appears to be making little therapeutic progress, going “over and over the same thing” (01:07:19). Therapists had a need to conceptualise the reasons for this in order to mitigate their anxiety regarding the effectiveness of their intervention due to their client's lack of progress.

*Sometimes I felt that-that I wasn't sure if the counselling actually had ... I think it had helped, but I don't know whether it was actually completely resolving the issue, umm, particularly of the-the grief. (06: 13:15-18).*

Thus, the repetitive nature of the therapeutic process meant that participants were less able to gauge the success of their interventions. This appeared to be due to the lack of the markers of progress. All participants agreed “there's a lot of satisfaction” from their work when “there is progress being made”. However, in general, this progress from session to session proved hard to predict in the learning disabled, even for very experienced therapists, with progress being indicated only through infrequent bursts of awareness in their clients.

*There can be more- sometimes a repetitive quality with the communication ... and sometimes, over a course of sessions- can be very much the same. You feel you are not getting anywhere and something suddenly happens, a small thing which comes out of the blue and it's like 'something's gone on here, something's changed' (04:23:03-09).*

Although there were occasional bursts of awareness, nevertheless the lack of progress limited the validation of the participants' work as therapists, leading therapists to doubt the effectiveness of their interventions. This was linked to a

reduction in satisfaction in their work. The sudden breakthroughs in the work had the effect of confirming the effectiveness of an intervention and acting as a marker of success for the therapist. However, the very nature of the “*sudden and unpredictable*” changes reduced the perceived efficacy of their work, as the therapists were often unable to determine the cause of this progress.

To summarise, participants found that their success was challenged by the pace of the therapeutic process. There would often not be a complete resolution of difficulties or issues, but rather clients would return repeatedly to the same issues, in a process that was almost circular, which led many participants to describe feelings of inadequacy and ineffectiveness. However, they had a feeling of exhilaration when clients finally ‘got it’ and integrated the therapeutic input, enabling them to resolve an issue.

### **3.3.2.1 Complicated Grieving or Trauma**

The pace of therapy can also be affected by the complicated nature of the grief and associated traumas which might come to light and which the therapist needs to support clients in overcoming prior to the resolution of grief. Bereavement work with people with learning disabilities would often involve the need to treat complicated grieving, where grief had not been resolved after a number of years.

*people with learning disabilities they don't have that sort of normal, umm, support around them that the rest of us would hope to have when they're bereaved, which makes bereavement a lot more complicated for them (02:02:12-14)*

Commonly, individuals were unable to express these difficulties at the time as:

*“there's a fixed smile on their face; nothing's wrong and then that's having to do more with messages they've had all their lives” (03:06:12).*

It appeared that society found it difficult to accept that people with learning disabilities can have negative emotions. These emotions and historic losses have often been ignored until they displayed behavioural problems;

*he was referred ... with unresolved loss in relation to his mother who died a couple of years ago ... and his- his sister died [over 10 years previously] and*

*his Dad died after that. His sister died [suddenly and tragically, then he was] moved into this residential service ... it seemed he regressed and became much more challenging, violent. [02:06-15].*

Thus, following what one assumes might have been a traumatic experience of the tragic death of his sister, followed closely by the death of his father, the client was not offered bereavement support but was moved into residential accommodation where he began to regress and display challenging behaviour. In fact, participants found that difficulties in bereavement of their clients were often due to unresolved losses, which were commonly related to a trauma. The referrals being received were summarised by one participant:

*[Difficulties in grieving] might be to do with unresolved loss in the past or some other type of trauma that has been triggered. If someone has not ... worked through their grief after about two years, then you are wondering what's happened. If they are still in the same spot that they were when it first happened.... It's always a worry and you get this a lot with people with learning disabilities (03:06: 05-09).*

Clients with mild or moderate learning disabilities were found to commonly have difficulty moving on from and processing their unresolved loss, which was often associated with a traumatic experience.

*that was where the problem was, really. She kind of was stuck in her childhood and couldn't move on.... She couldn't understand why her mother ... treated her the way she did. ... and I think probably because she had this disability ... it seemed harder for her to move on. She was very stuck in the past, very, very stuck there and ... that was the main problem. She couldn't look forward. She was always looking back and she knew that as well. ... so it was quite a trauma, actually. And I think she was quite traumatised by it. (06:26:10-23-29:02-04)*

This therapist reflected on a client who was rejected and treated abusively by her mother due to her disability, leading her to become traumatised. The trauma led her to be 'stuck' in these childhood difficulties. In fact, this was true of a number of clients who also suffered trauma in childhood because of their disability:

*an incredibly neglected and abusive childhood and that her coping mechanisms have been really to ... shut down her thinking (07:19:19-21).*

It was interestingly after a bereavement that these traumatic issues came to light, particularly if the individual involved in the traumatic experience had died.

*well, he—he does actually have bereavement issues, but again, they were bereavement issues from a long, long time ago ... that he seems to have,... not really processed very well ... and he's stuck, stuck in this stage ... but in the context ... of the emotional and abuse issues around it. (08:19:19-23).*

Thus, it emerged that the reason for not being able to process the bereavement was often due to being “stuck” in their development at some point in childhood as a result of a trauma related to abuse in childhood which could be either physical or emotional and often linked to the experience of disability.

Equally, for one participant this trauma occurred after witnessing a death:

*There was a lot- a lot- a lot of guilt [following witnessing the death]. Umm, (slight pause) so- so he- and I think it was also clear he was traumatised (04:17:19-20).*

This appeared to be related to the client's limited comprehension of the manner in which this event was treated by his family, who attempted to protect him from full impact of the death, leading to confusion and self-blame which partly resulted from;

*the pain [of] being sent next door to the neighbours, while his Mum and Dad were off to [hospital] (04:17:20).*

As the trauma gradually emerged, it was thus evident that clients were stuck in a developmental stage related to the trauma; therefore, for the majority of participants initial work would often need to focus on the trauma before even beginning to address issues around the bereavement

*before you can get into ... bereavement and the grief you need to work with the trauma ... focusing on the trauma ... getting him to tell his story, very simple ... being with him when he tells the story ... being with him with that and the trauma. The trauma then becomes less of a trauma and then you can start to deal with the grief of losing his father. (04:17:22).*

When therapists did not work through the trauma initially, they often found that this became a barrier to later work.

Participants found that when the client was supported in processing the trauma, it enabled them to move on in both their emotional and intellectual development.

*As I work with people and I work with trauma, I definitely see a surge of intelligence coming through that wasn't there before.... The trauma often freezes people so that they are unable to learn how they would be ... has a crippling effect on the child's development.... Even in their own ability to learn.... [following the work] they have gone and signed up for college courses and have found they are able to take in information more, all sorts of things really. (04: 06: 09-16).*

Thus, for individuals with mild or moderate learning disabilities, a trauma associated with a loss might, in fact, be a contributor to the extent of their learning disability. After the trauma has been worked through in therapy, clients were found to develop skills which they did not have before, and progress from developmental levels in which they had previously been stuck.

Clients' grief was often denied by others in the system surrounding the client, with the result that grief was often never addressed. It appeared that clients with a learning disability suffered more trauma associated with bereavement because they were more likely to have traumatic experiences associated with their early attachment relationships. Additionally, being protected from the family experience of grieving, and having a limited understanding of death, were found to make the bereavement more difficult for clients and lead to the development of trauma. When traumas were not worked through initially, they often became barriers to later work, however, when these were addressed, clients developed new skills and progressed through developmental levels which they had not previously reached.

### **3.33 Summary: Challenges to therapeutic success**

A number of factors were found to be challenges for therapeutic success and these came from several areas; the views of family, carers and other professionals. However, these could be resolved by educating others. Challenges could come from the therapists themselves, who were very aware of the vulnerability of their

clients and might be at risk of overinvesting in the therapeutic relationship, which became a measure of their own effectiveness. The pace of therapy might be particularly challenging, being slow or circular, which could lead to feelings of inadequacy in therapists. When these challenges were overcome and clients progressed, there was a feeling of exhilaration. Challenges also come from the attitudes of society, encouraging the denial of grief in people with learning disabilities. People with learning disabilities were also likely to have traumas associated with the bereavement which could be obstacles to the therapy; when these were addressed, the client progressed in therapy.

### **3.4 Effecting Good Outcomes**

The theme of Effecting Good Outcomes focuses on the challenges inherent in successful therapy. It consists of five subcategories; dilemmas of a client-centred relationship, counselling space, therapist anxieties, out of their depth, and endings.

#### **3.4.1 Dilemmas of a Client-Centred Relationship**

Therapists working from a client-centred orientation faced a dilemma in the use of a purely person-centred approach. They experienced difficulty in striking a balance between the use of client-centred techniques, on the one hand, and the need to be somewhat directive, on the other. This balance was particularly difficult to gauge for counsellors who were new to working with people with learning disabilities. They saw this dilemma as confusing and found it affected the therapeutic relationship: *“one client requested more direction” (01:03:04)*. For this participant, it shook her confidence in the usefulness of the person-centred model. However, even a more experienced therapist, described his dilemma over this:

*On the one hand, I think you do have to be more proactive ... with people with learning disabilities, because they sometimes don't have ... the skills there, or they have limited skills there, but on the other hand ... it's tempting to want to sort of say, “Okay, what would you like to talk about today?” [Laughs] and ... they sort of look at you in a slightly bemused fashion and say, “Well, I don't know.” (08:23:03).*

Usefulness of the person-centred approach appears to be divided, with other therapists finding it especially effective with a learning disabled population. Despite this, they still found there might be a need to offer some direction in order to move the therapy on.

*I would say it [work with people with learning disabilities] was quite person-centred really and, uh, not very directive. Although, on occasions, you probably have to be slightly [directive]. (03:02:22).*

The reason that people with a learning disability might need more direction in therapeutic interventions is that “*they are sort of marginalised and they often don’t have the voice to speak for themselves*” (03:05:14-15), “*often people are quietened down*” (07:09:05) and do not expect to be listened to or their opinion valued or heard.

*That would ... impact on the therapeutic relationship in ... that people are often,... expecting to ... [be] told what to do or ... have things explained to them ... rather than being asked what they feel or what they think ... they just ... expect to slot into the role where the other person is the one who’s doing the guiding ... and not really taking responsibility (08:21:14).*

Since society has not given people with learning disabilities this voice, they are often unable to use it even when encouraged to in therapeutic sessions, which can be a challenge for the relationship. Counsellors and clients have very different expectations; clients can feel challenged when asked direct questions about their own thoughts and feelings, whereas, at the same time, therapists do not want to be so directive that they tell the client what to think; they want the individual to gain control and responsibility over their own lives. A source of therapists’ frustration was that they wanted to, and were willing to, give their clients the sense of equality that the rest of society was denying them, while clients had internalised this denial so much that they expected counsellors to be in the guiding role, placing the counsellors in an uncomfortable emotional position.

Overall, the use of person centred methods of working presented therapists with a dilemma. This could be an effective tool as it enabled a client, often devalued by society, to be in control of their therapy, whilst, even when this was effective, it would often need to be adapted, to provide the client with some extra direction.

Therapists found that often clients might initially find this method difficult as they were not often asked for their opinions or placed in a position of power.

### 3.4.2 The counselling space

It emerged that as therapists gained more experience, they became more confident in the ability of the therapeutic relationship to hold and bring about change in the client. Therapists described being very reliant on tools to aid therapy when they initially trained. Whilst a number still advocate these tools in their training of new therapists, they themselves rely on the therapeutic relationship, at least with individuals who have a milder learning disability.

*to be honest I'm not a great one for [communication aids] ... I would rather just be with somebody in a room and often when I do training I talk about using books about words or cards (04:15:14-17).*

Another therapist who is more arts-based concurred with this as reflection and attending to the client became of greater importance as his experience increased.

*As I've worked for more years I actually use probably less of the things ... than I used when I first did my training 'cause I also now recognise that actually we can just sometimes sit and talk and reflect and that's part of my job, I think, is to enable people to be able to reflect and recognise,... their ability to think,... and put some of those thoughts into words. So I think I do that now more than I probably did when I first was fresh from my training (07:04:01-07).*

As counsellors developed in experience they realised that they had the ability to enable the client to reflect and to develop their thoughts and vocalise these, which is something that people with learning disabilities often have little opportunity to do. This was considered especially important with issues around bereavement:

*[clients] think that they're going to upset people by talking about the person who's died so there's no space to do it...providing a place to express feelings that maybe are seemingly unacceptable outside of the counselling session (07:09:04-10).*

It is the space that the therapeutic relationship allows that makes it uniquely important in bereavement, when clients often experience very strong feelings such

as anger, which are “very uncomfortable for other people” (03:05:22-23) who support them and which “may have felt ... unmentionable,” (07:06:04) such as being “angry with the person who you’ve been really dependent on, which would have felt perhaps very dangerous” (07:06:05-6) outside of the containment of the therapeutic relationship. In fact, it can be the therapist's very ability to hear all these feelings which are so uncomfortable for others to hear, that is important:

*being with someone, you know, in their distress, giving that distress some words, some meaning to understand it. I think that can be very ... effective as well. (04:14:01-04).*

It is important to strike a balance between communication aids and counselling space; the client has a range of materials which they are free to use to tell their stories, rather than the therapist using materials *with* clients as such.

*I just gave him space really, to talk about his dad in his own way ... and he used to tell some stories but he didn't use a lot of language. He was able to tell me through drawings and words about attending the funeral. (03:06:08-10).*

On the other hand, one experienced therapist, trained in the use of creative therapies, advocated the “use [of] expressive therapies with anyone, whether or not they had a learning disability (03:10:24). Clients were free to choose any materials they wanted with the therapist using those to reflect back to the client.

*I'll always try and take the lead of the client and I'll build rapport,... even if somebody can't talk very well [they] will use other types of equipment in the room, like play equipment and I'll often build rapport through maybe copying what they are doing ... it's a bit like reflecting, but non-verbally. (03:09:04-08).*

Alternatively, a psychodynamic approach, rather than using the creative arts, advocated listening in a creative way. With clients with communication difficulties it was again seen as possible to work without additional materials.

*listening ... not just with your ears, but you have to really observe what's going on for that person and really attend to them. and really attend to the transference and the counter transference because I think the less*

*somebody's able to verbally communicate to you the more you need to attend to the non-verbal communication. (07:12:01-05).*

Again, it was important to put effort into accurately attending to the client but on a deeper level. In this way the client could be allowed the space to express himself without other materials.

Participants described the process by which, as they became more experienced, they used communication aids such as books or cards to a lesser degree. This came with a realisation that it was the therapeutic relationship which was of paramount importance in bringing about change. They recognised that clients not only need to be heard but also to be supported to reflect upon and express their own thoughts and feelings that might have been difficult for others to hear. This should be done in a way, which is comfortable for them, but this should be a way in which they can express *themselves* whether this was through their use of words, drawings or other mediums but not by using aids designed by others. This was considered to be of particular importance following bereavement.

### **3.4.3 Therapist anxieties**

When participants, even experienced therapists, examined their reactions to both death and bereavement, they found these concepts had the potential to trigger a great deal of anxiety in them.

The anxiety which working with people with learning disabilities generated was attributed, by one participant, to being raised in a society in which disabled people are considered almost as second-class citizens. He found that he had unconsciously accepted this stereotype and was afraid of the potential for these biases to enter into his work;

*I probably was a bit worried that I might be a bit,... I don't know if judgmental is the right word but maybe a bit prejudiced or had been in the past. (06:12:09-12).*

This participant had recently entered the field of learning disabilities and was afraid both of the challenges of working with someone who had a learning disability and

also that his biases would preclude a non-judgemental environment, which he believed necessary for effective therapy to take place.

In fact, it was found that even for participants experienced in working with people with learning disabilities that “*people with more severe learning difficulties generate more anxiety*” (04:22:22). This was true for the majority of participants who were not trained in creative therapies. Anxieties commonly centred around effective communication.

*I think ... and I (slight pause) have an anxiety about how we're going to communicate. How- how will it be received (04:22:22).*

Some participants expressed anxiety around both understanding, and being understood by, a client with a more severe learning disability. This will be examined later on.

Death itself can be a frightening concept. One participant noted the universal nature of this anxiety, which was experienced by both client and therapist.

*A lot of clients, people with learning disabilities, they do have and talk about anxieties about death but this develops over a period of time ... about their own death. Which is ... human ... whether learning disability or not. But I think that quite often people try not to think about it, death, or they don't talk about it but its often, for most people, bubbling away (03:03:14-18).*

As a result of this, working therapeutically with death can often be difficult. Participants expressed a number of worries about entering into the field of bereavement. This can be due to people's own existential concerns.

*I suppose people generally ... struggle with death,... what happens to us when we're death—dead because I—I think it's very difficult to imagine your own non-existence. (08:13:18-20).*

People find that death generates a different kind of anxiety in them than other work with people with learning disabilities. In fact one participant working with people with learning disabilities found himself confronted with bereavement but was not

*“particularly drawn to the loss and bereavement aspect of it and remember being a bit anxious about it” (04:06:11-13).*

Due to the difficulties experienced with both bereavement and with learning disabilities, it is possible that the combination of the two could generate an almost crippling level of anxiety.

*It was hard. I have to say it was hard. I did find it... it-it could be quite hard (06:12:03-04).*

It was not only actual bereavement faced by people with learning disabilities which therapists found difficult, it also applied to other losses. They commonly perceived people with learning disabilities as vulnerable, making it difficult to confront what they commonly believed to be the pain which the individual must live with on a daily basis. Their clients had experienced what, for them, were “*Unthinkable*” losses” (07:08:03).

*And when they lose that parent, there are so many other losses connected with that, you know, quite unthinkable things that most of us wouldn't have to put up with...all at the same time—losing your home and....a community and maybe the day centre ... your friends and your religious community—everything sometimes goes for people all at once and it's quite, uh, terrible to think about it (07:08:02-07).*

It is this compounded sense of loss, of multiple loss that “*must be horrific, really it must be horrific*” (06:28:22). It was so horrific therapists felt almost unable to empathise with such difficulty. This missing empathy then caused anxiety. In fact they saw that their clients also appeared to be missing this sense of comprehension of their losses or at least the ability to express them, therefore, therapists feel a need to express these verbally.

However, once therapists began to work in this area they found the work rewarding and were able to lay aside their initial anxieties. They then discovered interesting aspects of the work, with some even uncovering hidden aspects of their own personality.

*It was a very good experience and I think I learned a lot, umm, about myself*

*and about the clients as well, that, you know, particularly about myself that I could be really, really patient (06:12:05-07).*

Participants also reported that anxiety was reduced through experience and teaching others.

*Death and dying, it's a terrifying concept... I think a lot of my anxieties are around talking about it, have sort of dropped away through ... through teaching, talking to people. (04: 07:08-11).*

Death and dying can be terrifying concepts for people with and without disabilities, including therapists facilitating the grieving process. This is also true of working with those whom our society considers to be disabled. Therefore, it can be common for therapists initially to experience anxiety when confronting these issues, however after some time these anxieties reduce, sometimes even leading to personal insights for the therapist.

#### **3.4.3.1 Out of their depth**

It appears that few counsellors or psychologists are comfortable and willing to work with people with severe or profound learning disabilities. There are a number of factors which contribute to this.

As one participant remarked:

*People like that [with severe or profound learning disabilities] haven't been referred to me but maybe you could argue the other way that maybe people ... would refer to me [if they knew that I could work with these clients] I don't know ... (09: 23:02).*

This stems from the fact that many participants were reluctant to work with individuals with a severe or profound learning disability. Eight out of the ten participants reported that either people with profound learning disabilities had not been referred to them, or, that they were unsure of how to work with them effectively. This was mostly due to their own anxieties and uncertainties around this, as mentioned above. For example, one participant questioned:

*How do you work with somebody who's got a vocabulary of 15 words? [Slight pause] How do you-? How-? Those are challenges. (04:10:14-15).*

Perceptions of participants' ability to be successful also affected their desire to work with people with a more severe learning disability, as explained below. Participants found it difficult to track progress with clients with more severe learning disabilities.

*Well, with mild to moderate, I'm much more aware of how you can get in touch with them and things like that.... People with sort of more ... severe/profound learning disabilities, I, I just think its that other people would be better working with them. I don't feel that's my forte (09: 23:10-14).*

Participants appeared to be afraid of failing in their interventions and would rather remain on ground on which they felt more confident.

*Sometimes I felt that-that I wasn't sure if the counselling actually had.... I think it had helped, but I don't know whether it was actually completely resolving the issue, umm, particularly of the-the grief. (06:13:04-07).*

Therapy with people with learning disabilities often makes slower progress, the more profound the learning disability is, and, as we saw above, this was one of the frustrations, which participants experienced.

*The pace ... [of therapy is] much slower in those with a more profound a learning disability, umm, and I look, you know, a large part of the earlier sessions will be just in developing a relationship and a way of communicating, umm, so that-that the more learning disabled somebody is the longer that process will take as well. (07:08:15-19).*

Another suggestion is that, psychodynamically thinking, people with a more profound disability could have a greater sense of helplessness, which is then transmitted on to the therapist through a process of transference.

*[Working with individuals with a more profound learning disability] generates ... a greater sort of sense of helplessness perhaps. You know thinking about ... transference and counter-transference.... I'm more likely to work with staff, rather than directly with the client. (05:12:18-20).*

Therapists, particularly psychologists, were inclined to work with people with a more severe learning disability systemically, but not actually with a one to one talking therapy intervention. They report receiving few referrals but in some cases, when clients were actually referred to them, they worked for a couple of sessions as an assessment and then offered training to the staff team in supporting them through their bereavement in almost an avoidance, and would not feel that they could successfully carry out a talking therapy with these clients. One participant recounted that the team which he previously was employed in had reflected together on the meaning of this:

*I think that's the same for all psychologists working in my area.... We've had quite a few discussions ...and I think there's a consensus within our area that people with sort of a more severe and profound learning disability aren't getting the same level of service from psychology as those with a mild to moderate learning disability (09: 23: 18- 22).*

*I don't think that enough people with severe learning disabilities are referred for counselling.... There is a feeling that they don't have thoughts and feelings.... I think there is a need for some form of therapy to be developed for more disabled clients (10:22:18-21)*

However, two participants were more comfortable agreeing to work with someone with a severe learning disability. Although they experienced similar anxieties, they had developed strategies to be able to manage this work. One through her training in creative therapies:

*The way that I work ... with somebody with a more severe learning disability [with] who[m] I have used a lot more, like play therapy techniques (03:02:20-22).*

The other participant had experienced a number of close personal bereavements and had recognised that one client with a severe learning disability was having trouble grieving. He subsequently discovered that other clients could also understand, and were helped by, the recognition of their grief. Therefore this knowledge and a sense of social justice led the participant to pursue and promote work with people with severe learning disabilities. This participant believed that all humans traverse the same stages of bereavement (conceptualised by Worden's task model). Work with individuals with severe learning disabilities was therefore

much the same as those without, simply the techniques used to achieve this needed adaptation.

*Talking to them, rather than expecting them to talk to me ... trying to guess how they might be feeling. And I don't mean guess as in just sort of guess. Building on my knowledge of how people without learning disabilities grieve and the sort of things that they needed to do. Building on the feelings even though it might not have been clear they had them.... And the sort of things that they need to do to cope with their bereavement and adapting the way that I work so that those needs were filled with the person even though it might not be obvious that they had them (10: 23: 07-14).*

The trust that people with learning disabilities have the same emotions as anyone else led to the success of this work, and enabled the creation of an effective therapeutic relationship.

*It might just be sitting and looking at pictures of the person who died, telling them that they've died and to say 'it's okay to be sad' ... people are sad when somebody dies ... just talking to them so that anything that gets through might help them to know what's happened ... (10:23: 18-22).*

It was important to acknowledge the death as the individual may not have been informed of it, to just normalise some of the feelings around the death. Even this experienced therapist did not know the extent of the difference his work was making, yet just the fact that some difference was made was enough.

Work also might initially involve others to establish communication but would then revert to one on one therapy:

*[The presence of support workers at psychology sessions] helps sometimes for them to explain what the problem is. If there is a communication difficulty it is more helpful for me sometimes for someone to act like an interpreter until I can get used to them (03:05:05-08).*

To summarise, most participants found work with people with severe learning disabilities to be anxiety provoking, due to factors such as the threat of the disability and lack of indicators of success. They would go so far as to ignore these clients as being treatable, instead working systemically with staff who support them. However, the two participants who did report doing individual work and being

successful in it, also identified anxieties around this work. Both had adapted creative means of working with these clients. Their confidence was born either of an awareness of the effectiveness of these creative tools and transference, or of a sense of social justice for grief support for all. These participants had very different ways of working, but they trusted that even the most profoundly disabled would be able to use the therapeutic relationship to a positive end. However, it does appear that in most cases people with profound learning disabilities are being denied access to talking therapies, which may be due to the few therapists willing to carry out this work.

### **3.4.3.2 Endings**

Premature endings were a particular source of anxiety for participants who described an uncertainty of knowing when their intervention should end.

For the client with a learning disability, counselling might take longer for a number of reasons. In fact, there may be a number of stages that must be traversed prior to even beginning effective work directly on grief (see section 1: *Process* where these stages are described). Once they begin to address the bereavement issues, participants described some difficulty in deciding when to end therapy. Clients have commonly experienced a series of multiple losses and often do not have access to peer or family support for the grieving process, meaning that they might be unsupported after sessions.

*I think ... I'll probably ... hope to get to a point where we could begin to, umm, plot an end point, even if that end point was quite a long way away.... So, at the moment, I'm prepared to offer him to be seen on an open-ended basis, but at some point, we'll bring on to the agenda where the end point would be ... that's a little bit more than usual. I mean, most people [without bereavement issues] I—I would try to have at any point planned in for the close [at the] beginning. (08:20:01).*

Participants described a great deal of uncertainty about when they should end the therapeutic intervention with a bereaved client with learning disabilities, which can be seen from both the content of, and the hesitation in, the above participant's speech. Additionally, clients with learning disabilities, unlike other clients who have been bereaved, will not be 'cured' following counselling, as their disability; both primary and secondary will remain with them.

*That's what led to the difficulty. One often feels slightly unfinished.  
(04:19:05).*

The opportunity for continued therapeutic involvement was often limited in people with learning disabilities, and reflected the degree of control they had over their lives. Particularly for individuals with severe learning disabilities, therapeutic sessions might be terminated prematurely due to the beliefs held by support staff.

*I don't know how successful it was because after a while the staff reported he was saying that he didn't want to come ... but I wasn't sure how believing the staff were in the process ... after about 6 months, they started attending less and it was harder to make connections with what he said (04:22:03-10).*

Premature endings limited the ability of therapists to accurately determine the outcome and effectiveness of their interventions, particularly if the client was unable to communicate these. This participant found the loss of the therapeutic connection to be particularly difficult. Unexpected loss or breaches of the therapeutic relationship for these clients were found by therapists to be a particularly difficult experience, as they appeared to mirror some of the clients' earlier losses.

*He had a lot of loss relating to all these former places ... there was a loss there and often in his care ... there was a loss (06:12:05-07).*

In the case of this client, the therapist believed that the client had consistently lost connections with previous day centres and previous carers and attachment figures. Thus, the loss of a therapist meant the loss of a place he had attended each week for six months and the loss of another attachment figure.

Although planning endings proved difficult for participants, unplanned endings were particularly hard. The importance of planning endings with people with learning disabilities was particularly significant with a population who had suffered many, often unexpected, losses. Planning an ending, or the loss of the therapist, was a dilemma for participants as they were forced to directly confront the fact that they were contributing to their client's sense of loss.

*She was really sad, umm, to think that the counselling was coming to an end ... she was feeling quite sad ... as it was sort of getting nearer and nearer to the end, umm, she was feeling very, very sad 'cause, umm, she would be missing seeing me (06:25:05).*

Participants were able to identify with the impact of the ending on their clients, and found that it impacted on themselves, as they were in effect the 'cause' of the ending.

In essence, endings meant the loss of a therapist from the lives of vulnerable clients who had experienced many "*unthinkable*" losses in their lives. On some level, therapists clung to the therapeutic relationship, at times not wishing to define the boundary of an ending with a client, and experiencing their own sense of loss if endings were terminated prematurely. There was an awareness of causing the client the pain of another loss and perhaps a desire to avoid doing this.

#### **3.4.4 Summary: Effecting good outcomes**

The theme of Effecting Good Outcomes focuses on the challenges inherent in successful therapy. One of the challenges consisted of a wish to engage the client in the therapeutic process in a person centered manner. Clients were often unable and unwilling initially to make use of this approach, leading to some discomfort as therapists attempted to demonstrate to the client that they were valued and would be leading the therapeutic process. A challenge which was often overcome with experience was reliance on the counselling space. With experience, therapists were able to rely on the client's own chosen method of expression and on the effectiveness of the therapeutic relationship, rather than other aids. Therapists expressed a number of anxieties about working with clients with learning disabilities in addition to those around death. When beginning this work, a great deal of anxiety might be felt around these issues, however these can reduce over time, often leading to some insights and growth for the therapist. These anxieties increased with the severity of the disability, with a number of therapists believing they would be unable to carry out this work effectively with clients with profound disabilities. This was attributed both to the threat of disability and the lack of indicators of success. However, of those who did see these clients, there was a

recognition that even the most profoundly disabled could benefit from the therapeutic relationship. Endings of therapy presented yet another challenge. Some of the hardest aspects of this were the potential for withdrawal of clients before the work was completed, and needing to leave the client who would remain disabled after therapy. This could lead to feelings of adding to the client's losses and a lack of evaluation of the effectiveness of interventions, leading to a reduced sense of satisfaction and positive feedback from this, often difficult, work.

### **3.5 Motivations**

Work with people with learning disabilities proved to be motivated by a complex number of factors. Two themes were identified under *Motivation*: Motivation for Initial Involvement, and Energy. The emergence of these factors kept participants motivated and interested in this work, which proved to be very challenging on both a personal and an emotional level.

Within the main sub-category of Motivation for initial involvement came two further sub-categories: motivation for work with people with learning disabilities and motivation for bereavement work.. The sub category of Energy consisted of further subcategories of Emergence from behind the mask of disability and Successes.

#### **3.5.1 Motivation for initial involvement**

Participants were found to have a variety of motivations for entering into work with people with learning disabilities and bereavement. Some participants were unable to identify any particular conscious motivations but were able to note a number of influences under the surface. Motivation for the work of participants can be broken down into their motivation for work with people with learning disabilities and motivations in carrying out bereavement work.

##### ***3.5.1.1 Motivation for work with people with learning disabilities***

A number of participants reported that they entered the field of learning disabilities by chance with no particular motivations for the work other than it having been an opportunity that presented itself at an appropriate time

*People don't know about it [learning disability] really. And then people, you know, they discover it (04:03:03).*

Learning disability was seen as a field, which was 'discovered' and could be a complex and interesting field.

*I actually would say that often learning disabilities is ... immensely interesting ... people's relationship with their disability, their feelings about it. Their ... relationship with the staff members and how they feel about disability and how they respond. (07:03: 4-11).*

Despite the intellectual interest, which participants were readily able to identify, a closer examination of their motivation often revealed personal reasons behind this decision; either in terms of the aspect of disability or of the perceived status and role in society of the participant:

*There's always a personal angle, and ... for me, my sort of personal angle would maybe ... lean to my dyslexia. I ... didn't academically achieve at school, not because I wasn't good at writing, but I just had a very- immense difficulty in putting across my ideas ... on paper ... and I always had a sort of internal struggle about being stupid or being perceived as stupid...which on some level maybe [I am] still thinking about, and working out in my work, and that's why I'm sort of drawn to this work ... [I] have some identity with, maybe being perceived as somehow 'different' or feeling different. (04:04:03-09).*

Some participants discovered that their work with individuals with a learning disability was a reflection of their own early experiences and the impact of what was often a hidden disability on their self-identity. The feeling of difference from their peers enabled a deeper understanding of individuals whose disability was often far more prominent. This might be a disability which was experienced personally or as a result of systemic change brought to a family as a result of the experience of disability.

*In my own family that there is, uh, a sort of constellation of people with traits of autism and ADHD ... which would mean that I would identify with people ... who have those specific sorts of difficulties.... I'm a little bit dyspraxic ... and ... I do [also] have some autistic characteristics (08: 04:22).*

Participants also discovered that often the reasons, which they had initially identified for their interest, also reflected a much more personal experience of disability, whose effects on their work had previously gone unacknowledged.

Participants often discovered far more complex reasons lay behind their decisions to work with a learning-disabled population. One participant reflected on the effect of birth order in relation to his relative power in his birth family. This enabled him to gain some insight into the lives of people with learning disabilities, who also tend to have limited power, not only in their family of origin, but also in the society in which they live, despite their age.

*There may be some feelings around that in relation to being the youngest [in his family]. Feeling not so powerful and can identify with feelings around that. I mean this relates to people with learning disability as well. (04:04:18-21).*

#### **3.5.1.2 Motivation for bereavement work.**

A similar pattern was also evident in the matter of bereavement. Participants initially identified no particular interest in bereavement, but later it became apparent that there might be some underlying motivations.

*I don't remember being particularly drawn to it [bereavement] ... But I'm curious about that now. Thinking back about that ... [Participant talks of his experience with death immediately prior to his bereavement work with individuals with learning disabilities] ... So I'd had a hugely significant experience of bereavement (04:05:14).*

Another participant discovered that, although he had not considered this before, his motivation for working with grief and loss might be due to factors in childhood, and a motivation to enable others, who perhaps have a very limited understanding of death, to develop this understanding, which he had been denied as a child.

*Actually I do think that maybe there is something else. For a long time in my childhood, I had ... like a phobia about death so its quite odd that I now work in the field ... where you obviously do ... a lot of work around bereavement and grief and loss.... So maybe there was a part of me in a way that that wanted to ... help ... people in an ... area that I would have liked to have been helped in when I was younger (03: 01:19-28).*

In this manner work with death and loss might be motivated by a need to rectify the conflicts of therapists around this area.

Counsellors reported a variety of reasons for entering the fields of learning disabilities and bereavement. However, upon reflection they were able to identify the influence of personal experiences on both of these aspects. This either reflected a known disability from which they have suffered themselves; their perceived social position, often echoing that of their clients; or of their own bereavements.

### **3.5.2 Energy**

All participants displayed a great sense of purpose and motivation in their work with people with learning disabilities. This was for a variety of reasons but on some level, the work was motivating. This was also true of bereavement work with these clients; the motivating factors for the work produced an energy and inspiration for the participants that maintained their interest in the work.

In fact, work with people with learning disabilities was found, not only to be interesting and rewarding, but also inspiring. There was a level of respect and admiration for their clients, at having faced and survived great adversity, not only that of having a learning disability but of surviving often numerous losses.

*I find them very interesting ... and I think there's a lot of survivors in people with learning disability (03:04:08-09).*

This work was inspiring due to their clients' resilience but also because therapists were likely to reveal aspects of the individual which were previously hidden beneath their disability. The theme of energy was divided into two subcategories: Emergence from behind the mask of disability and Successes.

#### **3.5.2.1 Emergence from behind the mask of disability**

Offering bereavement counselling to people with learning disabilities often enabled therapists to feel that they were able to allow the 'real' person to emerge from behind the mask of their disability. They found that therapy with a person who had a learning disability could be intrinsically rewarding for this very reason.

*Just seeing people ... starting to ... allow themselves to think and get in touch with their abilities rather than, uh, switched off by their disability...I think it's,... really, really powerful experience, actually, very rewarding. It's a bit like seeing people come-come alive (07:06:10-13).*

Therapy would enable a therapist to uncover an individual's true abilities, meaning that a live, more fully functioning, person emerges from the midst of death and despair. This was often a surprising development and led the therapist to appreciate and even admire the individual.

*So he really was an extraordinary person, actually. You know, and quite different to the person that you would first see when he was brought into the room before you knew him (07:18:23).*

Although people with learning disabilities are often seen as disadvantaged, and by association, the therapist becomes isolated, the work can bring extraordinary rewards. Considering the disadvantaged and vulnerable group of clients, who were working through very difficult and painful issues, there was an overwhelmingly positive attitude to this work and a sense that the therapists were witnessing something quite special:

*Once you do start talking [about the bereavement] quite in depth ... they can say something that ... is quite profound (09:22:04- 08).*

Additionally, as the mask of disability slips away, not only the therapist but others also, can see the individual for who they are – a caring, sensitive human being, rather than an individual who is very disabled and has limited communication.

*So he was able to tell us actually some really complex stories about his life that he hadn't been able to say ever [before].... So that was quite extraordinary ... 'cause I don't [think] he talked about [these] before ... [the others in the therapeutic group] could see him for more than he at first appeared (07:16:05-17:01-02).*

The trusting therapeutic relationship can produce extraordinary results, such as the discovery of previous losses hidden beneath the disability. In a client as visibly disabled as this client was, the change was easily identifiable and therefore very rewarding. Counsellors saw this as:

*a unique role and sometimes the role itself, umm, has—has an important impact because people see that the person is then making them talk about something they perhaps don't with other people (08:19:09).*

There was a universal belief that, through their work, counsellors could make a significant difference to the lives of their clients, both through revealing the true individual, and providing a forum, for which they might often have an opportunity, to discuss painful issues. This was something which was intrinsically rewarding.

### **3.5.2.2 Successes**

Counsellors remain in this field as they describe a sense of energy and achievement from their bereavement work, despite death being the very antithesis of energy. This sense of energy develops through the ability to move someone on from the grief, to normalise it and improve their functioning. In fact, the discussion of bereavement itself was viewed as intrinsically motivating by one participant:

*There's an energy there. It can focus on death.... I think people's relationship to loss is fascinating (04:07:12).*

The ability to bring about such a significant change in the lives of their clients was particularly motivating and seemed to be very personally meaningful.

*Without being 'big headed', I think I can help people. I really do and, umm, you know, and (slight pause) I think that's that. You know, that has to be among the motivators as well ... that I can do some good (04:8:23).*

On the whole, therapists believed their role in working with people with learning disabilities to be unique or privileged.

*It's a real privilege about it as well.... Privileged position to be in and to have that one-to-one special relationship with someone when you are talking about reaching difficult, significant life events (03: 08:12).*

Bringing about this change in clients was true as a rule for work with people with learning disabilities, yet many participants thought this achieved a particular significance in bereavement work, as bereavement is an issue which is often taboo and may not be something that others would discuss with them. One participant

found it was important:

*Helping people overcome their grief, really. ... just kind of to accept ... what's happened and going through all the different stages of grief. (06:05:17-21).*

In fact bringing about a change in clients with learning disabilities was seen by some as especially evident in bereavement work:

*[Therapeutic work around bereavement leads clients to] be less sad or angry or guilty of all those things that brought them on in the first place. So, yes, seeing some change.... I-I find the work very motivating. I don't think I'd have kept going for so long if I hadn't (07:06:22- 07:05).*

Participants were motivated by their successes. The indicators of a successful outcome were the behaviour and improvement in the emotional well-being of their vulnerable clients. This is especially pertinent with this client group, as their disability and societal responses to it were often seen to prevent expression of their true selves. The success generated an energy borne of a fascination and reward from the visible signs of the successes of working with one of the most vulnerable and neglected populations, whom the counsellors were able to help to move on and develop as individuals. From the pain of death and loss, a new person came alive. Witnessing this transformation was intrinsically motivating.

### **3.5.3 Summary: Motivations**

This theme explored the motivations for working with, and motivation gained from, bereavement work with clients with a learning disability. Often a complex series of reasons lay behind a decision to work with a learning-disabled population. Therapists often felt that their own life experiences had led them to identify with some issues that these clients might experience. This was also true for their motivation to pursue bereavement work with this client group.

Work with people with learning disabilities was found to be motivating, it produced an energy and motivation which maintained the interest of therapists in this, often challenging, work. This was brought about through a belief that the work would make a significant difference to the lives of the individuals they worked with. It was

this that was rewarding in the work. In addition to this, participants described that work that was successful was particularly motivating with these clients. It enabled their vulnerable, and often marginalised, clients to move on from the pain of loss and to develop and grow as individuals, sometimes not only overcoming their grief, but also developing additional skills.

### **3.6 Summary of the analysis**

A complex pattern emerged from the data. Bereavement counselling for clients with learning disabilities was viewed as particularly challenging, raising a number of fears and anxieties and presenting a number of practical difficulties. Experienced therapists were often to overcome these which led to a feeling of achievement and success.

Despite their varying theoretical orientations, therapists agreed that successful bereavement work with this client group would normally follow a six-stage pattern. These stages were all considered important, although they need not be carried out sequentially. These were working with the system surrounding the client; establishing a trusting therapeutic relationship; assessing the comprehension of death; working with trauma associated with bereavements; and, only once these initial stages were achieved, working through the stages of grief.

Therapists found that they were often handicapped in their work with their 'handicapped' clients. A number of obstacles to therapy come from the system surrounding both themselves and their clients. Clients' grief is often denied or unrecognised, meaning that therapists must often tease out the presenting problems. Communication difficulties obstruct the therapeutic relationship in the practical sense of a lack of mutual understanding but also in the sense of equality and freedom of expression for clients who may not expect to be heard or valued. As therapists develop more experience, they were able to become more reliant on the therapeutic relationship to hold the client and enabled the client to use their own method of communication. However, difficulties in communication could handicap therapists own perceptions of the effectiveness of their input, leading to fear of

therapeutic rupture and to attributions of their own deficiency. A lack of training led to handicaps in peer support and supervision and, as a result, therapists became isolated and marginalised in, what was almost a reflection of their clients' social position.

A number of challenges, both internal and external to the therapist, affected therapeutic success. The therapeutic relationship was often threatened by others in the surrounding system although this could be mediated through education. It was also affected by the values of a wider society in which the grief of the learning disabled was denied and by the past experiences and attachment styles of clients which were likely to lead to traumas associated with bereavement. Challenges were also presented internally to the therapist in which they were at risk of interpreting the slower and often repetitive pace of therapy as a measure of their own ineffectiveness or which led to a risk of over-investing in clients. When these issues were addressed; the client progressed in therapy and therapists felt a sense of achievement and even exhilaration.

Effecting good outcomes to therapy proved challenging due to different expectations of clients and therapists and dilemmas over the use of the therapeutic space versus communication aids. With experience, therapists became increasingly able to enable clients to use a chosen method of self-expression and became more reliant on the therapeutic relationship to bring about change. Therapists again were affected by internal challenges; experiencing a number of anxieties around working with death and working with individuals with learning disabilities. These anxieties often increased with the severity of the learning disability, with many expressing an inability to work with individuals with a severe or profound learning disability, due to both the threat of disability and an increasing lack of markers of success. However, reliance on the effectiveness of the therapeutic relationship enabled therapists to work with these clients, although these therapists also experienced similar anxieties. Anxieties reduced with experience, leading to insights and growth. Endings to therapy proved challenging either due to a lack of ability to evaluate outcomes, of worries about adding to losses experienced by a client, or of premature endings forced by the system which could lead to a reduced sense of satisfaction in the work.

Therapists were often motivated to work with this client group and bereavement issues after overcoming challenges in their own lives. Their work produced increased motivation as they overcame the numerous barriers, to enabled their clients from the margins of society to overcome the pain of grief and loss, leading to further development and growth. This, in turn, brought about a sense of positive energy and reward.

## Chapter 4: Discussion

### Introduction

This discussion will examine participants' accounts of, and their perspectives on, the process of bereavement counselling for people with learning disabilities. It will draw on literature from both the areas of bereavement and learning disability, with the aim of explaining these processes and providing guidance for future research, training and practice.

The aim of this research was to identify the process of bereavement counselling for people with learning disabilities. However, as research progressed, what was striking was the sense of challenge, which therapists found to be inherent in this work. Due to the nature of grounded theory, this became a focus of the present research. Therefore, although the research has identified a pattern in the manner which therapists typically structure their work with people with learning disabilities following bereavement, analysis has focused on the challenging aspects of the work, and the way in which participants were able to overcome these difficulties. This discussion will first define the stages of work, which therapists identified in their practice. Themes, which emerged from the data on the impact of the bereavement work on therapists and their dilemmas, will then be linked with existing theoretical literature in the areas of bereavement, psychotherapy and learning disabilities.

The core category that emerged from the analysis was challenge. I will explore here how the experience of 'challenge' for the counsellor is rooted in values absorbed by the counsellor from the society in which he or she is raised. Despite their empathy towards people with learning disabilities, this will inevitably affect counsellors both through a need to constantly challenge their own beliefs and the reflected impact on them of working with a minority group. Society and its expectations also impact upon the client with a learning disability, often in the form of a secondary handicap (Sinason, 1986). Thus, the counsellor not only has to contend with his or her own internal perceptions of society but those of the client. Additionally clients with

limited independence are more dependent on others in their support system and this can have a direct impact on the therapeutic alliance.

It was found that all participants initially focused on the challenges posed by individuals who had a learning *disability* i.e. a lack of *ability* in comparison to other clients. Despite the aim of therapists to use a societal model of disability, in some way their concept of disability was in accordance with the medical model of disability. There was a conceptual scale; on one end a participant with limited experience with people with learning disabilities described his prejudices and doubts before beginning the work. This scale ranged to the more experienced participants, who were well aware of the negative effects of the views of the wider society on their disabled clients as viewed using a medical model of disability. On the surface it appeared that the latter participants held none of these prejudiced and disabling views themselves. However, despite their level of experience, participants still held a great many anxieties around their work. A number of these were directly related to the dilemma of working with individuals with a disability and, most surprisingly, many participants felt unable to work effectively with people with a profound learning disability. Anxieties were also related to death and to other aspects of the relationship with the disabled individual. Their choice of work may have reflected their own needs and there may be some motivation to work through these in their work. Once participants had begun this work, they became invested, perhaps over-invested, in the recovery of their clients. However, this investment allowed them to unleash a sense of hope and energy which, in turn, provided an environment for their clients to flourish and develop, uncovering the client's true abilities and restoring functioning to a level sometimes beyond their initial abilities. There was a dilemma for the counsellor of when to end this productive relationship, especially given the extent of clients', often complex, losses. If the relationship was ended prematurely, it tended to have a large impact on the self-worth of the therapist.

#### **4.1 Stages of bereavement work with people with a learning disability**

Counselling adults who have experienced a bereavement would normally start with examining the individual's bereavement experience. The grief would then be

worked through using the model in which the therapist practices, whether this may be a task, stage or a process model. In some cases there may be additional depression or trauma which would need to be worked through initially before bereavement work can begin (Faulkner, 1995; Raphael & Dobson, 2000). However, this data indicated that, in people with learning disabilities, this process might be more complicated and one would need to work through a series of stages before the bereavement work could be carried out effectively. The research indicated a series of six possible phases in bereavement counselling with the learning disabled. These stages did not necessarily need to be traversed sequentially but were all considered to be necessary in the process of bereavement work with clients with learning disabilities. This model is summarised below:

- 1. Making contact with and involving the support network surrounding the individual in the work.
- 2. The establishment of a trusting therapeutic relationship
- 3. Addressing any secondary handicap
- 4. Exploring and defining the concept of death
- 5. Overcoming traumas if these are present
- 6. Supporting the individual through tasks, stages or the process of grieving.

This model provides a good account of the way in which participants , of different theoretical orientations, worked for a successful outcome and provides the basis for an effective bereavement intervention. However, this is a reflection of the experiences of only ten participants. This would merit further research to establish whether most therapists would define the process for successful work in this way. This would offer guidance to less experienced therapists in how to proceed with effective bereavement work with this client group.

## **4.2 Personal Experiences**

The majority of participants initially identified no particular motive for entering work with people with learning disabilities in loss and bereavement, reporting the “discovery” of the field by chance. However, on reflection, they were able to identify

a number of personal reasons that, perhaps subconsciously, had drawn them to the work. Participants pointed to personal and familial experiences of disability, particularly of learning difficulties (e.g. dyslexia). This perhaps lent them a greater deal of empathy for those with learning disabilities through the experience of having felt “different” from their peers. Another factor was birth order, which one participant reflected was related to his empathy for a sense of powerlessness experienced by people with a learning disability. This is supported by the literature which identifies second-born children as lacking in relative social power in comparison to their older sibling (Binger, 1974), perhaps resulting from differences in the degree of parental investment. This has been seen to lead to differences in behaviour (Sulloway, 2007). This empathy was also evident in the bereavement dimension to their work. A number of therapists described having immensely significant experiences of bereavement before starting this work, whilst one participant described himself as having had difficulties in his own bereavement in the past.

## **4.3 Anxieties, prejudices and doubts**

### **4.3.1 Fear of disability**

Therapists who were new to the area of learning disabilities found it difficult to be non-judgemental with their clients. This was evident both from the responses of established therapists and from a participant new to the area. This led to anxiety around the work. Although more experienced therapists did not report the same extent of difficulties, these having lessened with experience, they did report a number of anxieties, which were a direct result of that disability, such as anxieties surrounding communication or the therapeutic alliance. Wilson (2003) explains that therapists can be consciously or unconsciously affected by a fear of disability and difference. This is then reflected in their countertransference, i.e. the client generates an emotional response in the therapist. The client with a learning disability can trigger a countertransference response of castration anxiety in the therapist, which is manifested through the fear of a loss of ability (Thomas, 1997). Strikingly, many counsellors experienced both in learning disabilities and in bereavement felt unable to work effectively with people who had severe learning

disabilities and had been bereaved, and those who did work with them expressed many anxieties around a successful outcome with these clients. Thus, it appears that counsellors are all affected by some anxieties around the ability to be successful in their work with clients with learning disabilities, whether these may be conscious or unconscious. These appeared to dissipate with experience, but the more evident the disability, the greater the likelihood of these fears being triggered. The majority of participants who directly reported this anxiety, had some significant personal past experiences of disability. This has implications for their practice as a therapist as:

*“any unresolved personal issues, conflicting values, biases and distortion can significantly affect the therapist’s capacity to provide competent psychotherapy, or any other professional help” (Wilson, 2003, p.23).*

Thus, learning disability generated anxieties in all therapists. Although these lessened with experience, counsellors' own experiences led them to feel a higher degree of anxiety.

#### **4.3.2 Communication:**

Communication was seen as a major obstacle to successful therapy. Not only was it vital initially to negotiate, and mutually agree, on a method of communication, but therapists found it to be an overarching source of anxiety. There was a disparity of expectations, since clients anticipated being judged according to a medical model of disability, where the able bodied person would devalue the *disabled* individual, whilst therapists attempted to work from a social model of disability in which the individual is enabled and valued (McCarthy, 2003). These difficulties significantly impacted on the therapeutic process. They presented a challenge to the effective management of the therapeutic space, threatening the therapist’s own sense of competency and bringing the threat of therapeutic rupture.

One might be tempted to interpret these anxieties as a manifestation of a therapist’s practical disabilities in the absence of specific training in learning disabilities. However, Wilson (2003) offers another explanation. Language is used to

'clothe' the naked internal world of both client and therapist, thus,

*“when language is absent or impaired, therapists may feel naked and exposed and grow anxious. They are deprived of the protective mechanism by which they express their own and their clients’ raw internal processes” (p.82).*

Therefore, it may be the absence of the protection of language, which leads to anxiety, as the therapist feels overwhelmed by the client’s exposed unconscious world.

#### **4.3.2.1 Use of aids to communication:**

Cathcart (1995) called for the development of more non-verbal means of communication for people with learning disabilities, in order to facilitate their understanding of emotions surrounding the experience of death and loss. However, it emerged that, although therapists of all levels of experience expressed anxieties around communication, those with more experience were less tempted to use produced communication aids. Surprisingly, some of these therapists were actively involved in developing and training others to use these very communication aids. Experienced counsellors in the field had a greater reliance on the therapeutic relationship to hold and to bring about change. They allowed themselves to trust the client’s abilities to develop and reflect on their thoughts, and believed it important to listen to and value the speech of clients even if this was slow or difficult to understand and a struggle for both themselves and the client. It was also seen as important for clients to be able to express *themselves* rather than merely looking through communication aids. Communication aids were perceived as getting in the way of the therapeutic space and therapeutic relationship. Sometimes there was some element of discomfort if they were forced, through a client’s disabilities, to use communication aids. However, aids such as books were found useful in aiding comprehension of the concept of death.

An explanation of this difference may well be that novice therapists can have a tendency to take a more rigid ‘textbook’ approach to their work (Greene & Geller, 1980), whereas the more experienced tend to have greater flexibility (Hellman, Morrison & Abromovitz, 1987; Farber & Heifitz, 1981; Deutsch, 1984).

Alternatively, it could be explained that when the novice therapist, or the counsellor new to the field of learning disabilities, becomes fully aware of the imperfections of

the disabled client, the relationship mirrors that of a mother and infant. A mother recognises the imperfections of a baby who is different to her expectations and, in response, erects a barrier between herself and the infant (Wilson, 2003). With communication aids, the therapist creates a barrier both through the absence of a humanising manner of connecting i.e. speech, and through the physical obstruction of non-verbal communication aids, which are often placed between the therapist and client.

#### **4.3.3 Impact of bereavement counselling on the therapist**

Working with bereavement can highlight the significance of a therapist's own losses, potential losses and of their own mortality (Worden, 1991). A number of participants were aware of the impact of their own personal experiences with death on their therapeutic work. They expressed some anxieties about working with death and acknowledged that this is often a universal anxiety "*bubbling away*" both for people with and without disabilities. Fear of death is common in counsellors (Steele, 1977), but anxieties around death did appear to impact more on these therapists. They believed it was due to the fact that they were working with individuals who had experienced cumulative losses and also had been devalued, as one participant remarked "*learning disability is a loss*". This "*societal death wish*" (Sinason, 1992) may lead the therapist to develop a greater sense of their own mortality and may induce feelings of guilt.

Societal taboos around death and disability can lead to a psychological defence of wishing to protect the disabled client from the harsh realities of death (Oswin, 1991; Conboy- Hill, 1992). Bereavement counselling with children is often found to be particularly challenging as counsellors are forced to question their beliefs '*in the sanctity of childhood*' (Gamble, 2002, p.352). The same reaction may affect work with the learning disabled client who may function cognitively at the level of a young child.

For most participants, anxieties did appear to reduce over time. Recognition of these feelings enabled them to understand and overcome them, making the counsellor more effective in helping the bereaved individual. This is likely to have

facilitated the development of greater self-knowledge and growth, enabling the counsellor to become less judgemental in the future (Faulkner, 1995).

*“A central element in working successfully with people with mental retardation who need to explore their feelings and experiences about loss and mourning is our own progress in coping with past experiences of grief ... every new experience of mourning opens old wounds and asks us to look again at what we have lost and what we have become [and] what we have now that we could lose ... by helping ourselves we learn better how to serve our clients” (Howell, 1989, p.330).*

However, although it did become easier over time, all participants reported a continued struggle with uncomfortable feelings associated with an attempt to understand the pain and background of their clients, which *“was just too terrible to comprehend”*. Thus, appropriate and effective support such as supervision, informal support groups, peer support and personal therapy (Read, 2002) would be important to reduce the stress involved in the work (Steele, 1977; Gamble, 2002).

#### **4.3.4 Reflection of the Experience of Disability on the Counsellor**

Participants reported a lack of training in working with people with learning disabilities. This was evident across the variety of models which therapists had trained in: Client Centred Counselling, Psychodynamic Psychotherapy, Counselling Psychology, Drama Therapy and Creative Arts Psychotherapy. Only one participant had received any formal training before beginning work with clients with learning disabilities. However, this was not provided on his counselling training course but rather as an additional in-service training. Thus, therapists were forced to *‘learn on the hoof’*. Without any consistent manner of gaining the knowledge they needed, they constantly had to pick up skills from colleagues, adapt basic therapeutic techniques and think about differences in process during supervision. This required a great deal more mental effort than work with other clients and made their job much more challenging.

The lack of training meant that work with the learning disabled was also often undervalued by participants’ peers, leading to a sense of isolation in the work.

Hawkins (2003) described a colleague who held the belief that counselling was impossible with this group as the clients had no speech and “were not ‘intelligent’ because counselling relies on speech and intelligence” (p.181). Noticeably her research indicated that not one counsellor whom she surveyed, who was working in the UK with learning disabled clients, had received any specific training. Perhaps this reflects the lack of adequate training both in bereavement counselling (Charkow, 2002), and in disability issues (Kemp & Mallinckrodt, 1996; Olkin, 1999; Pledger, 2003). Although much empirical literature reflects trends in the USA, it is likely that a similar picture would be found in the UK. Thus, disability and death continue to be taboo subjects (Oswin, 1991; Hodges, 2003) which even counselling training programmes seek to avoid.

Participants viewed their clients with learning disabilities as ‘*marginalised*’ and ‘*isolated*’, without ‘*intimate relationships*’. These descriptions appear to be reflected in the experiences of their isolated therapists. By extension, if individuals with learning disabilities have less worth than other citizens, then surely the work of those who specialise in this group will be similarly devalued.

Greater availability of training may not only mean the wider availability of counselling for bereaved people with learning disabilities but would also increase awareness of this field and thereby reduce the isolation of their counsellors. Recent attempts have been made to increase the availability and quality of therapy available to people with learning disabilities. The Institute of Psychotherapy and Disability was established in May 2000. It aims to both create courses, and to support existing psychotherapy courses to meet the needs of therapists working with clients with learning disabilities (Institute of Psychotherapy and Disability, 2009). In addition, its work is likely to lead therapists to feel less isolated; they have created a network providing supervision, advice and support to therapists.

#### **4.3.5 Out of Their Depth - Counselling Individuals with Severe Learning Disabilities**

I was interested in examining any differences in the process of counselling when working with people with mild to moderate, or with severe to profound learning

disabilities. However, the majority of participants responded that people with severe or profound learning disabilities were not often referred to their services for counselling and, indeed, if and when they were, they would be reluctant to work with them. All participants, except two (8 out of 10), noted a heightened level of anxiety associated with counselling people with severe learning disabilities. This was mainly due to a belief that they would not be able to work with them successfully. This can be seen on the diagram illustrating themes around this 'Out of their depth' (see Appendix G).

Therapists who believed that they had developed the resources or skills necessary for working with people with a severe disability, would feel confident in taking the client on for therapy. Indeed one participant actively sought to promote the efficacy of therapy with these clients amongst her colleagues. These participants did have some specific methods of communication they might use, but, like experienced counsellors working with clients who had mild or moderate learning disabilities, were confident that use of the therapeutic relationship would enable a therapeutic connection, which would help clients to overcome their grief. Hawkins (2002) believes that the use of a person centred approach, with its focus on relational skills, enables counsellors to:

*“identify with the people we are supporting. This can lead to us challenging destructive and prejudiced perceptions of this grouping of people [with severe learning disabilities] we may encounter in others and ourselves, and further recognising the equal value and worth of people with severe learning disabilities” (p.54).*

These two participants practised using very different theoretical orientations (psychodynamic and person centred approaches). Some differences were noted in the practical techniques used to facilitate this work, although there were a number of techniques, which were the same. One participant used techniques taken from play therapy, whilst the other emphasised talking to clients using his knowledge of the stages of grieving . He believed that this would aid comprehension of grief and the completion of tasks of mourning for his clients. It was also important to these counsellors to give their clients 'permission' to express feelings of grief. One participant would use of puppets to facilitate this. Both participants reported the use of photographs of the deceased and books such as 'Books Beyond Words'

(Hollins, 1991) for this purpose, in addition to body language, non-verbal responses, sounds and movement. Support networks were also used to establish effective communication and to find information on the client's history.

However, work with individuals with severe learning disabilities was believed by some to generate "a greater ... sense of helplessness", which again, may be a reflection of castration anxiety (Thomas, 1997). Counsellors' anxieties in working with people with learning disabilities were greater in proportion to the severity of the disability. Anxieties may reflect the guilt of therapists as, whilst they themselves are considered normal by society, their clients have suffered as a result of their disability (Sinason, 1992).

Therapists often had difficulty in connecting with severely disabled clients. They were often unable to judge their success as they received limited feedback on the effectiveness of their interventions. One participant who did this work achieved this feedback through questioning carers on variations in the client's mood or behaviour and through the client's non-verbal communications.

Counsellors who felt uncomfortable with severely disabled clients might either support the staff team in using a grief intervention, which might also involve individual assessment of the client, or consider using a behavioural intervention. Participants from specialist learning disabilities services reported that, as a rule, they did not receive many referrals for people with a severe learning disability for one-to-one counselling. If they were to receive such a referral, however, they would often work with the team of carers surrounding the individual, rather than the individual themselves. However, it is likely that the reluctance of therapists to work with people with more severe learning disabilities means that services would not refer clients to them nor expect talking therapies to be available to people with severe learning disabilities.

#### **4.3.5.1 Reliability**

There is a reason to doubt the reliability of this finding. It is possible that participants were not able to adequately distinguish the difference between a

moderate and a profound disability. Seven participants had a great deal of experience in counselling people with learning disabilities (experience > 10 years). It could be expected that this experience may have given them some knowledge of the distinction between, and assessment of, people with different levels of learning disability. However, one could argue that the true severity of intellectual impairment can only be determined through psychometric assessment. Even then, it can still be difficult to determine if the impairment is due to organic damage as opposed to a secondary handicap (Sinason, 1992).

#### **4.5 Inclusivity of therapy**

If the explanation of secondary handicap as the main cause of a more severe learning disability is to be believed, the distinctions, which we draw between people with different levels of disability, may be artificial. This has implications for the inclusivity of therapy for these individuals as, according to this theory, it is therapy, which is likely to act to ameliorate these disabilities, thereby enabling the individual to function at a higher level (see Srauer-Foner, 1963). Thus, by denying the individual who is perceived to have a severe learning disability therapy for his or her bereavement and loss, one may actually reduce the opportunity for their IQ to develop, particularly as compounded losses (Wandsworth & Harper, 1991; Clements et al., 2004) might contribute to the secondary handicap. Additionally, it is specifically due to the disenfranchisement of their grief that people with learning disabilities often suffer complications in their grieving (Read, 2006).

Participants commonly reported working with the staff team surrounding a severely learning disabled individual following bereavement. This has been shown to be effective in ameliorating the ignorance of grief-motivated behavioural changes, and may allow the individuals to be supported in their grief, rather than it becoming disenfranchised (Read, 2006). However, despite this training for staff, it is possible that they will continue reacting to people with learning disabilities in the same manner. Grief will remain a taboo as will the severe learning disability. Staff training approaches in the literature emphasise training staff in active listening to support their service users through grieving (Conboy-Hill, 1991; Kauffman, 1995). However

for individuals with a very limited ability to communicate, despite a compassionate attitude by staff, their distress might not be displayed in a manner which staff are able to listen to. For example, people with learning disabilities commonly display a behavioural reaction to bereavement, which is often not recognised as grief by their carers (Conboy-Hill, 1992; Read, 1997). These individuals may need support to understand and express their emotions around grief and loss. It could be argued that this support is unlikely to be provided by care staff in an, often busy, residential environment, as can be deduced from a study by Dowling, Hubert, White & Hollins (2006).

Even if support staff have received a qualification in working with individuals with learning disabilities, they are not trained in this level of intervention. Support staff are often young and have a lack of experience with death (Tuffney-Wijne, 2006). Issues of death may also evoke fear or anxiety and prevent staff from addressing grief with service users. Therefore, there is a greater need for a professional counsellor or therapist who has a thorough understanding of the grieving process and the therapeutic relationship, in bringing about healing. In fact, some participants suggested that it is the one-on-one therapeutic relationship with a counsellor who takes the time to be interested in the client, as an individual, which is important in bringing about change.

It would appear that therapists, both counsellors and psychologists, are not immune from the taboo associated with severe learning disabilities, despite their experience and training. This has serious implications for the level of service provision for people with severe learning disabilities, as counselling intervention for these individuals seems, at best, to be patchy. At least some counsellors and psychologists have a reluctance to take on these clients, reporting that they would provide interventions for staff rather than to individuals in their care. This does not seem to fulfil the criteria of the government's White Paper, *Valuing People*, for inclusive services for people with learning disabilities, as, rather than including these individuals in mainstream services, they are excluded even from counselling provided by learning disability services, as, on some level, therapists are uncomfortable working with them. In the words of Oswin (1991), counsellors may

be making the mistake of thinking, or at least implying, that “*they do not have the same feelings as us*” (p. 32).

#### **4.6 The pattern of the therapeutic intervention- the circular nature of therapy**

Participants often found the very process of therapy with individuals with learning disabilities to be a source of frustration. It could be circular and repetitive, with the client needing to recover old ground again and again, until finally there was a breakthrough as the client displayed an understanding of the grief process. When the breakthrough was achieved, it was intensely rewarding for the therapist, yet appeared to be something, which occurred “*out of the blue*”, reducing therapists’ own agency to bring about change. This resulted in a lack of validation of their therapeutic effectiveness. Other research supports these findings, indicating that progress in counselling individuals with learning disabilities is often slow, resulting in a protracted period of treatment (Laman & Reiss, 1987).

The emotional development of clients with learning disabilities may have been impeded due to the self-object relationship with their caregiver (Rosenthal, 1992). With such clients,

*“the recognition of limitations and the motivation to grow, the emergence from the narcissistic deprivations and preoccupations may be slow, tedious, and even appear circuitous”* Rosenthal (1992, p. 219).

Rosenthal (1992) recommends that by offering “*empathic attunement*” which may have been absent from infant self-object relations, a counsellor enables the client to develop a fully formed self. This might take time as the individual traverses the sectors of development which were absent from their early life. This might be especially relevant to bereavement counselling. According to Rosenthal, approval by the self-object is necessary to reinforce an individual’s sense of wholeness and self-worth. An adult with learning disabilities is likely to have limited social and peer relationships. Therefore, the role of self-object might have been ascribed to the deceased.

It might also be useful to consider that individuals who are grieving have a need to recount stories of their relationship with the individual who died and details of their illness or death. Hearing this allows them to put what happened into perspective, to come to terms with the reality of what had happened and to adapt to the new reality without that individual (Weizman & Kamm, 1985; Cook & Dworkin, 1992). Due to the relatively small social support group surrounding the person with a learning disability, and the isolation they can often experience, a person who is willing to listen may hear this same story many times (Luchterhand & Murphy, 1998). Perhaps for many clients the therapist may be the only person who they can talk to, and who they have ever talked to, about death, or even the only person who has ever been willing to listen to them. Perhaps having a realisation that this repetition is actually of therapeutic use would enable therapists to realise that this might be a grieving need rather than an indication of the value of their interventions.

#### **4.7 Investment and Dependency**

The notion of dependency was found to affect the therapeutic relationship on a range of fronts. However, it should be noted that a negative focus on dependency is a Western concept (e.g. see Yamaguchi & Arizumi, 2006) and dependency might sometimes be beneficial. Participants believed that it was often necessary to have longer therapeutic relationships with clients with a learning disability than would be necessary with others. Other professionals often viewed the lengthy therapy negatively, as a dependence on the therapist. This represented a dilemma for the therapist, as dependent or care-seeking behaviour normally becomes activated in times of distress (Bowlby, 1988; Guntrip, 1953) and dependency can be viewed as necessary for "*the early establishment of the helper-recipient relationship*" (Bloch & Chodoff, 1991, p. 146). This is applicable to the therapeutic relationship regardless of the therapeutic orientation (Tait, 1997). Gagnier & Robertiello (1991) distinguish between 'good' dependency, which is the universal need for "*love, affection, admiration, emotional support and empathy from another person*"(p. 248), whilst "*bad dependency*" is "*allowing another person ... to rule our lives, to take over our responsibility for making choices, to inhibit our growth, creativity and*

*self-actualisation*" (p. 249). It would seem that the former best describes the therapeutic relationship.

Individuals with learning disabilities are more likely to be dependent on others for their needs, whether these may be physical or communication based (Conboy-Hill, 1992). In some cases, bereavement may result in the loss of the main carer on whom the individual was were dependent for emotional support and who understood their communication (Kitching, 1997; Hollins & Sireling, 1991). Learning disability itself can impede an individual's passage through the stages of development necessary to gain autonomy (Hodges, 2003). Thus, one of the common areas of difficulty associated with work with individuals with learning disabilities are dependency needs (Sinason & Hollins, 2000). In fact, due to their clients' dependency on their support system, the counsellors often also became dependent on this system both to support their work and even for the very attendance of their client at appointments.

Participants all displayed a heightened awareness of the needs of their clients resulting from their learning disabilities and were all strongly invested, or perhaps dependent, on the improvement of their clients' difficulties. When clients are dependent on counsellors, the counsellor can feel an increased responsibility for the client's wellbeing (Tait, 1997). All counsellors are motivated in some way by a need to nurture (Mueller & Kell, 1972), a feeling which may be heightened when clients are vulnerable and, on some level, considered almost childlike. This can be displayed by a need to protect the client, as described by the majority of participants. Indeed, Gelso & Hayes (1998) suggest that therapists who convey deep levels of empathy will occasionally experience an over-identification with their clients' issues. This can carry a significant emotional cost (Figely, 1995). Rehabilitation counsellors who have a "save the world"-type attitude or those who display high levels of empathy are at risk of emotional and physical exhaustion, known as 'empathy fatigue' (Blandertz & Robinson, 1996; Cranswick, 1997; Gomez & Michaelis, 1995).

Although therapists saw dependence as a necessary part of the relationship, they also described some concerns about the client's dependence on them. This could

be a reflection of countertransference associated with 'fear of the loss of the object', a client's fear of losing the counsellor to whom they become attached (Thomas, 1997). When counsellors become aware of a client's dependency, they have been found to feel "*doubtful of ability to be good enough*" (Tait, 1997, p.24). This dependency can lead to a high level of discomfort in working with clients, which could explain some of the counsellors' anxieties around dependence and their increased reluctance to engage in work with clients, in relation to the severity of the disability, as more severely disabled clients are more dependent on support. A fear of dependency of the client perhaps represents counsellors' own need to be cared for. It has been suggested that counsellors may enter the profession because they learned in infancy to respond to the needs of others, in particular, the primary caregiver, whilst repressing their own needs (Skynner & Cleese, 1983; Storr, 1990).

Although others could view this negatively, research indicates that some level of dependency on the therapist is necessary for an effective therapeutic relationship. Clients with learning disabilities are often more dependent on others and therapists also became dependent on the system surrounding their clients. This could pose difficulties in the therapeutic relationship and pose the risk of over-identifying with their client's issues and possible empathy-fatigue. Therapists often feared the development of a dependency, limiting their work with those perceived to be particularly dependent i.e. those with severe learning disabilities. It was suggested that, on some level, this might represent a therapist's own need to be cared for.

#### **4.7.1 Counsellors' fear of loss of the client**

When the relationship has been intense, the loss of a client has a greater impact on a counsellor (Eisenberg & Delaney, 1977). Participants took it as a personal blow when other professionals removed a client from their therapy. They also tended to be quite sceptical of reports by other professionals of a client's wish to disengage. Termination of therapy without having achieved the contracted goals can be threatening to a counsellor's sense of adequacy (Mueller & Kell, 1972). Some of the anxiety which counsellors felt appeared to be due to a lack of ability to evaluate the effectiveness of their interventions, in addition to being an adequate

force for change in the vulnerable client's emotional functioning (Goodyear,1981).One assumes that this would be particularly heightened if the termination were perceived to have been due to others who do not fully understand the emotional needs of the client.

Termination is a loss for the counsellor and, as such, it is related to some stressful life tasks similar to those occurring in a death loss. Clients' bereavements may raise a counsellor's awareness of their own bereavement experiences i.e. the counsellors have not fully grieved early losses of significant individuals and thus much energy may be involved with these unfinished emotions. Termination may therefore trigger a sadness which is out of proportion for a farewell to any particular client (Maholick & Turner, 1979).There is also a possibility that this might be yet more salient when the client has a learning disability, as they often have experienced complicated or multiple bereavements or losses. Thus, the unexpected loss of a client with a learning disability may have a significant impact on the counsellor. Counsellors cannot be certain that clients have made the choice to disengage, and may feel undermined if they are told by someone else that their client no longer wishes to attend. They also have fewer means of measuring their success with these clients. This cannot only threaten the counsellor's sense of efficacy but can also trigger sadness in the therapist, which is disproportionate to the loss.

#### **4.7.2 Ending Therapy**

Some participants described a dilemma of when to end therapy with bereaved clients with learning disabilities, and again, this can be seen to be a reflection of dependence in the relationship. There is a recognition that an individual who has experienced multiple bereavements or intense grief may benefit from longer term therapy (Lendrum & Syme, 1992). Psychodynamic thinking has indicated that the correct judgement of the length of therapy is important when working with a disabled individual (Hodges, 2003; Symington, 1981; Sinason, 1997). Clients often have secondary, emotional handicaps (Sinason, 1986) although these often slip away after the first year of therapy (Carlsson, Hollins, Nilsson & Sinason, 2002). Once any secondary handicap is removed, the individual will become more aware

of their true feelings and further difficulties may be revealed, which can lead to depression. Terminating therapy too early may leave the individual with these newly uncovered underlying difficulties

*“of having recognised their defensive coping mechanisms and perhaps a feeling of having been ‘found out’, but without any further work on ego strengthening or developing the ability to think” (Blackman, 2003, p. 92).*

and an increased vulnerability to the symptoms of depression which they might be experiencing.

On the other hand, there is a risk that therapy might become too protracted. Therapists might be reluctant to end therapy due to their difficulty in containing negative feelings about the individual’s disability or grief. They may wish to remove the pain of grief and disability by mirroring the relationship with caregivers and creating an environment in which separation will not happen. Thus, in some way they may be overcompensating and allowing the client to become overly dependent on the therapeutic relationship. Wilson (2003) cautions that therapists should be aware of the attraction to *“hide behind this all-powerful parental position”* (p.121). In work with people with a learning disability this position is less than easy as clients are more vulnerable. They have often experienced a number of compounded losses and multiple bereavements and may be progressing slowly through therapy.

Therefore, the decision to end the therapy presents a delicate balance between over-dependence on the therapist and the adequate completion of the work. The therapist would need to carefully weigh up this difficult decision. The means by which a therapist makes this decision when working with clients with a learning disability who have been bereaved is area in which would benefit from greater research.

### **4.7.3 Trauma**

Another factor, which might contribute to the length of a bereavement intervention for learning disabled clients, is trauma. Interestingly, participants described that the majority of their clients had experienced trauma, which was linked to their

bereavement. This necessitated work before issues specifically related to the grieving process could be addressed.

This could be explained in the words of Cheikin (1981), “*every loss creates a trauma, and different types of loss result in varying degrees of trauma.*” However, loss is not considered to be a true traumatic stressor, as it does not involve a threat to the individual’s own life. On the other hand, deaths can be traumatic in their circumstances meaning that the bereaved are exposed to personal life threat, shock, helplessness or sudden, unexpected, and untimely events. These bereavements can be viewed as an encounter with death, which form criterion A for a diagnosis of PTSD (DSM IV-TR American Psychological Association, 2000; Raphael & Dobson, 2000). Whilst many people with learning disabilities probably are not experiencing PTSD following a death, for some individuals, particularly those who have been sheltered from the concept of death, the death of a loved one might come as a surprise. Therefore, this death can be seen to be sudden, unexpected and untimely. It might also lead them to think about their own mortality in a different way and, thus, truly can be viewed as a personal encounter with death. People with learning disabilities often have a reduced understanding of the inevitability and universality to death (Harper & Wandsworth, 1993) which is related to their Piagetian level of cognitive development (Bihm & Elliot, 1982). Such a scenario can be seen from the quote taken from an interview with one participant, below:

*I realised when I was talking to her ... that her understanding ... that was a terrible tragedy that they happened to die, but under normal circumstances people would live forever.... And, I mean, it just suddenly sort of hit me that that was where she was coming from. She didn't really understand that everybody dies ... she wasn't making that assumption or she hadn't drawn that conclusion ... which seemed unbelievable (08:12:20).*

People with learning disabilities are more likely to have difficulties in their early attachment relationships. In infancy, the necessity of accepting a child who is less than ‘perfect’ may inhibit the bonding of parents with their disabled child (Clements et al., 2004; Bicknell, 1983). Thus, the disability itself can be experienced as a trauma by the parents and for the child when they develop an awareness of it (Hollins & Sinason, 2000). Thus many individuals with learning disabilities can be

said to experience a secondary emotional disability (Sinason, 1986) in response to this initial trauma which would need to be overcome in therapy (Sinason, 1992).

Grieving can be said to be related to the loss of an attachment figure and therefore may trigger traumas which were experienced in the early attachment relationship. Attachment styles with the caregiver in infancy are paralleled in the grief reactions of an individual (Parkes, 2001; Shaver & Tancredy, 2001). An early diagnosis of a learning disability is likely to result in an insecure attachment style (Esterhuzen & Hollins, 1997) and may result in an increase in displayed behaviours which are viewed as challenging and of pathological grief following significant losses (Hollins & Esterhuzen, 1997).

Research into trauma and bereavement in the general population has indicated that, once the traumatic circumstances surrounding a death are addressed, the individual focuses less on the trauma. Only then can an individual feel secure enough to begin the grieving process (Raphael & Dobson, 2000). This could further support the premise and may go some way to explain why some people with learning disabilities appear not to grieve initially. This area would merit further research but if it is proved to be the case, it is proved to be the case, bereavement therapy for people with learning disabilities across all orientations might need to focus on initially addressing any traumas. When there is a bereavement accompanied by trauma, it is important that attention is paid to the manner in which therapy is done and adapted to the specific needs of each individual. However, there must be clear end points in mind, with an especial focus on factors which will enable a person to live with what has occurred and facts which cannot be changed (Raphael & Martinek, 1997).

If one is to say that people with learning disabilities have a significantly higher incidence of trauma related to bereavement, then one might expect that the therapist could become vicariously traumatised. This was hypothesised to be the case when counselling children who had experienced a traumatic bereavement (Gamble, 2002) and may provide some insight into some of the difficulties and anxieties therapists experienced surrounding grief work with people with learning

disabilities. Indeed Gamble (2002) believes that this effect would apply to work with all clients regardless of their age or developmental stage.

However, some caution needs to be taken in interpreting these findings. Firstly, symptoms of trauma often go unrecognised in people with learning disabilities (Hollins & Sinason, 2000). Therefore it might not necessarily be the bereavement which triggers a traumatic response, but the trauma may have been something that was present and had never been recognised previously. Alternatively, it may be that clients are referred to counsellors precisely because traumas associated with the bereavement are making bereavement more difficult for them. This area would merit greater research.

The fact that many clients with learning disabilities were able to reveal past traumas once rapport had been established may be an indication that they may have fewer psychological defences than other individuals. This often occurred despite the paradox that these individuals were initially harder to reach. Therefore, the fact that a client is able to engage on such a profound level can result in an increased sense of achievement and reward for the counsellor, which was noted by participants.

#### **4.8 Bereavement and hope**

*“Seeing some change.....You know, it’d be the hope.” (07:07:02-04).*

Despite the challenges inherent in work with people with learning disabilities and the anxieties that the work can trigger in therapists, participants described that they were incredibly motivated in their work. Therapists found that their interventions enabled the true individual to emerge from behind the mask of their disability. From the despair and pain of bereavement, the client appeared to ‘*come alive*’ which was described as a “*really powerful experience*”. Clients were able to reveal things in therapy, which they had never previously been able to mention to anyone. Indeed, participants found that their clients had very profound, and often surprising, insights into their grief.

Some of the experiences described by participants appeared to echo the literature on hope in bereavement counselling. It has been suggested that people feel a greater sense of hope and ability to move on from the bereavement once their own abilities have been recognised (Cutcliffe, 2006). It seems that this would be especially relevant for the learning disabled population whose abilities have often been denied by a society which seeks to disable them. Cutcliffe (2006) found that hope increases with the self-awareness of a client. When they realise that they do not have to remain in a position of hopelessness or to be restricted by others who might have a controlling influence over them, clients come to the realisation that they are free to grieve for their loss, engendering a sense of hope at the awareness of their progress. This would seem to describe clients with learning disabilities well as they often have been denied the permission to grieve from those who support them.

Thus, the stages of the process of therapy which were identified above, in which any secondary disability was to be addressed initially, before going on to confront bereavement, enable these individuals to develop a recognition of their own *abilities* rather than *disabilities* and provide grounds for hope in which the bereavement can then be addressed.

This could explain the extent of the “*energy*” which was found in this bereavement work. It has been shown that energy can develop from a state of crisis. This can be the impetus for growth as it provides an opening in which obstacles to development can be addressed (Coles, 1964). The person with a learning disability is often not just inhibited by their mental capacity but also by other factors which have been addressed above, such as the secondary handicap which is influenced by the manner in which they are perceived by society (Sinason, 1992) and multiple and cumulative losses (Blackman, 2003).

People with a learning disability perhaps have a predisposition to the grief of a loss as, due to their learning disability, as they may often be considered to be a loss to society. The very nature of the learning disability also means that these individuals have a number of cognitive deficits, which make them more vulnerable. This vulnerability is heightened when they experience bereavement. If this is ignored it

can lead to further complications. On the other hand, if this grief is addressed it can be a turning point from which there is a great potential for the development of the individual (Erickson, 1964).

## **4.9 Conclusion**

A number of factors were found to be important for successful bereavement work in individuals with learning disabilities in addition to strategies used with other bereavement clients. This was formed into a six-stage model.

Therapists discussed a number of personal experiences which influenced their decision to pursue bereavement work with individuals who have a learning disability. This was explained in terms of their own experience of disability, relative social power or difficulties in their own bereavements. Therapists often held beliefs leading to a fear of disability. This was explained through a countertransference reaction of castration anxiety, leading to a lack of confidence in their ability to carry out effective work, and was found to increase with the severity of the disability. This led to a reluctance to work with severely or profoundly disabled clients, for many, and increased anxiety around achieving a successful outcome for others. It is likely that these anxieties were also affected by unresolved personal past experiences of bereavement which, if not addressed, may have implications for the practice of therapists.

Communication difficulties were another source of anxiety for counsellors who are exposed to the raw and painful feelings of a client's distress without language to disguise this. Aids to communication were used to a greater extent by less experienced counsellors and could be compared to the creation of a physical barrier between themselves and their 'imperfect' client. Experience brought a greater reliance on a client's speech or preferred method of expression and use of the therapeutic space. A disparity of expectations of clients and therapists could also be an obstacle for success. As a result, the counsellor must spend time aiding the client to understand the purpose of therapy before beginning the work.

Participants highlighted the significance of their own experiences of bereavements and recognised a number of anxieties that they held around working with death. A fear and anxiety of death is common in therapists, yet, this appeared to be more evident in therapists supporting those with learning disabilities. This was explained by the fact that learning disability itself can be considered to be a loss both the family and individual. It was acknowledged that society also aims a 'death wish' against these 'defective' individuals. It was suggested that this combination may cause the counsellor to recognise their own mortality and lead to feelings of guilt. Additional challenges may arise from a conflict with the desire to protect 'innocent' learning disabled clients from the pain of the reality of death. These feelings could be triggered each time bereavement is faced. With awareness and understanding of these feelings and experience, work with clients is improved and anxieties reduced. Despite this, therapists reported a continuous struggle with uncomfortable feelings regarding the extent of their client's pain. This can lead to greater stress in bereavement counselling work, which needs to be recognised and ameliorated through supervision, informal support groups, peer support and personal therapy.

A lack of provision of appropriate training for working with bereaved individuals with learning disabilities was highlighted. Thus, participants needed to constantly adapt therapy, requiring a great deal of mental effort and making their role more challenging. Society's views of their learning disabled clients as 'marginalised' and 'isolated' were reflected in the lack of interest and understanding of the value of this work. It is likely that wider availability of training would not only ameliorate this isolation but lead to more effective therapists.

Working with individuals with severe or profound learning disabilities aroused a greater degree of anxiety and helplessness in counsellors. This was explained by castration anxiety and guilt of the 'normal' therapist at the suffering of their more obviously disabled client at the hands of society. A lack of a means to evaluate progress made work more difficult. Many experienced therapists were reluctant to engage in this work, preferring to work on a behavioural level or to train care staff in grief interventions. Implications for the inclusivity of therapy were discussed which highlighted issues such as the anxiety and reluctance of carers to face

bereavement with those whom they support and the communication difficulties which may impede carers from this grief work. Complications in grief often occur precisely due its disenfranchisement. It was concluded that therapists share the taboos of the society, of which they are a part, of perceptions of individuals with severe learning disabilities, despite their experience and training. Thus, even therapists, could be guilty of denying the needs of these individuals. It was suggested that carrying out work with these clients could enable therapists to identify with the client and, thus reduce their prejudices.

Therapists often found bereavement work with clients with a learning disability to be slow, tedious and circular, leading to negative evaluation of their therapeutic input. This slow progress was explained as something which actually enables the learning disabled individual to achieve a number of tasks necessary to successfully complete the grieving process. It is hoped that recognition of this will steer therapists away from negative self-evaluation.

Counsellors experienced some difficulties with others in the system surrounding their clients who may view therapy as a dependency on the therapist. Research indicates that some level of dependency on the therapist is necessary for an effective therapeutic relationship, especially in clients with a learning disability. Therapists were strongly invested in their clients, leading to an increased sense of responsibility for their welfare which may carry risks of empathy fatigue. Therapists also expressed concerns about the level of the client's dependency. This was explained in terms of countertransference associated with 'fear of the loss of the object'. This fear perhaps also represents a counsellor's own need to be cared for. Fear of dependency is also suggested as an explanation for the increase of anxiety in proportion to the extent of disability.

Termination of counsellors' work due to the intervention of others was particularly challenging. The lack of ability to assess the effectiveness or achievement of contracted goals may be a threat to therapists' sense of adequacy. Termination of bereavement therapy is often more salient as it raises issues of therapists' own losses. This effect may be heightened due to the complicated or multiple nature of losses in this client group. Deciding to end therapy can be just as challenging;

premature endings could leave the client at a vulnerable stage or could lead the client to become over dependent on the therapeutic relationship.

Many clients with learning disabilities appeared to have experienced trauma associated with bereavement. This may be explained by a reduced understanding of the inevitability and universality of death. This may lead to the experience of death as a sudden, unexpected and untimely. The experience of disability itself may be experienced as a trauma, leading to a secondary emotional disability. It was suggested that delays in the expression of grief in people with learning disabilities may be due to experiencing traumas associated with the death. These, therefore, must be addressed prior to engaging in bereavement work. Therapists counselling those who have experienced a traumatic bereavement may be at risk of becoming vicariously traumatised, thus partially explaining their anxieties in the work. It remains unclear whether traumas are associated with the bereavement, with unidentified past traumas or whether traumatic bereavements would be more likely to be referred for therapy.

Therapists work became motivating when they witnessed clients emerge from behind '*the mask of their disability*'. It was suggested that the recognition of a client's abilities enables them move on from their grief. When their, often denied, right to grieve is recognised, a sense of hope emerges. Energy and growth may also develop from a state of crisis, leading to potential for greater growth as both grief and secondary disabilities are overcome.

#### **4.10 Limitations of this study**

Although this study produced some interesting results, it should be noted that a small sample of only ten participants was used. This provided a rich picture of the experiences of the participants interviewed but is not necessarily representative of the experiences of all counsellors/counselling psychologists in this field. Participants were asked to speak about the process of their work and any dilemmas they faced. Whilst it is assumed that participants were honest in recounting their experiences, it is recognised that any descriptions of client work may not give a full and accurate picture of the actual

experience, but rather are coloured by memory and the implicit interpretations of the participants. In order to fully observe process in therapy, one would need to observe each therapeutic session for client and counsellor interactions. A fuller picture would have been obtained by asking clients what they believed to be the factors contributing to effective therapy. This is an area into which this research could be extended.

#### **4.11 Recommendations for future research.**

This study highlighted a number of interesting points which might warrant future research. Counsellors were clearly affected by their therapeutic work with clients with learning disabilities. It might be interesting to discover the manner in which this may have affected their therapeutic practice and how they manage this anxiety. This might be useful both for training and supervision. A need was highlighted for professional counselling and counselling psychology training courses to focus on teaching skills of working therapeutically with people with learning disabilities, especially following bereavement or loss. This may serve to reduce some of the stresses, anxieties and isolation which counsellors reported experiencing around this work.

The identification by participants of the frequent need to address traumatic experiences connected to bereavement would merit further study aimed at examining the incidence of trauma in bereaved individuals with learning disabilities. Future research should focus on identifying the possible causes of this trauma and examining if the trauma was present prior to the bereavement i.e. an unrelated traumatic experience or the trauma of having/being diagnosed with a learning disability and if those with pre-existing trauma are more likely to be referred for help with bereavement issues. It would also be interesting to examine in further detail if bereavement triggers any traumas due to attachment difficulties with the caregiver.

Many of the anxieties of participants centred around their therapeutic success. The use of regular outcome measures may help counsellors to

monitor progress and receive feedback, and ultimately decide when to end therapy. More research on effective outcome measures for bereavement work in this client group may be indicated.

Furthermore, the finding of the lack of service provision for people with severe or profound learning disabilities should be examined further. If the responses of participants are substantiated, then more research may be needed in order to establish which interventions might help these individuals. This may also ameliorate some of the anxieties of professionals entering this challenging field. Service provision should be extended for these individuals in order to cater for their emotional needs and to provide equal access to services in line with Valuing People (2001). Some suggestions on effective interventions have been mentioned here but further training may be needed for therapists in effective ways of counselling this client group.

#### **4.12 Reflective Account**

This reflective account details my journey through this research study. It was compiled from my research diaries. This was the first time that I had used grounded theory. My journey can be likened to a roller coaster, with a steep climb up and then many ups and downs along the way. At times I struggled to grasp the principles behind and method of analysis used in grounded theory and spent many evenings sitting in front of a transcript attempting to categorise and code it. However, as I became more familiar with the approach, I came to enjoy it and the themes and categories which emerged. I spent much time moving index cards to examine themes and writing memos. At times, the coding was a struggle and I was brought back again and again to Strauss and Corbin's (1998) book. Many entries in my diary were to debate which direction my research should take and which was the most salient theme to focus on. I feel that I have gained a great deal from this research as I reflected:

*'I'm finding this really inspiring. I am inspired by participants' enthusiasm for the work and the sensitivity that they show. It is clear that some have*

*reflected a great deal on their practice and are very sensitive to the needs of people with learning disabilities’.*

When I began this research I was uncertain of the direction I wanted to take in my future career as a psychologist. However, I have been inspired to work with clients with learning disabilities. Below I will record some turning points for me in the research.

#### **4.12.1 The Departure from Process**

At the beginning of this research, I was concerned that the methodology I had chosen might not be the most effective for accurately examining process. I spent a great deal of time thinking about alternative methods I could be using, none of which seemed practical at the time. I spent some time discussing this with my colleague and pilot participant and refining the questions. At this point I decided to interview the first participant. All went well but he spent much of the time discussing his own experiences and feelings around his work, in responding to what were designed to be a few brief, preliminary, questions. I found myself caught up in this as his experiences were incredibly interesting and insightful, yet I also felt myself becoming frustrated as I saw time ticking by while we were not discussing process. We did discuss the process of work with his clients but it was not the detailed step by step account that I had wanted. This was similar with the next participant. I found that participants found it difficult to just talk about process. After thinking about this and analysing the emerging themes, I began to think that perhaps they talked about their own experiences and the way in which the work impacted on them for a reason. Perhaps that was what was important to them. By failing to pay attention to this, I would be failing the integrity of my participants and the responsibility to reflect their contributions accurately. Therefore the focus of the investigation gradually moved away from the process of the therapeutic relationship and began to focus on the experience of it for the counsellor. In fact it seemed to come full circle when I asked the last participant about his experiences and he himself brought up the process of working with one particular client. This indicated that examining effective interventions across time was clearly important in the work of participants, although this alone could not give a true picture of their work.

#### ***4.12.2 Severe Learning Disabilities and Communication***

One of the early participants reported anxieties around working with people with severe learning disabilities, especially around communication, although he actually trained others on the use of communication aids. There are a number of resources which have been developed or adapted for use with clients with learning disabilities. I was originally interested in how one might best put these resources into use in a therapeutic setting. There is limited guidance on this and I thought it might be useful for new counsellors entering the field. What surprised me was the unwillingness to actually use these! At first I was astounded, yet when I came to analyse the themes of the interview, I recognised that this was mostly due to the ability to use and fully engage in the counselling relationship with a client and it was later echoed by others.

One latter participant also reflected the anxiety of working with clients with severe learning disabilities, despite also being an experienced counsellor. In fact he even expressed strong thoughts that if these individuals were referred to his service, he would not be able to work with them effectively and that, to his knowledge, local individuals with severe learning disabilities received no one-to-one interventions. Initially, I found it truly shocking that counsellors who claimed to be specialists in the area of learning disabilities would be unwilling to work with someone with a severe learning disability. This prompted me to go back and ask other participants their views on the matter. I also took the time to reflect on this myself. The rater whom I had asked to look over my transcripts and categories, asked if I had distinguished between severe learning disabilities and communication difficulties. I realised that this was the problem. I had conceptualised someone, perhaps wheelchair bound but with communication problems. This did not necessarily mean that the learning disability was severe. I returned and re-categorised all instances of communication. I realised that one of my participants had also made the same mistake and had described a client with a moderate learning disability when asked to describe a client with a severe learning disability. I reflected on this, particularly in light of what one later participant pointed out, that someone with a truly severe learning disability would have an IQ of a five or six year old child. As I wondered if I could use a talking therapy with someone with little ability to leave concrete experiences, no longer did it seem so unfair. However, as I spoke to participants

who were comfortable in doing this work, I got a sense that it was indeed possible and found this a useful dimension to add to my research.

#### ***4.12.3 Energy in Death?***

One theme that emerged early on was that participants felt energised by their work with bereaved clients with learning disabilities. This was puzzling for me as, death is the antithesis to energy. After all I had worked with this client group: I did not recall ever having felt an energy when it came to the very painful work around bereavement and grief. I spent some time thinking about how this theme might relate to the research and then asked previous participants to elucidate on this, in addition to including it in some of the questions I was asking future participants. Although I had actually provisionally chosen the topic of this research earlier, I had recently been bereaved. I felt that, perhaps it was my feelings of grief which were getting in the way of this research and took time to acknowledge this. Participants described through descriptions of energy and hope how their clients seemed to come alive as they were able to somewhat overcome their disability or their grief and I was left with a sense of hope and promise.

#### ***4.12.4 Organising categories- building a model***

Although I very much enjoyed the research, I did find it hard to organise the themes into categories and eventually build this into a model. Initially, I found that there were just so many themes which emerged from the data that they were almost overwhelming. Participants were describing what appeared to be very complex processes and very diverse themes. I attempted many times to link these together and thought about several potential models. I was struck very much by the fact that it can be very much up to the researcher which model is ultimately chosen. Even when I finally chose a model which I felt best fit the data, I was still unsure as to which theme was dominant. However, I feel that Challenge is a good explanation but one that perhaps is not adequate. Where is the challenge coming from? I asked myself repeatedly. Immersion in the transcripts of participants allowed me to suggest that it is society itself which brings about these challenges, through marginalising people with learning disabilities; both the client and all those associated with them are affected. I shared this with participants who seemed to be in agreement with this theme. Overall I enjoyed the process of this research although it was challenging at times, akin to the theme of this thesis, as it

challenged me both personally and professionally as a researcher who was unfamiliar with a qualitative methodology.

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## **SECTION C: CLIENT STUDY**

### **Overcoming Anxiety: The Impact of Disability and Cultural Values on the Therapeutic Relationship**

## **Overcoming anxiety: The impact of disability and cultural values on the therapeutic relationship**

### **Preface**

Unlike the majority of this portfolio, this client study details the case of a client who had a physical, rather than an intellectual, disability. It highlights anxieties in myself as a therapist which were raised through work with an individual with a physical disability who, in addition, challenged the norms of society in another manner. This has remarkable similarities to the manner that participants in the research section of this portfolio described anxieties and fears raised through their work with individuals with an intellectual disability when the issue of bereavement, a topic also anathema to acceptable society, needed to be addressed. Thus, this can heighten our awareness that individuals with arrange of disabilities can arouse feelings and reactions within us that we may find challenging and which we need to continually challenge.

Until recently, individuals with intellectual disabilities were typically denied the right to have their sexuality recognised. In fact, at times, society has gone beyond this to actively prevent those with learning disabilities from reproducing. Individuals with physical disabilities have often faced similar challenges.

Society has projected a number of myths and fears about sexuality onto people with learning disabilities. These have served to segregate them from sexual relationships with the rest of the public. Early models viewed these individuals as having a childlike innocence, incapable of understanding sexual activity (e.g. Weihs, 1971) and in need of protection from the wider public. Later, with the advent of the eugenics movement, individuals with learning disabilities came to be viewed as a threat to the public. Single sex institutions were set up in order to protect the public from 'degenerates and perverts'. It has been suggested that these ideas may continue to influence how we see individuals, despite the move to normalisation and life in the community (Brown, 1994). Even fairly recent research backs this up (e.g. Griffiths, Quinsey & Hingsburger, 1989; Scotti, Slack, Bowman & Morris, 1996; Katz, Shemesh & Bizman, 2000). It has been suggested

(Brown,1994) that support workers are often reluctant to support those with learning disabilities to fulfil “*ordinary sexual roles*” as society continues to disapprove of these. In some respects, she suggests, society expects services to act as a “*container and regulator of sexual behaviour for people with learning disabilities*”. As a result, people with learning disabilities are commonly prevented from having age and socially appropriate sexual experiences (Griffiths et al.,1989). As Bratlinger (1983) argues, the rights of individuals with learning disabilities do not depend on the law but upon the attitudes and behaviours of those who support them i.e. it is ultimately the taboos and hidden agendas of society that govern actual practice.

There does seem to be some difference in attitudes towards sexuality in those with physical and with learning disabilities. Research (Katz et al., 2000) found that the attitudes of university students were more negative towards the sexuality of individuals with learning disabilities than to those with paraplegia. However, despite this finding, at least one third of their sample displayed similar negative attitudes towards both people with learning disabilities and people with paraplegia. Not only does this appear to apply to society but also affects the opinions of disabled individuals themselves. Research (Gerschick & Miller, 1995) indicated that men who had internalised societal expectations of masculinity and had attempted to meet these, had greater emotional problems, resulting from an inability to meet the social standards of ‘masculinity’. Shakespeare (1999) hypothesised that the ideology of maleness rests on the denial of weakness and vulnerability and possibly even the body itself. Disabled males are seen to represent a lack of control, frailty and mortality. These vulnerabilities are then projected onto ‘disabled’ males who then become maligned and ultimately rejected by society.

Rowbotham (1973) conjectures that “*our most personal, private, experiences are affected by external social relations*” (p.55) whilst Weeks (1989) suggests that “*sexuality is shaped by social forces*” (p.24). Thus, it appears that sexuality is learned and is at least, in part, a social construction. Sexuality has immense social value, yet can be described as being, not a goal which is aspired to, but rather, something with which to attain group membership and social status (Weeks,

1989). This is something, which is clearly the case in the society in which this case study is embedded. Marriage and having a family are seen culturally as something both expected, and indicative of responsible adulthood. For the client to have difficulty in these areas, to some extent robbed him of his manhood and adult status, leading to a sense of frustration in addition to the taboo of being physically disabled.

Gilbert (2007) states that, *“therapeutic relationships should not be decontextualised from the wider social arenas in which therapists operate”* (p.117). As I complete my training in counselling psychology, I have been reflecting on and reviewing my earlier work and my progress. This therapeutic relationship took place amidst a society that placed a number of expectations on both client and therapist as to how they would approach the issue of sexuality. In addition, this highlights the fact that societal values and the values of the therapist appear to impact on the therapeutic relationship in a similar manner when facing physical disability as it does when working with a client with an intellectual disability. In this light, this client study will be extended to examine the impact on the interpersonal relationship between therapist and client, of the values of the society of which the client and therapist are a part with reference to the issues and double taboos of sexuality and disability. These will be incorporated into the text as appropriate.

## **Part A- Introduction and the start of therapy**

I chose this case as it illustrates my struggle with a number of challenges, faced throughout the process of forming and maintaining a therapeutic relationship with the client. This work challenged me both personally and professionally. Personally, the client and I shared a similar cultural outlook. He sought therapy specifically because his difficulties challenged the values of a society in which he was raised, values which I also subscribed to. As therapists, our own assumptions can affect our work and this case challenged some my assumptions and expectations. I felt uncomfortable with some of the issues involved and, even, at times, felt threatened by the client. Professionally, this case illustrates the dichotomy which can exist within what is to be a collaborative relationship, where the counsellor believes that, in order to act in the client’s best therapeutic interests, therapy might need to

concentrate on something other than what the client believed to be his difficulty, whilst at the same time, wishing to maintain a good relationship with the client. As a trainee, this represented a major challenge to my confidence in the effectiveness of my therapeutic interventions and led to a reflection on and re-evaluation of my practice and skills. This study demonstrates how I was able to use supervision effectively to explore these issues.

## **1.1 Theoretical orientation**

Cognitive behavioural therapy (CBT) draws on both behavioural (e.g. Bandura, 1977) and cognitive models (e.g. Beck, 1970, 1976). According to this model, it is our perception and interpretation of events which lead to dysfunction, rather than the events themselves. Dysfunctional patterns of thinking can lead to dysfunctional behaviours which act to maintain emotional problems. Accordingly, events which are interpreted in different ways can elicit different emotions. Individuals commonly experience many events which elicit negative emotions. Sometimes these emotional reactions can be more intense or prolonged, interfering with the individuals' functioning. It is believed that these exaggerated emotional responses result from distorted or dysfunctional thoughts. These cognitive distortions can occur at three levels of thinking. *Automatic thoughts* occur spontaneously. They originate from *assumptions* which lie at a deeper cognitive level. These are more abstract and generalised and take the form of a set of rules, expressed as "shoulds" or "If-then" statements which can leave the individual vulnerable to critical experiences (Hawton, Salkovskis, Kirk & Clark, 1989). At the root of these assumptions lie *dysfunctional schemas*. These are basic models which the individual forms of themselves, the world and others.

### **1.1.1 Social Anxiety**

Anxiety disorders are due to deficits in information processing leading to a preoccupation with danger and the underestimation of the ability to cope (Beck, Emery & Greenberg, 1985). These reflect the activation of underlying hypervigilant cognitive schemas related to danger (Beck et al., 1985). These schemas contain assumptions and beliefs of danger and of the individual's inability to cope. Such overestimates of danger can automatically activate anxiety reactions (Beck, 1976).

There are a number of models of CBT for social anxiety and also specifically for heterosexual-social anxiety. According to a cognitive-evaluative framework, the source of heterosexual-social anxiety is in an individual's faulty cognitive-evaluative appraisal of his performance and the expectation of aversive consequences, and not in the performance itself (Smith, 1972). Therapy was based on such a model suggested by Clark and Wells (1995) who state that social phobia results from a desire of an individual to present him or herself in the best possible light to others while lacking confidence in their ability to do this. Social situations are therefore perceived as dangerous, where the individual may be rejected or humiliated by others. Upon entering a social situation rules, assumptions, and negative beliefs become activated. When individuals perceive themselves to be at risk of negative evaluation, an attentional shift occurs towards detailed self-observation, with monitoring of internal sensations and images. This internal information is associated with feeling anxious, and vivid or distorted images are imagined from an observer's perspective (Hackmann, Clark & McManus, 2000). Other factors which maintain social anxiety are safety behaviours; actions taken in situations perceived as dangerous which are designed to prevent feared catastrophes, and anticipatory and post-event processing focusing on the feelings and imagined images of the self in the event which leads to selective retrieval of past failures, encouraging negative self-processing in advance of social situations, which maintains this preoccupation with feelings and distorted self image.

## **1.2 Referral and setting**

Ari<sup>1</sup> self-referred to a private clinic in Jerusalem which specialises in training counsellors and is widely known as offering free counselling by trainees, in addition to a fee paying service from qualified counsellors. Ari asked for help with an addiction problem. He appeared to have a good knowledge of CBT and requested that he be treated using this approach.

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<sup>1</sup> Pseudonyms have been used throughout this client study in reference to all individuals mentioned and all identifying details have been changed.

### **1.3 Convening the first session**

Ari was well dressed in casual yet smart clothing and appeared to take care over his appearance. He seemed to be quite anxious, not making much eye contact, screwing up his eyes and constantly moving about in his seat. He had a tic, displaying an often pronounced, repeated sniff. As the session went on the tic became less pronounced and, although Ari remained quite tense and stiff in his movements, he appeared to be a little more at ease, leaning back in the chair. Despite the obvious anxiety, Ari engaged well and was eager and willing to talk to the therapist.

#### ***1.3.1 Client's View of Problem***

Ari came seeking help for 'addiction problems', however, when asked to describe these, he reported a belief that he had a problem with being addicted to masturbation. This was significant for him as his religious beliefs precluded masturbation and he requested help to stop this behaviour as he believed it to be a problem.

#### ***1.3.2 Assessment***

Assessment revealed that Ari had experienced anxiety problems in the past and suffered from Tourettes' Syndrome. Further discussion revealed that Ari was spending a great deal of time alone in his room and felt frustrated at his lack of social contact, especially with women. He believed that he was unable to realise his aim of marriage and his frustration led to 'sexual tension' and then to masturbation. This then led to guilt that, religiously, he should not be engaging in this behaviour.

Ari previously worked as a newspaper reporter and acted as a mentor to boys with special educational needs at a local college. Following a broken engagement three years previously, Ari reported that he found it harder and harder to go out in public and found socialising very difficult. He became distant from friends and found it hard to talk with others in his office, concentrating on his computer rather than talking to work colleagues during breaks. He also found it particularly difficult to

attend conferences where he was to report if there were ‘many beautiful women’ there. Ari found work increasingly difficult and eventually left to become a freelance editor working from home. At the time of assessment he had been working at home for one year and spent less and less time out of his home. He had ceased his participation in the mentoring project although he regularly received phone calls inviting him back. He had gone from attending synagogue three times daily (a requirement for Orthodox Jewish males) to only occasional attendance. He described this attendance as important and was frustrated that he was unable to attend. He had previously been studying in his spare time and now this was also at a halt as his previous two study partners had left when they got married. He felt unable to find a replacement who would ‘want him’. He also had a new flatmate of three months whom he had ‘never really spoken to’.

### ***1.3.3 Therapist’s view of difficulties and formulation***

I was quite surprised and even shocked when I discovered the nature of Ari’s ‘addiction problems’. Initially, I was very worried how I could possibly help him with this difficulty as it was very unlike the drug or alcohol addiction which I had expected. However, although Ari initially presented with a masturbation problem, he also described problems which affected many areas of his life. These difficulties were especially evident in social situations, particularly with young women. Therefore, I believed that the root of Ari’s difficulties lay in social anxiety. This may have been brought about or heightened by Ari’s failed dating experiences. Failures in dating encounters have been shown to result in a high degree of social anxiety (Curran, 1977).

Ari described having suffered from tics from his early teens and was diagnosed with Tourette’s Syndrome at age fourteen. The criteria for a diagnosis of Tourette’s are the presence of number of motor and at least one verbal tic with an age of onset prior to the age of 18. A tic is defined as a “*sudden, rapid, recurrent, nonrhythmic, stereotyped motor movement or vocalisation*”(DSM IV-TR, 2000). At the time of diagnosis, tics are experienced many times a day, often in bouts intermittently throughout a period of a year. The tics are suppressible; however they are commonly preceded by premonitory sensory phenomena, often experienced as an

uncomfortable sensation of the build up of tension which individuals can experience as needing to release (Prado et al, 2008).

In the past, Ari had been able to repress the urge to display tics and these had not affected his day to day life. However, currently he described a difficulty in successfully repressing these, particularly at times of heightened anxiety. In turn, these tics contributed to the experience of social anxiety due to the constant worry of how others might perceive any tics he displayed. This is often part of the symptomatology of Tourettes (Comings & Comings, 1987). Social anxiety or social phobia is described in DSM IV-TR (2000) as a '*marked and persistent fear of social or performance situations in which embarrassment may occur*'. This appeared to have worsened following Ari's broken engagement, which he saw as evidence of an inability to have successful relationships with women. Ari experienced immediate anxiety on exposure to social situations, which was significantly interfering with his daily routine, occupational functioning and social life, to the extent in which he had left his job and was working from home. Additionally, Ari described his current career as failing because he either avoided business meetings or cancelled them at the last minute as he became overwhelmed with anxiety. He had few friends as he did not feel comfortable to go out and had not even 'really spoken to' his new housemate of two months. Although Ari displayed heterosexual social anxiety, his anxiety was provoked by almost all social situations and therefore a generalised subtype of social phobia (DSM IV-TR, 2000) might be more appropriate. It is common in this case to show a greater lack of social skills and more severe life impairment. A score of 52 on the Beck Anxiety Inventory (Beck & Steer, 1990) indicated anxiety in the severe clinical range whilst a score of 19 on the Beck Depression Inventory II (Beck, 1996) indicated mild depression.

#### **1.4 Cognitive model of social anxiety**

A cross-sectional situational cognitive model (Wells and Clark, 1997) was constructed, linking the main negative automatic thoughts, safety behaviours, anxiety symptoms and the contents of self-consciousness.

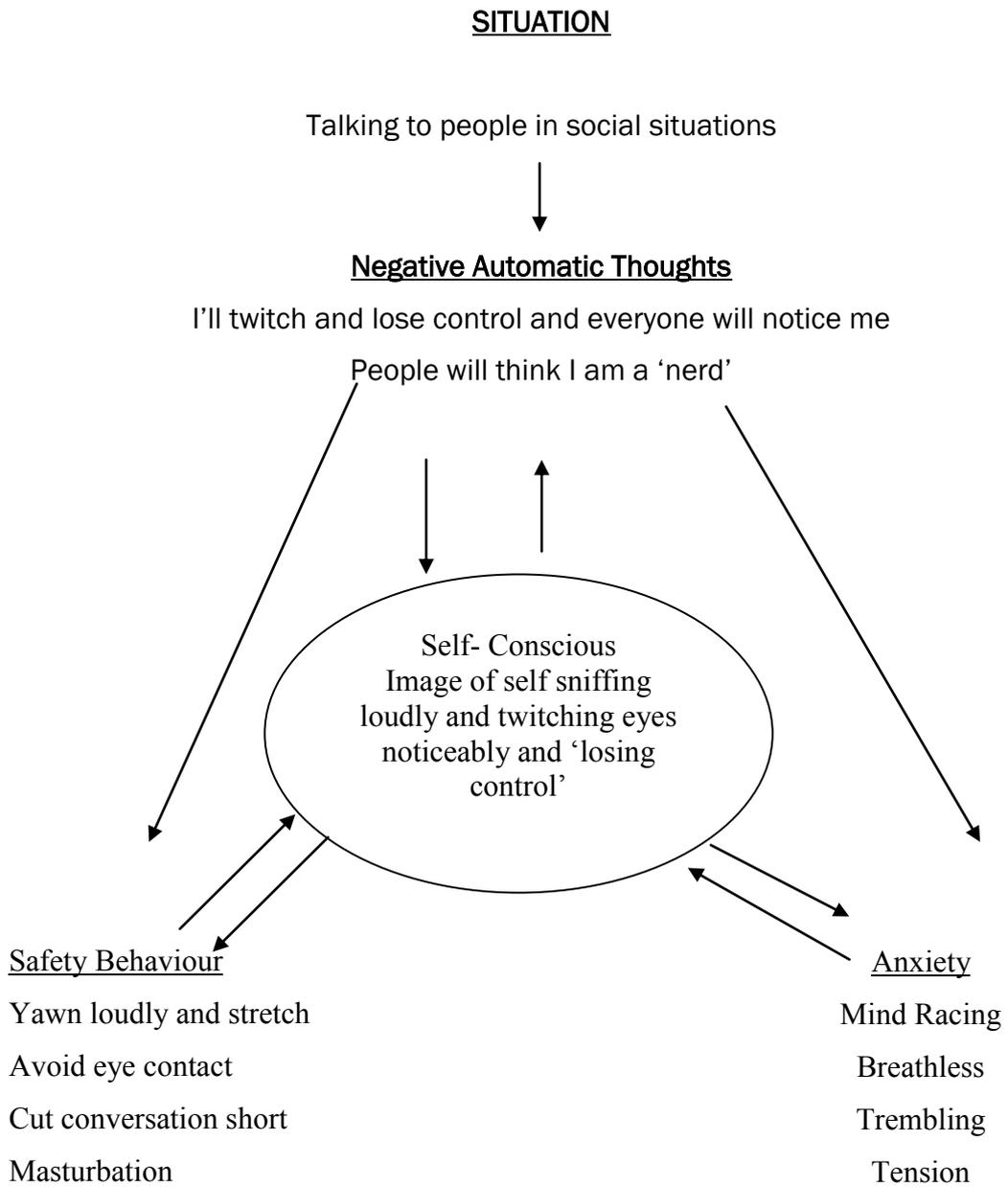
*Negative automatic thoughts* – ‘I’ll twitch/display tics and lose control and people (particularly women) will see me as stupid or inferior and I’ll look like I am trying too hard/being over-friendly’, ‘I’ll lose control’.

*Anxiety symptoms* – Increased sniffing/eye twitching, sweating/feeling hot, mind racing, dry mouth, feeling paralysed.

*Self-processing & imagery* – Self-conscious: ‘Everyone sees me sniff and twitch –it looks bad and I appear strange’. Image of self losing control sniffing loudly with wildly twitching eyes whilst others stare and keep their distance.

*Safety behaviours* – take deep breaths and yawn loudly with hands stretched out over head to disguise tics, avoid eye contact, talk little or rehearse sentences mentally before saying them. Run to toilets and masturbate before re-entering social situation.

The diagram below (figure 2.) illustrates the formulation in all these areas and their interaction.



*Figure 2. A cognitive model of social phobia adapted from Wells and Clark (1997)*

## 1.5 Negotiating a contract and therapeutic aims

Aware of the importance of collaborative empiricism to CBT (Beck & Emery, 1985) and in light of Ari's marked difficulties in social functioning, I engaged in some negotiation and discussion of the aims and goals of therapy with Ari. I was aware that Ari considered himself inferior to others and that it was likely that this and the social anxiety carried through into the therapeutic relationship (Gilbert, 2000; Heyes, Hope, VanDyke & Heimberg, 2007). Ari had read a great deal about the use of CBT for the treatment of addiction and I was aware that reconceptualising Ari's difficulties as a social phobia could be viewed as a threatening, which would have implications for the formation of a truly collaborative partnership (Beck, 1995), in which both client and therapist are "*on an equal footing in their quest for a shared goal*" (Liotti, 2004). Therefore, time was spent educating and socialising him into the cognitive model of social phobia in order to create a framework which enabled him to understand the vicious cycle of social anxiety, in particular his difficulties relating to women. This was achieved by examining occurrences of Ari's social anxiety in light of the (cognitive) model of Self-Regulation Framework of Emotional Vulnerability (Wells & Matthews, 1994; Clark & Wells, 1995). Guided discovery (Beck, 1995) was used both to explain the components of the model and to lead Ari to understand the role of the components of the model, and their interaction in maintaining his difficulties (Wells, 1997). We therefore decided to initially focus on confronting the social anxiety and to then focus on any addiction problems if Ari felt that they were still pertinent. We agreed on an initial contract of 12 sessions which could be revised if necessary.

As part of socialising Ari to the model, I felt that it was important to identify the role of masturbation in maintaining his social anxiety. I believed that identification and examination of his distorted thinking patterns regarding women, and his need for their approval, would allow for normalisation of his masturbation as a normal expression of sexual desire. This might have assuaged some of Ari's guilt about the behaviour. This did seem partially effective; however, Ari's concerns with his masturbation stemmed from cultural and religious expectations of male behaviour. According to Jewish law, male masturbation is prohibited. This is derived from Genesis (38:8-10). Rabbinic law brought in the Talmud forbids any act of '*ha-sh'cha'tat zerah*' (destruction of the seed), that is, ejaculation outside of the vagina.

Ari was clearly aware of the laws on this matter and, as Loewenthal (2006) suggests:

*“any indication that these practices can be condoned or supported is not appropriate for orthodox Jews, even though of course all these practices can and do happen. .... Therapists who do not share orthodox Jewish values and beliefs may think or suggest that an orthodox Jewish client is being made guilty or anxious as a result of religious prohibitions about sexual behaviour”*

Although Sue & Lam (2002) suggest that a shared culture of client and therapist can improve outcome and reduce premature termination of therapy, in this case, sharing the same taboos as both Ari, and the society of which we were both a part, made addressing these issues much more challenging for both of us. As an Orthodox Jew myself, I held a number of assumptions about male and female interactions and of appropriate behaviours. It is likely that these issues presented a threat to my self-schema (Bennett-Levy & Thwaites, 2007) and as such, may have limited my processing of these issues, in preference for a focus on the issue of social anxiety. It is possible that unconsciously, my body language might have also indicated some disapproving reactions which Ari had imagined receiving from society. It is also possible that some of my anxiety was communicated through my countertransference reactions (Leahy, 2001). However as Lowenthal (2006) states:

*“Appropriate therapeutic support can only be given by a therapist who understands that the religious prohibitions are givens, and the feelings and conflicts of clients must be dealt with in the context of the clients' probable acceptance that the laws about sexual behaviour are right, even if s/he does not find them easy or convenient.”*

Thus, I would need to accept that although Ari believed in the same laws as I, it was appropriate to support him to deal with the conflicts this evoked.

## **1.6 Biographical details**

Ari is a 28 year old Modern Orthodox Jewish male who is the oldest of three siblings. His two sisters are both married. At the age of 12 he moved with his family from the United States to Israel. His parents separated acrimoniously when he was

around 14 years old, which concluded with an 'ugly' divorce when he was around 18. Ari depicted a distant relationship with his father, nor did he feel close to his mother, describing feeling terrified to 'be on the wrong side of her' with a lack of trust in their relationship. Ari portrayed his relationship with his sisters as close, yet felt they often acted in a rather cool and detached manner towards him. He described having few friends and no close friends. Ari had a number of failed relationships with women. He was engaged to be married three years ago when the woman concerned broke off the relationship. Ari worked as a reporter for an English language newspaper until one year previously when he lost his job.

## **PART B - The development of the therapy**

### **2.1 The therapeutic process and changes over time**

In the initial assessment, Ari mentioned that he had difficulties in relating to women, especially those of a similar age to him. I was aware that I fell into both parts of this category, and that in another situation he might feel quite 'inferior' and 'intimidated' by me, as he had described feeling with other women. When clients feel inferior to the therapist feelings of shame and humiliation can result (Gilbert, 2000). This may have been particularly evident when discussing his masturbation. He did not mention such feelings, but it is likely that he attempted to hide them for fear of losing status in the relationship (Gilbert, 2000), particularly as he had a lack of success in other close female relationships. I felt this might affect the process of therapy. I mentioned my concerns about working with a female therapist to Ari in our initial session in order to check that he felt comfortable to form a therapeutic alliance with me. Although he was aware this might be a problem, he felt comfortable to go ahead with therapy. Upon reflection, I feel that this may have actually benefited the therapeutic process as I was able to help Ari model and role play talking naturally with a young woman. This became evidence that he was capable of coherent conversation with women. Initially, Ari came across as being nervous and uncomfortable in sessions and his tic was quite pronounced. However as the sessions went on, particularly after the fourth session, he appeared to become more relaxed and at ease, evidence of the tic was hardly noticeable and Ari became increasingly verbally descriptive.

It was clearly important to address Ari's social difficulties, nevertheless I wonder if it was largely my own anxieties which made me uncomfortable with the sexual issues and whether a focus on the social anxiety represented an avoidant strategy on my behalf (Leahy, 2007). In fact, particularly in the initial sessions, I felt threatened not only by these issues but by Ari himself. Due to the schedules of other therapists, at this time I was often alone with Ari in the clinic and was concerned about my safety. Although I aimed to provide therapeutic conditions of warmth and acceptance (Rogers, 1951) I feel that I might have been somewhat distant. It is likely that this affected the degree to which I was '*compassionately engaged*' (Gilbert, 2007) with Ari, being less than fully open and sensitive to his distress. Ari might have picked up on this as he mentioned masturbation less. At the time I assumed that this was probably due to normalising it, but might have been that he sensed my unease.

## **2.2 The therapeutic process and content**

Ari's functioning and progress was objectively assessed in each session with the Social Phobia Rating Scale (Wells, 1997), guiding the content of sessions (see appendix I).

### **2.2.1 Relaxation exercises**

Ari appeared to have had social skills in the past, evidenced by a good job and his past engagement. His interactions in therapeutic sessions also suggested that he possessed these skills to some extent. Therefore, it seemed that anxiety was preventing him from using these skills in other social situations (Curran, 1977). Initially, it seemed important that therapy focus on teaching anxiety reduction methods (Spense, 1994) as Ari reported being tense and unable to relax even at home. This would also allow Ari to demonstrate that he had some control over his symptoms (Clark, 1989). This was attempted through teaching Ari applied relaxation (Ost, 1987). He was initially enthusiastic, but did not want to continue using these techniques, being convinced of the efficacy of yawning loudly as a method of relaxation. I found Ari's inability to engage in relaxation to be quite frustrating. At this point I was also in a dilemma as Ari believed that yawning loudly

and stretching helped him to relax in social situations and disguised his tics. He failed to grasp this behaviour might actually be off-putting to others. I was torn between a need to raise this with him on one hand and a desire not breach the therapeutic relationship on the other, particularly as he was very sensitive to negative social evaluation. He may have believed that I was acting in a critical role, thereby confirming his belief that he acted in an inappropriate manner and thus reducing his status in my eyes, which might have confirmed his beliefs of social ineptitude with young females. I perhaps also held the negative assumption that I should avoid raising issues which cause conflict.

I found my lack of success at this point to be particularly difficult as he was the first client I had worked with who met a diagnosis of social phobia and I was relatively new to the model of CBT. I felt that it was not the application of the model, but rather I, who had failed. This appears to have highlighted a self-schema of being rejection-sensitive (Leahy, 2007) and it was this that was impeding therapy, as it paralysed me, stopping me from collaborating with the client to find a more effective solution. On reflection, I was hyper-vigilant to any possible instance in which I could have been failing with the therapy, which perhaps stems from personal issues but was highlighted by being a trainee and applying a model with which I still felt awkward, with a very vulnerable client. I was also wondering if this could work – had I bitten off more than I could chew? This was the start of a placement and I found it difficult to talk about apparent failure with my supervisor, particularly as there had initially been a number of issues around my awkwardness in seeing this client therapeutically. However, being able to be honest and laying my vulnerabilities in my apparent failure and worries as to my own lack of knowledge of the model open to my supervisor, improved our supervisory relationship. It also allowed her to support me to identify the stumbling blocks represented by schema that I held and as displayed in Ari's behaviours.

In retrospect, this apparent failure in engaging in relaxation was actually useful. Supervision enabled me to see that Ari was using the seemingly bizarre behaviour of yawning and stretching as a safety behaviour (Salkovskis, 1991) in social situations. The use of this behaviour may not only have prevented disconfirming evidence as to Ari's capability to tolerate social situations, from emerging but may

have also provided confirmatory evidence for his belief that people were looking at him and considering him to be 'weird' (Wells, 1997). In order for therapy to be successful the removal of safety behaviours needed to be targeted first.

### **2.2.2 Safety behaviours**

I encouraged Ari to complete some modified Dysfunctional Thoughts Records (Wells, 1997, see appendix I) in order to determine the negative automatic thoughts (NATs) (Beck, 1967) which occurred in social situations. Negative self-evaluation in addition to the fear of the negative evaluation of others is believed to be important in maintaining social phobia (Wells, 1997), therefore, Ari was asked to record any social situations, his emotions which occurred at the time and negative automatic thoughts regarding self-evaluations. From examining these together with Ari, it became clear that many NATs centred on feeling inferior to others. Guided discovery was used in order to enable Ari to understand that information collected was not objective but rather was due to his negative self-appraisal. These negative self-appraisals were then targeted for re-attribution. We searched for alternative explanations for the evidence, identified and aimed to alter thinking errors that were evident.

Work also began on decreasing safety behaviours and refocusing attention on external events, rather than on an internal analysis of his own behaviour that was evident from information through the thought records. Discussion of these also drew attention to other safety behaviours he was using. These included avoiding eye contact (so as not to see others' expressions) and cutting any conversation short.

I was aware that any implied criticism of Ari's behaviours might confirm his negative self-appraisals. I therefore, suggested that Ari attempt some behavioural experiments in which he would enter social situations without using safety behaviours. He was then asked to evaluate the reactions of others towards him, using a Social Balance Sheet (See Appendix I). The effective disconfirmation of belief in negative appraisals is moderated by both behavioural and attentional responses (Wells & Mathews, 1994). Ari returned the next week with very positive results, having managed not only to go out to synagogue but also to concentrate on

retaining an external focus for some of the time. He had talked to others, if only briefly, and assumed that they were most likely not staring at him but were willing to engage him in conversation. However he remained wary as to their motives. Although Ari had dropped his previous safety behaviours, he began to use a positive self-statement to allow himself to face the situation. 'I can do it, I am a cool guy. I am great'. Initially I believed that this would be helpful for Ari as it would help him to manage his anxiety and pre-occupation with himself which might impair his performance and might be useful in light of his negative self-appraisals that he was inferior and people would notice him twitch. However, upon further exploration, it appeared that Ari believed that repeating this statement prevented a catastrophic outcome in social situations (Wells & Clark, 1995) in which people would perceive him as 'weird' or 'uncool'. I was concerned that this was used as another safety behaviour, thereby preventing disconfirmatory evidence of an inability to cope in social situations. I discussed this with Ari who agreed to use it only when all else failed to help him combat any NATs as they were forming.

### ***2.2.3 Challenging negative self-processing***

In order to change the content of Ari's self-processing I asked him to have a brief conversation with my supervisor. This was videoed and enabled him to view himself in the same manner that others observe him. This was important as the (negative) way in which individuals attribute others' appraisals of them serves to maintain their low self-confidence (Wells, 1997). However, although my supervisor is female, she is older than the women whom Ari often feels particularly anxious around. I felt that, although Ari would be exposed to a social situation, it may not mirror the specific anxiety he felt with younger women he was attracted to. Upon reflection, this might have been beneficial, as all that was required was for him to view his performance in a social situation, and being with a younger woman may have been too anxiety provoking at this point. Initially, Ari was encouraged to run a 'mental video' (Wells, 1997) and describe behaviour that he felt he would demonstrate in the conversation, such as excessive twitching/tics and 'saying stupid things' as a way to measure his initial self-appraisals and compare these against objective evidence. Watching the video later indicated very limited evidence of twitching and, although his use of conversation was poor, he was able to have a short coherent dialogue. This gave Ari a picture of his real performance and provided some

evidence of the inaccuracy of his self-perception in social situations. A Social Balance Sheet (Wells & Clark, 1995) was also used to monitor internal and external evidence of NATs in this and other social situations and also to look for external disconfirming evidence. This was completed in sessions looking back at previous situations and evaluating exposure experiments together. Ari was also asked to try and record any evidence against his NATs which he noted on the social balance sheet when he was at home.

#### ***2.2.4 Anticipatory processing and post mortem***

Prior to social interaction, Ari believed that others would judge him as strange due to his tics, and not wish to spend time interacting with him, as he believed that they would perceive him as a 'nerd'. Together we reviewed how Ari saw himself in the experiment with my supervisor, and how this differed from his actual observed behaviour. Upon reviewing this, Ari came to the realisation that anticipatory processing (Wells & Clark, 1995) caused him to be prone to higher anxiety levels upon entering social situations, and those situations often did not turn out as he imagined them. Ari also realised that his processing after social encounters was equally flawed and this was leading him to continue to think of himself as a failure in this area. This was even to the extent of ignoring his documented successes and focusing on the negative post mortem as he had done with homework exercises (see below). Both of these processes were therefore outlawed; he was eventually able to see some positive confirmation of his abilities in social situations. By this time I felt much more comfortable working with Ari and no longer felt threatened; this can be seen from our improved working relationship and the fact that Ari was engaging better in the therapeutic relationship.

#### ***2.2.5 Work on residual negative thought/self appraisals***

Ari retained some thinking errors (Beck, 1995; Wells & Clark, 1995) particularly *mind reading* and *projected self appraisal*, believing his negative self-perception to be held by others 'I look stupid ... they think I am a nerd'. Work focused on education on the nature of thinking errors, looking for evidence and testing it using experiments e.g. when experiencing difficulty in talking to a girl, is she really thinking 'I am beautiful, I don't have time for a nerdy guy'?

### **2.2.5.1 Challenging conditional assumptions and beliefs**

Ari had a few conditional assumptions such as 'I am a failure so I am not a good role model'. Socratic questioning (Beck, 1967) was used in order to define Ari's exact fears. This allows and encourages clients to explore the meanings and implications of events and thoughts, making connections between them (Gilbert & Leahy, 2007). A *continua* technique (Padesky & Greenberger, 1995; Wells, 1997) was used to look at the definition of a good role model and the extent to which Ari's skills fit this description. Continua were also used to look at the characteristics of someone who was a 'failure', which enabled Ari to view his own considerable skills and talents. He also held conditional assumptions and some unconditional self-beliefs regarding his tics and regarding conversation with women, which were addressed in a similar manner.

## **2.3 Difficulties in the work and use of supervision**

Having initially assessed Ari, I was unsure if I felt confident to work with him. This was largely due to his expressed explicit thoughts and feelings of sexual desire when he saw women of my age or younger. I felt that perhaps he was sharing these feelings with me for his own sexual needs, rather than for any therapeutic benefit. I felt that working with a client, whom I perceived to be threatening, impacted on my therapeutic abilities and the ability to use what Bryne (1995) refers to as *theory of mind* i.e. the ability in therapy to deduce Ari's mental stages and behaviours. Feeling threatened by the client and being anxious in how to proceed therapeutically, led me to respond to Ari in a manner which was might have been defensive to the perceived threat (Holmes, 2005). I was also concerned about the cultural propriety of a young single man consulting with a young unmarried woman about a difficulty which appeared sexual in nature.

In Orthodox Jewish circles men and women are not encouraged to mix. In synagogue and at most social events unmarried men and women who are unrelated sit and socialise apart from each other, neither would it normally be appropriate to go out socially with one another. Young men and women commonly date through *shidduchim* or guided dating in which the man and women arrange dating through a *shadchan* or matchmaker. They will arrange to meet in a public

place where they can be unobtrusive but not be totally alone or secluded together. This is in accordance with Jewish laws prohibiting men and women who are not direct blood relations to be alone together or to have any physical contact e.g. holding hands. The man and woman may meet a number of times, during which they will discuss their general outlook on life and what they wish to achieve from marriage. No issues of a sexual nature would be discussed at these stages.

Thus, I was uncomfortable to be alone with Ari which raised issues of possible seclusion which might go against my religious beliefs and also could be a real risk to my personal safety. I felt particularly awkward to discuss issues of a sexual nature with an Orthodox Jewish male. Reflecting on this, I would have felt much more comfortable if this had been a non- Jewish or non- Orthodox male as, not only was the issue of sexuality so alien to this context, but, perhaps in some ways this represented a paradigm of my own dating situations.

After I and my supervisor had consulted with the clinic's religious advisor, I felt more comfortable with the situation as the advisor had given me some clear advice and guidelines about the situation. We followed his advice to continue to work with Ari as long as I felt comfortable, and to continue to discuss any concerns in supervision. This proved to be useful advice as, after the first two sessions, I realised that many of my concerns were unfounded. Support from my supervisor provided me with a feeling of safeness (Gilbert, 2007). I felt comfortable enough in my relationship with my supervisor to discuss my concerns and feel this is the reason I was able to remain with this client.

Initially, Ari was very enthusiastic about therapy and had clearly read a great deal of information on CBT. He expressed a great desire for improvement, and quickly came up with his own ideas for homework. However, after completing homework for the first few sessions, Ari appeared not to pay attention to his successes and continually changed the subject when I raised these with him, preferring to repeat a litany of his problems. . I tried to redirect Ari, yet progress seemed to be slow and I felt we were going around in circles. My supervisor suggested that I discuss this feeling with Ari. He revealed that he wanted to give up on CBT. He then went on to say that he had been to many different therapists seeking a 'cure' but had not

found one. He confided that he had also just begun seeing an alternative therapist as CBT did not appear to be the 'quick fix' he had imagined it to be. He thought he had incurable difficulties and whenever it appeared that his 'problem self' might feel threatened he gave up that therapy and tried a new one.

This indicated difficulties in the "*working alliance*" (Bordin, 1979) between Ari and I, that is the relationship between a client and therapist in which there is a therapeutic bond and an agreement on tasks and goals in therapy. It appears that my anxieties may have prevented this from developing effectively, which could have resulted in the failure of our therapeutic alliance (Horvath & Greenberg, 1986) and at how much Ari could be fully engaged in treatment and follow its recommendations (Horvath & Symonds, 1991). Ari may have arrived at his belief that his difficulties were 'incurable' due to the lack of interest which I may have initially appeared to demonstrate in them, and my anxieties at my own abilities to contain and help Ari therapeutically with these issues.

However, Ari believed that he had made a major step forward in being able to discover the NATs that he held, for example 'I am a failure and will always fail' and 'I have insurmountable problems which are incurable'. These had previously acted as a self-fulfilling prophecy, preventing the success of therapy. We discussed CBT as a collaborative relationship and how I would not be able to 'cure' him, but that the work had to come from himself. I shared a tentative hypothesis with Ari that he did not appear to want to recognise his successes in counselling and perhaps acknowledging his success would contradict the belief that he was a failure. Ari agreed and this became a turning point in therapy.

I asked Ari if he truthfully thought he would be able to try and complete a course of CBT; by the very action of doing so, he would be able to achieve a success. Ari agreed to try this seriously. This might also be due to the fact that, again, I was prepared to invest in the relationship, as I recognised and challenged my own prejudices, and Ari picked up my heightened acceptance of him. We renegotiated our contract to include the completion of a total of 15 sessions of CBT, while Ari agreed to put effort into working within sessions and completing homework tasks.

He also agreed not to see any other therapists simultaneously until he had finished a course of CBT.

## **2.4 Changes in the formulation and therapeutic plan**

The original therapeutic plan was changed, as Ari initially was unwilling to try out exposure to social situations due to his awkwardness with small talk. This deficit was apparent in role-plays and exposure offered in sessions. It indicated there was actually some evidence for his NATs. In line with Wells (1997), I taught Ari some strategies to develop socially appropriate behaviour. Using some techniques from overt behavioural social skills training (Kelley, 1982), I modelled the appropriate posture, volume of speech and topics for making small talk which we then practiced using role-play. These skills were then practised by Ari at home, in his imagination. Research indicates that both methods lead to short term improvement in social skills, with little difference in their effectiveness (Kazdin, 1982), whilst modelling serves to improve the efficacy of this practice (Friedman, 1971). Indeed, following practice, there was a noticeable improvement in Ari's conversational ability and he reported that his confidence had grown so that he was ready to try out exposure to a real life social situation.

### ***2.4.1 Overcoming residual avoidance***

By session six, I noted that Ari had not mentioned his masturbation for a while, which could have been due to my discomfort around it. As Ari and I reviewed his progress, I asked for feedback on his difficulty with masturbation. He might have seen this as an acceptance from me, not only of the behaviour but also of him. Indeed, discussion and support from my supervisor, as well as my developing confidence in therapeutic techniques, enabled me to feel 'safe' (Gilbert, 2007) in the therapeutic relationship with Ari. In this climate I was able to be more accepting of the behaviour which so contrasted with my personal beliefs. Ari was able to open up, and we discussed how much of his time continued to be spent alone and unstructured. This encouraged him towards negative anticipatory processing which both distressed him and prevented him from going out. When at home he engaged in negative rumination regarding his ex-girlfriend and worried about never getting married, leading to masturbation, and then a cycle of guilt. Ari suggested that

having a structure to his days and doing exercise would serve both to decrease this rumination and masturbation, and encourage him to leave his home. This was the first time, since the very early sessions, that Ari had volunteered his own ideas for behavioural work, perhaps marking a new stage in the relationship. Perhaps Ari's increased confidence was motivated by the confidence and trust which I displayed towards him, remaining in the relationship even when it was difficult for me. It was perhaps a novel experience for a woman to remain invested in Ari. We worked collaboratively (Beck et al., 1985) to develop activity scheduling (Beck, 1967). Structuring times for attending synagogue, exercise, working, tutoring and social activity proved successful in helping him leave his home and gradually gave him some social confidence.

## **Part C- The conclusion of the therapy and the review**

### **3.1 What I learnt from practice and theory, and of myself as a therapist**

At the time of completing this course of therapy, I noted that, Ari's lack of confidence in therapy represented a challenge to me as a trainee. I had not seen many clients using a CBT approach and was quite self-conscious about my own ability to be an effective therapist. I felt that my inexperience with CBT, especially as applied to social phobia, led to some difficulties in therapy. When I felt stuck, I often resorted to Person Centred techniques as was suggested by my supervisor. Although components of client-centred counselling such as unconditional positive regard and empathy should be used in CBT (Trower, Casey & Dryden, 1998) I felt, at times, lack of an adherence to clear agenda setting and its implementation was partially responsible for Ari becoming ensnared in a circular pattern of thinking. He often returned to focus on his difficulties rather than using or developing techniques to tackle them. I felt that perhaps my own lack of confidence in the model led Ari to abandon hope in it. Discussion of this in supervision led to increased awareness of my strengths and limitations, which enabled me to enter into a dialogue with the client. This allowed me to see beyond my own perceived capabilities, revealing a stumbling block for Ari in his past experience of therapy. The identification of this enabled him to confront and finally to overcome his fears

which led to the completion of his first course of therapy. My initial attempt at an intervention included the use of relaxation exercises. I had worked with anxiety problems previously but was unfamiliar with effective approaches for the treatment of social anxiety. Effective supervision enabled me to understand and use an effective comprehensive approach to alleviate his social anxiety. It was also clear that Ari was attempting to avoid some social situations. Completion of an avoidance questionnaire at each session might have identified these difficulties at an earlier stage.

Before meeting Ari, I considered myself as someone who held few biases and prejudices. I had spent a number of years working with people with mental illness and individuals with learning disabilities, confident that I was treating them equally and fighting for the rights of the socially oppressed. Therefore I was shocked at my reactions to Ari, which led me to examine my own beliefs and schemas as a therapist. I learned a lot about myself and also my ability to overcome my own difficulties, resulting in a successful outcome.

### **3.2 The therapeutic ending and evaluation of the work**

As a result of therapy, Ari compiled daily and weekly schedules of activities. He began tutoring again, although he found it difficult at first. He also advertised and was set up with a study partner. Gradually, Ari began to go back to synagogue at least once a day and began talking to some male peers. Weekly exposure led to Ari feeling increasingly confident in social situations. By the end of therapy, Ari had attended a social event where he successfully and competently spoke to a young woman in a brief conversation. Ari's anxiety about masturbation reduced and he reported that it had become much less of a problem. He thought this was mainly due to activity scheduling and feeling less anxious about relationships. Although he did still masturbate to some extent, he now believed himself to be more in control of it. He was offered extra sessions in order to focus on any remaining difficulties regarding masturbation, which he declined, believing he was able to manage this himself. Ari may have picked up on my discomfort in discussing the subject which could be the reason for this, however, this seems unlikely as he reported having regained a sense of control in different areas of his life. However, one area which

remained a problem for Ari was in speaking with women. Wells (1997) suggests that the therapist accompany the client into social situations to carry out 'bandwidth' experiments, in which Ari would have been asked to attempt to demonstrate severe tics and a failure at conversation with a woman in order to observe the reactions of others. This was not carried out, partly because I felt uncomfortable. This was due both to my own inhibitions, and cultural factors in the religious community of Jerusalem disapproving of an unmarried woman going out socially with a man. Upon reflection, some of this work could have been carried out by going to a local supermarket and might have helped Ari to realise that the event that he feared would not occur.

Overall, although this work was particularly challenging for me, it caused me to identify and challenge some of my own beliefs and assumptions which impacted on my practice and a sense of success at the improvement in Ari's symptoms.

## **4.1 Conclusion**

In conclusion, this client study highlights some of the issues faced when a therapist without a disability sees a client to whom society has ascribed a disability. This raised issues of anxiety, awkwardness and uncertainty in myself as a therapist. This was compounded by my relative lack of experience and by issues of sexuality which the client presented with. These themes appear to reflect some of the reported experiences of therapists carrying out bereavement counselling for clients with learning disabilities (see thesis above).

Society, which is afraid of becoming damaged, projects their own insecurities onto those who are considered to be disabled. If the emotional pain of the disabled was recognised, society would be forced to accept their own deficiencies, thus these subjects become taboo. In response to emotional discomfort caused by taboos, strategies of denial are created i.e. that disabled people are not capable of experiencing these feelings. Thus, Ari being disabled and expressing difficulties with sexuality faced a double taboo. In this case, issues of sexuality were complicated by the religious-cultural environment. These sexual issues were

something which were considered to be unacceptable and taboo by the society and, by extension, by myself as a therapist who was also a member of this society.

In a similar way, learning disability is a societal taboo and issues such as bereavement or sexuality are seen as another taboo by society, leading to denial of the right of these disabled individuals to express any feelings about these issues. Despite my professed dislike of the differential treatment of those who are viewed as different or disabled, the views of the society, of which I was a part, affected not only my perceptions of the client I was working with, but led to a number of difficulties and anxieties in the work as I grappled with these issues. Ultimately these attitudes affected the therapeutic relationship and therapeutic work.

I felt a sense of isolation in this work, as, although I was able to discuss these issues in supervision, I was very much aware of the taboo nature of these issues with my colleagues. When I did attempt to discuss this during group supervision, this was something that the group did not appear to want to hear. Again this mirrors the experiences of therapists working with individuals with learning disability who have experienced a bereavement and is perhaps indicative of the affect of challenging a societal taboo by discussing these painful issues. However, akin to therapists working with bereaved individuals with learning disabilities, the recognition of these issues and my own assumptions, beliefs, anxieties and fears through supervision, led to an improvement in the therapeutic relationship, reengaging Ari. This enabled me to grow and develop as a therapist and to experience a sense of achievement and exhilaration at the success of therapy.

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## **Section D: Critical Literature Review**

### **The Effectiveness and Delivery of Bereavement Counselling for Adults with Learning Disabilities**

# The effectiveness and delivery of bereavement counselling for adults with learning disabilities

## Abstract

Relatively little empirical research has been carried into the benefits and effectiveness of techniques of bereavement counselling for adults with learning disabilities. Psychinfo, Medline and the British Nursing Index were used to find relevant literature, which was then examined in detail. This paper reviews the literature and looks at some methodological limitations, which exist in much literature in this area. It then goes on to suggest opportunities for further research.

## 1. Introduction

Adults with learning disabilities have been shown to react to bereavement in a similar emotional manner to the rest of the population (Bonell-Pascual et al., 1999). However, there is often an absence of support and information to enable them to understand and cope with the experience of loss.

Carers often overlook or misinterpret grief responses in adults with learning disabilities (Oswin, 1991). They are often excluded from death rituals, such as funerals (Conboy-Hill, 1992; Oswin, 1991), which can facilitate healthy grieving (Worden, 1983). Until recently, counselling was not recognised as a useful intervention with this client group, with interventions focusing instead on either medication or behaviour therapy (Crick, 1998; Elliott, 1995). Despite the fact that some individuals with a learning disability may not have the ability to express their grief (Yanok & Beifus, 1993), Oswin (1991) observed they

*"have the same stages of grief as anyone else, the right to grieve as individuals, the same right to consideration and to special help for particular difficulties".*

Indeed, counselling may be even more important for these individuals as they often do not receive enough information and support to enable them to cope with their

experiences and emotions following bereavement (Stoddart, Burke & Temple, 2002). They often have limited social networks (Robertson et al., 2001) and, in some cases, they may have lost the main carer upon whom they relied on for emotional support and who understood their communication (Kitching, 1997; Hollins & Sireling, 1991). Research suggests that learning disability is a predictor of atypical and prolonged grief, and points out the importance of the impact of bereavement on challenging behaviour (Hollins & Esterhuyzen, 1997; Bonell-Pascual et al, 1999).

The majority of literature regarding psychotherapeutic interventions for individuals with learning disabilities focuses on the process, rather than on the outcome of therapy (O'Hara & Sperlinger, 1997) with little empirical investigation of the outcomes and effectiveness of interventions (Stoddart et al, 2002; Summers & Witts, 2003; Read, 1996) with Summers & Witts (2003) calling for more research to be carried out to evaluate different interventions.

A critical review of the outcomes of psychotherapeutic interventions following bereavement in individuals with learning disabilities is needed to inform professionals of the usefulness of varying therapeutic approaches and methods. It seeks to pinpoint gaps in our knowledge of outcomes and thereby stimulate research into these areas. This literature review aims to collate relevant research in this area and presents ideas for future study.

Literature on the use of and effectiveness of bereavement counselling for adults with learning disabilities is reviewed briefly, followed by a more detailed review of clinical studies of bereavement counselling.

## **1.1 The need for counselling**

Many case studies describe the reactions to individuals of varying cognitive levels to the loss of friends, relatives, carers and even pets (Brandt & Bower, 1975, Kloeppel & Hollins, 1989; Hollins & Esterhuyzen, 1997, for example). These reactions are often expressed behaviourally. Such responses may include self - injury, selective mutism, anorexia, loss of continence and aggression (Conboy-Hill,

1992). Therefore it seems likely that individuals with a learning disability do both perceive and respond to loss; the perception is likely to vary with the level of their cognitive development and behavioural reactions may differ widely from observed reactions in studies of grief with individuals of average cognitive functioning (Conboy-Hill, 1992).

Individuals may not always need therapeutic interventions to adjust to a loss if their feelings are acknowledged and they are supported (Elliott, 1995). Bonell-Pascual et al (1999) followed up parentally bereaved adults who had displayed heightened behavioural disturbance following bereavement. Five years later, those whose basic emotional needs had been met *constructively* by carers adapted to the loss with greater ease. However, delayed or prolonged grief was particularly common in individuals who did not receive any bereavement- related intervention.

## **1.2 Techniques to facilitate effective bereavement counselling**

The majority of approaches to bereavement counselling for individuals with learning disabilities examined were found to be based on Worden's (1983) task model of grief counselling (Cathcart, 1995). The use of such a model was suggested by Elliott (1995). Other methods of bereavement counselling have also been used with varying results including a combination of psycho-education followed by a psychodynamic approach (Summers & Witts, 2003), a psycho-educational structured workshop (Read, Papakosta-Harvey & Bower, 2000) and an integrated intervention based on the Dual Process Model of bereavement of Stroebe & Schut (1999) (Dowling, Hubert, White & Hollins, 2006).

Some adaptations to bereavement counselling for individuals with a learning disability have been suggested. See table 3. below:

**Table 3 .Worden's grief tasks - adaptations for clients with learning disabilities.**

<b>Worden's Tasks</b>	<b>Adaptations for individuals with learning disabilities</b>	<b>Methods Used</b>
<b>1. Accepting the reality of the loss</b>	<p>Facilitating individuals to realise the person whom they are grieving over is dead and will not return</p> <p>Enable individual to comprehend both emotionally and cognitively the finality of death (Conboy-Hill,1992)</p>	<p>Establish individual's understanding of death. Establish how individual was informed of the death. Visit the graveside (Elliott, 1995); Visit the hospital where deceased died (Kitching, 1987).</p> <p>Create photograph album of significant events in individual's life including the deceased and the grave (Elliott, 1995); a book recording memories and significant events (Dowling et al, 2006); a life event book, memorial prayer service (Gault, 2003), family trees or genograms; eco map; pictorial books about death, e.g. <i>When Dad Died</i> (Hollins &amp; Sireling, 1989; Read, Frost, Messenger &amp; Oates, 1999).</p>
<b>2. Working through the pain of grief</b>	<p>Exploring feelings individual has following the bereavement.</p>	<p>Discussion of emotions and how these are expressed (Gault, 2003); pictures of blank faces and body outlines to facilitate exploration of emotional and physical understanding and effects.</p>
<b>3. Adapting to an environment in which the person is missing</b>	<p>Exploration of coping skills following the death and life without the deceased.</p>	<p>Discussion of how life presently differs from when the deceased was alive (Elliott, 1995).</p>

<p><b>4. Emotionally relocate the deceased and move on with life</b></p>	<p>Encourage client to reminisce about the deceased</p>	<p>Photographs and objects which have special significance for the individual (Elliott, Kitching, 1987 ); record recent life events to indicate that life did not cease following the death (Gault, 2003) poetry; memory boxes (Read et al, 1999); Devising and attending a memorial service for the deceased (Kitching, 1987; Blackman ,2003)</p>
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### **1.3 Effectiveness of individual bereavement counselling as a therapeutic intervention**

Studies using counselling as an intervention have met with a great deal of success amongst individuals with learning disabilities. However, relatively few studies were found with any evaluation of the outcome of these interventions.

Dowling, Hubert, White & Hollins (2006) found a bereavement counselling intervention based on Worden’s grief tasks (1983) to be very effective. Prior to the counselling, carers viewed many behavioural reactions to loss as a function of the individual's learning disability. Following counselling, carers related that irritability and anxiety displayed by individuals when in group situations had lessened whilst some developed better strategies to communicate their feelings. As a result, some individuals went on to form new friendships whilst others developed new interests. The authors quote several inspiring stories of bereaved individuals who had difficulties in a number of areas and underwent ‘remarkable changes’ after counselling. For example, one participant reported that talking to a counsellor helped her a lot, a book she made together with her counsellor containing memories and the things which were important to her, appeared to comfort her and relationships with other members of her family improved. Carers noted another participant’s great anger had reduced since counselling and he was more able to enjoy life. The authors reported that, even for those who experienced less dramatic changes, an improvement was seen in their quality of life and emotional well-being,

developing a more positive mindset and being more settled in their home environments especially when moving was associated with the loss. The counselling relationship was considered to be uniquely important to participants, providing someone who was interested in them and their feelings. However, in three cases, counselling produced no noticeable changes either quantitatively or qualitatively; the authors point out that this may be due to other factors including a lack of engagement in therapeutic sessions and more recent bereavements. Carers reported counselling to be a useful, effective and practical intervention for individuals with learning disabilities and easy to incorporate into people's lives. Many counsellors also described how they were able to see the changes in individuals as the sessions went on and were surprised at how well the counselling had gone. Many felt that a very 'deep and trusting' relationship had been formed in counselling.

This was in stark contrast to an 'integrated intervention' also developed by the authors based on Stroebe & Schut's (1999) Dual Process Model which proved difficult and impractical to deliver. Carers often did not have time to carry out the intervention correctly, leading to disappointment and, in some cases, resentment by clients who were bereaved. Staff were also affected by their own losses, which influenced the support they were able to provide. Training regarding this prior to the intervention may have enabled them to maintain clear boundaries and treat the clients more sensitively (Blackman, 2002). In the one case where this intervention was carried out successfully, improvement was seen on a similar scale. Then again, the individuals delivering the only successful intervention were trained bereavement counsellors whereas carers delivered it in all other cases. This study indicates the marked effects which bereavement counselling can have for individuals with a learning disability and highlights the importance of substantial training in bereavement for those carrying out the interventions. However, methodological limitations of the study do not allow us to rule out the possible benefits that an integrated intervention may also bring when carried out with enough time and by trained professionals.

The bereavement counselling intervention appeared to be effective even though counsellors received only two days training, having never previously worked with

individuals with a learning disability. Therefore, the establishment of some training for trainee bereavement counsellors and psychologists may help to facilitate more effective interventions for this oft neglected group in the future. In particular Conboy-Hill (1992) points out that counsellors often do not know how to work with individuals with a learning disability, needing to develop more flexible and adaptable approaches (Read et al, 1999).

Summers & Witts (2003) published a case study of the psychodynamic and psycho-educational treatment of a woman with a learning disability who had been bereaved. Treatment met with some, limited, success. Joanne, a woman in her mid-forties with a moderate to severe learning disability had sporadic contact with her family prior to her father's death and there were suggestions of abuse and physical neglect in her childhood. Shortly prior to her father's death she saw him for the first time in 10 years. She was unusually quiet when her father visited and when she heard of his death looked 'ecstatic'. She did not attend her father's funeral or cremation. Following the bereavement, Joanne became incontinent of urine and faeces and was '*increasingly distressed and tearful*', developing a persistent cough. She seemed to be confused about the meaning of her father's death.

Twelve sessions of therapy were offered, consisting of psycho-educational and psychodynamic aspects. The first part of therapy was aimed at helping Joanne understand the meaning of death and the book *When Dad Died* (Hollins & Sireling, 1989) was used as an aid. The authors report that at the beginning of therapy Joanne found it difficult to express her feelings. They explain this in terms of feeling guilty about expressing negative feelings and therefore projecting them on to others. Later on in the therapy she was more comfortable in expressing her feelings, becoming able to understand that her father was dead and its implications. Staff reported that following the intervention; Joanne was less confused about the death and both her incontinence and cough ceased. However, although there was a reduction in her angry outbursts, distress and tearfulness, Joanne's mood remained changeable. This indicates that the therapy was partially successful, yet, no standardised measures were used, rather relying on staff and the therapist's opinions which are quite likely to be biased. Individuals with a learning disability have been found to be capable of evaluating the effectiveness of

a therapy themselves although one may need to be creative to enable them to express their opinions (Blackman, 2003).

Elliott (1995) describes the case study of seventeen-year-old Mark, who had been bereaved of his mother. His father reported that prior to beginning counselling he occasionally lost his temper for no obvious reason. After creating an eco-map and diagram of significant people in his life, Elliott observed Mark beginning to relax. Following counselling using Worden's (1983) task model, Mark's father reported that his son was more communicative and expressive of his feelings.

Another case study by Kitching (1987) describes JB, a woman in her mid forties with a learning disability whose mother had died of cancer. When told of the death she did not show any sadness but later became more withdrawn, took less pride in her possessions, appearance and had less interest in her hobbies and activities she used to enjoy. Ten months following the death she showed increasing signs of anxiety, did not want to be left alone and cried a great deal, she complained of pain when none was evident and then was very aggressive to staff and residents. She started a process of 'guided mourning' and psychodynamic counselling. At first she sat quietly or cried, later became angry with the psychologist and then with her mother for leaving her. She gradually began to talk about her mother but needed much encouragement and support. After counselling, JB's aggressive behaviour vanished, however she remained slightly withdrawn and appeared wary of people in a new hostel she moved to suggesting that counselling had indeed helped her but was not completely effective.

A case study by Gault (2003) considered "Mr Croft", whose father died suddenly. He did not attend the funeral. Over the next five years Mr Croft became growingly agitated and upset over the death until he reached the stage where he was inconsolable over any mention of death. A counselling picture book facilitated education about death and discussion of emotions whilst a life event book was compiled and used to identify people whom Mr Croft had known who had died, allowing death to be discussed without mentioning his father. A focus on positive memories of his father enabled Mr Croft to discuss his father's death without becoming distressed for the first time in many years. A short church prayer service

was held for Mr Croft's father and later became a focal point for his grief. The authors report a change in Mr Croft's behaviour following counselling, being able to enter a church, say a prayer for his father and light a memorial candle which would have been inconceivable before counselling. This represents some concrete, observable changes but again, no attempts were made to use standardised measures.

On the whole, therapeutic grief work for individuals with learning disabilities appears to be highly effective and to be judged useful both by participants, carers and therapists although there is a lack of empirical evidence.

#### **1.4 Bereavement/Death Education Groups**

Bereavement groups can be effective as they empower individuals by allowing them to offer their advice and experiences to the rest of the group. This both boosts the person's self-confidence and self-esteem, in addition to reducing group members' dependence on facilitators for the answers (Blackman & O'Driscoll 2003). Observing other people coping with grief can help those with a learning disability to be aware of how normal the uncomfortable feelings associated with loss are (Hollins & Esterhuyzen, 1997). Additionally, research has indicated that, in order to ensure understanding and reduce behavioural disturbance, both non-verbal methods of communication and continual explanations of new experiences are necessary (Hollins & Sireling, 1991).

Yanok & Beifus (1993) developed an educational curriculum, Communicating About Loss and Mourning (CALM), which involved the delivery of eight, fifty-minute sessions involving education about dying, death and common terminology surrounding death. Materials such as pictures and tangible objects were used in addition to group discussion in which individuals related their own thoughts and worries about death. In comparison with a control group, there was a significantly greater understanding of death amongst group participants, following the intervention. The authors hoped that small successive doses of distress provided by the CALM programme would reduce participants' suffering during the group and

allow quicker recovery from greater distress in the future, with the aim of preventing chronic grief. They conclude that adults with learning disabilities both have a need for, and can benefit from, death education and grief counselling. It must be noted, however, that not all experimental participants scored well when tested on their knowledge of death at the end of the course and almost half of them were unable to tell another person directly that he would die eventually, yet perhaps many individuals without learning disabilities would also find this difficult due to social norms.

Read, Papakosta-Harvey & Bower (2000) developed educationally based workshops on loss aimed at enabling participants to explore issues surrounding loss in a safe, structured setting. The group was evaluated both by participants and therapists. Although participants related that some topics triggered painful memories, they reported having enjoyed the workshop overall. Additionally the assertiveness and confidence of group members increased and they were able to express their thoughts and feelings more easily.

Stoddart et al (2002) offered eight, weekly, sessions of a structured counselling group to individuals already receiving individual counselling. Results were mixed with some measures indicating an improvement whilst others showed no change. This may be due to mainly methodological factors as will be discussed later. Scores on two measures of depression significantly reduced following group participation yet whilst one measure (The Children's Depression Inventory – short Form) was considerably lower than the threshold for clinical depression, another (Hopkins Symptom Checklist-25; depression subscale) remained in the range for mild depression. A measure of anxiety showed little change, remaining in the mild range. Neither did participants' understanding of the loss and bereavement process improve. However, the authors report that scores were high before the intervention, indicating that participants had a substantial understanding before therapy. This may be due to having received individual counselling previously. When split by diagnosis, participants with a dual diagnosis were found to have significantly improved on both depression scales but not anxiety. On the other hand, participants with only a learning disability did not show any significant changes on these measures. Individuals with a dual diagnosis of learning

disabilities and mental ill health had higher initial levels of anxiety and depression. This highlights the importance of splitting participants by diagnoses when analysing the effects of counselling, which others (eg. Dowling et al, 2006; Read et al, 2000) failed to take into account, perhaps skewing their results.

Mappin & Hanlon (2005) based an educational bereavement group on that of Yanok & Beifus (1993). The group aimed to establish an understanding of the concepts of death and dying, reactions to, and emotions, behaviours and physical sensations following, grief and, lastly, to develop some strategies for coping with death. Results pointed towards an increase in the understanding of both the physical aspects of death and dying and emotional, physiological and behavioural reactions to it. However participants' concept of death showed little improvement. The authors mention that this could be due to a high score prior to the study. This shows a similarity to the findings of Stoddart et al (2002) who comment that the great variation between their findings and those of Yanok & Beifus (1993) may be due to a their questionnaire being a much longer 28 item compared with Yanok & Beifus's eight item measure. Mappin & Hanlon's use of a fourteen-item measure may also account for some differences. However, these three pieces of research were measured using different questionnaires, which were not standardised, and this might be the cause for the differing results. It may also be possible that individuals who are referred to a bereavement group benefit from a support system capable of providing the necessary understanding and support to cope with bereavement (Stoddart et al, 2002).

In criticism of these studies, Llewellyn (2006) questions the relevance of the group which Mappin and Hanlon's term a 'bereavement group', which was carried out with participants many of whom had not actually been bereaved. If this was intended as a bereavement *education* group, the use of abstract pictures of emotions in order to develop an understanding of death is questionable and may not generalise easily to being able to cope with and recognise these emotions following bereavement. Furthermore, many individuals with a learning disability lack strong support networks, often depending on staff supporting them to enable them to express their emotions. Rather than educating clients in a group, a more effective use of resources may be to educate carers to support their clients

following bereavement, providing more sensitive support tailored to each individual. However, as mentioned above, group support has been shown to be very effective following bereavement in terms of emotional support and normalisation of grief reactions (Blackman & O'Driscoll 2003).

### **1.5 Counselling and staff training and support**

Conboy-Hill (1992) suggests running workshops for carers to enable them to support clients through the normal grieving process should include analysis of how loss impacts on clients and guidelines for active listening.

Blackman (2002) describes a systemic approach to grief therapy. The ROC loss and bereavement intervention provides both individual therapy and training to staff supporting the individual. The intervention aimed to provide support outside the therapeutic setting to maintain the effects of therapy and to build the confidence of staff working with the bereaved. Staff training was delivered over two days. The first day dealt with loss and bereavement and how this applies to individuals with learning disabilities. The second day focused on the specific needs of the individual, with the aim of staff developing an understanding of the therapeutic process and a consistent, effective approach to support it.

This paper does not mention any outcome measures yet the author reports that referrals to the service began to focus on those experiencing complicated grieving rather than *all* bereaved individuals with learning disabilities. She takes this as confirming her hypotheses regarding the effectiveness of offering staff training as part of the therapeutic approach. However, the author does mention that the effect may be due to the referring teams growing to understand the criteria of the, now better-established, service.

Staff may indeed now feel more confident in addressing grieving clients needs but there is, as yet, no empirical proof of this. Outcome measures are needed in order to examine this closer. However, on a positive note, Blackman mentions the joint venture between therapist and staff enabled the development of a more integrated therapeutic approach, which, she claims, led to 'long term positive changes once

the therapy ends'. Blackman predicts that training will allow staff to provide more emotional support, promote death rituals and the recognition and facilitation of grieving in the initial stages, resulting in a possible reduction in future referrals for complicated grief. Again, no empirical support is provided for these assertions, although the approach does seem promising. More research is needed to compare traditional therapy with an integrated, systemic service such as ROC. A longitudinal study on the outcomes of therapy for both styles of therapy would be necessary in order to determine this. Additionally, the effects of staff training could be studied to see if they lead to a more positive outcome for other clients who later become bereaved. This would need to be carried out in such a manner as to distinguish between the effects of the training intervention and other recent training packages which staff are now required to complete to become a trained carer, for example, National Vocational Qualifications in the United Kingdom.

## **1.6 Can outcome results be generalised? Some Common Methodological Limitations**

Few studies were found that evaluate the outcome of bereavement interventions with adults with learning disabilities. These will be examined here in detail with close attention paid to methodological considerations, which may act as severe limitations, restricting the applicability of the results.

### **1.6.1 Design of Therapeutic intervention**

Dowling et al (2006) developed an innovative 'integrated intervention', which was based on the Dual Process Model of bereavement (1999) developed by Stroebe & Schut (1999). The authors' description of the intervention, however, appears to be a little unclear and ill defined. Activities designed to focus both on loss and restoration were planned. Yet, although some loss-orientated activities are mentioned, none are stated for the restoration-orientated group. There are no details of the length or content of the sessions or whether the schedule of the sessions was fixed. This means that the study cannot be easily replicated.

If this was also unclear to the carers who were facilitating the programme, especially if there were no specific session plans in place, this may have caused confusion and could have been one of the reasons why this intervention did not succeed. It would also mean that different carers might have carried out the intervention in a different manner, meaning that the interventions used for each participant would not be directly comparable. For future studies, facilitators could be given a clear plan and guidance on each session's focus, duration and content which would allow them to plan specific times for sessions and simply to carry out a session which has been planned out for them rather than feeling responsible for as well as finding the time for the creation of each session.

Stroebe & Schut's (1999) principle of oscillation implies that a balance between the loss and restoration orientations must be achieved following bereavement. Focusing on only one of these orientations would be psychologically exhausting and would not allow effective adaptation. The model assumes individual differences in the path oscillation will take. Successful grieving would involve the discovery of the orientation which a person is focusing on and the provision of counselling in the other orientation, enabling an individual to successfully switch healthily between the two (Schut, Stroebe, De keijser & Van den Bout, 1997). Dowling et al state that individuals with learning disabilities often experience 'atypical and prolonged grief' following bereavement. Stroebe, Schut & Stroebe (2005) label this chronic grief and, based on the Dual Process Model, theorise that these individuals would be focused on and preoccupied with the loss orientation, showing little or no oscillation to the restoration orientation and therefore grief would not lessen over time. Consequently, therapy should focus on the restoration orientation in order to achieve a balance between loss and restoration orientations, not merely workshops in both processes. If this intervention is truly based on the dual Process Model then surely this should have been taken into account when designing any intervention rooted in the model.

### **1.6.2 Sample**

Most studies reviewed had small sample sizes. Where quantitative measures are used, this increases the possibility that some significant effects may go unnoticed. Effect sizes are not reported in any of the studies reviewed, but are likely to be

weak in this field where relatively small changes may have occurred, meaning that the study lacks power (Cohen, 1992). Mappin & Hanlon (2005) for example had only six participants and found that participation in their group brought no significant effects. Dowling et al (2006) had only 20 participants in the counselling and 11 in the integrated intervention, of these only 2 completed the integrated intervention. As the authors pointed out themselves, this put limitations on the study preventing a focus on the time since bereavement, the degree of learning disabilities, age or gender to be controlled for, however the original sample appeared to be quite well matched on these. Yanok & Beifus (1993) found that a larger group of 25 participants and a control group of equal size indicated significant effects.

Summers & Witts (2003) used a single case study which allowed a rich insight into counselling an individual who had a rare combination of circumstances, having experienced the bereavement of her father whom she viewed as 'bad' and had irregular contact with, seeing him for the first time in many years shortly before his death. Read et al (1999) used case studies to illustrate the value of more creative methods of counselling such as poetry for one individual. Another case study examined an intervention delivered to a group home following the death of a resident, allowing a unique insight as to the benefits of intervention in this complex group situation. Although as a case study the results may lack generalisability, it would probably not have been possible to investigate therapeutic work under such circumstances amongst a wider group of participants as each is unlikely to experience a similar set of circumstances. However, in case studies, some check on reliability can be made. Research by Summers & Witts (2003) included observations of carers and the researcher as well as the individual that indicated a greater understanding of bereavement, but no objective measures were used. The results might have been more accurate if some standardised measures such as observation charts for both staff and therapists were used both before and after the intervention. Similar criticisms could also be made of other case studies (Kitching, 1987; Elliott, 1995, Read et al, 1999). Gault (2003) also used only observational measures but used concrete examples to indicate the effectiveness of therapy, e.g. the ability of the client to say a prayer for his father whereas prior to counselling he could not tolerate even the mention of death.

### 1.6.3 Measures

Stoddart et al (2002) mention that there are few appropriate, standardised measures for individuals with learning disabilities. The HSC-25 that they used was designed for children and has not been demonstrated to be valid with this client group, however Stoddart et al. reported it to be useful in monitoring symptoms of depression and anxiety. One measure, The Knowledge in Bereavement and Death Questionnaire was created by the authors for use in this study and it is unclear whether it was standardised or not. None of the measures used in Mappin & Hanlon's (2005) study the Knowledge About Death Questionnaire, Death Concept Questionnaire and Understanding Emotions Questionnaire were standardised and, as the authors point out, their reliability and validity are therefore in doubt.

The study by Dowling et al (2006) involved the use of two qualitative measures in addition to detailed semi- structured interviews both before and after intervention and participant observation, enabling triangulation which, according to Madill, Jordan & Shirley (2000) can enable 'completeness' by presenting multiple and diverse perspectives or may allow convergence on the findings. Other cited studies (Stodart et al, 2002; Yanok & Beifus, 1993; Mappin & Hanlon, 2005) make use of only quantitative measures meaning that, whilst the data indicates changes which are easily and accurately measured, data lacks the richness of qualitative measures which may also be able to indicate which specific aspects of the counselling were found to be the most useful by clients, counsellors and individuals.

Blackman (2002) reviews the effectiveness of a counselling service and makes some quite sweeping statements about the value of the provision of staff training, stating that an integrated approach led to long term positive results for clients following the conclusion of therapy. However, no empirical evidence is offered to back this up and without evidence can be considered at best the author's opinion. Outcome and follow up studies would be necessary to establish the benefits of this approach. None of the studies cited here were followed up to note if benefits or changes from counselling were maintained. Kitching (1987) mentions that the

client, JB, was still withdrawn at the conclusion of a counselling but predicted that encouragement and support from others would allow her to reinvest in a new lifestyle. However, it was not established whether this took place. It would be useful to know if reinvesting following bereavement would be as true of an individual with learning disabilities as Worden (1983) theorises it is for the rest of the population. This criticism is especially relevant in the case of educational groups whose outcome measures examined only knowledge of death and concepts. (Yanok & Beifus, 1993; Mappin & Hanlon, 2005). It is not yet clear whether this knowledge will be of any benefit following a bereavement which surely is the aim of the group. There is a need for follow up studies to be conducted to establish whether the learning in the group carries over into 'real life' following bereavement.

#### **1.6.4 Control groups**

A major limitation of most outcome studies on the effects of bereavement in adults with learning disabilities is the lack of a control group against which to compare them. The improvement demonstrated from counselling could be a function of receiving one to one attention for an hour a week, a factor which may be in short measure in a busy care home environment. Many studies are single case designs, which preclude the use of a control group, although clients could be paired with an individual with similar experiences who is not currently receiving treatment.

Dowling et al (2006) justified their lack of a control group by citing a study by Bonell-Pascual et al (1999) which used the same instruments as the authors have used in a seven year long longitudinal study of parentally bereaved adults. Dowling et al state that participants in Bonell-Pascual et al's study had received no therapeutic intervention. In fact a close reading indicates that a quarter of participants did, in fact, receive some 'recognised bereavement support', which included individual counselling. Therefore using them as a control group is, at best, questionable. Although it would have been ethically problematic of Dowling et al. to use a non-treatment control group this difficulty could have been overcome by using a waiting list control group who were to receive a bereavement intervention at a later date. Yanok & Beifus (1993) did use a matched control group. However, the group's knowledge of death was only tested after the group was completed and

not prior to it and it is possible that the controls may have had a lesser prior knowledge of death than group participants. Mapplin & Hanlon (2005) on the other hand, used measures of knowledge of death before and after an intervention but used no control group; there may have been some spontaneous improvement or practice effects although the order of administration of measures was counterbalanced.

### **1.6.5 Selection of participants**

In all the studies reviewed, the selection criteria were quite wide which may have masked any individual differences between participants.

#### ***1.6.5.1 Nature of loss***

Hollins & Esterhuyzen (1997) found marked differences in behaviour in adults with learning disabilities following the death of a parent. They discuss this in light of the significant loss of a major attachment figure. The loss of a parent who was a main carer may possibly lead to a longer period of adjustment than other forms of bereavement, particularly as many individuals with learning disabilities have limited social networks. However, most studies reviewed did not split participants by their relationship to the deceased (Dowling et al, 2006, for example). In one study (Stoddart et al, 2002) some participants had also suffered multiple losses, which may have re-triggered the pain of past losses making a direct comparison of the effects of therapy between different participants difficult.

#### ***1.6.5.2 Time since bereavement***

Bereavement theorists suggest that the symptoms for psychopathology and grief have reached resolution in the general population within one to two years following bereavement (Parkes, 1972). The continuation of symptoms after this time can be taken to indicate 'chronic grief'. In evaluating a grief therapy it would therefore seem important to distinguish between a recent bereavement within two years after the death and that which was still affecting an individual in terms of psychopathology after a longer time period had elapsed. However many studies fail to pay attention to the time elapsing following death. For example, in the study by Dowling et al (2006) the time since death ranged from one to thirty years and Stoddart et al's (2002) between one and ten years previously. Summers and Witts

(2003) do not mention how long after the death their intervention was carried out, as if this has little importance, whilst Yanok and Beifus (1993) do not mention how many group members had experienced grief in the past.

#### ***1.6.5.3 Support following bereavement***

Stodart et al (2002) specified the varying settings in which participants lived and pointed out that this led them receiving a different level of support, a fact that may well also have effected the research of others such as Dowling et al. (2006) who did not specify the exact nature of support each individual received. Of course, this may be a confounding variable in all studies as the amount and effectiveness of support an individual receives is liable to mediate the way they cope with bereavement.

#### ***1.6.5.4 Degree of Learning Disability***

The term 'learning disability' is a wide ranging one, referring to those with an IQ of less than 70, while individuals may fall anywhere on this scale. It is hard to say that an intervention which is effective for those with borderline levels of learning disability, will be equally as effective for individuals with severe learning disabilities, who may need the development of different mediums to enable communication and understanding. Dowling et al (2006) make no mention of the level of functioning of the participants. Stoddart et al. (2002) break down their participants according to their level of functioning, but do not appear to have controlled for this in their study with one participant in the severe range of learning disability, three in the moderate, ten in the mild and seven in the borderline range. Participants in Yanok & Beifus's (1993) research had a range of IQs from 18 to 73, although they were matched on verbal ability. Mappin & Hanlon (2005) had 'no formal assessment of [participants'] cognitive functioning' in their educational group, describing one participant whose verbal communication was very limited. If the group were educational surely it would make sense to assess the level of their intellectual functioning before the group began, if not to evaluate the outcome results against, then at least to tailor a group in which every individual would be able to comprehend and participate on a similar level.

## 2.0 Suggested Directions for Future Research

Throughout this review several directions for future research have been suggested. To summarise; whilst the difficulties of finding participants from this client group are recognised, the design of research studies should take into consideration factors such as individual differences whether these may be age, sex or, most importantly, the degree of learning disability. Individuals with differing degrees of disability may benefit from different interventions and a closer examination of this is needed. Time since bereavement occurred and the nature of the loss and any previous losses may be important factors in determining the need for counselling and these differences should be explored both with individuals referred for counselling and those who are not. Support following the loss and networks of support available following the loss should both be noted and examined in order to give a clearer picture of mediating factors. Closer attention must also be paid to methodology of studies, taking care to have larger sample sizes, control groups, standardised measures and objective measures of outcome. A range of outcome data would allow the creation of a fuller picture of its impact. Evaluation by individuals with learning disabilities themselves has been shown to be reliable in addition to measures of carers and therapists.

The number of both individual and group counselling outcome studies is few. Therapists should consider collecting outcome measures for all therapeutic measures with this client group, which could then be pooled and used to inform practice. The long-term benefits of counselling have yet to be examined. Clients of bereavement counselling services should be followed up and the long-term impact of counselling examined.

Overall, there is a need for more psychological research to be conducted in this field. As Conboy-Hill (1992) pointed out, psychologists are better placed than other bereavement counsellors in being able to take into account psychological constructs and the role of cognitive functioning in the understanding of death and facilitation of the grieving process. Despite this, there has been little research into this area by psychologists with the majority of input coming from social workers, nurses and psychiatrists, who may have a very different theoretical perspective.



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# Appendices

## APPENDIX A: Ethical Approval from City University

## Ethics Release Form for Psychology Research Projects

All students planning to undertake any research activity in the Department of Psychology are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department of Psychology does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2004) Guidelines for minimum standards of ethical approval in psychological research (BPS: Leicester) should be referred to when planning your research.
- **Students are not permitted to begin their research work until approval has been received and this form has been signed by 2 members of Department of Psychology staff.**

### Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

BSc  M.Phil  M.Sc  Ph.D  D.Psych  n/a

Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project

The process and practice of offering counselling to individuals with an intellectual disability following bereavement.

2. Name of student researcher (please include contact address and telephone number)

Liz Kliman (07971485927 - 9, Kenmore Rd, Sale Cheshire M33-4LP)

3. Name of research supervisor

Susan Strauss

4. Is a research proposal appended to this ethics release form?  Yes  No

5. Does the research involve the use of human subjects/participants?  Yes  No

If yes, a. Approximately how many are planned to be involved? 8 (approx.)

b. How will you recruit them? advertising on a mail / in magazine

c. What are your recruitment criteria? counsellors offering bereavement counselling  
(Please append your recruitment material/advertisement/flyer) based on worden's (1983, 1992) stage model to individuals with

d. Will the research involve the participation of minors (under 16 years of age) or those unable to give informed consent?  Yes  No intellect disability

e. If yes, will signed parental/carer consent be obtained?  Yes  No N/A.

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? (If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).

A semi-structured interview approx. 90 minutes long.

7. Is there any risk of physical or psychological harm to the subjects/participants?

Yes No

If yes, a. Please detail the possible harm? They may become distressed from questions in the interview.

b. How can this be justified?

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

Yes No

(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

9. Will any person's treatment/care be in any way compromised if they choose not to participate in the research?

Yes No

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

Yes No

(Please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

tape recordings / transcriptions

12. What provision will there be for the safe-keeping of these records? They will be locked

away and tapes will be deleted after use. Transcripts will be cross checked and only known by participant numbers.

13. What will happen to the records at the end of the project? tapes will be deleted.

14. How will you protect the anonymity of the subjects/participants? Participant names or

details of service they work in will not be used - they will be referred to by pseudonyms or participant number only.

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

Participants will be debriefed and offered resource lists

of local counselling services.

(Please append any de-brief information sheets or resource lists detailing possible support options)

If you have circled an item in bold print, please provide further explanation here:

Questions in the interview might make  
counselors think of difficult experiences they may have  
had or their own bereavement which might  
be distressing.

Signature of student researcher [redacted] Date 01/11/06

**Section B: To be completed by the research supervisor**

Please mark the appropriate box below:

Ethical approval granted

Refer to the Department of Psychology Research Committee

Refer to the University Senate Research Committee

Signature [redacted] Date 12 Nov 06

**Section C: To be completed by the 2<sup>nd</sup> Department of Psychology staff member** (Please read this ethics release form fully and pay particular attention to any answers on the form where bold items have been circled and any relevant appendices.)

I agree with the decision of the research supervisor as indicated above

Signature [redacted] Date 22/11/06

## APPENDIX B

### Information and Consent Forms

## **Information for participation in a study of bereavement counsellors who work with adults with a learning disability**

Thank you for agreeing to participate in this study. I am carrying out a study to investigate the process of counselling individuals with learning disabilities as part of my D.Psych in Counselling Psychology which I am undertaking at City University, London. My research supervisor is Dr Susan Strauss.

Adults with learning disabilities have been shown to experience bereavement in a similar way to the rest of the population. This may affect them to a greater extent, as there may be a number of other losses associated with bereavement. This may be coupled with a lack of understanding about the death process and limited social contacts. They are often not included in death rituals and their need for bereavement counselling has often been overlooked. Where counselling has been provided there is a lack of outcome data. However, merely examining outcomes may not reveal the reason behind the benefits brought about by bereavement counselling. Firstly, it is almost impossible to measure recovery from bereavement (Walter,1999). Grief has been shown to come in waves. Therefore the measurement at any point in time may not be an informative measure of psychological and physical health and functioning. Traditional measures of may not indicate the client has really overcome their loss (Rubin,1992). Some have recognised that, whilst counselling in palliative care acknowledges that process should be noted and monitored in addition to the outcomes, bereavement research appears to take the view that it does not matter *how* it works. The only important factor is which intervention has a better outcome for clients (Walter, 1999).

There is some existing research into process when counselling adults with learning disabilities who have been bereaved, however a majority of this examines single case studies. Detailed research is needed to examine the process and tools used in counselling adults with LDs following bereavement.

I am also interested in what factors might affect the counselling process and the experiences of counsellors in working with this unique and, oft- neglected client group. Additionally, therapists all have their own innovative methods of working

with clients, especially in the field of learning disabilities and particularly in bereavement . I would like to get an idea of how existing practitioners make use of different tools, materials and techniques. It is hoped that this will provide some guidance for new and existing therapists. A need for such guidance in using these techniques and tools has been indicated (Read, 2002) and might enable these counsellors to structure successful therapy for this client group.

This study will use a qualitative method of data collection and analysis, Grounded Theory. That is, data will be analysed using the words and expressions of participants to describe their individual and collective experiences. These will be constantly compared and continually analysed for themes which link the experiences of different therapists with the goal of developing an insight into the area of research, developing a 'theory'.

I will tape record interviews with participants and then make transcripts of these. All tapes and transcripts will be made anonymous and any personal details will be kept strictly confidential.

Each transcript will then be analysed in accordance with grounded theory. I will then present the transcripts and themes which are generated to participants who can then check if their thoughts have been transcribed accurately and if they believe the themes suggested to be correct. Participants may then alter or revise the themes suggested according to what they felt they were trying to convey in the interview.

Please feel free to contact me by email: [REDACTED] or by phone [REDACTED] if you have any questions.

## Consent form

My name is Liz Kliman and I am a Counselling Psychologist in training. I am carrying out a research study as part of a D. Psych in Counselling Psychology at City University, London. This aims to explore the process of counselling individuals with learning disabilities.

The interview will last for approximately sixty minutes and will consist of two parts, during the first part of the interview, I will ask some questions about your experiences and practice. During the second part of the interview, I will ask you to talk about the process of counselling one or two clients with whom you have recently worked who have either a severe or a mild learning disability.

The interviews will be tape recorded to enable them to be transcribed. The tapes and all information collected will be kept entirely confidential and will be labelled and referred to only by your participant number. After the study is completed, all tapes will be stored securely for six months and then destroyed.

After the interview, I will type the transcript and will send you a copy to check its accuracy. I also may need to ask you a couple of questions, at a later date, to clarify what you have said.

As part of my D.Psych , I may wish to use some of the interview material or for journal articles. In any written materials in which I might use the material from your interview, I will not use your name, names of your clients or counselling service. I will use only pseudonyms.

If, at any time, you find a question too difficult or do not want to answer it, please say so and we can move on to a different subject.

During this interview material may come to light which is difficult to deal with or painful. I will provide a list of free counselling services that you could speak to about any issues which you may have become aware of.

You may withdraw from the study at any time. You may withdraw your consent to have specific excerpts used, if you notify me at the end of the interview series. If I subsequently were to wish to use materials in any way not specified above I would ask for your written consent.

By signing this form, you are also agreeing that you will make no financial claims for the use of the material in your interviews.

I agree to the above conditions and am happy to participate in the study

Signed (participant) .....

Date .....

Interviewer .....

Participant number .....

## APPENDIX C: Interview Script

## Initial semi-structured interview questionnaire

(Suggested prompts are in italics)

How long have you been working as a counsellor with adults with learning disabilities?

I am just interested in what's drawn you to work in the area of learning disabilities?

...and anything which specifically drew you to bereavement work?

What keeps you going/ what motivates you in this work?

Approximately how many clients have you worked with providing bereavement interventions?

Did you have any other background or training you have in working with people with learning disabilities?

Could you describe this briefly?

How did your *counselling* training help you work with this client group?

What (if any) are the differences in your grief work interventions with clients who have intellectual disabilities and those who have not?

What would you say that these differences are?

How do the differences manifest themselves?

I am wondering what particular difficulties and dilemmas you have encountered when offering bereavement interventions to individuals with learning disabilities?

In what ways do you feel bereavement counselling might specifically benefit individuals with learning disabilities?

Why do you think this is?

I am curious if there are any differences in your feelings in working with this client group and others?

Have you found any particular rewards (personally) of doing this type of work with this client group?

I am curious about any differences in the process of your work with people with learning disabilities versus those who haven't that you may have observed?

Have you noticed any impact on the process depending on the level of severity of the learning disability?

*I am wondering ... when you think of effective bereavement work in this population what makes it work?*

Are there any specific qualities of a good therapist in this area?

I wonder what kinds of reading or other things have guided you in this work?

*What exactly was this?*

In practice, how did you find this helped?

During the next part of the interview I'd like to ask you to focus on one or two clients with a learning disability who presented with bereavement issues or

perhaps someone whose bereavement issues became apparent as you worked with them.

It would be useful if you could think of one client with what you would consider to have a moderate learning disability and one who you would consider to have a more severe learning disability.

Thinking of the first client ...

Male/ female

What would you consider to be the level of his/ her learning disability?

Mild/ moderate/ severe

How were his/her communication skills?

What age was this client when referred to you?

How long before meeting you had he/she been bereaved ?

Can you just talk me through how you worked with this person?

Did he/she understand about the meaning of death?

What was his/her view of what happened?

How did you change this?

*Materials/ resources used to aid death understanding/ communication*

*Can you tell me a little more about that?*

*Why was he/she experiencing difficulties with bereavement?*

*What was that like for you/ your client?*

How would you describe the therapeutic alliance and what was particularly important?

*Can you describe any specific process issues of how you worked with him/her?*

*were there any specific adaptations that you needed to make to the session in light of their Learning disability?*

What do you think were some of the ingredients of success here?  
*(if not why do you think this was/ client/ surrounding issues?)*

Did anything unexpected crop up in a session which meant you had to adapt it and how did you do this?

Now, can you think of the second person ( if you have one)

(repeat above questions)

Are there any things that you haven't had a chance to comment on that stand out for you?

## Revised semi-structured questionnaire (Revision1)

(Suggested prompts are in italics)

How long have you been working as a counsellor with adults with learning disabilities?

I am just interested in what's drawn you to work in the area of learning disabilities?

Have you ever reflected on anything that personally enables you identify with or brought you to work with people with learning disabilities?

*..and anything which specifically drew you to bereavement work – how do you find working in the area of bereavement with this client group?*

What keeps you going/ what motivates you in this work?

*How do you imagine fellow colleagues, not in the field of LDs perceive your work?*

Do you have any thoughts about the role in society of the clients and any effect on the relationship?

Approximately how many clients have you worked with providing bereavement interventions?

Did you have any other background or training you have in working with people with learning disabilities?

*Could you describe this briefly?*

How did your *counselling* training help you work with this client group?

Do you think society's expectations or perceptions of people with learning disabilities effects the work?

Do you find that you use resources or tools to enable communication to the same extent now as you did when initially starting in this area?

*Does the work involve a lot of creativity/ adaptation?*

*How does that impact on you?*

What (if any) are the differences in your grief work interventions with clients who have intellectual disabilities and those who have not?

*What would you say that these differences are?*

*How do the differences manifest themselves?*

I am wondering what, if any, particular difficulties and dilemmas you have encountered when offering bereavement interventions to individuals with learning disabilities?

*In what ways do you feel bereavement counselling might specifically benefit individuals with learning disabilities?*

Why do you think this is?

*I am curious if there are any differences in your feelings in working with this client group and others?*

Have you found any particular rewards (personally) of doing this type of work with this client group?

I am curious about any differences in the process of your work with people with learning disabilities versus those who haven't that you may have observed?

Have you noticed any impact on the process depending on the level of severity of the learning disability? anxieties / difficulty?

*How do you decide when to finish with a client?*

*What are your greatest hopes regarding the aftermath of therapy?*

*I am wondering.. when you think of effective bereavement work in this population what makes it work?*

Are there any specific qualities of a good therapist in this area?

*I wonder what kinds of reading or other things have guided you in this work? What exactly was this?*

*In practice, how did you find this helped?*

Do you involve/ have contact with the support network around the client. How is this done?

*Why do you think its important to involve them*

Do you get many referrals for people with more severe learning disabilities for bereavement work?

During the next part of the interview I'd like to ask you to **focus on one or two clients with a learning disability who presented with bereavement issues or perhaps someone whose bereavement issues became apparent as you worked with them.**

It would be useful if you could think of one client with what you would consider to have a moderate learning disability and one who you would consider to have a more severe learning disability.

Thinking of the first client ...

*Male/ female*

What would you consider to be the level of his/ her learning disability?

*Mild/ moderate/ severe*

How were his/ her communication skills?

What age was this client when referred to you?

How long before meeting you had he/she been bereaved ?

**Can you just talk me through how you worked with this person?**

*Did he/she understand about the meaning of death?*

*What was his/her view of what happened?*

*How did you change this?*

*Materials/ resources used to aid death understanding/ communication*

*Can you tell me a little more about that?*

*Why was he/she experiencing difficulties with bereavement*

*What was that like for you/ your client?*

*How would you describe the therapeutic alliance and what was particularly important?*

*Can you describe any specific process issues of how you worked with him/her?*

*were there any specific adaptations that you needed to make to the session in light of their LD?*

*What do you think were some of the ingredients of success here?*

*(if not why do you think this was/ client/ surrounding issues?)*

*Did anything unexpected crop up in a session which meant you had to adapt it and how did you do this?*

- Now, can you think of the second person (if you have one)  
(repeat above questions)

Are there any things that you haven't had a chance to comment on that stand out for you?

**APPENDIX D: Additional Research Questions**

## Copy of an email to check the understanding of participant's responses:

Dear ....

Thank you so much for taking part in my research into the process of bereavement counselling with people with learning disabilities who have been bereaved. I wondered if you could answer a couple more questions?!!

Firstly, I am attaching the transcript of the interview. Do you think any areas of the transcript are inaccurate or need any correction?

### Findings so far

So far I have found some interesting themes in the research: The core theme which is emerging is that all participants experienced a number of challenges and anxieties related to working with bereaved people with learning disabilities, both personal and professional. However, as therapists become more experienced, they are able to rely on the therapeutic relationship and process to a greater extent and, through this, clients secondary disabilities slip away, enabling them to progress both in therapy and in other areas of their lives. Some other things that were noted about the process is that often the work appeared to be quite slow and almost to go around in circles, making little progress which many found somewhat frustrating. However, these challenges gave way to feelings of achievement if there was a successful outcome and sometimes a feeling of exhilaration or energy. Results also indicated that some clients had suffered trauma associated with the death. There was also some debate about deciding when to end the therapeutic contact.

I wondered if I could ask you a few questions:

1. How many sessions do you commonly offer to an individual with a learning disability who has been bereaved? How would you decide when is the right time to end therapeutic intervention? Do you find that you ever have any dilemmas around this?
2. Do you find that your clients have experienced trauma associated with bereavement/ s (or linked to the relationship with the deceased) ? Is this have you noticed any particular group of clients this might be found in?

3. Do you receive any referrals for people with severe learning disabilities? If you did would you be willing to work with them using a 1:1 counselling intervention. Would you use anything in particular to facilitate this?
  
4. Do you find that working with people with more severe or profound learning disabilities generates different emotions for you than those with more moderate disabilities?
  
5. Do you think there are any attachment issues which are pertinent in this work? How might you work with these?

Thank you again so much

Liz Kliman

Liz Kliman   
[ruchama66@yahoo.com](mailto:ruchama66@yahoo.com)

Send instant messages to your online friends <http://uk.messenger.yahoo.com>

## Appendix E: Examples of selected memos

*Examples of selected memos which explored and developed the theme of 'out of their depth'- bereavement work with individuals with severe or profound learning disabilities*

12/05/08

Memo 4- Working with profound LD

*Identifying & developing Properties of difficulty in working with profound LD*

I am noticing that even experienced professionals express difficulty in working with people whom they consider to have a severe learning disability. I wonder why this may be?

*People like that [with severe or profound learning disabilities] haven't been referred to me but maybe you could argue the other way that maybe people ... would refer to me [if they knew that I could work with these clients] I don't know ... (09: 23:02).*

After interviewing participant 9 I thought about this issue as being something which was pertinent and which when I think about I, that others had described to me... **barriers** to working with people with severe learning disabilities and, almost a **fear** of the work. I wanted to go back to look at other transcripts to find evidence of this. Participant 4 mentioned this a great deal. Although he was experienced and worked in a LD service for many years, he still reported that he held a great deal of anxiety around working with people with severe LDs. Interestingly he also reported getting few referrals. I am wondering if perhaps participant 9's perception was accurate... maybe these clients don't get referred because the therapists **do not believe they can do this type of work** and therefore colleagues who may refer to them do not as they believe that the service (bereavement counselling interventions) is not offered to people with severe LDs.

*People with severe disability- it's interesting we don't get so many referrals around that. I think there's a 'weeding out' process. I noticed it when I worked in [a bereavement service for people with learning disabilities] that the more severe disabilities tend to get referred to the creative therapists. Where there's people with more mild- moderate disabilities getting referred to us, the 'talking' tree. So there's often a filtering- before they get to us (04: 19:18).*

Again...

*I would try to talk to him about this, umm, he was challenging and I wasn't sure how well I was understood or received by him... Umm....and I don't know how successful it was because after a while the staff reported he was saying that he didn't want to come. ....What I was doing- I was often a bit 'by the seat of my pants' really with him trying to work out, "What am I going to do here? How is this helpful?" and ...I wasn't sure how successful that was. I think people with more severe learning difficulties generate more anxiety concerning you and me. ...and I have an anxiety about how we're going to communicate. How- how will it be received? (04: 20: 13-21:14).*

*“people with more severe learning difficulties generate more anxiety” (04:22:22).*

Now I can see a pattern of participants finding it difficult to work with people with severe LDs including participant 4 who also reported (in addition to participant 9) that he doesn't get people with severe LDs referred to his service. I wonder if this is true for all participants? I have chosen to interview participant 10 as I know that he has worked with people with severe LDs.. what makes the work successful or indeed possible? What gives him the confidence necessary to do this work?

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12/05/08

Memo 06

Brainstorming- identifying and developing properties of reluctance in work with  
severe LD

Work with people with severe/profound learning disabilities

People were reluctant to work with severe LD due to their own anxieties around this and their ability to be successful. One participant (4) found it "less interesting"

Will work with people with severe LDs systemically but not actually using 1:1 counselling interventions. They report receiving few referrals but in some cases, when clients were actually referred to them, they worked for a couple of sessions as an assessment and then offered training to the staff team in supporting them through their bereavement. This appeared to be almost an **avoidance** and participants would not feel that they could **successfully** carry out a talking therapy with them.

*Well with mild to moderate, I'm much more aware of how you can get in touch with them [making a connection?/ establishing communication?] and things like that.....People with sort of more... severe/ profound learning disabilities, I, I just think its that other people would be better working with them. I don't feel that's my forte ..people like that haven't been referred to me but maybe you could argue the other way that maybe people would refer to me. I don't know.....I think that's the same for all psychologists working in my area... We've had quite a few discussions ...and I think there's a consensus within our area that people with sort of a more severe and profound learning diasability aren't getting the same level of service from psycvhology as those with a mild to moderate learning disability [I wonder why that is???) .....[this work] Generates..greater sort of sense of helplessness perhaps. You know thinking about ..**transference and counter-transference** ..I'm more likely to work with staff, rather than directly with the client*

This participant describes feeling a greater sense of helplessness- which he sees as perhaps a reflection of transference/ countertransference realater to the cleint's level of disability as clients who are more severely disabled will thus be more helpless..less able to do things for themselves. This appears to be connected to the theme of **slow progress** and of **success**

**See memo 12a on communication-**

*Some people with learning disabilities can throw up technical challenges.*

*How do you work with someone who's non-verbal? (04:10:11-12)*

At the time this seemed like a rhetorical question and to be connected to **challenges/ therapist frustration** theme but, looking back at it- it seems to be indicating that he finds it difficult to work with people with severe learning disabilities as he refers to later in the interview..especially those with limited communication/ language skills [note difference between those with limited communication vs. severe LD are they the same/ perceived the same?] in this way this could be a very real question

Perhaps there are links between challenges/ communication/ anxiety?

30/05/08

## Memo 12- Working with people with profound learning disabilities

### **Fear of connection?**

*Brainstorming- a comparative and question asking memo*

Participants seemed very **reluctant** to **form a close therapeutic relationship** with people with severe LD, they seemed to have a **fear of connecting** with someone so disabled and of **feeling out of their depth** – a **lack of speech** as a medium also seemed to leave the counsellor just as **vulnerable** as the client.

Perhaps the counsellors were **afraid** of working with someone so disabled and with so much raw pain which was never addressed previously (compounded losses)?

Perhaps the greater the disability, people were afraid of how to treat them effectively (links to theme of **lack of assessment of effectiveness**- makes therapy difficult with PWLD/ **circular therapeutic process** theme).

Therapists wondered, could they do effective therapy with these individuals? If not then would they leave them with a realisation of their pain and therefore be worse than before?

Use of a psychological defence to ignore the pain and say that they would be unable to connect on a 1:1 basis but rather only able to use systemic/ behavioural interventions??

Are therapists all not just as vulnerable as others to attributing a lack of emotional awareness to those with severe learning disabilities??

Relationship- Participants who could do this work- relied on effectiveness of therapeutic relationship as effective for all BUT others stated that change in people with mild/moderate LD came about through the relationship ...what is different? What prevents people from building up a relationship with people with more severe LDs? (our stereotypes? Communication? Therapists fears? Traditional service provisions?).

For mild/ moderate LD clients- therapists had a number of anxieties but they were able to work through these anxieties to use their therapeutic skill and the relationship to come to an often successful conclusion (although hampered by others' attitudes and values/ commitments to & understanding of therapy/ process issues such as circular nature-lack of markers of success) Why is this different in severe LD??

For mild/ moderate LDs even though therapists have so many anxieties, they were able to rely on the *client* and their ability to engage in the therapeutic relationship to reach a successful (if perhaps slower) conclusion, yet with severe LD, they were unable to rely on it. It is almost as if they believe that a **client is not capable of engaging in a therapeutic relationship** or a **fear of connecting** with the client?

These themes are interesting and perhaps it would be useful to ask other participants about their work with people with severe LD and guides my theoretical sampling I would like to ask ..are people with severe LDs referred to their services? Would they work with them? Why might they not work with them. If they would -how would they go about this? What are the barriers to the work? This is where theoretical sampling could lead next.

**Next steps**

I will send an email to participants 7& 8 returning typed copies of their transcripts and asking about the themes that have been emerging and ask these questions:

Do you receive any referrals for people with severe learning disabilities? If you did would you be willing to work with them using a 1:1 counselling intervention. Would you use anything in particular to facilitate this?

Do you find that working with people with more severe or profound learning disabilities generates different emotions for you than those with more moderate disabilities?

05/06/08

Memo- severe LD memo 15

**Fear of connecting 2-** *identifying/ developing properties of the category*

Participants seemed very reluctant to form a close therapeutic relationship with people with a severe learning disability. They seemed to have a **fear of connecting** with someone so disabled and feeling out of their depth as the **lack of speech** might also leave them vulnerable (see communication memo 26)

Perhaps someone so disabled and in so much raw pain i.e. not disguised by the façade of language and a person whom participants felt 'sorry' for which had never been addressed before was just too large an obstacle?

It seems to emerge that the **greater the disability the greater the fear** of how to treat these clients **effectively**. I.e. could the counsellors meet this challenge and effectively treat these individuals? If not then they might leave them in even greater pain and they would be much worse than before so they might use a **defense** to ignore it and say that they are unable to connect on a 1:1 level but could only use behavioural interventions. Is everyone not (even therapists) vulnerable to falling into the same trap of attributing to the severely disabled that they do not have an **emotional awareness**?

As counsellors and psychologists it appears that they are just as afraid of severe learning disability as the rest of the population. And actively seek to avoid it using psychological defenses.

How are some participants successful in work with severe LD?

It appears to generate the same amount of anxiety as in the 'unwilling' counsellors. The reason participants were able to successfully work with other clients with LD was due to their ability to rely on the therapeutic relationship..its ability to let mild/ moderate LD 'Slip away' and see the person improve and develop. However those successful at this work used the **therapeutic relationship**.

## Memo

### Working with people with severe learning disabilities

Memo-17 05/06/08

Fear of connection? Brainstorming

- Participants seemed very reluctant to form a close therapeutic relationship with people with severe LD, they seemed to have a **fear of connecting** with someone so disabled and of feeling **out of their depth** – a lack of speech as a medium also seemed to leave the counsellor just as **vulnerable** as the client.
- Perhaps the counsellors were afraid of working with someone so disabled and with so much **raw pain** which was never addressed previously (compounded losses?)?
- Perhaps the greater the disability, people were afraid of how to treat them **effectively** (links to theme of lack of assessment of effectiveness- makes therapy difficult with PWLD/ circular therapeutic process).
- Therapists wondered **could they do** effective therapy with these individuals? If not then would they leave them with a realisation of their pain and therefore be worse than before?
- Use of a **defense** to ignore the pain and say that they would be unable to connect on a 1:1 basis but rather only able to use systemic/ behavioural interventions
- Are therapists all not just as vulnerable as others to attributing a **lack of emotional awareness** to those with severe learning disabilities??
- **Relationship**- Participants who could do this work- relied on effectiveness of **therapeutic relationship** as effective for all BUT others stated that change in people with mild/moderate LD came about through the relationship ...what is different? What prevents people from building up a relationship with people with more severe LDs? (*our stereotypes? Communication? Therapists fears? Traditional service provisions?*).
- For mild/ moderate LD clients therapists had a number of anxieties but they were able to work through these anxieties to use their therapeutic skill and the relationship to come to an often successful conclusion (*although hampered by others' attitudes and values/ commitments to & understanding of therapy/ process issues such as circular nature-lack of markers of success*) Why is this different in severe ID??

15/07/08

**Memo 22 on severe LD**

*Identifying properties of concept*

***What would it take to work with people with profound LDs? i.e specific techniques?***

Participant 10 said:

*Talking to them, rather than expecting them to talk to me..trying to guess how they might be feeling. And I don't mean guess as in just sort of guess. Building on my knowledge of how people without learning disabilities grieve and the sort of things that they needed to do. Building on the feelings even though it might not have been clear they had them...And the sort of things that they need to do to cope with their bereavement and **adapting the way that I work** so that those needs were filled with the person even though it might not be obvious that they had them*

Talking to the client and verbalising their thoughts and feelings it was hypothesised they had was important. It seemed to be about going beyond himself in order to pick up on what work needed to be done even though it might not be clear that clients had any of these needs-it seemed fuelled by a passion that everyone shares the same types of emotions surrounding bereavement, that grief is humanising also for people with severe disabilities- a sense of connection with these clients, of not being afraid to be the same as and to be identified with them. This participant had 'very significant' grief in the past which he felt affected his life and how he thought and interested him in this work. Perhaps because he was very in touch with these feelings, he had also done bereavement counselling in the mainstream for a number of years, he could identify that grief is universal.

*Er ..it might just be sitting and looking at pictures of the person who died, telling them that they've died and to say 'it's okay to be sad', you know..people are sad when somebody dies..erm just talking to them so that anything that gets through might help them to know what's happened*

Accepting someone's feelings and even going beyond this to a level of advanced empathy. Although this is a client centred therapist, he is also talking about using body language as an indicator of feelings as clients were unable to communicate these verbally, for him, it was important that he verbalise these for the client, also about **acceptance** of the client and their feelings. It seems a bit hit and miss. This participant would talk to clients about the recognised stages of grief and hope that something might 'get through'.

*even with people who haven't got any speech I don't think that's a reason not to work with them and try and help them ...and try and help them in any way with their bereavement and what's happened*

*..it's all about **adapting and using your best instincts** ..if you only have a 5 minute session. You only have a 5 minute session..because..there's not too many clients that can sit for 50 minutes.*

Participant 3

*well I don't think a lot really, although obviously it depends if someone's got a language difficulty erm or a speech problem or what have you, because then I am looking much more for sort, sort of finding a communication..mutual communication. But I would still use the same type of tools depending on the needs and interventions depending on the needs of the client whether or not they had learning disabilities*

*I so not that much difference then*

*P- I don't think so. I mean, I know there is certain differences but the way that I work, other than with somebody with a more severe learning disability who I have used a lot more, like play therapy techniques.*

**I'll always try and take the lead of the client and I'll build rapport, sometimes, you know, even if somebody can't talk very well, it may be that they will use other types of equipment in the room, like play equipment and I'll often build rapport through maybe copying what they are doing and things like that. So it's a bit like reflecting, but non-verbally (laughs).**

**I think that sometimes people with more severe disabilities can surprise me.**

22/07/08

Memo 32 on profound learning disabilities

*elaborating the paradigm*

It appears that few counsellors or psychologists are comfortable willing to work with people with severe or profound learning disabilities and there are a number of factors contributing to this.

As one participant remarked;

*People like that [with severe or profound learning disabilities] haven't been referred to me but maybe you could argue the other way that maybe people woul- would refer to me [if they knew that I could work with these clients] I don't know.....(09: 23:02).*

This stems from the fact that many participants were reluctant to work with individuals with a severe or profound learning disability due to their own anxieties and uncertainties around this. However participants who *did* feel more confident in working with those with more profound learning disabilities also felt a degree of anxiety, at least in the beginning but they were able to get over this after establishing rapport- suggesting that the relationship is effective in both bringing positive change but will also reduce the therapist's anxiety when they are able to see that they can connect to their clients and this then brings about a feeling of enjoyment as was seen in people with milder LDs. Therefore it seems to be that the difficulty is getting beyond the barriers of their perceptions which they had held..or society holds around those with more severe LDs.

*I probably feel more anxious in the beginning because there is no clear contract of why they are coming and I suppose I think their behaviour might be more unpredictable. Also there are practicalities which I might have to support them in such as going to the toilet or on occasions dealing with incontinence etc.Once rapport has been established I really enjoy working with more severely disabled clients.*

Perceptions of participants regarding their ability to be successful also affected their desire to work with people with a more severe learning disability. In fact they felt that they could not do ie. Had an inability to do this type of work.

Participants found it difficult to **track progress** with clients with more severe learning disabilities – a feeling that there was almost a **lack of progress**.

Participants appear to be afraid of failing in their interventions and would rather remain on ground where they feel more confident.

*Sometimes I felt that-that I wasn't sure if the counselling actually had... I think it had helped, but I don't know whether it was actually completely resolving the issue, umm, particularly of the-the grief. (06:13:04-07).*

Thoughts seemed to centre around their ability to be successful with these individuals. There was a fear that if unsuccessful then would they leave their clients with a realisation of their pain and therefore be worse than before.

*immediate emotions that spring to mind are hopelessness and sorry ....Possibly the thing that makes a difference here is whether one can find a way to help (participant 8 on what might make it possible to be able to work with clients with severe LDs.)*

Therapy with people with learning disabilities often makes slower progress, the more profound the learning disability is and this was one of the frustrations which participants experienced.

*The pace.....[of therapy is] much slower in those with a more profound a learning disability, umm, and I look, you know, a large part of the earlier sessions will be just in developing a relationship and a way of communicating, umm, so that-that the more learning disabled somebody is the longer that process will take as well. (07:08:15-19).*

*Well with mild to moderate, I'm much more aware of how you can get in touch with them (09: 23:10).* There is a feeling of a **lack of connection** with these clients which I feel may be down to the fears expressed about this work. There seemed almost to be

a doubt of whether these clients could effectively make use of therapy. In some way these therapists were as vulnerable as others to societal influences in attributing a lack of emotional awareness to those with severe learning disabilities. As Participant 10 said, *'I don't think that enough people with severe learning disabilities are referred for counselling ....There is a feeling that they don't have thoughts and feelings'*. With this comment he was referring as much to his colleagues and other professionals in the multidisciplinary team as to care staff.

Another suggestion is that psychodynamically thinking, that people with a more profound disability could have a greater sense of helplessness (also due to societal influences? But perhaps also physical and cognitive limitations) which is then transmitted on to the therapist through a process of transference.

*[Working with individuals with a more profound learning disability] generates.. a greater sort of sense of helplessness perhaps. You know thinking about ..transference and counter- transference .....I'm more likely to work with staff , rather than directly with the client.*

If therapists were feeling a sense of helplessness and a feeling of being *'out of their depth'* then they would have severe limitations on being able to help a client effectively.

It also seemed as if the lack of speech as a medium also seemed to leave the counsellor just as **vulnerable** as the client. From reading, it is likely to be as Hodges suggests that language clothes the unpleasant emotions and therefore when this is lacking the therapist experiences raw pain which can be *'unbearable'*. It can also be **raw pain** as it results from compounded losses which had never been addressed previously or had been ignored.

It also seems that the **lack of language/ speech** is a barrier and this theme is very much related to that of **communication**. Having reflected upon this, and thinking of my own client work, It is not so clear that one can separate out the severe LD from a severe communication difficulty. Perhaps even some of the descriptions and limitations of work were more related to communication issues rather than to the profound LD. However, it may be too difficult to separate these as they often go hand

in hand. Perhaps, if I had time, it would be an idea to continue to explore this with people who have severe communication difficulties but lack a severe LD but I wonder how easy this would be to define- perhaps someone with cerebral palsy or brain damage?

### **How do therapists tend to work with profound LDs?**

Therapists, particularly psychologists were inclined to work with people with a more severe learning disability systemically but not actually with a one to one talking therapy intervention. They report receiving few referrals but in some cases, when clients were actually referred to them, they worked for a couple of sessions as an assessment and then offered training to the staff team in supporting them through their bereavement in almost an avoidance and would not feel that they could successfully carry out a talking therapy with these clients. One participant recounted that the team which he previously was employed in had reflected together on the meaning of this:

*I think that's the same for all psychologists working in my area... We've had quite a few discussions ...and I think there's a consensus within our area that people with sort of a more severe and profound learning disability aren't getting the same level of service from psychology as those with a mild to moderate learning disability (09: 23: 18- 22).*

Many participants were unwilling to do 1:1 work with these clients but rather would work systemically, often assessing clients and then either training support workers in bereavement and suggesting ways of working or through behavioural work for challenging behaviours. This could be explained by the use of a defense to ignore the pain of the person with such a severe LD who is the repository of so much pain/ suffering of society which can be seen even in specialist trained therapists who work with other clients with learning disabilities. They say that they would be unable to

connect on a 1:1 basis but rather only able to use systemic/ behavioural interventions.

*the immediate emotions that spring to mind are hopelessness and sorry, particularly if there are accompanying issues of physical health problems, pain and /or distress (participant 8)*

**How do some manage to do the work? What makes it successful?**

However some participants were more comfortable to agree to work with someone with a severe learning disability. Although they also experienced similar anxieties, they had developed strategies to be able to manage this work.

*I think you have to be able to listen, uh, in a creative way, really, not just with your ears, but you have to really observe what's going on for that person and really attend to them. and really attend to the transference and the counter transference because I think the less somebody's able to verbally communicate to you the more you need to attend to the non-verbal communication. (03:12:01-05).*

Participant 10's statement appeared to agree with this:

*trying to guess how they might be feeling. And I don't mean guess as in just sort of guess. Building on my knowledge of how people without learning disabilities grieve and the sort of things that they needed to do. Building on the feelings even though it might not have been clear they had them...*

*....using your best instincts*

A level of advanced empathy or awareness of transference/ countertransference were the theoretical explanations given for perceiving the non verbal communication and an awareness of the feelings of clients. Body language was seen as an indicator of feelings if clients were unable to communicate these verbally

*Talking to them, rather than expecting them to talk to me..trying to guess how they might be feeling. And I don't mean guess as in just sort of guess. Building on my knowledge of how people without learning disabilities grieve and the sort of things that they needed to do. Building on the feelings even though it might not have been clear they had them...And the sort of things that they need to do to cope with their bereavement and **adapting the way that I work** so that those needs were filled with the person even though it might not be obvious that they had them*

Talking to the client and verbalising their thoughts and feelings it was hypothesised they had was important. It seemed to be about going beyond himself in order to pick up on what work needed to be done even though it might not be clear that clients had any of these needs

*Er ..it might just be sitting and looking at pictures of the person who died, telling them that they've died and to say 'it's okay to be sad' , you know..people are sad when somebody dies..erm just talking to them so that anything that gets through might help them to know what's happened*

For participant 10, it was important that he verbalise these for the client, also about acceptance of the client and their feelings which was emphasised by both therapists who did this work.

*The way that I work .....with somebody with a more severe learning disability [with] who[m] I have used a lot more, like play therapy techniques (03:02:20-22).*

This might involve others in the treatment but it would remain a one to one time for a direct therapy with the client and therapist:

*[The presence of support workers at psychology sessions] helps sometimes for them to explain what the problem is. If there is a communication difficulty it is more helpful for me sometimes for someone to act ,like an interpreter until I can get used to them (03:05:05-08).*

However it seems that participants who felt comfortable with the work with people with profound learning disabilities worked in a similar manner that they would work with any client.

*although obviously it depends if someone's got a language difficulty erm or a speech problem or what have you, because then I am looking much more for sort, sort of finding a communication..mutual communication. But I would still use the same type of tools depending on the needs and interventions depending on the needs of the client whether or not they had learning disabilities (participant 3)*

*even with people who haven't got any speech I don't think that's a reason not to work with them and try and help them ...and try and help them in any way with their bereavement and what's happened (participant 10).*

In both of these participants work appeared to be fuelled by a passion that everyone shares the same types of emotions surrounding bereavement, that grief is humanising also for people with severe disabilities- a sense of connection with these clients, of not being afraid to be the same as and to be identified with them i.e. that grief is universal and people have similar reactions to grief even if this is displayed in unusual ways.

#### **What else would be useful?**

Participant 10 thought that

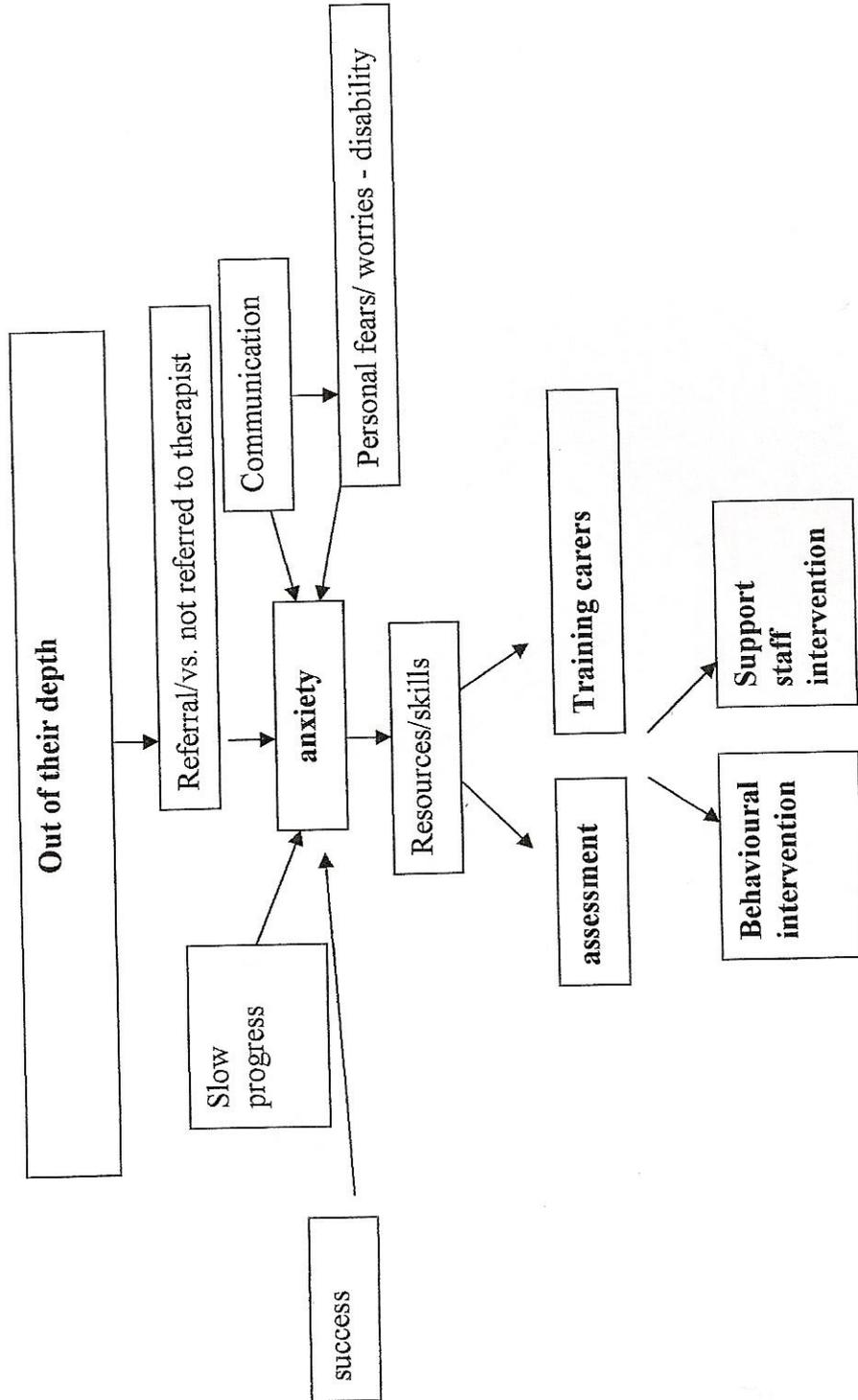
*I think there is a need for some form of therapy to be developed for more disabled clients*

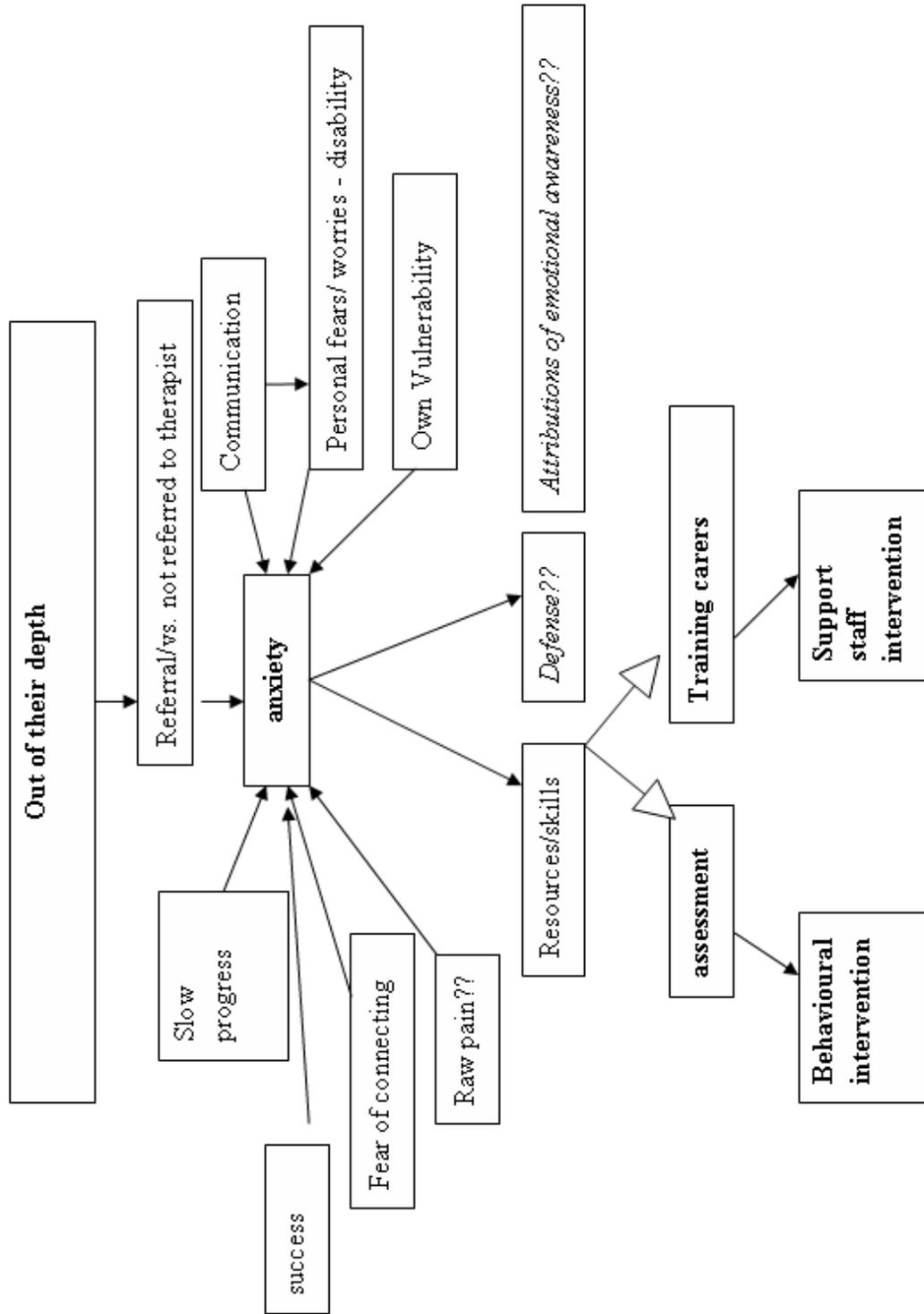
He is already delivering this therapy but felt that it was not necessarily respected by others in his department, parents or carers as being something which was legitimate and effective. Even when people are doing successful work there appears to be very little **recognition** of it and clients could be removed from therapy by others. This added to the sense of helplessness felt by therapists. Perhaps more mainstream theoretical knowledge in this area would be helpful as would the recognition of the effective work which is already being done. There also seems to be some sense of frustration and a need to promote what they view as important work which is being neglected by others. Additionally this was acknowledged even but those who were reluctant to engage in this work but if they just refuse to see these clients who will? A feeling of a need to provide a service but yet a lack of knowledge of what this would be like seemed to be true in these participants and perhaps there is a recognition amongst many that a specialist type of approach needs to be developed.

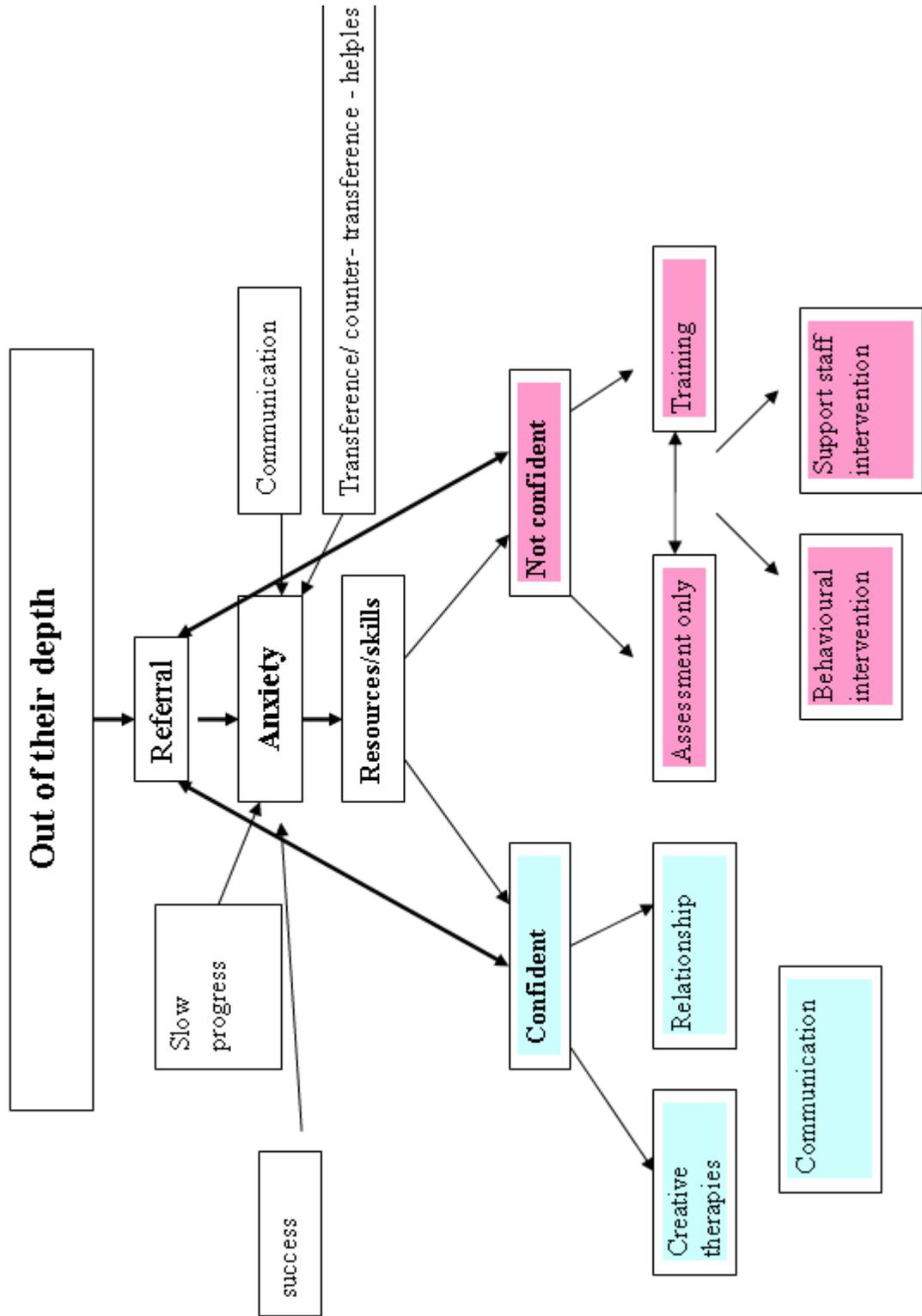
## Appendix F: Development of the theme 'Out of their depth' through diagramming

### Development of the theme 'Out of their depth' through diagramming

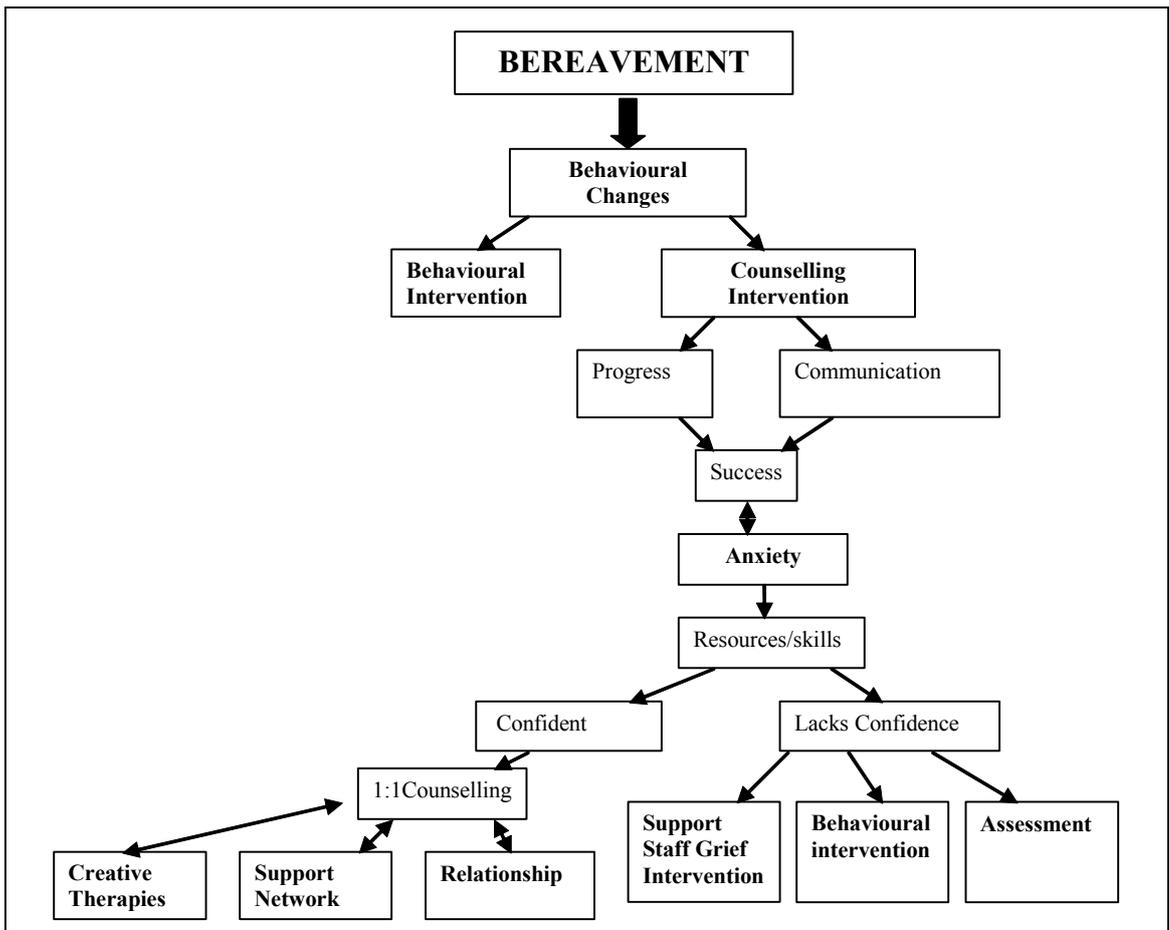
- Diagram- stage 1
- Diagram- stage 2
- Diagram- stage 3







Appendix G: Diagram - Out of their depth



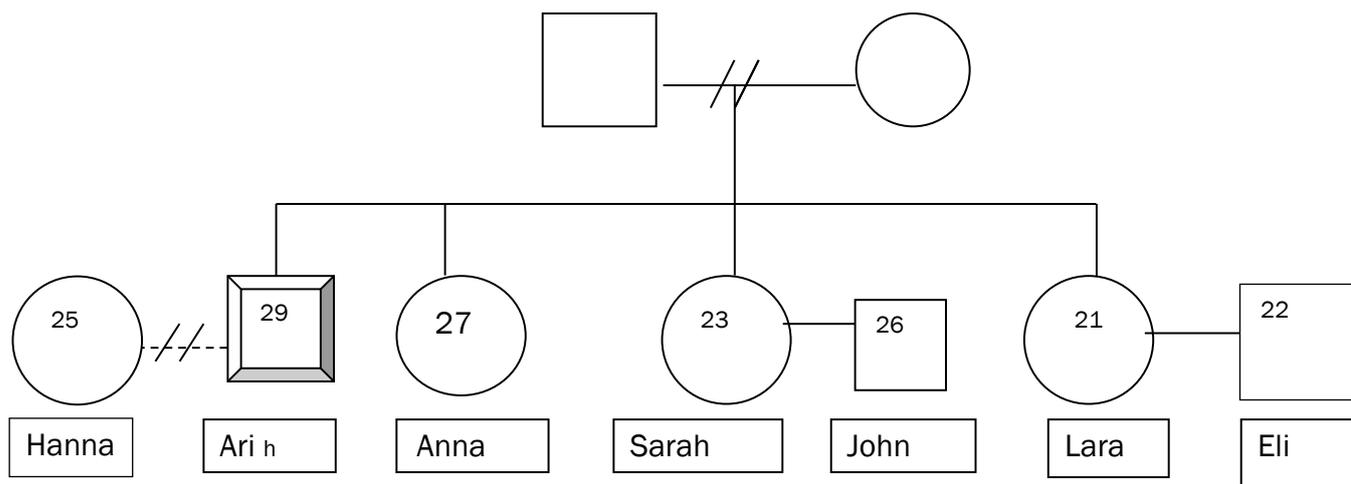
**Figure 3. Diagram to Show the Relationship Between Referrals for Bereavement Counselling for People with Severe Learning Disabilities and the Counsellor's Beliefs of Success on the Intervention Received.**

As can be seen from the above diagram, when an individual with a severe learning disability is referred to a counselling service, all therapists have concerns about the client's ability to make progress with the therapy and their ability to communicate within the session. This leads to anxiety around working with the individual. However, if the therapist believes that they have developed the resources or skills for working with people with a severe disability, which was, in these participants, a knowledge of creative arts therapies, then they might feel confident in taking the individual on as a client. They will then involve the support network both to achieve effective communication and to get the client's history and also use the relationship to bring about change. However, if the therapist feels helpless and has a lack of confidence in working with these clients, they will either support the staff

team in using a grief intervention, which might also involve individual assessment of the client, or consider using a behavioural intervention. Participants from specialist learning disabilities services reported that, as a rule, they did not receive any referrals for people with a severe learning disability for counselling. If they were to receive such a referral, they would work with the team of carers surrounding the individual, rather than the individual themselves.

## Appendix H: Client Study Genogram

## Genogram



**Key**

male  female  client  divorced  broken engagement 

**Figure 4.** Genogram of family members described by Ari

## **Appendix I: Social Phobia Rating Scale, Dysfunctional Thoughts Record, Social Balance Sheet**

- **Social Phobia Rating Scale**
- **Dysfunctional Thoughts Record**
- **Social Balance Sheet**

**SOCIAL PHOBIA RATING SCALE (SPRS)**

1. How distressing has your social anxiety been in the last week?

0	1	2	3	4	5	6	7	8
Not at all				Moderately				Extremely—The worst I have ever been

2. How much have you avoided social situations because of your anxiety in the past week?

0	1	2	3	4	5	6	7	8
Not at all				Half of the time				All of the time

3. How self-conscious have you felt in difficult social situations in the past week?

0	1	2	3	4	5	6	7	8
Not at all				Moderately				Extremely self-conscious. The most I have ever felt

4. People cope with their social anxiety in different ways. Place a number from the scale below next to each item listed to show how often you do the following when you are socially anxious.

0	1	2	3	4	5	6	7	8	
Not at all				Half of the time				All of the time	
Say little	_____			Control my thoughts	_____			Hold my arms still	_____
Take slow breaths	_____			Try to relax	_____			Focus on my voice	_____
Grip objects tightly	_____			Sit down	_____			Avoid eye contact	_____
Move slowly	_____			Cover my face	_____			Speak quickly	_____
Use distraction	_____			Wear certain clothes	_____			Focus on my hands	_____

5. Below are a number of thoughts that people have when they are socially anxious. Indicate how much you believe each thought when you are socially anxious by placing a number next to each one from the scale below.

0	10	20	30	40	50	60	70	80	90	100
Do not believe the thought										Completely convinced the thought is true
I look bad			_____				They'll notice I'm anxious			_____
Everyone is looking at me			_____				I'll drop and spill things			_____
I'm losing control			_____				I'm boring			_____
I'll be unable to speak			_____				I'm inadequate			_____
I'll babble and talk funny			_____				They think I'm stupid			_____
I look abnormal			_____				They don't like me			_____
They won't respect me			_____				I'll look foolish			_____
Other thoughts not listed							Rating			
1. _____										
2. _____										
3. _____										

DYSFUNCTIONAL THOUGHTS RECORD (DTR)

<u>DATE</u>	<u>SITUATION</u>	<u>EMOTION</u>	<u>AUTOMATIC THOUGHT</u>	<u>ALTERNATIVE THOUGHT</u>	<u>OUTCOME</u>
	Note situation or thought/recollection leading to unpleasant emotion	<ol style="list-style-type: none"> <li>Note type of emotion (sad, anxious, angry etc)</li> <li>Rate intensity of emotion (0-100)</li> </ol>	<ol style="list-style-type: none"> <li>Write automatic thought</li> <li>Rate belief in automatic thought (0-100)</li> </ol>	<ol style="list-style-type: none"> <li>What's another way of viewing the situation</li> <li>Re-rate belief in automatic thought (0-100)</li> </ol>	<ol style="list-style-type: none"> <li>Note type of emotion</li> <li>Re-rate intensity of emotion (0-100)</li> <li>What further action can I take</li> </ol>

## Social Balance Sheet

**Date:**

**Social Situation:** *e.g. in a bar/ at the shops*

<b>Internal Evidence</b>  - How you feel in a social situation e.g. feeling like the centre of attention	<b>External Evidence</b>  - Evidence that others believe what you expect to e.g. several people staring at you	<b>External Counter- evidence</b>  -Evidence that others might not be thinking or behaving as you expect them to



