

**The Use of Psychotherapy in Supporting People with  
Intellectual Disabilities who Have Experienced  
Bereavement**

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## **Abstract**

This study aimed to build an understanding of the internal and external factors that affect the bereavement process in people with intellectual disabilities (PWID). This was achieved by drawing on my previously published works, by analysing the research of others and by applying a critical clinical reflection to examples from my practice as a dramatherapist with PWID, through the use of vignettes.

The study is uniquely concerned with what can be learned by exploring the significance of the attachment relationship, the complexity of dependency and the effect of living with the primary trauma of disability on bereavement and grieving.

A comprehensive analysis of the existing research revealed that there is little understanding of the normal bereavement process in PWID and that there is a high incidence of complicated grief. The critical reflection on practice enabled me to enlarge upon the emergent theory of complex grief and to identify important components.

By applying the lens of attachment theory a greater awareness of how grief can become complicated has been reached that can inform the design of more responsive services for PWID.

This study has highlighted that there are both internal and external reasons which may explain some of the emerging evidence that points to an abnormally high incidence of complicated grief in PWID (Brickel and Munir 2008 and Dodd and Guerin 2009),

A new model of psychodynamic disability psychotherapy has emerged from this study, which proposes to include the supportive network as a component of the therapeutic treatment for PWID.

The model and findings from this study can be used to inform the development of appropriate bereavement support for PWID. The findings can be further used in order to promote more supportive and effective practice from Health and Social Care Professionals towards families when a baby with intellectual disabilities is born.

## **Glossary**

**Bereavement** - the loss through death of a significant other person in one's life

**Clinical Supervision** – Good practice within many different professions, in particular counselling and psychotherapy. The main aim is to separate out the issues of the patient/client from the practitioner and to ensure that the patient/client receives the best possible practice from the professional. Can also focus on the dynamics of the organization and throw light on how these are impacting on the work.

**Complicated grief** - characterised by a unique pattern of symptoms following bereavement that are typically slow to resolve and can persist for years if left untreated (Lichtenthal et al 2004)

**Countertransference** - the conscious and unconscious reactions and feelings of the therapist to the patient and to the transferred feelings of the patient. The therapist uses her/his understanding of these feelings in order to work with the patient

**Intellectual disability** – International term to describe learning disability

**Learning disability** – when a person has:

A significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently. Which started before adulthood and which has a lasting effect on development. (taken from DoH 2001)

**Mental handicap** – Historical term for the above

**Transference** - the process by which a patient displaces on to the therapist, feelings which derive from earlier relationships

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This work is dedicated to Stanley Thomas Benjamin Blackman who without knowing it was the driving force behind my research.

## **Chapter 1 - A brief introduction to the study**

### Background to the Study

Over the last century there has been a rise in the longevity of the entire UK population (Office for National Statistics 2010), the major contributing factors to this being the benefits of improved medical treatment and better living conditions. This in turn means that there has been a rise in the population of adults with intellectual disabilities in the UK (Seltzer, 1992). Because this group are now living longer than previously expected, there is also a rise in the number of older people with intellectual disabilities (PWID). The longer a person lives, the more likely it is that they will have experienced at least one death of someone of significance in their life. The older they are the more likely it is that there will be several bereavements.

The loss of a significant other through death is psychologically traumatic. Engel (1961) has argued that:

...grief represents a departure from the state of health and well-being, and just as healing is necessary in the physiological realm in order to bring the body back into homeostatic balance, a period of time is likewise needed to return the mourner to a similar state of equilibrium (as cited in Worden 1991).

However "...just as the terms healthy and pathological apply to the various courses in physiological healing process, Engel argues that these terms may be applied to the courses taken by the mourning process" (Worden 1991).

There is currently an ongoing debate (Stroebe et al 2000, Prigerson et al 2008) amongst generic bereavement practitioners and researchers regarding what constitutes healthy or complicated grief (formally known as pathological grief). This is fuelled by the impending 5<sup>th</sup> edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V). The DSM classifies psychiatric disorders in order to assist in the diagnosis and provision of effective treatment. There is currently a proposal to enter 'Complicated Grief' (CG) as a diagnosis in the new manual. CG is described as being "... characterised by a unique pattern of

symptoms following bereavement that are typically slow to resolve and can persist for years if left untreated” (Lichtenthal et al 2004).

### Rationale for the research focus

There is little focused or empirical research on clarifying the grief experience of people with intellectual disabilities (PWID) who have been bereaved. None have effectively advanced the understanding of the bereavement process for bereaved PWID. There is even less clarity regarding what constitutes ‘normal’ or ‘complicated’ grief within this client group. Recent research by Dodd et al (2009) is now beginning to turn to this question. However, what makes this study unique from Dodd’s is that it is concerned with what can be learned by exploring the significance of the attachment relationship, the complexity of dependency and the affect of living with the primary trauma of disability on bereavement and grieving for this client group. This thesis aims to achieve the above through examining what can be learned about these factors through grief therapy with PWID from a psychodynamic perspective and from a critical examination of the literature.

### The key research question

The question that this thesis aims to address is:

Can the insight gained from the practice of psychotherapy contribute to supporting people with intellectual disabilities who have experienced bereavement?

This question has arisen from my clinical work; however, I aim to consider how that which has been learned can be utilized more broadly, to best support PWID.

The study has its foundations in the work that began in 1997 when I set up a unique NHS Loss and Bereavement Therapeutic Service for PWID. I have since become well published on this subject. It will use what I have learned as a practitioner with over seventeen years experience as a dramatherapist. This includes working directly with bereaved PWID, providing support and training for staff and families and providing clinical supervision for other therapists

working in this field. Throughout this thesis I have used the terms dramatherapist, arts therapist and psychotherapist interchangeably. The reason for this is that in my experience therapists from many different trainings will incorporate creative approaches when working with PWID. But what is of particular focus for this study is the psychodynamic model of therapy and the relationship between therapist and client and this can be the model employed whether the therapy is mainly a talking therapy (psychotherapy), one which incorporates aspects of drama and theatre (dramatherapy) or other arts based therapies. I am a dramatherapist and I am also a clinical supervisor to many other forms of therapist and have discovered, that all that I have learned within my own practice, is also true within the practice of other forms of practitioner working with the same client group.

This study aims to build an understanding of the internal and external factors that affect bereavement in this client group, by drawing on my clinical experience, my previously published works (Blackman 1999a; Blackman 1999b; Blackman 2002; Blackman 2003; Hollins; Dowling; Blackman & Brighton 2003; Blackman & Todd 2005; Blackman 2005; Blackman 2007; Blackman 2008a; Blackman 2008b; Blackman 2008c), and by analysing the research of others.

The literature analysis is divided into three parts; the first part reviews the research and literature on bereavement and intellectual disability, the second part defines an understanding of bereavement within a historical context through a review of the literature, and the third part examines the literature on psychological therapies with PWID.

The study will focus on the growing ability of psychodynamic psychotherapies to work with PWID and highlight the gap in the research literature on this area of practice, in particular, bereavement psychotherapy.

Throughout the study vignettes based on clinical material will be presented in order to highlight specific theoretical points. Jones (2007) has described how useful the vignette is as "a device of connection" (p325) he explains that "...the vignette is absolutely only of its situation, but can also stretch and build a bridge through its use in the process of research with a wider meaning" (ibid).

Through the use of this device I aim to bring together the examined theory with the reality of the clinical example.

The argument put forward, is that through this exploration a clearer understanding of what contributes towards healthy or complicated grief in this client group will be gained in order to promote more supportive practice from Health and Social Professionals towards bereaved PWID.

Below is a brief overview of each chapter:

### Chapter 2 – Setting the Scene

This chapter defines the population who are the focus of this research. It sets the historical context and also provides an introduction to one of the core concepts of psychodynamic psychotherapy - Countertransference.

### Chapter 3 – Reflection on the journey from practitioner to researcher

This chapter describes the journey from practitioner to researcher. It describes how without realizing it at the time I was carrying out a form of continuous enquiry and development. I undertook this process through writing and speaking about the work from early on in its development, and through continually reviewing and refining the practice. The chapter charts how continual research of the most current and relevant theories combined with clinical discovery led to the development of a new clinical model for the practice of psychodynamic forms of psychotherapy with PWID.

### Chapter 4 - Bereavement and people with intellectual disabilities: A critical review of the literature

This review highlights that there is only a small amount of rigorous research on this subject. Therefore, evaluative work, individual case studies and recommendations drawn from practice have been included. Much of the work is practitioner led rather than part of empirical research programmes. A large amount of what exists has flawed or limited methodology. The major focus in the literature was on the environment disabling the natural bereavement process. There is little that contextualises the bereavement experience within a

relational or societal perspective. There is a significant emphasis on educating both PWID and also their carers to understand more about bereavement and death.

It is only within the recent literature that there has been a more in depth shift of focus to the nuance and complexity of grieving generally, and in particular what this might mean for this client group; this can be seen in the work of Blackman (2003, 2008,) and Dodd et al (2005, 2009).

The findings of this study are therefore extremely important, especially as the aim of this work is to influence the practice of professionals and services provided for PWID in order that they can be more sensitive to the needs of bereaved PWID, and avoid making an already painful process even more complicated and distressing than it might otherwise be.

#### Chapter 5 - The search towards understanding bereavement: A literature review

This part of the literature review examines theories and models of grief and mourning which are based on clinical experience and empirical research. It reflects on the expected outcomes of the state of bereavement and how perspectives on this have developed. The review ends by considering 'complicated grief,' and how we know when this really exists as opposed to when this might sometimes become a judgmental attitude governed by societal 'norms'. Within this part of the literature review, no specific reference to people with learning disabilities is made within the texts analyzed. The examination of bereavement theory provides a backdrop to considering grief and its meaning for people with learning disabilities.

Much of this is drawn from a chapter in 'Loss and Learning Disability' (Blackman 2003), which is part of the published work contributing to this thesis. It has, however, been updated with more recent theories and models.

## Chapter 6 - Psychotherapeutic interventions with people with intellectual disabilities: A review of the literature

Historically PWID have not been considered suitable candidates for the 'talking' therapies. This chapter considers this history and explores the literature on the use of counselling and psychotherapy with this client group today. It incorporates some of chapter six from Loss and Learning Disability (Blackman 2003).

It highlights how it is well documented that this client group is significantly vulnerable to psychological disturbance. Yet historically and currently, how this is often managed through behaviour modification, or medication rather than through psychodynamic psychotherapy. It describes the barriers to accessing psychotherapy but also describes how, when this does take place, there are newly developing models for this form of 'disability psychotherapy'.

## Chapter 7 – A review of the author's contribution to developing an understanding of bereavement in people with intellectual disabilities

This chapter examines my contribution to understanding and responding to the bereavement needs of PWID. It assesses the need for and difficulties in, developing the skills and confidence of direct care staff to support PWID through a period of bereavement. It also introduces a new model of 'disability psychotherapy' which engages the supportive network as part of the treatment process.

## Chapter 8 – Conclusion and recommendations

This study concludes by drawing together the combination of insight gained from the practice of psychodynamic psychotherapy, with an understanding gathered from a critical review of the literature. It establishes that this can contribute to supporting people with intellectual disabilities who have experienced bereavement in a number of different ways. It acknowledges the importance of increasing the skills of the workforce, developing their confidence but also offering direct care staff a framework with which to more effectively understand the people that they are supporting. It also allows for

greater understanding of complex bereavement in PWID through the lens of attachment theory. A brief account of the limitations of the study is explored. Finally it offers a new model of disability psychotherapy which proposes to include the supportive network as a component of the therapeutic treatment.

## Chapter 2 – Setting the Scene

### Introduction

This chapter defines the population who are the focus of this research. It clarifies the terminology used for this and describes and contextualises the study. It also provides an introduction to the core concepts of transference and countertransference used in this study, illustrating these with clinical vignettes.

### The client group on which the study focuses

In the UK the term 'learning disability' is used by health professionals rather than the term 'intellectual disability'. Learning disability is defined as being when a person has:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
  - a reduced ability to cope independently (impaired social functioning);
  - which started before adulthood, with a lasting effect on development.
- (DoH 2001, p14)

The term 'intellectual disability' is a term which has become more commonly used internationally. Baum and Lynggaard (2006) state:

The International Association for the Scientific Study of Intellectual Disabilities' (IASSID), an interdisciplinary scientific nongovernmental organization with official relations with the World Health Organization, has promoted the term 'intellectual disabilities' in an attempt to foster consistency and dialogue across different countries. IASSID promotes worldwide research and exchange of information on intellectual disabilities. (p xxv).

In order that this study can be usefully employed as a part of this international dialogue, I have chosen to use this term.

Whilst there are no reliable statistics for the number of people with intellectual disabilities currently living in the UK, it is estimated that there are currently 210,000 people with severe and profound intellectual disabilities, and 1.2

million people with mild/moderate intellectual disabilities in England (UK. DOH, 2001).

This study mainly focuses on adults with a mild to moderate intellectual disability, with an age range from twenty years upwards. According to Gates (2007), "The World Health Organisation has characterised the degree of disability ('retardation') according to how far an individual is from the normal distribution of IQ for the general population" (p5). He continues by explaining that an individual with "...a measured IQ of less than 70, is said to have a learning disability. Individuals whose IQ is in the 50-69 range are generally identified as having mild learning disability" (ibid) whereas "...moderate learning disability is identified when the IQ is in the range 35-49" (ibid).

Many of the older people with intellectual disabilities (PWID) that have been the subject of this study will have lived in large institutions for much of their lives, Gates (2007) reminds us that "It is only relatively recently that the large learning disability hospitals have been closing. In the past, thousands of people with learning disabilities were segregated from society and led very impoverished lives" (p7). However it is also important to remember that some older PWID will have spent all of their lives living with their family (Blackman 2007). These families would have been advised to place their disabled infant in an institution, but instead they instinctively kept their child at home, perhaps avoiding contact with any statutory services for fear of the child/adult with ID being taken away from them. The effect of growing up in either of these situations will have had a profound influence on the person with ID and their family affecting the pattern of attachment. This in turn will have an effect on how the person with ID copes at a time of bereavement.

In keeping with the ethical principles underpinned by the Research Governance Framework for Health and Social Care (Department of Health 2005), only pseudonyms have been used in order to protect the anonymity and maintain confidentiality of all PWID featured in this thesis. All of the clinical vignettes that have been drawn upon have been taken from my clinical work carried out before this research study began. In all cases where it was possible, written informed consent was sought and granted from the person involved. However

in cases where this was not possible, greater care was taken to ensure that the identity of PWID who were part of my clinical work was protected by adhering to the local policy and practice at the time. It is to be noted that most of these practice examples are already in the public domain as they have featured in the work published previously. It would not have been appropriate to have returned to these previous clients in order to try to gain further consent for this study. The clinical work drawn on has been carried out within my role as a dramatherapist, I am bound by the code of conduct by my regulatory body – The Health Professions Council.

### Historical context

Historically, it was thought that PWID did not have an emotional life (Clark 1933) or make emotional attachments and therefore would not find separations from significant others painful. This can be seen by the way in which children and young PWID were placed into institutions and isolated from their families and the rest of society in the early part of the twentieth century. This way of thinking about PWID also extended to thinking that they would not understand what had happened when someone died (Ray 1977, Kitching 1987, Oswin 1991, Conboy-Hill 1992) and therefore would not notice the absence of the deceased.

What is clearly highlighted within the literature is that limited comprehension of the death concept does not protect someone from the painful reactions to bereavement (Cathcart 1995). What also begins to emerge is the thought that if someone cannot express how they are feeling through words, this does not mean that they do not have strong emotions. These feelings can often be seen through behaviour changes but the challenge is that they may not always be understood as such.

Oswin (1984) studied the effect of the short-term loss of a parent on disabled children in respite care. She charted the children's grief caused by the experience of short term care and confirms in this study how grief was expressed in specific patterns of behaviour. This author has documented how

this can also be seen in adults (Blackman 2003). These observations have similarities to those made by the Robertsons (1953) when they observed children who had been separated from their mothers in early infancy. These findings informed the attachment theory of Bowlby (1973). It is this theory and its relevance to this study that will be examined.

It is now also well known that PWID are more prone to complex grief following bereavement (Ollendick & Ollendick 1982, Hollins & Esterhuyzen 1997) than many others and the reasons for this will also be examined in more detail in this study.

Dodd et al (2005) have stated that understanding and assessing the emotional states of PWID in general is still in its infancy and as a result, the challenge to try to distinguish 'normal' grief reaction from 'abnormal' is even greater in PWID than in the general population. This highlights the importance for this study to focus on building a deeper understanding of what contributes to 'complicated' grief in this client group.

#### The clinical concepts of transference and countertransference

Transference and countertransference are core concepts of the psychodynamic and psychoanalytic approaches to psychotherapy and counselling. This author's clinical work is informed by a psychodynamic approach and it is therefore important at the start of this study to introduce and clarify this model of working in more depth.

Transference is the process by which a patient displaces on to the therapist, feelings which derive from earlier relationships. Countertransference means the conscious and unconscious reactions and feelings of the therapist to the patient and to the transferred feelings of the patient. The therapist uses her/his understanding of these feelings in order to work with the patient. This is particularly important when working with a non-verbal patient as transference and countertransference are the main tools the therapist has with which to understand the thoughts and feelings of the patient and with which to bring about change. In order for the therapist to be able to use countertransference

it is essential that they can, as Hodges (2003) has said “think about his or her own feelings and prejudices. Supervision and indeed personal therapy can make an essential difference in understanding the very complex emotional relationships created through our clinical work” (p 26).

This is why all trained arts therapists, psychotherapists and counsellors will have been required to have completed extensive personal therapy whilst in their training; there is also a professional requirement for clinical supervision of all case loads, which is a continuing need throughout one’s professional career. All therapists and counsellors are required to become members of their specific regulatory body, such as the Health Professions Council which regulates arts therapists. These regulatory bodies require evidence of continuing professional development and include clinical supervision within this.

Within this framework we are able to untangle some of the complex dynamics that can arise in relation to working with someone with a disability and we can begin to understand what feelings belong with whom. This can greatly benefit our client and also ourselves as professionals, enabling us to be competently effective in our role. It is important to consider that these unconscious processes are at play also within non therapeutic relationships and in particular in the relationship between paid carer and client. Although of course, these usually remain unconscious, it is important to raise the issue as it is the complex dynamic within this particular type of relationship which forms a key part of the argument in this study. This will be referred to in more detail in chapter three (in the case study – Maureen) and will be returned to in chapter seven.

It is crucial for the therapist to focus on recognising the transference and the countertransference, as these processes can become extremely debilitating or even destructive within the therapeutic relationship if they remain unconscious. However they can become powerful diagnostic tools, once conscious, with which to facilitate fundamental relational changes within the client. The therapist will need to be resilient in order to hold firmly to the hope for change

as the countertransference can sometimes be full of hopelessness (Corbett 2007) and when this happens, it becomes easy to feel like giving up.

Sinason (1992) referred to Bion's (1959) concept of the analyst as a container, she says "The younger the child or the more severely handicapped the child or adult, the greater the need to work more by understanding the countertransference or the nature of the communication the patient has sent to the therapist to be held." (p80-81) The therapist offers 'containment' through the therapeutic framework (uninterrupted time, in the same place, at the same time and in a consistent fashion) in which feelings can be expressed consciously or unconsciously by the client. Rather than reacting to the feelings, the therapist thinks about and tries to understand the feelings expressed, in a way that is of use to the client, in order for the client to move forward and develop.

It can be helpful for an inexperienced therapist to know that there are particular unconscious reactions that are commonly experienced when working with a client with learning disabilities. This is one of the reasons why it is important for this work to be supervised by someone experienced in working with this client group. Thomas (1997) has noted that although the full gamut of countertransference reactions may occur when treating a client with disabilities, the following particular reactions may predominate:

#### 1. Castration Anxiety

Freud (1926) used the term castration anxiety very broadly, as the fear of the loss of a body part. Thomas (1997) suggested that for the client, a disability may represent a form of castration. He was mainly focussing on clients with physical disabilities, but if we were to think of castration anxiety as also holding the meaning - fear of loss of potency as in 'ability to do' this is very relevant for the client with an intellectual disability. He suggested that all humans have a conscious or unconscious fear of being damaged, and that the condition of disability in one's client could easily trigger a countertransference response of anxiety/fear in the therapist of loss of potency or agency. It is common for a

therapist to feel quite helpless and ineffective when working with a client with ID, this can be helpfully understood through considering the transference.

## 2. Fear of loss of love

Thomas (ibid) has stated that the 'therapists feelings of rejection, loss, or depression when treating patients with disabilities may suggest that the therapist's reactions are accurately mirroring what the patient is feeling' (p153). As a student training to become a dramatherapist, I remember that I struggled to work with a group of people with ID. I was on placement and my task was to run a drama group. I reported back to my supervision group, my feelings of failure and rejection as I failed to motivate any interest in my group. Through the supervision I came to realize that this was a group of wary people. They were perhaps used to being set up to fail, because like me, other people had often gone to them with expectations of what they could do, and then perhaps not thought of adapting the task in order to make it accessible, resulting in the project failing. This sort of experience can happen over and over again for PWID and the people working with them. It seemed that possibly years of this sort of experience had left the group unwilling to take a risk with me. My first task was not to concentrate on making the drama happen, but to empower the group in order that they felt safe enough to risk experimenting creatively with me. Once I had understood it became possible for me to work with them. The first thing that I did was to tell them that I was feeling unsure whether or not they wanted to be doing drama with me; it felt important that I aired some of the feelings that I felt were in the room. Some people said that they did want to, but that other people 'would muck about' or 'spoil it', they did not say that I might spoil things; that remained unspoken. This discussion led me to suggest that we make some ground rules as to how we should all work together, we worked on these and continued the process at the beginning of the next few sessions and I wrote them up. I made sure that I found a way to engage every member of the group in the process of negotiating the rules; they were brought out at every session, and anyone in the group could remind any group member, or me, of the rules if they started

to lapse. By bringing out into the open some of the concerns of the group and through making the rules, the atmosphere in the room completely changed. Addressing the group's fears in this way and giving group members a tool with which to take control (i.e. the rules), seemed to free them up and they were able to go on to do some very creative work.

I had been supported by the supervision process to understand the group's anxieties as well as my own. By recognizing my own countertransference to their fear of failure and their fear of my rejection of them, I was able to address this, which resulted in freeing the group from lethargy and freeing myself from feelings of rejection.

### 3. Fear of Loss of the Object

In psychoanalytic terms 'object' means a person or thing to which the client is firmly attached; that to which the subject directs their feelings or action. The therapist can begin to fear the client becoming overly dependent on them or they can experience the client shutting off for fear of making a meaningful relationship in case they are rejected or abandoned. These responses could be considered through the lens of attachment theory, as will be demonstrated in chapter three.

In working with a young woman with moderate ID who I will call Christine, I struggled to feel any warmth towards her. For the first six months of our work together I experienced her as difficult to be with. This shocked me because reading her notes before our first meeting I had felt moved by her early life experience. She had a history of neglect and sexual abuse from early infancy. I held the hope that I could make a difference in her life. As I went to collect Christine from the waiting room each week she would make a big show of affection towards her escort and she often started the session by telling me how much she loved her escort. This felt as though she was aiming to make me feel left out and also to let me know that she did not 'love' me. She would easily get cross with me, this was often because she did not clearly understand something I said or she completely misunderstood and took offence which she did very easily. This led to me feeling as though I was

'walking on eggshells' with her. The other thing that she did was to tell me regularly that she might walk under a bus before our next session, which felt like a test, in order to check whether it would matter to me or not if she was dead before I next saw her. I always said that I hoped that she would not do this as I would be really upset to hear that anything so awful had happened to her. In supervision I was gradually able to see that in fact she was keeping me 'emotionally' at arms length, as this felt safer for her. This made sense as her experience so far, of people who were supposed to take care of her, was that they had not been able to or worse - they had abused her. With the help of supervision I was able to withstand the transference, to hold hope for this to change and to contain her difficult and confused feelings towards me. My feelings towards her gradually changed and at one point I noticed that I was experiencing her as a very small and vulnerable infant in the sessions who was in need of very real nurturing. These feelings came interspersed with the same strong feelings of disdain and it therefore felt very difficult to act on them as, if I showed too much concern or warmth, she would again become aggressive towards me. Then one day, she arrived for her session with a terrible cold. This was about one year into the therapy. I said that she looked like she needed to be wrapped up warmly under a blanket, and that she needed someone to take good care of her. She seemed to hear this and accept it. I said that perhaps I should buy a special blanket for her that I would keep in our room, and in future if she did not feel well she could use it. She liked this idea, so before the next session I brought her a soft red blanket. She seemed amazed that I had remembered to buy it, and a few sessions later she again arrived feeling unwell and decided to lie on the sofa under 'her' blanket. I felt that she really did, for a short while revert to a small infant and that for the first time, I was the watchful attentive mother that she had never experienced before. This was a landmark change in her therapy and in our therapeutic relationship. I noticed how much warmer I felt towards her and also how much more responsive and available she had become towards me. I also noticed a change in her ability to think more clearly and to be more coherent.

#### 4. Fear of Death

This issue is central to the topic under discussion and therefore deserves special attention. The therapist can become painfully conscious of the 'social death' (Todd 2002) that many clients will experience; this may be heightened by a client who is very in touch with the 'societal death wish' (Sinason 1992 this is discussed in more depth in chapter 6). These thoughts may raise feelings of guilt in the therapist and also an awareness of their own mortality.

A client with mild intellectual disabilities that I will call Claire, heard news that she was to become an aunt. She initially responded by becoming very excited. However this quickly changed, as the birth grew nearer and Clare became increasingly concerned as to whether the baby would be born 'alright.' This demonstrated, not only an awareness of her own disability, and the effect it has on others as well as on her own life, but also perhaps an insight into the reality that babies may be killed off if they are not 'right' through abortion. Clare would have been aware of her family discussing the pregnancy and the various screening procedures. This triggered thoughts for Claire about her disability and her family's response to her own birth.

Both these fears (3&4) are crucial to have in mind during bereavement therapy with PWID. Both are connected to fear of loss through death, one's own and a loved one's. In the light of society's death wish (Sinason 1992), fear of death can be viewed as a very strong unconscious dynamic. Fear of loss of the object (see above) may be accentuated by the real death of a parent, but it is also crucial to consider it in the light of dependence. All people with learning disabilities will be dependent on others for certain aspects of their life, to a greater or lesser degree. The experience of dependency is usually less one of reciprocal dependency than for someone without a disability, although there are many examples of PWID mutually caring for others such as an elderly parent or a spouse. Death of a parent may well have stirred up painful issues around dependency, and there may be many questions over who will now be providing support for the client, and anger and other complex feelings connected to the need to be dependent. An example of this can be seen in Caroline, a member of a loss and bereavement group. Caroline is a very able

woman who lives independently. She had a very close relationship with her mother who provided a certain amount of needed emotional support and also encouraged and developed Caroline's independent living skills. After her mother's death Caroline's grief has been exacerbated by her dependent needs not being 'seen' or being ignored. Because she appears able enough to manage independently, she has been 're-classified' by the ID team as needing less support than she feels she needs (this is particularly so under the current financial climate of austerity). The decision has been made by the ID team that she is now too low on the spectrum of ID to need much input from LD Health or Social Service Departments. However, what has failed to be taken into account is the fact that, up until the point of her mother's death she had managed independently because she had her mother's emotional support. Her grief has now become complicated by multiple psychosomatic illnesses that are an attempt to pull in the care she feels so desperately in need of. She often dominates the loss and bereavement group that she attends with her anger at these unmet needs for care and support, she feels that there is no-one who really cares whether she lives or dies. This example illustrates why loss of the object can carry such a strong element of fear.

#### 5. Fear of self disintegration

This is very common when working with PWID, the therapist can experience disintegration of their own thinking. This comes from a client who may find it very difficult to think, and who may have a fragmented sense of self from a constantly interrupted dialogue with their primary carer during early development, below is a clinical example.

Philip is a man with severe learning disabilities in his early forties and was referred to the service after the death of his mother; his father had died some years previously. He had also witnessed the long stay hospital, in which he had lived for many years, being pulled down around him. As he was moved into a new bungalow on the same site, this meant that he had also seen many staff leave. Philip had experienced a form of physical lameness as a child, which had required a lot of medical treatment and separations from his family at a young

age. Although he was verbal, he had difficulties with communication and often appeared muddled and confused. Philip had not attended either of his parent's funerals.

He had been referred to the bereavement service because he had become obsessive about losing or breaking any of his possessions, to the extent that a large lockable cupboard had been bought and installed in his house in order for him to lock away his possessions. The care staff in his home found it challenging to support him, as he would often ask very direct questions about death, to which they felt ill-equipped to respond. It was hoped that through bereavement therapy, Philip would be able to get some answers to his questions about death and that he might be able to work through his fears of losing things that were important to him.

In our early sessions together, it was difficult to understand what Philip was saying a lot of the time, but there were snatches of dialogue which sounded as though he was repeating the kind of conversations he may have heard. Sometimes he appeared to be scolding himself, as though he felt permanently in the wrong and useless. I often found myself feeling unable to think. I felt quite lost and de-skilled not knowing how to begin to work with him. In my supervision we considered the countertransference and reflected that it seemed as though Philip may also often feel lost and de-skilled and was projecting these feelings into me. I also noticed that it was not easy to admit in supervision just how lost I was. It was even difficult to talk about the content of sessions, as I understood so little of what Phillip was bringing to them and it was hard to remember clearly what happened between us during our time together. Gradually I discovered an important snippet of information from the staff, that Philip's father was very strict with him. This was helpful as sometimes these monologues were about politics or building work and I felt that these seemed to connect to issues that were of importance to his father. Whenever he chose to use creative materials in the sessions, such as paint, he would use them in a very practical workman-like style, often telling me details about how to care for or use the materials; these seemed to be skills that he might have learned from his father. I sensed, as time went on, that these were

techniques that Philip had developed in order to keep his father alive for him in some way. Although he had been referred following his mother's death it seemed that he was at present more preoccupied with his father. I began to explore this theory with Philip; I focused on direct reminiscences with him about his father. We compiled a book together with pictures and I wrote down memories for him composed of fragments recalled here and there of time spent with his father. As this work progressed his dialogue became more lucid and he appeared much calmer; he also became more able to cope with small changes in his life. I also noticed that I was becoming able to think much more clearly in his sessions and that I stopped feeling so deskilled.

Thomas (ibid) goes on to say "In addition to these psychodynamic responses, therapists may expect to experience many of the same situational, socio-cultural, and historical reactions to disability as other persons" (p156-157).

Marks (1999) has referred to psychoanalytic theorists such as Kohon, 1986; Raynor, 1991; Symington, 1986, and Gomez, 1997, who placed emphasis on real experiences in the social environment shaping the psyche. She described different levels of 'external reality' these may be interpersonal relationships such as between the mother and her infant, family dynamics or influences from and within wider groups, and also from popular culture. She said, '...the insights of psychoanalysis can be used to look at disability at the socio-cultural, institutional, group and interpersonal levels as well as on the intra-psychic level' (p20).

## 6. Insight

Bicknell (1983) has suggested that insight into having a disability is far more present in PWID than has often been believed. The therapist needs to be able to keep in mind the loss or pain that a client may feel in connection to having a disability; a client may or may not be able to verbally acknowledge this. It is all too easy for the therapist to collude with the defensive behaviour of the client that can be a response to the insight (this is described in more detail in chapter 6) one example of this is for the client with ID to shut down all possibility of

thinking. There is a fine balance between being gently supportive of the client and making demands on the intellectually disabled person to think.

## 7. Suggestibility

There may be a propensity to suggestibility for some clients with an ID. This may partly stem from a desire to please and therefore to give a 'right' answer, or it might come from a fear of getting something wrong and therefore failing. It is important for the therapist to be aware of any signals that they may give towards a particular answer or statement and to think carefully as to how questions are worded; they need to be impartial.

In an article on working with sexually abused children with learning disabilities Allington-Smith et al (2002) stated that "We should not expect children who have been severely admonished for their slowness to make therapeutic attachment and treatment progress at the same rate as their more able peers. Their ability to think without anxiety will have been impaired by a history of failure and subsequent criticism..." (p68). They go on to say "A posture of openness and willingness to accept and understand each particular child's confusion and anxiety is often sufficient in itself as a starting point for building a therapeutic alliance" (p68). This applies just as well to adults with learning disabilities. As Sinason (1992) warned us "To reach and explore this emotional intelligence a great deal of guilt must be dealt with, guilt of the patient for his handicap and guilt of the worker for being normal" (p74). I return to examine the subject of countertransference and how it is written about and understood within a review of the literature in Chapter six.

The next chapter describes the journey from practitioner to researcher. It explains how this study has been built on my clinical observations.

## **Chapter 3 - Reflection on the journey from practitioner to researcher**

### Introduction

This chapter examines my journey from practitioner to researcher. It also includes some personal contributory life factors which have unconsciously contributed to my work in this field. By the end of this chapter I aim to have presented the central point of the argument thus far which is that understanding the attachment pattern of the bereaved client through the use of psychotherapy can lead to a greater awareness of how grief can become complicated.

This research has been carried out over many years within my role as a dramatherapist. The learning process has mainly taken place within my clinical practice as I have developed more understanding of the client group, of the process of grief and as I have developed and grown into my role.

I have written and spoken about this work from early on in my career, which has given me the data from which much of this study is drawn. It would seem that without fully realizing it at the time, I was carrying out a form of continuous enquiry and development. I have often found myself presenting papers alongside full time researchers, at these times I have felt myself to be rather ignorant about research (Payne 1993) and concerned that the work I was presenting would not stand up to scrutiny because of this. Undertaking this detailed examination of my work alongside an analysis of the relevant literature has in some way diminished my fear and, has also, reinforced my professional intuitive understanding of the bereavement needs of PWID.

### Methodology

Most research begins with a carefully constructed plan based on a tried and tested framework or methodology; my study is unusual in that it does not. It is only now, as I come to write up and make sense of all that I have learned, that I need to consider methodology and whether or not I can apply this retrospectively. As Lindsay (2010) has stated; "Our practices and stories are

always a work-in-progress" ( p280), she goes on to say "It matters to explore our experience as one way to make our knowing coherent and transparent, even if only for that moment" (ibid).

As I examine some of the methodologies that seem appropriate to this research, it becomes clear that this study has used qualitative methods. All qualitative research is based on a phenomenological position (Maykut and Morehouse 1994) "In the phenomenological position the observer is perspectival, that is, has a singular perspective."(p19). This study has been undertaken from the perspective of a psychodynamically informed dramatherapist, with underpinning theories such as attachment theory (Bowlby 1975) and the concept of containment (Bion 1963), it is these theories which have informed my observations and reflections. Maykut and Morehouse (1994) have described "...the *human-as-instrument* for the collection and analysis of data" (p26). A weakness in this method is the fallibility of human memory and the challenge of remaining objective.

Within qualitative research, reflexivity is an essential part of the process, this means having an awareness of the multiple influences the researcher personally has on the research process and also being conscious of the way in which the research processes affects them (Gilgun, J. F. 2010). It could be said that because my training and orientation as a psychodynamic dramatherapist has placed me in a natural position for continuous reflection, this may support me becoming reflexive as a researcher. As a dramatherapist I am constantly reflecting on my own unconscious process and how this affects the work. This is apparent in my reflection of the clinical work and particularly in the focus on transference and countertransference which is discussed in more detail in chapter 2. However, there is a need for caution in comparing these skills too much as there are clear differences. Jarvis (1995) describes a model of reflexivity that has 7 different levels of reflection. This model is helpful in slowing down the process and making a number of different checks on the way in which a reflection has been arrived at, this includes checking on some of the influences such as personal judgement which will occur.

Payne (1993) has stated that "Just as it is important for therapists to understand their motivations for working within a particular medium...or with a specific client group, so it is important for the researcher to be aware of their motivations and identify their vested interest in order to validate the research" (p25). It was not, however, until I came to write up this study that I made such strong connections to themes of loss in my own life. These connections have been unconscious, and yet have informed my professional path of inquiry. It has been important to bring this into consciousness, and understand my underlying motivations; this has enriched the study but may also have influenced some of my perceptions and could hinder the search for objectivity. In the course of developing the work I have had both an 'internal supervisor' (Payne 1993 p20) and a variety of 'external supervisors'. These voices have also been important and influential in the development of the work, especially in challenging assumptions that I may have made.

In writing up and analyzing this retrospective study, I am aware that there is a danger that I may be so close to the work that I could lose my critical subjectivity (Reason 1986 as cited in Payne 1993). I therefore need to be vigilant of this and keep an awareness of the conscious and unconscious processes that may affect my critical judgement.

#### Recognising the need for a greater understanding of bereavement for PWID

My realisation about the importance for this work began over twenty years ago. I was working as a drama teacher in a further education college with people with intellectual disabilities.

One day, in a class for people who had severe intellectual disabilities, a student, who was often an anxious man, came into the room looking particularly distressed. I asked if anyone knew why he might be upset. I was told that he was in respite care because his father had been taken ill. The next week he seemed very withdrawn. I asked about his situation again, and was told that he was still in respite care. In fact, his father had died several days earlier but I was told that no one was supposed to tell him. I was appalled; I felt instinctively that this was wrong. However I am ashamed, even now, to

admit that I colluded with everyone else, and neither told the man the news, nor found out who was going to tell him, or what support, if any, he was getting. He stopped coming to my classes and I never knew the outcome of that man's story, although I could guess that it was not a very happy one. This is a real example of how oddly people can behave around PWID who have been bereaved. Why did we all go along with the idea of not telling him? Was it because this seemed easier than trying to find a way to make him understand something so difficult and so painful? Were we afraid of how he would react if he knew? Were we worried that we would not be able to support him and to contain his feelings? I now think that it could be all of these reasons, and more. I have often thought about him since and I now know that this is a very real example of disenfranchised grief (Dokka 1989) where this man's grief was not acknowledged and had become invisible to those around him.

Some time after this experience, I came across Maureen Oswin's (1991) seminal work 'Am I allowed to cry?' I suddenly recognised the awful situations in which so many of the people I was working with were living. Many of my students were having to make sense of difficult and upsetting changes in their lives on their own; their grief was unacknowledged by everyone around them. I began to see the people with ID that I worked with in a different light.

For example, I worked once a week in a day centre for PWID, one of the people who attended the day centre was a man who I will call Simon. Every time Simon saw me, he asked me how my father was (he asked everyone the same question). Reading Oswin's book prompted me to find out a little bit more about Simon's life. I discovered something that no-one seemed to have made any connections to before. His father had recently died; yet very few of the people who worked with Simon knew this information. I believe that Simon was repeatedly asking the same question because he was trying to make sense of his father's death. He needed to talk about it, and he wanted to find out if this happened to other people too. No-one around him understood this; they just jollied him along, often not answering his question or not taking time to understand what he was really asking. I was later to discover research (Hollins

& Esterhuyzen 1997) that would highlight how common this lack of recognition of grief was amongst staff working with PWID.

More and more, I began to recognise situations like this. At the same time as I was beginning to appreciate the extent of pain in the lives of many of my students, I began training part time to become a Dramatherapist. Once qualified, I began working for an organisation then known as Playtrac, a small service within an NHS Trust which provided training to direct care staff working with people with intellectual disabilities. We were situated in an old ward of a long stay hospital which was in the process of resettling PWID into the community as directed by the National Health Service and Community Care Act 1990. I was working for Playtrac as a trainer and not as a therapist at this time. However as a newly trained dramatherapist, I was extremely aware of the overwhelming feelings of loss that were being stirred up within the whole organisation (Obholzer & Zagier Roberts 1994) by this process of closure and resettlement. PWID many of whom had been placed into the hospital during their childhoods by their families as was often suggested by their doctors, were now being moved into small houses in the community, away from all that had become familiar. As preparations were put in place for individuals to move out, the original history that had led to them moving into the hospital, often thirty years or more before, became rekindled. Strong feelings were often aroused, if not always openly, in the person with ID at least within the staff working with them or remaining family. There was also an underlying sense of loss within the staff as they prepared to empty the hospital and ultimately lose the jobs that many of them had held for decades, often having followed other generations of their family in to the post. This was the back drop that gave me the opportunity to write and run a training course on loss and bereavement. It was for staff in the community as well as for those still working in the hospital. The course addressed resettlement and the losses that accompanied this, as well as bereavement following a death. I discovered in running the course that staff members were concerned that when PWID experienced difficulty grieving, and needed more support than they felt that they could offer. They were

unable to find any counselling or therapy services to which they could refer people with intellectual disabilities.

#### The setting up of a specialised loss and bereavement service for PWID

The above led to my proposal to set up what was to become a specialised loss and bereavement therapy service for PWID. The service was located within what had been Playtrac and was in the process of being renamed the 'Resource for opportunity and change' known as 'roc', hence the service became known as the 'roc Loss and bereavement service' (Blackman 1999). This is a service which offers therapy to PWID who experience difficulties connected to a bereavement or loss. It is the only service of its kind in the United Kingdom (UK) and is still open today, although I no longer work there.

In those early days I was finding my way in the dark. I had learnt from my experience in private practice, as a dramatherapist working with people with ID, that it was important to establish a positive professional relationship with the staff supporting the individual referred. I had discovered that it was important that therapy did not happen in isolation but instead was fully supported and understood by the supporting network. This had been reinforced by my experience of working with care staff in the training courses I had been running. I wanted to build on the transformative nature that I had already witnessed in training, and that others have recorded (Reynolds et al 2008), and find a way to build an alliance with the support staff around the therapy. On reflection this was an unusual approach to providing a therapy service and at that point in time I did not know of any others developing similar work. Therapy is usually a private transaction which happens behind closed doors, where confidentiality can be fiercely guarded to the point that it can sometimes, with some client groups be seen as obstructive. I, however, had learnt from my previous clinical practice that when a client is dependent on others for much that happens in his or her life, some adjustments need to be made to the traditional model of delivering psychotherapy. I did not know at the time that other therapists were also finding their own way to work with this

client group. For example Corbett (2009) has described how his patients rarely attended their psychotherapy sessions alone. He stated:

One man lives seemingly on the cusp of such catastrophic epileptic seizures that, in addition to the crash helmet he wears to his sessions, he is accompanied by two carers. These are worried, anxious, shadowy parental figures who have had to fight their desire to come into the consulting room with him, so disbelieving are they that I could cope if the patient were to have a seizure (p47).

He added 'With these figures tending to people at the borders of the analytic space, I am never truly by myself with an intellectually disabled patient' (ibid).

It seemed important for the newly developing Loss and Bereavement Service to find a way to maximise the support of a client's supportive network and to find a suitable way to exchange information if there was a need to. With all of this in mind, therefore, a vital component of the 'roc Loss and Bereavement Service' became the working partnership set up with the support system surrounding the individual (see also chapters 6 and 7). This was originally established through a two-day training programme.

Many of the referrals were linked to behavioural problems. Often disturbed behaviour may be seen as an expression of psychological need not having been met (Hollins and Esterhuyzen 1997). Below are some examples of referrals made to roc:

- A man who was regularly self-injuring himself after the death of a close female friend with whom he had lived.
- A man displaying bizarre behaviour after the death of his brother, including spending large amounts of time watching strangers funerals.
- A woman involved in 'searching' behaviour triggered by the loss of a close member of staff but linked to the death of her mother.

I used the insight that I could gain about each client who had been referred to the Loss and Bereavement Service from gathering a detailed history (where possible) and from my therapy assessment sessions. Corbett (2009) has stated

"...individual clinicians also have to decide how much information they will seek to get from the patient's carers, and how much they trust will emerge from the patient himself or herself" (p48). I made the decision to gain as much information as I could from the referrer and direct care staff at the start of each referral and then supplemented this with my own assessment process with the client.

The training programme with support staff which was a part of each new referral incorporated what I had learnt about the client, in order that the training was specific to the client. In this way I was able to help the staff to gain an insight into my reflections on the connection between the client's life history, and the disturbances that they were experiencing as a response to the bereavement. Evaluations collected from each training session evidenced that I had also been able to help the staff to gain confidence to provide bereavement support to the clients outside of the therapy sessions.

In 1998 the Loss and Bereavement Service expanded and took on a new therapist, Linda McEnhill a palliative care social worker and counsellor, who was later to become instrumental in the development and direction of my work. During this time the service was still based in the long stay hospital which by this stage, had emptied almost all of its residents due to the drive to resettle PWID back into the community, as directed by the 'National Health Service and Community Care Act 1990'. However we began to notice that PWID who had already been resettled into the community, were coming back to the sick ward in the hospital when they became ill; particularly if they were seriously ill and that this was often where they died. It seemed to us that there was unwillingness amongst general hospitals to treat PWID as they would any other patient. This could be understood as an unconscious attack on PWID, the societal death wish Sinason (1992) has referred to. This was long before the Disability Rights Commission report 'Closing the Gap' (2007) or the Report 'Death by Indifference' by Mencap (2009). These reports highlighted the appalling indifference and lack of equality experienced by PWID in the health service that often led to death through neglect. We were concerned about the people who were returning to the hospital to die, as the ward was about to

close. We wondered about where they would go to die after the closure and started to think more widely about what was happening with regard to palliative care for PWID on a national basis. This led Linda McEnhill and I to form the National Network for Palliative care for People with Learning Disabilities (NNPCPLD) which is now known as the PCPLD Network. Through this network we were eventually to raise awareness of palliative care and bereavement issues for PWID nationally and internationally it has also led to us taking part in consultations with the Department of Health over key policy developments.

One other important contributing factor in the development of the clinical work was meeting Dr Valerie Sinason at the Tavistock clinic. She is a world renowned child psychoanalyst, one of the first pioneering psychotherapists to have developed psychoanalytic work with people with learning disabilities, and is also the author of 'Mental Handicap and the Human Condition' (1992). I asked her if she would be willing to become my clinical supervisor which she accepted. It was through this clinical process with Valerie that I really began to develop my own practice, experience, knowledge and confidence, and it is also at this point that my ability to understand and theorize my work really began.

#### The painful process of becoming an expert

Within a couple of years of having established the 'roc Loss and Bereavement Service' I felt a need to share all that I had learned, though I had at this stage never spoken or written in a public forum. I felt anxious but could also see that this would be a way for me to continue to develop the work. Payne (1993) writes about the vulnerability of opening up ones work to the scrutiny of colleagues, academics and other practitioners. She says "...but by being open about my vulnerabilities I was able to improve my practice..." (p27). Having to formulate and articulate the development of the work moved on my thinking about it, and having to defend the work when I presented it, was invaluable. An opportunity arose within the NHS Trust that I was working for, to present a paper and to write this up to be published within a small Monograph (Blackman 2000). At around the same time a colleague encouraged me to submit papers

for the International Scientific Study of Intellectual Disabilities (IASSID) conference which was being held in Seattle USA which I did and to my amazement they were accepted, I also began to work on a proposal for a book. It is important to go back in time as this journey is in danger of sounding remarkably easy. It is also important for another reason, as I have been writing up this study; I have become curious about why I focussed so intently on this subject. I have been so busy doing the work that although I had a vague sense why, I had never stopped to give this any depth of thought. I have just described that I have always been someone who has found it easier to do things rather than to write or talk about the thoughts and passions that drive my actions. I struggled at school, barely got any GCEs, no A levels and did not go to University - in fact there was absolutely no expectation in my family that I would. Indeed I would go so far as to say that my father despised further education and all that he thought that it stood for. He had been someone who had made his way from apprentice boy in a large advertising firm to become a manager with contracts of his own and I suspect that he felt threatened, perhaps even undermined by new young graduates who came in to the organisation straight from university. His way of managing his feelings about this was to scorn and undermine any signs that he saw of educated thinking within young people around him, stating instead that the best school to learn from was 'the school of life'. I think that his insecurity deeply affected my ability to learn and my own confidence to show any intelligence that I had. This was exacerbated by my parents' separation during my first year in sixth form and the emotional turmoil that came with this, brought about the final decline in my ability to apply myself to passing exams.

I spent a couple of years after leaving school drifting in and out of dead end jobs, until I eventually secured a place at an acting college and completed three years training. It was during my career as an actress that I found myself running creative drama workshops with different community groups, including PWID. I quickly realised the therapeutic qualities of drama and became fascinated by this. I looked into this further and it was then that I discovered the existence of the profession of dramatherapy. I enquired about a course and

found that as a mature student, with many years experience of working as a professional actress and running creative groups, I could apply for a place without having a degree, which I did, and so began two years of training. I also had to undertake my own process of personal therapy. I entered into three years of weekly one to one psychodynamic psychotherapy; this was to become a core part of my learning. To be in therapy at the same time as training as a therapist is very important as everything learnt is deepened by the experience of the personal process. This is now a requirement of all dramatherapy training. Personal therapy is a place where one can begin to understand how one works in relation to others and to gain some insight into why and how this connects to one's original relationships within family. It is this process that has continued to inform my learning, it opened up a way for me to reflect on things more deeply and it has been an invaluable part of this research.

So, to fast forward to over twenty years since having left school, and finding myself in the position of feeling driven to discuss my thoughts and findings about my practice and the vulnerable people I was working with, I was terrified to be standing up and speaking to audiences made up of academics and experienced practitioners. I found it hard to keep at bay, the loud internal voice rubbishing me and asking "Who do you think you are?" "What on earth do you know?" It was only the passion for my work and for the clients that I was working with that kept me going.

I was unsure whether I would ever really do any more than dream of the book that I believed needed to be written about the work. Until, by extraordinary chance, one day the phone rang. It was a former clinical supervisor who had re-established herself as a publisher. She was looking for suitable books to publish and wanted to know whether I had written up anything about the work with PWID that I used to take to her supervision group. She had always encouraged me to write about the work as she thought that people would be interested. I was able to tell her that I had begun to draw up a book proposal but had got no further than that. I think looking back that this was the

beginning of a huge transition for me; the book (Blackman 2003) took me four years to write. I had many doubts and times when I could not write at all; but the relationship that I had with my publisher was crucial to maintaining momentum. The fact that she had been my clinical supervisor was critical in that she knew that I had something important to say and she never lost faith or patience in my ability to eventually write it all down.

The publication of the book (Blackman 2003) was transformational, my publisher threw a wonderful launch party at the Institute of Psychoanalysis, to which we invited key professionals from the field and my family and friends. This was the first time that my father had ever seen me in my professional capacity and I was to address the audience from a podium before the party began. First of all my publisher spoke, then Dr Valerie Sinason, both saying extremely lovely things about my work and the book and then it was my turn to speak. When I had finished I felt relieved, people began to move into the next room to have wine and buy copies of the book. I looked up to see my dad approaching the stage and filled with apprehension as to what he would say, I braced myself as he came up close and whispered to me "why didn't you understand my grief?" I was so shocked and also confused as to what he meant I could hardly say anything. I gave him a hug and ushered him into the next room where he drank far too much and I later discovered that he said several odd and similar things to some of my friends and colleagues. I was sad that he didn't say anything to acknowledge my achievement but spent many months after this trying to understand what he had meant. It was impossible to get a direct answer from him but when I spoke to him in subsequent weeks, I found myself talking over with him how it had been at home after my mother had left. We tried to talk about the painful subject of whose needs were or were not met by whom. But I found myself much later on thinking about how he had suffered the sudden death of his own father at the tender age of nine, and how this must have shaped the rest of his life in a way that I had not considered before. I believe now that this was a hidden and unresolved pain which he carried with him all his life and which spilled over invisibly to affect my brother and me. A review (Mireault et al 2002) of studies on childhood

parental separation (such as death) reports that these separations were associated with symptoms such as depression, anxiety, aggression and separation disorders in later life. There is little doubt in my mind that my father's childhood bereavement had affected him similarly. As I come to make sense of this now in the distance of time, I can see that this also affected me and unconsciously perhaps led me to focus on this work. Without either of us realising it I was responding to his grief, and trying to understand as much as I could.

People often ask what has led to me specialising in this area of work and I have up until now found this hard to answer. I thought that I just fell into it without any planning. However, as I reflect more and more on this, I can see many of the elements of my own life that are intrinsically bound up in the work. For example, the difficulties with learning that made me feel so separate to my peers and the struggle sometimes just to think, resonates within me something of how it appears to be for someone with an intellectual disability. Also the impact of my father's hidden childhood grief on his attachment to us, his children, and how he sometimes seemed to be emotionally frozen at the point of a grieving nine year old struggling to make his way in a cruel world. But there is another event and this has only really surfaced in my consciousness very recently and yet I think it is possibly the biggest contributing factor. When I was about eight years old, a good friend of mine Kim, was diagnosed with a brain tumour. No-one explained this but I started to notice that she stopped being able to play out or join in with us all. Then one day she turned up with a head scarf which was hiding a bald head, I had no idea why and found it slightly frightening. Over many months she became weaker and weaker until eventually, whenever I visited her, she was in bed. I realised at this point that she was quite ill but I still had no sense of what this might mean. Then one day my mum told me that Kim had died. I was so shocked; I had no idea that she was dying. She must have had a funeral but I do not remember being told about it and I certainly did not go, she just seemed to disappear. It was clear that to talk about her made everyone unhappy so I kept quiet. Kim's death had a profound effect on me but I had

hidden it away, as it was so painful. It is only recently that I can see how this is such a blueprint for my work with bereaved PWID, who also often experience an expected death as a sudden death (Blackman 2003) and have such trouble piecing together all the information that no-one wants to explain to them.

### The shaping of a therapist

I have worked with many clients over the last seventeen years and they have all contributed towards making me the therapist that I am today. However one client – Maureen (not her real name), stands out from the others. This is partly because I saw her for such a long time – 8 years, but also because her story was so full of loss and on so many levels. The effect of this in turn made her quite a challenge to work with and through sticking with her I learned so much. I will describe in detail my work with her, and then follow this with another case study that is in complete contrast. The two case studies that follow offer a small glimpse into the clinical work, and highlight the theoretical orientation that informs the clinical practice.

### Case Study 1

Maureen was a woman with mild intellectual disabilities in her late thirties. She referred herself for bereavement therapy when she came across a leaflet about the 'roc Loss and Bereavement Service' whilst she was working in a centre for sheltered employment. She had experienced several major losses in her life and had identified these as the reason for many of her difficulties.

The early sessions with Maureen were difficult; she was often silent for the whole of each session, and would leave suddenly before the end if she felt overwhelmed. She found it very difficult to speak. None of this is unusual in working with clients with ID but somehow knowing that Maureen was a very able person who could and did talk outside of her sessions made this more than a communications issue. The transference (this term is explained fully in chapters 2 and 6 and summarised in the glossary) was very powerful, I often felt de-skilled and useless. I sometimes felt completely annihilated, and I sometimes felt hated. All these feelings were coming from Maureen, and

reflected within me how she was feeling. It was my job to be able to sit with these feelings week after week, to be able to withstand them and, eventually to be able to understand them.

It did seem that Maureen wanted to continue coming to her sessions with me as she was showing great commitment by arriving punctually every week. So despite the sometimes agonising fifty minute silences every week, I continued to meet with her for several months. Sinason (1992) has described how one way that infants learn to survive the experience of feeling frightened daily due to the absence of an emotionally available mother, is to "give up all hope of communication and become quiet, sleep a lot, and become deeply depressed" (p189). It felt to me as though this was a state that Maureen had entered into in early infancy and that this was what I experienced when I was with her. It was difficult however, to have any sense of what was growing between us in the therapeutic relationship, or to gain any idea of who she was.

She seemed to have no sense of her own history, and very little detail had been filled in on her referral form. So partly in order to make the situation more bearable for myself and also because I thought that eventually it might help Maureen as well, I decided to try to find out more about her life. I was aware that there could be some risks emotionally for Maureen if she was to become more conscious of her life history. She had 'forgotten' the details of her life as a coping mechanism, it was therefore important that I was going to be sensitive as to how I introduced this information back to her and that I did not 'force feed' these to her but simply offer small pieces when, and if it seemed appropriate. I explained all of this to her and she seemed to trust me enough in how I would use this information and gave me permission to go and search for it.

I contacted social services to ask for their permission, and for some help to access her files going back to childhood. After many phone calls to different departments to clear permission and to track them down from all of the different departments, I was finally told that they had been gathered together out of storage, and that I could make arrangements to go and see them. I spent many hours going through them and building up a sense of Maureen's

life, and this gave me a context in which to understand her. I was also able to gently offer some of her story back to her bit by bit over the years. What follows is a synopsis her life story (in italics), and our time together.

*Maureen was the second eldest child in a sibship of six. Her mother had mild ID and had spent some time in care before she became pregnant with her first child at the age of 16, she was pregnant with Maureen very quickly after this by the same man with whom she had a brief unhappy marriage. When Maureen was 4 years old and her mother's third child had just been born, the family were discovered by social services living in a small caravan by the side of a dual carriageway, at around this time the children were taken into care for a short while. Not long after this Maureen's mother entered into a relationship with the man who was to become the father of another three children and who Maureen would come to know as her stepfather.*

*Although the records indicate that Maureen and her eldest brother spent a lot of time with their maternal grandmother, it seems that her mother was also becoming increasingly dependent on Maureen's support to manage the house and the other children, so Maureen returned again to live with her. Records from this time describe the living conditions in the family home as very poor. This new man was an alcohol abuser and was violent; he and Maureen's mother had a very turbulent relationship which continued until Maureen was 16 years old.*

*During one of the stays with her grandmother Maureen was sent out to the shops and returned to find her grandmother dead; she had committed suicide. Not long after this at the age of sixteen she formed a relationship with a sixty year old man; they became engaged and planned their wedding, but days before the wedding he died suddenly. Following these sudden and shocking losses Maureen's behaviour became very unsettled, this was the first time that depression was recorded in her medical notes, during this time she took several overdoses and there were other attempts at self harm. Three years after these deaths she became pregnant, she was still living at the family home which was small and overcrowded and the arrival of the new baby added a lot*

*of tension to the family dynamic. Maureen found it difficult to cope; she continued to self harm on a regular basis and a significant entry in her notes records that she was briefly detained in hospital under a section of the 'Mental Health Act 1983' for harming herself with a bread knife. When the baby was six months old she began to leave him regularly with her mother whilst she travelled to London to meet up with a new boyfriend, a man that she had met whilst on section in hospital. A few months later she fell pregnant to this man but three months after the birth of the baby he married another woman.*

*A month later Maureen left both babies with her mother and moved in with this man and his new wife. Records show that in the same month she was put on remand in Holloway for threatening behaviour. Over the next six years her mental health deteriorated, she is reported to have had repeated admissions to psychiatric hospitals and the criminal justice system and during this time her children were made wards of court.*

*In 1993 she was admitted to a secure ID service under Section 3 of the Mental Health Act (MHA), although she was well known to psychiatric services, this is the first time she had been formally recognized as having an intellectual disability. She is described as presenting a 'very serious management problem due to her frequent attempts at suicide and to being reckless and aggressive in her behaviour'. Records describe her as frequently self harming when she became upset about anything happening to herself or her children or when she found it difficult to cope. She would 'hit her hands violently against hard objects, cut herself, open up old wounds, insert needles into her body or swallow sharp objects'. She was also described as absconding at any opportunity and then 'creating a scene outside', this usually involved the police being called, she would then refuse to come back in and the police would need to restrain her and bring her back in handcuffs.*

She continued to be detained under the MHA for the next four years, which could be understood as a culmination in her search for containment (Bion 1963). When she was eventually discharged for the first time she was described as having done well in such a structured environment. However,

there then followed many years of bouncing backwards and forwards between being a patient under the MHA and then becoming an informal patient. It is interesting to consider that this first experience of a predictable environment became the only form of safety or containment that she had ever experienced and I believe that it became hard for her to give it up.

*Sadly, during this time spent in the secure unit Maureen's mother died suddenly and unexpectedly under a general anaesthetic for routine surgery. This has been very hard for Maureen to come to terms with and has been something which she has continuously blamed herself for.* It would seem that Maureen felt responsible for her mother's well being throughout much of her life, and this combined with her belief that any one close to her would be likely to die, because she was a bad person. Whenever Maureen felt particularly anxious or stressed, this belief became overwhelmingly real for her even though there was, of course, no reality to the idea at all. It was comparable to a child's 'magical' thinking about a death (where a young child might believe that they have caused a death because they have done something naughty) but as the therapy progressed it became clear that the idea that people she cared about might die originated from threats that her stepfather had made.

When I began to work with Maureen, she was living in a medium secure unit. She was very preoccupied by her mother's death and the loss of her sons, who she had not seen since her mother's funeral several years before, and who had both refused to see her ever since.

One year into the therapy, I noted in a review of our work together, that we discussed how positive it was that she had been able to recognise that she needed help. She had also demonstrated her commitment by attending all the sessions even though she had found them hard. We talked about how she still found talking really difficult, but how we had found other ways of being together. One of the things that we had begun in our sessions was a memory book for each of her sons as a way of keeping a connection to them. This was a mixture of writing down snippets of their life stories and adding photos and drawings, as well as putting in cards on their birthdays at Christmas and at other times when she was particularly preoccupied with them. She said, as we

reviewed the process so far, that making these had been really helpful in managing her feelings about missing them. This had been a useful therapeutic tool in enabling her to internalise some of the more positive memories that she had of her sons, and to hold some hope of being able to continue a relationship with them if they ever returned. This is an example of working on internalising the relationship which Worden (1991) has described as an important part of the grieving process or 'Continuing Bonds' (Klass et al 1996). This active way of working also took the focus away from the experience of being in a therapeutic relationship with me, in order that she felt less threatened by the intimacy and instead became able to talk to me through the process of being creative.

We acknowledged how well she had coped, when only five months into our work together I had gone off sick for six weeks, and how she had survived this with only minimal self injury. Although she had worried sometimes that I would die and not come back she had mostly been able to hold onto the thought that I would come back. *(She received regular reassurance from my team which was important in keeping her stable)*. The fact that I had returned had been a very positive experience. She said that she had learned to use by herself, some of the strategies to help her to cope when she felt like self harming or absconding, such as writing down her thoughts and feelings, or using her relaxation tape, strategies that she had been using in her sessions. But most of all, I think that she had learned that she had not killed me off, and this was to be the key to our work together. She was beginning to learn that I could withstand her presence, contain her feelings, and also that I did not prove a threat to her through the intimacy of being together. However, I began to see how entwined death and love were for Maureen. The concepts of 'holding' (Winnicott 1960) and 'containment' (Bion 1963) are very important within a therapeutic relationship, and I was working towards helping Maureen experience containment in our relationship in the hope that this would lessen her apparent need to continually experience containment through being held under the MHA.

Because she was mostly unable to instigate conversation with me, in the sessions we began to develop our own ways of communicating. For example

when she wrote or drew things for her sons' books, we were able to use these as a starting point to talk a little. This gradually grew into a method whereby she would write me a letter or write in a book in between sessions with the things she wanted me to know, she would then give me this to read and it would prompt us to have a conversation about what had been on her mind.

I also used music and relaxation techniques to help her regulate her feelings. In an ideal mother infant dyad the baby learns to regulate their emotions through the careful containment of the mother (Gerhardt 2004). This is done in a mainly non-verbal way. Mothers' facial expressions, her tone of voice and her touch are all important in regulating the baby. For example if her baby is distressed Gerhardt (2004) has written, an 'attuned' mother "soothes her baby's loud crying and over-arousal by entering the baby's state with him with a loud mirroring voice, gradually leading the way towards calm by toning her voice down and taking him with her to a calmer state" ( p23).

However, Gerhardt continued that "Caregivers who can't feel with their baby, because of their own difficulties in noticing and regulating their own feelings, tend to perpetuate this regulatory problem, passing it on to their own baby" (pp23-24). It was clear to me that Maureen found it very difficult to regulate her own emotions, so I began to introduce an awareness of this into the sessions and also some strategies that she could begin to use on her own once she had been led through them for long enough with me.

When she arrived at sessions she was often in such an anxious state that I could see the tension in her body. I introduced a relaxation tape and sometimes at the start of the sessions if she seemed particularly tense, I would suggest we tried this in order that she could relax enough to engage with me. This was very successful and she gradually began to recognise for herself if she needed to use the relaxation tape or not. This also became something that she learned to use outside of the session as a method of calming herself down and regulating her own feelings. This is important as it demonstrates that even if emotional regulation has not been learnt in infancy it is not too late to learn.

She reported in the one year review that she had not self harmed for three months and said that she had been able to get through this years anniversaries

of the deaths and her son's birthdays more easily. And best of all she said "I like myself more now."

However, as positive as all this seems, I was soon to learn that with Maureen, things never stayed stable for long. Over the years that I saw her, just as we had a positive period and these were often for longer and longer stretches of time, there would be a spectacular fall backwards, usually resulting in going back to being detained under the MHA if she had become an informal patient or in her having to move back into a secure health setting, just as she had seemed stable enough for an ordinary placement in the community.

For the staff, who had supported her for many years it was hard, they would often express in their communication with me or at case reviews how let down they felt by Maureen when she self injured again. They felt that they were doing all they could to support her, and yet nothing seemed to work for very long. Using a psychodynamic perspective to think about this, it could be described as an example of 'transference' which would lead us to suppose that this was connected to transferred feelings from Maureen about her life long experience of 'being let down' by anyone who was supposed to be in the position of taking care of her. The experience of the support staff described above illustrates why the new model of 'disability psychotherapy' which has evolved within my work is so important. The above example highlights the importance of supporting care staff in understanding the cycles that they can become entrenched in with clients, and how they can be active in bringing about a change to this (see chapter 7). The model includes an initial training day and regular support with the professionals and direct care staff. This approach offers a framework of reference in order that the supportive network can understand the confusing and frustrating dynamics that play out in their relationships with the PWID that they support. I describe how this model began to take shape below.

If Maureen was really going to achieve any long term change she needed the staff to understand her from the perspective that she and I were working from in the therapy. I began to arrange more regular communication between the staff, Maureen and I. This began when Maureen started to let me know quite

clearly in the sessions when she was having thoughts about hurting herself. As part of our ground-rules for how we worked together, I had always told her that I would need to let the staff know, and she seemed to feel quite contained by this.

We would think together, what the staff might do that could help her to keep safe. One of the things that Maureen did regularly was to fall into a pattern of blaming herself for her mother's death if something else was going on in her life which made her feel unhappy or angry, and then this would lead her into a spiral of self harm and absconsion. Through my regular communications with staff they began to understand this and they were then able to work supportively with Maureen on helping her to break this pattern.

I always attended Maureen's review meetings and wrote reports that I shared with her first of all. We would also think together in the sessions about what she might want to say in those meetings. At first she could not think of anything as she had up to that time, always been quite silent in the meetings. Gradually, she allowed herself to be helped to write down what she would like to say, and could take this away, asking her key worker to support her to speak up.

During our second year of working together Maureen told me during one session how frightened she was of her stepfather. She described him living in one room downstairs at the back of their house and how he drank a lot and they never knew what sort of mood he would be in, how violent he would be and how she often felt that she needed to protect her mother from him. She had told me little bits of this before but this time she went on to say how he had sexually abused her on an ongoing basis for many years. She didn't think that he had ever done this to any of the other children, just to her, and that she had never told anyone as he said that if she ever did he would kill her mother and other people close to her.

This combination of abuse at an early age from a parental figure combined with a mother, who was unable to mother her, had set up a disorganised attachment pattern (Main and Hesse 1990, Carlson et al 1989) in Maureen and this was to manifest in all subsequent relationships. The very people who were

supposed to keep her safe were the people that caused her harm. This subsequently set up a dilemma in her at times of stress throughout her life, and made it very hard for her to believe that anyone could ever help her. Therefore, instead of turning to others for help, she punished herself through self harming or became overwhelmed with a sense of hopelessness and made attempts to take her own life. She had been given a diagnosis of borderline personality disorder as have many of the clients that I now see who have similar histories. However, there is a new diagnosis for children currently being researched and suggested as a new entry for the Diagnostic Statistics Manual V which will be called 'developmental trauma disorder' (Bessel A. Van der Kolk 2010). This diagnostic category aims to capture all the symptoms and life history of someone like Maureen and it is my hope that this will eventually become used as a diagnosis for adults with such a history as well, as it highlights the root causes of such disturbance.

Going back to the disclosure this was the most that Maureen had ever said to me in one session, and by the end of the session she was very upset and quite frightened about what might happen now that she had told me. I reminded her that her stepfather was dead now, and would never be able to hurt her again. We talked a bit more, and I said that I felt concerned about her going back to the unit without them knowing how vulnerable she was feeling, she gave me permission to tell her key worker, who she had known for many years. I rang after the session, and spoke to the key worker, and reminded them about some of the coping mechanisms that Maureen had developed such as listening to her relaxation tape, and writing in her book, and asked if they could keep a close eye on her, and remind her of these strategies if she was feeling self destructive.

In the next session I discovered that Maureen had self injured several times during the week; she was quiet and very tense in the session. Again, with Maureen's permission, I called her key worker to register my concern, and ask for their vigilance. I also decided to give them my mobile as I felt really concerned about Maureen, I suggested that if they felt worried about any further deterioration in her mood or behaviour they could call me. There

followed a period of great unsettlement with Maureen absconding, taking overdoses, cutting herself and inserting needles, and there was very close communication throughout all of this between the staff team and I, and all the while Maureen continued to come to her sessions but found them difficult to use. During one or two of the phone calls from the unit when they were at their wits end with Maureen, I suggested that I spoke to her on the phone. I found that she was far more able to tell me what she was thinking about by phone than in person.

During this time she was haunted by flashbacks of her stepfather, she was convinced that he was still alive, that she had seen him, and that he was going to kill her sons. Each time I was able to talk her through it and convince her that he really was dead, and that he would never be able to harm her or anyone else again. I encouraged her to talk to the staff when she was feeling frightened and I talked to the staff about what was going on for Maureen, and told them that they also needed to gently reassure her that he really couldn't get to her anymore. We began to unpick the connection she had made with people she cared about dying and the abuse she had suffered at the hands of her stepfather. She believed that she had caused these deaths because she was a bad person, and that anyone connected to her was likely to die. Now that she had finally talked about the abuse she was highly anxious that she was even more likely to cause harm to people she cared about. The many attacks she subsequently made on herself can be understood as a combination of self punishment as well as a tool with which she sometimes tried to find out who, if anyone, could keep her safe.

Not long after this, I was planning to go on annual leave for three weeks and I discussed in supervision my great concern about leaving her at such a difficult time. My supervisor and I decided that in the circumstances it seemed really advisable that I should keep contact with her via a weekly telephone call at the same time as our usual session. The combination of this, and the staff understanding of the situation held her fairly well until my return.

Not long after my return there were big plans for Maureen to move out of the health unit, and into an ordinary group home. I felt uneasy about this as I felt Maureen was still very fragile, and needed staff around her that really understood her mental health. However, plans were put in place and Maureen was very excited. I did manage to insist that she still kept her therapy sessions, and she was also keen to do this.

Eventually after a quite well planned transition she moved into a home quite a long way away, where the staff were determined that she would be making a fresh start and who were, I felt, unwilling to really take on board her psychological frailty.

There was a blissful honeymoon period of about six weeks, and then it all fell apart. Maureen became violent with staff, made several suicide attempts and ended up back in hospital detained under the MHA. She was very depressed, and was back to extreme self harming. She would not leave her room to come for sessions but agreed that she would see me if I went down to her unit.

She spent another year in this unit, gradually seeming less depressed and eventually returning to see me in my room. I had begun to notice that Maureen's thinking was becoming more expansive, she was able to reflect a little more and become a little bit curious about things with me, and I commented on this to her. It was by no means like this all the time; there were still plenty of sessions where she hardly seemed to be there at all. I said that to me, it felt as though there were times when I was with her that she had her brain switched off making thinking very hard, and sometimes when it seemed that she switched it on, and it felt like I was with a different person. This began to take on a huge significance in our work together. We were actually able to talk about this absence or dissociation as something that we could notice together. She described not only how tiring it was to keep her brain switched off, and how hard it made it to cope with even the simplest things, but also how frightening it was sometimes to allow herself to think. She began to notice herself switching off, and making a choice in the session to switch on. This became an exciting point in our work and I noticed in myself how much less tired I felt in the sessions.

Sinason (1992) has described how young infants, in an attempt to survive the fear of living with an emotionally unresponsive mother “get rid of all emotional baggage.” She says that “if the mind is permanently emptied to avoid being annihilated from within, nothing can be experienced as good. Anything taken in, words, or thoughts, or learning, becomes instantly transformed into something dangerous and annihilating.” It seemed to me that this was a pattern of survival that Maureen had learned but which, through our work together, had begun to gradually change. What I experienced in relation to this phenomenon was an attack on my thinking through the transference, I often felt sleepy in sessions or found it difficult to think clearly. I write about this more in my chapter in a book on clinical supervision (Blackman 2009b), as it is important to recognise this happening in other therapists when they are working with similar clients.

Eventually, another move was planned for Maureen, this time into a purpose built flat with support from more highly trained staff. However, this time I was beginning to detect a very definite attack towards the therapy, in meetings other professionals were saying things such as “it had been going on too long”, “it wasn’t working”, and “she was too dependent”. At around this time I went on my annual three week holiday and came back to find that she had been moved and during this time she had apparently said that she didn’t want to continue seeing me. At this point I had been seeing Maureen for five years, I felt uncertain as to what the circumstances were in which Maureen had come to state this. I also felt clinically concerned that we had been given no time in which to bring the sessions to a gradual end. It seemed to me that it was far too sudden a move, and I felt that people had not put good enough planning in place to ensure success this time. I was so worried about how it would be for Maureen’s sense of herself if this move did not work out. If I apply psychodynamic thinking to try to understand what had happened amongst the support network working with Maureen, it would lead me to consider that there was frustration amongst the team. They could see that in many ways Maureen was extremely able, she had plenty of independent skills that should equip her for moving into a less supported living situation. However what was so difficult

for the team to think about was Maureen's emotional fragility, this made people feel uncomfortable. It would seem that an unconscious decision was made that if the network denied her need for emotional dependency the need would go away. It was easy to blame the slowness of this need to change on the therapy, especially as I was not there to explain the therapeutic process or to remind them of the extent of the damage she had experienced in her life.

I had not been given a chance to discuss the ending with Maureen, and had been subjected to some very difficult meetings where I had been told that it was Maureen's choice, and that it was also in her best interest that she ended the therapy as she was getting on so well in her new placement. I was eventually able, after making a huge fuss, to secure three ending sessions.

I met with Maureen for two of the three prescribed ending sessions, and then in the week before the last one she attacked a fellow resident with a knife (which was very out of character for her) and she was immediately arrested and sent back into another secure unit where she was detained once again under the MHA. When she came for what should have been her last session, she asked if she could continue to see me. When I approached the psychiatrist with this request on her behalf it was, thankfully, agreed to.

She stayed in the secure setting for a further year and then another placement was found for her; this time with better planning, and an agreement to keep the therapy providing that a long term plan for ending was put in place.

Once she had moved out of the secure setting into a large group home, we continued to see each other weekly for the first three months. We then reduced to fortnightly sessions and then by the end of the year we were seeing each other monthly. During this time she did not self harm, take an overdose or abscond at all. The therapy ended over two years ago and Maureen is still living successfully in the community. When I last saw her, she had the huge and complicated family tree that we had made together and which I had given back to her at one of her ending sessions, up on her bedroom wall and this seemed symbolic of her now having reclaimed her own sense of herself within her own narrative in a very conscious way.

Maureen was in therapy with me for 8 years, which is a long time. I have been reviewing our work together in the light of my recent experience at Respond where we now offer psychotherapy to young people. I have really been able to see not only why it is so important to be able to work with adults, long term, but also the importance of early intervention with young people wherever possible. The effects of early neglect and childhood abuse leave deep and lasting emotional scars and complicated and destructive coping mechanisms. The longer this is unaddressed the more entrenched the effects become.

I learnt so much from my work with Maureen, but one of the most important things was how her early attachment pattern had affected so much of her adult life. In particular, I learnt how this had impacted on her bereavement experiences and further complicated her grief reaction.

#### Understanding attachment and grief

Grief is the emotional response to the loss of a significant relationship; it therefore seems important to understand something about relationships in order to gain some understanding of the impact of grief. As I have already stated, my practice is informed by the theory of attachment (Bowlby 1969). Attachment theory focuses on the formation of the significant early relationships of infants with their primary carer (usually but not always the mother) and how these patterns of relating build the 'internal working models' of the world within the child. These internalised models then become the blueprint for all relationships for each person throughout their lifetime. Bowlby worked with a team of researchers, amongst them Mary Ainsworth, who applied his theories, and developed them further by making the important distinction between strength of attachment and security of attachment (Ainsworth 1963). She came up with a way of studying relationship patterns between infants and their primary carers by observing the effects of separation on young children through a systematic method that was known as 'The Strange Situation Test' which enabled her to classify specific patterns of attachment. Through this method, Ainsworth found one pattern of secure attachment and two patterns of insecure attachment (Ainsworth et al 1978).

Her colleague, Mary Main, carried out further research and added a third insecure pattern (Main and Goldwyn 1984). This research highlighted that each pattern of attachment is associated with specific patterns of parenting. The three insecure patterns of attachment are – Anxious/ambivalent, Avoidant and Disorganised.

**M**any PWID develop insecure attachment patterns (Clayton, P. 2010), this is connected to the complications which can arise from the birth of a disabled baby. The first few days of a baby's life are a crucial time for parents and child to bond (Schaffer 1958, Ainsworth et al 1974, Bowlby 1979). The mental health and emotional robustness of parents at the time of birth will affect this process as will the surrounding environment. When a baby is born with an obvious disability, there are often many obstacles standing in the way of the important process of child and parent bonding. Receiving news about their baby's disability in often stark or insensitive ways will be traumatic; this has been described as the trauma of disability (Sinason 1992) which can have a life long affect on the family and each individual within it. Parents may need to grieve for the 'perfect' baby that they did not have (Bicknell 1983). Many expectant parents will have developed a vision of their growing baby before it is born and for most parents this will not include the presence of a disability. The baby may have difficulties feeding, may be very passive and not respond in expected ways to the parents' early attempts to communicate, or may have medical concerns which lead to the baby spending time in intensive care wired up to all sorts of monitors. They will have to adjust themselves to a different vision of their own and their baby's future. They will have to cope with their own responses to this baby, whether they can see beyond the baby's disability and possible disfigurement, to family resemblance and other features on which new parents commonly linger with delight. They will have to cope with the responses of other family members, friends and professionals and the general social stigma that disability carries (Sooben 2010). The differing responses that the mother and father of the baby have from each other may put additional strains on their relationship. With all these conflicting and possibly upsetting

feelings and responses to deal with, the parents then have to nurture and respond to their baby's needs.

The mother in particular may become very depressed and withdraw from her child or she may respond by being over protective. Either of these reactions will affect the bonding process and consequently the developing child. These responses are likely to become established in the pattern of their relationships for the rest of their lives.

We begin to form our own identity in relation to others and negative attachment patterns contribute to a number of difficulties such as low self esteem, being either too self reliant or not trusting one's own judgement. The case study above describes how Maureen's disorganised attachment pattern complicated her bereavements. A disorganised attachment is formed when the very people who are meant to keep the infant safe cause them harm and this sets up tension within the child of seeking comfort from the parent who is also neglectful or abusive. This leads to the child having little sense of their own identity, low self esteem and feeling that they are to blame for everything that happens to them. Someone who has grown up with this attachment pattern can become self punishing and they are likely to turn away from others when in distress as they cannot trust that others will help them (Parkes 2006).

We could see this in Maureen's behaviour when she withdrew and became silent and when she absconded or self harmed. Paradoxically however, it felt as though she was sometimes crying out through the suicide attempts for someone to take care of her; this clearly shows the confusion that was set up in her earliest relationships. Maureen's behaviour often provoked rejection from staff who found it so hard each time she regressed after they had worked so hard to support some positive steps forward. This in turn confirmed Maureen's sense of the world as being against her and locked her into a destructive and repetitive pattern. I applied the theory of attachment more broadly and considered the responses that Maureen's disorganized attachment pattern elicited unconsciously from the people who were in close working relationships with her. I also supported the staff to understand how they were unwittingly

playing a part in this destructive cycle and helped them to find ways to change this.

Through psychodynamic therapy Maureen developed a stronger sense of self in relation to me, her therapist. This enabled her to begin to reflect and reframe some of her feelings, in particular her overwhelming feelings of guilt. She developed an ability to feel worthy of care and support from others and enlist this in appropriate ways when needed. She also learnt to regulate her own emotions. The systemic work with her supportive network enabled the carers to understand the dynamics and to make changes to avert the continuous negative cycle.

Someone with Avoidant attachment will have experienced a primary carer who does not show feelings and who does not tolerate closeness, and they are likely to punish the child's attachment behaviour. The infant will learn to inhibit their tendencies to cling or to cry. We are likely to see an infant (or adult) who may appear indifferent but this will be more apparent than real. In a stressful situation, they are in fact physiologically aroused but they will have learned to mask this. Many mothers of avoidant infants are responsive to low levels of stress but become less responsive if the infant's stress level rises, which is the reverse of how it should be, and can leave the infant very vulnerable.

In the following case study I describe some group work with a woman who has an anxious attachment pattern and a very different way of managing her grief.

### Case study 2

*Anne (not her real name) is a woman with mild ID in her 40's, she was born with serious intestinal complications and spent much of her early childhood in and out of hospital undergoing complicated medical procedures. This was before Bowlby's research had changed practice within paediatric wards, parents were not allowed to stay in hospital with their children and parental visits were brief and strictly controlled. Anne had lived in her parental home up until her mother's death twelve years previously. Anne's mother had died suddenly when she and her parents were on holiday. Anne had witnessed her mother collapse as they were all getting into the car and the paramedics were unable*

*to resuscitate her. This was a very traumatic experience for Anne. She was made to feel that she was 'in the way' and felt very isolated in trying to make sense of what was happening. Her father was unable to cope with her on his own when they returned home and she was quickly moved into residential care which was a further loss. This trauma remained unprocessed for the following twelve years and when I met Anne she was a very reserved, anxious woman.*

She had been referred to the service because she was about to appear in court against a man who had raped her and the anxiety had become almost paralysing. Although it would be expected that facing such a difficult situation would be stressful for almost anyone, her carers had recognised that her unresolved grief might be playing a part in exacerbating this. It was decided that the loss and bereavement group would be the best setting for Anne as she found it difficult to talk about her loss. When Anne first attended the group she spent each session sitting and crying silently. As the weeks went by she did, however, begin to listen attentively to the other group members as they told of their own losses and life stories. She showed a commitment to the group by attending punctually every week and after a few weeks she cried less but still found it hard to say very much. The ethos of the group is to encourage curiosity as to what thoughts and feelings others in the group might have and also to find similarities and differences in each others stories. Gradually the group provided a container (Bion 1963) for Anne; she could see that her feelings could be tolerated by the therapists and by the other group members. The unthreatening nature of the group and the fact that others were interested in her experiences enabled Anne to take part albeit passively at first. The group began to tentatively explore how she may be feeling even without her participation to begin with, by 'wondering out loud' if she may be feeling one way or another, this seemed to lessen her experience of being overwhelmed and to dispel her sense of isolation.

Anne had an anxious pattern of attachment; this would be consistent to having experienced many separations in early childhood and also to a parental message that she would not survive without them. We could surmise that her mother had been very protective of Anne after such a difficult early start in life.

Children with this pattern of attachment can be difficult to please or placate and can grow up with low self trust; they are also prone to severe protracted grief (Parkes 2006). Anne stayed in the group for two years and gradually became less sad and more participatory. During this time she coped extremely well with the stress of the court case. She also had another very difficult experience during the course of the group. She had planned a trip to America to visit her brother and was very excited as she had not seen him for many years. Sadly, just one week before she was due to fly out, she received the tragic news that he had died unexpectedly. She was of course shocked and saddened by this, yet she coped with the news very well and was able to talk about her brother with the others in the group. She shared her feelings about his death and also memories that she had of him. It was really possible through this bereavement experience to see how much Anne had changed, and how much more resourceful she had become in coping with difficult experiences.

#### My own experience of loss

As I have suggested already in this chapter, I have been the '*human-as-instrument*' (Lincoln and Guba cited in Maykut and Morehouse 1994) in this study. One aspect of this is that my life experiences, and how I have made sense of them, have had some bearing on this work, especially my own experiences of loss. Therefore the death of my father three months after I had begun this PhD study was significant. He was diagnosed with pancreatic cancer in October 2007 and died three months later. This was a challenging time, particularly the speed at which it all happened. Looking back on this experience now, I am able to see that this very personal trauma has had a big effect on my study; it has made it even more important for me to make personal sense of his traumatic childhood bereavement on the course of my life.

My father and I spent an intense time together in those last few months, during the whole time he was unable to acknowledge that he was dying, preferring instead to refer to the time ahead when he would have 'beaten this.' He spoke in this manner right up to the end, making any kind of important

'unfinished business' type conversation impossible as he invited me to join him in making plans for when he was better. I chose to spend as much time as possible with him during these brief three months, both of us enjoying each other's company and taking the time to do that. He knew that I had begun studying for a doctorate and was almost able to show me that he was proud; he knew that I was going to speak about my work at a conference in South Africa the following year and he was excited on my behalf; we had come a long way.

His death had a profound effect on me, our relationship had been full of difficulties when he was alive and I had often felt concern as to how I would cope when he died. I feared that all the ambivalence and unspoken tension within our relationship would be left forever unresolved. I really struggled in the first couple of months. I found it impossible to study and work was exhausting. However, I slowly found that my relationship with him hadn't really ended, and I began an intense internalised relocating of him within myself. In life I had struggled with the fact that he lived with my stepmother who I did not get on with, and it was often tricky having to negotiate my relationship with her in order to gain access to my father. Now I found the new internalised relationship was less fraught and complicated, I also felt more liberated to articulate and to write down some of the challenges within our relationship than I did when he was alive. This doesn't mean to say that I do not wish we could have got to this stage in a live relationship but what has surprised me has been the ability to continue the relationship in what feels to me a very real way after death, and I think that this experience will help in my work with bereaved clients. My clinical experience has shown me that many of the clients who are referred have unresolved relationships with their parents and suffer lasting affects from conversations that they were never able to have. I have always instinctively worked with them on relocating the relationship internally (Worden 1991) and have facilitated imagined conversations that they may wish they had been able to have. I now know from my own experience just how deeply this process can work.

## Conclusion

This chapter has encapsulated the story of how I gradually became aware of the previously unacknowledged loss experiences of my students with ID. This, in combination with my underlying life experiences and unconscious motivations, has led me to focus on this specific area in greater detail. The development of my professional interest began with the devising of a training course for direct care staff. The interest continued, and I moved on to develop a clinical loss and bereavement therapy service specifically for PWID. Continual research of the most current and relevant theories have been combined with progressive clinical discovery. The case studies have provided clear examples of how the underpinning theory has been used to understand the grief complexity and to support the therapeutic changes. All of the above has led to the development of a new clinical model for the practice of psychodynamic forms of psychotherapy with PWID. Some of the theories that have been introduced in this chapter will continue to be examined in the following chapters. The main argument so far, is that understanding the attachment pattern of bereaved clients with ID can contribute to a greater awareness of how the grief can become complicated. With this insight it is possible to use the therapeutic relationship as a means of supporting the bereaved client to find some resolution to the complex grief. From this perspective it is also possible to support the care staff and professionals to re-frame their understanding of the client and therefore their responses to them.

In the following chapter I will examine the literature on bereavement and PWID in order to assess what is currently understood and to identify what gaps there are in this knowledge.

## **Chapter 4 - Bereavement and people with intellectual disabilities: A critical review of the literature**

### Introduction

Following the exploration of my clinical practice in the previous chapter, this chapter examines in depth the most relevant literature on bereavement in PWID in order to clarify the understanding gained so far. It begins by drawing on an overview of historical literature, in order to set the context, and then focuses on key relevant points from the literature. Finally, I highlight the gaps that there are in understanding the bereavement experience of PWID and discuss this within the context of what is current within generic bereavement research and practice.

There has been very little empirical research on the bereavement of PWID. Much of what exists has flawed or limited methodology. As there is such a small amount of rigorous research, the author has included evaluative work, individual case studies and recommendations drawn from practice. A large portion of the work is practitioner led rather than part of strategic research programmes.

Studies are drawn from Europe and the USA, Canada and Australia.

### Search Strategy

The following terms were used for the search: Learning disability, Intellectual disability, Mental retardation, Mental handicap, bereavement, grief, loss, grief experience, bereavement interventions, death education. The following databases were used for the search: CINAHL, Medline, PsychINFO and Book Bank. Papers from any country were included as long as they were written in English.

The current searches were done from 2003-2010 and these were then added to the literature searches carried out for this authors previous publication (Blackman 2003).

This resulted in 72 papers and six books in total of which only 46 were relevant for this review.

In order to provide a sound foundation for the research, this critical review aimed to inform the following questions:

1. What is the history surrounding the understanding of the emotional impact of bereavement on PWID?
2. What is currently known about the grief experience of PWID?
3. What types of bereavement interventions are used with PWID?
4. Are there any obvious gaps in the current knowledge?

The papers were examined for their relevance to these questions, in particular questions 2 and 3, resulting in 35 papers that highlighted what is currently understood and 24 papers which were relevant to interventions (some papers were used for both questions). The 6 books cover all aspects of this subject, and have therefore been used more for supplementary information.

#### Historical context

The first academic acknowledgement that PWID were affected by bereavement was noted by Oswin (1971). She was a pioneering social researcher who carried out much of her field work in long stay hospitals. Although this first mention was an observation, rather than the main focus of her particular study, it led to Oswin's seminal work in this field (1981). The next formal report that bereavement was an issue for PWID that should be taken note of was made by Emerson (1977). She stated that there was a high incidence of bereavement amongst the PWID who had been referred to her following the onset of marked behaviour and mood changes. This was valuable in that it was the first time that a documented link had been made between changes in behaviour and experiences of loss in PWID. Emerson was working as a consultant to 'emotionally disturbed developmentally disabled clients' and described how she would often be contacted by a variety of services when a person with a learning disability had suddenly begun to manifest 'emotional and management difficulties' to which they could find no solution. She described the symptoms

as including either verbal or physical aggression or extreme withdrawal. She discovered that in 50% of cases there had been either the death or loss of someone close to the client. What is interesting about her account is that previously no-one had thought to link the behaviour with any precipitating factors in the person's life. Emerson described how traditional mental health settings using crisis intervention methods would routinely try to find a precipitating stress; but these same clinics, when presented with a client with learning disabilities, often did not ask the same sort of questions that they would of a non-learning disabled client. This could be seen as an example of transference (see chapter 2 for a more detailed explanation), an unconscious response by professionals who when faced by someone with an intellectual disability become unable themselves to think clearly. A similar phenomenon can be seen in the findings of the report 'Death by Indifference' (Mencap 2009), which highlighted the inequality of health care for PWID. Emerson highlights how once information has been made available concerning the events surrounding the loss, it is important to look carefully at the manner in which the bereavement was handled; from her experience, a number of circumstances had usually occurred. These are presented in the table below:

- |   |
|---|
| <ul style="list-style-type: none"><li>• The staff or family may have denied the event or were unwilling to admit that it had significance.</li><li>• The family, staff and peers have given inappropriate emotional responses to the grieving person.</li><li>• Family and staff may not have allowed or facilitated an emotional response by the bereaved person.</li><li>• Adequate time for an adjustment period to the changes in the client's life had not been allowed.</li><li>• The family might have misdirected angry feelings over the death or separation towards the client.</li></ul> |
|---|

Table I

These early findings point to the significance of the environmental response to the bereavement of PWID and how if it is insensitive and unsupportive it is

likely to trigger 'bereavement behaviour', this theme continues to reappear throughout the literature.

Ray (1978) reported on the way that two families respond to deaths which affect their young family member with ID, his report amplified the view that changes in behaviour and mood may be symptomatic of bereavement. He described the reactions of two bereaved children with ID. In both families the mothers were reported to be surprised by the intensity of the child's reactions, shown in behaviour and simple statements, each parent had previously down played the significance of the death on their child. Similar carer responses are described by other researchers (Emerson 1977, Oswin 1981 and Kloeppel and Hollins 1989). It may be important to place these findings in a historical context; at this time in our history society may have been more easily embarrassed by emotional issues and may have managed this by not discussing death directly.

The two papers described above are particularly significant historically for the two points that each raised for the first time; firstly that grief in PWID can be displayed through behaviour and secondly the significance of environmental impact on the grief experience of PWID.

Later Oswin (1981) backed up these studies when she made bereavement and PWID the focus of much of her subsequent research. She went further claiming that there was no evidence to support the idea that PWID do not have the same emotional range as other people, which implied that up until this time this was what the prevailing belief had been. She refers specifically to environmental difficulties surrounding the grieving process that are specific to PWID such as challenges regarding communication and lack of choice regarding practical changes after a bereavement. She applied the principles of normalisation (Wolfensberger 1972) to bereavement and stated that each person with intellectual disabilities (ID) is an individual and will grieve as an individual. This is an important concept and one that can sometimes appear to get lost in the search for understanding how PWID grieve, where it can seem as though PWID are treated as one large group (McCloughlin 1986) with the same needs and experiences.

Cathcart (1995) identified the need for the development of non-verbal ways of working with people with profound and multiple disabilities to enable carers to understand both their physical and emotional needs following a loss. This group of PWID can easily be forgotten when focussing on bereavement and although this group are not the main focus of this study, it is important to acknowledge this contribution. Particularly that focusing on creative and varied ways of communicating can enable everyone regardless of cognitive ability. Early research carried out with eleven bereaved adults with mild and moderate intellectual disability (Brelstaff 1984), again challenged the prevailing belief that PWID did not grieve. Although some of the people interviewed appeared not to show any reaction to the death of a family member, it was concluded that this could be because they had very little contact with the family member and therefore had no significant relationship with them. It could also be because the interview had taken place too early after the bereavement and the person had not yet begun to show signs of grief.

#### What is currently known about the grief experience of PWID

An important point established early on in the literature (Oswin 1985, McLoughlin 1986), is that PWID are no different from other people when they are bereaved. They will experience the same range of feelings, and the grief responses of each person with ID will be just as individual as for anyone else (Oswin 1981). However, what is highlighted is that there are many specific issues that particularly affect the bereavement experience of PWID (Oswin 1981, James 1995). These are issues that can be identified as specifically exacerbating the grief experience of PWID, such as attachment and dependency, cognitive ability, the response of carers to the bereavement, and the lack of training for care staff, and it is these points that are discussed below.

One overriding theme which has been already touched on above is the confusion that arises in carers when confronted with bereaved PWID and how this in turn affects their response. An early paper describing four cases (Kloeppel and Hollins 1989) made the first reference to a concept that they

name 'the double taboo of death and disability', they describe how the fear and avoidance that they each elicit in carers and professionals can contribute to the complication of grieving. It could be considered that the double taboo described above is another way of describing the 'transference' referred to previously (chapter 2) except that the 'double taboo' concept also includes the secondary impact of the taboo of death, this it seems makes it particularly difficult for carers and professionals to think clearly in response to bereaved PWID. There seem to be two distinct extremes of response described in the literature. On the one hand, carers feeling overwhelmed, anxious and unsure about how best to communicate (Kitching 1987, Murray et al 2000, Read 2000). On the other hand there seems to be a complete overlooking of any impact at all (Emerson 1977, Hollins and Esterhuyzen 1997), combined with a collusion of 'protecting' the person from the death, and any associated pain of grief (Kennedy 1989, MacHale and Carey 2002, Lynggaard 2002).

For example, in Strachan's (1981) study, nurses closest to bereaved PWID in an institutional setting were interviewed, and despite reports of having observed a wide variety of behavioural responses following bereavement, a common observation was "no response to death". This highlights the concern that an unconscious denial amongst staff further limits expression of grief by PWID. Deutsch (1985) also identified unhelpful beliefs held by carers, views such as:

- "Mentally retarded individuals do not/can not understand the concept of death".
- "Mentally retarded adults do not really form attachments and therefore cannot grieve".
- "It is better to distract mentally retarded individuals until they forget about the deceased".

(cited in Kloepfel & Hollins 1989 p35)

Although these studies were carried out nearly two decades ago, we can see from more recent studies (e.g. Hoover & Markell 2004-05) that staff attitudes

and knowledge are still described as being limiting factors. There are also many studies not included in this review that focus solely on this issue. The above confirms the hypothesis, which was held at the start of this study, that there is strong evidence to suggest that the responses of carers to the bereavement of PWID is an environmental factor which contributes to difficulties in grieving by PWID. This point is taken further in the recommendations drawn from Oswin's (1985) research she notes that PWID are disadvantaged in their grieving by their social environment. She stated the following three points as particularly exacerbating to the grieving process:

- Poor intellect and multiple disabilities which may deny them the many social, verbal, auditory and visual opportunities of realising the death which are available to able people.
  - The failure of professionals and other people to recognise their normal grief.
  - The inappropriate way in which their services are organised
- (p 198)

The points raised by Oswin highlight how vulnerable PWID are to difficulties when grieving because they are dependent on others who are ill equipped to support them in a helpful way.

There are other environmental factors that are considered, for example some studies discuss society's embarrassment and anxiety about death as factors which may inhibit appropriate responses (Kitching 1987, Conboy-Hill 1992) reinforcing Oswin's (1985) earlier ideas. The latter suggests that the response of PWID to bereavement is likely to be atypical due to the fact that Western attitudes to death and dying make it hard to have an open discussion, and that society's attitude towards disability can lead towards PWID denying their actual level of understanding or emotional functioning. This concept is similar to the double taboo of death and disability (Kloeppel and Hollins 1989) which is discussed above.

A study carried out in two states of North America aimed to elicit the attitudes and understanding of carers to bereavement in PWID (Hoover & Markell 2004-05). They found that a sense of over protectiveness or infantilisation emerged from the data. Assumptions were made as to what the person did or did not understand which were seemingly based on personal belief rather than clinical judgement. This study highlights an important environmental issue, that the personal perspectives of the carers create an added limitation alongside lack of skills, knowledge and confidence, already highlighted in previous studies. These researchers surmised that these views and actions can disenfranchise grieving PWID.

Interestingly one study (Gilrane-McGarry and Taggart 2007) found that PWID often did not 'bother' to communicate their feelings to front-line staff, and that the staff did not ask any questions or follow up news of their bereavement. These researchers argued that this passivity on the part of the person with ID could be perceived by staff, as the person adjusting well to the bereavement. This study is significant because it presents a whole new perspective on why it may appear that PWID often present with no reaction to bereavement. If this finding can be validated it highlights a further reason as to why it is important to give staff bereavement training. Furthering this argument an earlier study (Murray et al 2000) suggested that one explanation for lack of engagement by PWID when they are grieving could be explained by staff members' lack of skills and confidence to indicate a willingness to talk about, or listen to the bereaved person. This study emphasised that there is growing evidence that bereaved PWID are limited in the opportunities they have to resolve their feelings of grief. They state that one of the main factors identified in their research is the lack of staff knowledge and understanding about the grieving process within this group.

These two studies (Murray et al 2000 and Gilrane-McGarry & Taggart 2007) are interesting in that they highlight the passivity on the part of the bereaved person with ID and examine possible meanings behind this and the consequences that this could lead to. These studies have both been carried out with small samples, however, the findings are important and back each other

up. I would suggest that it would therefore be useful to design a larger study built on the outcomes of each of these studies, in order to provide clearer evidence of the impact of the care environment on the grief experience of PWID which could help to place more importance on the need for staff to have training in bereavement.

Sinason (1992) has also described how the behaviour of carers can lead to an environment that further handicaps PWID, in introducing the concept of the 'handicapped smile' which she described as being used by 'adults who know they are not wanted, smiling is a way of paying to stay alive" (p143). She stated "Guilt that people exist that have to bear unfair and appalling emotional, physical or mental burdens can be so unbearable that a state of denial is brought about where those in greatest pain are asked to be the happiest" (p 141) referring to many carers expectations of PWID to look cheerful. We could assume that some of the passivity observed within the studies above may also have been accompanied by 'handicapped smiles' in response to carers defence against unbearable pain, this would mask the grief and an assumption is likely to be made that they are coping positively.

Several research articles focused on trying to find out how much PWID understand about the concept of death and how, or even whether this affects their grieving. However, there are contradictory conclusions drawn about this. For example, Bihm & Elliot (1982) stated that cognitive development is related to an increasingly complex understanding of death by PWID and that an individual's cognitive level is considered a better predictor of their understanding of death than their chronological age, whilst Lipe-Goodson & Goebel (1983) found the opposite. In this study a group of 65 PWID were assessed on their understanding of the universality, irreversibility and inevitability of death. The authors predicted that living in an institution would shield residents from death. There were some flaws in the research including the assumption that residents would be informed of a death in their immediate family, and they did not look at the impact of non-family deaths. They concluded that the understanding of death in PWID appeared to be dependent on age and life experience and to a lesser extent on intelligence and also that

some PWID never have a fully developed concept of death. However, neither of these studies demonstrate how this might affect the grieving process.

In research carried out with 38 PWID (McAvoy 1989), structured interviews were used to assess the concept of death. It was found that there was an apparent lack of understanding of ageing and death as a natural part of the life-cycle. Kloepfel and Hollins (1989) carried out a study during the same year which reinforces this observation. This study goes further, concluding that the ability to draw causal relationships may be underdeveloped; they stated "Limited ability to understand events and put them in appropriate context, combined with significant dependence makes the mentally handicapped person particularly vulnerable to the uncertainties and insecurities normally associated with the death of a loved one" (p34).

This is an important finding and could lead us to consider that when PWID are bereaved, it is possible that they experience the death as sudden if they have not understood that the death was expected. If this is true, we know from generic bereavement research that recovering from the experience of sudden death is much harder and can be a predictor of complex grief (Worden 1991).

Meeusen-van de Kerkhof et al (2006) later examined the way in which PWID understood and coped with death and mourning using developmental theories such as Piaget (1954), Dosen (2005), and Fowler (1981). The study did not consider the relevance of this compared to the body of research on childhood bereavement. Blackman (2003) has considered this in more depth and makes some comparisons with the development of the concept of death within the 'normal' development of children and reflects on what we can determine from this in trying to understand more about how PWID grieve and how they can therefore be supported.

Several researchers and clinicians have focussed on trying to understand the process of grieving in PWID through applying established models of grief (Kitching 1987, Kennedy 1989 & Summers 2003). In America, Harper & Wadsworth (1993) confirmed that grief responses in PWID were more like

people without ID than different. This was also confirmed in a study of the dream life of PWID which highlighted that the deceased frequently featured in dreams, often with strong affect which is similar to bereaved people without learning disabilities (Turner and Graffam 1987).

Strachan (1981) has called for a further examination of the common responses to loss by PWID. This paper addresses the assumption that a relationship with a family member is of greater importance than that of a peer or member of staff when considering the much reported lack of a grief reaction to the death of a parent. Consideration that it may be the relationship itself that is the key factor in how the bereavement is experienced is an important point and very relevant to this study. This significant matter does not seem to be considered in many of the studies.

Crick (1988) has highlighted that at the time of writing the usual intervention for PWID, showing a bereavement reaction was medication and behaviour modification. It is likely that if behaviour changes brought about by the experience of loss are currently going unrecognised for what they are, they are likely to still be treated in this way.

McLoughlin (1986) has raised questions about attachment and dependence. He hypothesises that a greater investment in a few highly significant relationships may make the breaking of these bonds catastrophic. He goes on to suggest that this may mean there is less opportunity for PWID to access support from such a limited network resulting in extreme isolation during bereavement. This is of particular relevance to this study; few other papers consider the significance of attachment combined with dependence.

Day (1985) built on the work of Emerson (1977) emphasising the connection between changes in behaviour and bereavement, noting like Emerson that carers had often not considered loss as the trigger to the change in behaviour. Day (1985) examined the pattern of psychiatric disorder in ID patients admitted to the acute psychiatric ward of a Mental Health Hospital. In a study of over 300 patients from a long stay hospital and over 200 new admissions to

a psychiatric unit for PWID he found a higher incidence of neurotic disorders at first admission and in 50% of cases there was a precipitant cause of death or serious illness of a relative or carer. He discusses the difference in disturbance seen in people with a more severe handicap, suggesting that recognised neurosis is much lower but that their responses to stress may be behavioural and therefore often overlooked. This is a significant point as this may mean that for a high percentage of people with severe ID, carers may not recognise signs of grieving for what they are.

An important outcome from the study carried out by Kloeppel and Hollins (1989) is the suggestion that it is important to include the possibility of bereavement in any assessments of PWID undertaken for diagnosis or treatment purposes. However although this recommendation was made over two decades ago I have seen little sign of its impact in clinical settings.

The first systematic study of the reaction of PWID to bereavement was Hollins and Esterhuyzen (1997) this study seems to be an attempt to build stronger evidence in response to the original Emerson (1977) study as well as to build on the findings of Day's (1985) previous study. They compared a sample group of 50 parent bereaved PWID with a control group of 50 non-bereaved PWID and concluded that the impact in terms of psychiatric and behavioural morbidity of the loss of a parent with its associated life events in adults with ID had been underestimated. This study re-iterated the recurring theme of carers' inability to recognise or acknowledge the impact of the death of a significant other on a person with ID and how this then further complicates the grief process. They found that staff attributed anxiety, depression and challenging behaviour as being intrinsic to the person or associated with the learning disability, rather than a reaction to bereavement. This is an important point, the 'overshadowing' of other symptoms by the ID, makes it easy for carers to attribute all behavioural issues to the ID and not consider other causes.

A later study by MacHale and Carey (2002) emulated this research and re-enforced the earlier recommendation (Kloeppel and Hollins 1989) that a bereavement history should be included in all psychiatric or psychological assessments carried out with PWID who present with behaviour difficulties.

An interesting point not raised elsewhere in the literature, is made by McLoughlin (1986) who found that many PWID experience a greater number of childhood losses. Concluding that ID itself may act as a significant vulnerability factor when associated with other life events. This is a useful point to consider as it can be argued that pupils with ID experience a significantly higher rate of loss in its broadest sense than other children. They may be exposed to loss through death at school due to the higher percentage of children with life threatening or degenerative illnesses attending 'special' schools compared to other schools. But there are other losses as well, they may have to attend a school a long way from their home, often needing to board, this disrupts the sense of belonging and can be experienced as a significant loss. Many families need to use respite services which again can be experienced as a loss for the child and many children with ID are in foster care and therefore are likely to experience many broken relationships. It would be useful to study the effects of these early losses on adult bereavement in more depth.

### Complicated grief

Recent studies are beginning to recognise that there is a difference between supporting normal grief in PWID and the emerging evidence that there is an abnormally high incidence of complicated grief in PWID (Brickel and Munir 2008, Dodd and Guerin 2009). The causes of this are not yet fully understood, which is a key focus of this study.

The studies have drawn on the growing body of research on 'complicated' or 'traumatic' grief within mainstream bereavement studies (Stroebe et al 2006, Prigerson et al 1997). There has been a strong focus over the last decade on what constitutes 'complicated' grief (see next chapter). It is also interesting to see ID research use mainstream findings to inform the direction of enquiry.

Dodd et al (2005) were concerned that PWID seem to suffer a high percentage of atypical grief responses. They carried out a literary review of the emotional, psychiatric and behavioural responses to bereavement in PWID, and concluded that further work was needed in order to accurately describe the nature, time

scale, severity and frequency of the symptoms of 'traumatic grief' in PWID, they have continued to research in this area. They also highlight that the study of pathological grief (or complicated grief) in mainstream bereavement research suffers from a lack of clarity concerning definition, and has numerous terms ascribed to it. This has, however, changed during the last five years and there has been focussed debate and continued research on this subject which will be discussed further in the following chapter.

Brickell and Munir (2008) build on the findings from Dodd et al (2005). They agree that it is important to advance the understanding of specific symptoms of 'traumatic' grief in PWID but they go further stating that it is "equally important to examine how situational factors and individual characteristics mediate the ability of individuals with ID to cope with grief" (p2). They echo the motivation behind this author's study, that if we can understand and identify the factors that place bereaved PWID at risk of complicated grief, then we can provide environments and interventions that promote healthy grieving within this population. Their study provides a justification for the proposition that all PWID should be considered as potential candidates for targeted bereavement interventions. However the review of research examined here seems to indicate that if we educate and support care staff as suggested earlier (Oswin 1981, Kloepfel and Hollins 1989 etc) in being able to provide appropriate support we might see more clearly which individuals really have complicated grief as opposed to grief exacerbated by external factors such as lack of support. It would then be more appropriate to provide specific bereavement interventions to these people.

The search for further understanding in this area is particularly evident in the continuation of the exciting research development that has been taking place in Ireland (Dodd and Guerin 2009). These researchers have been interested in bereavement and PWID for the best part of a decade. More recently they have focussed on the prevalence of atypical grief in this client group. This work has been systematically building on a literature review (Dodd et al 2005). The study is unusual in that it relates directly to developments in the generic bereavement research literature in order to compare and further understand

grief in this particular part of the population. This thorough approach has been missing from much of the research reviewed in this chapter. Many of the other studies have been small, and although they call for further development, rarely have I seen researchers developing their own studies, or those of others. More often there is a sense of reinventing the wheel. This is perhaps because the research is on the whole carried out by practitioners who have limited time and resources for research, rather than academics who have made this their research focus, and is also driven by the specific focus of the practitioner from their own experience rather than from a broader perspective. Although there are similarities between the research of Dodd et al (2009) and this author's study they differ in that the former is not concerned with the relationship between attachment pattern and bereavement as a focus for trying to further understand the causes of complicated grief within this client group.

Dodd et al (2008) have used a bereavement history questionnaire, and a newly developed measure examining for symptoms of complicated grief with a group of carers of people with mild or moderate ID, who had experienced a parental bereavement within the previous two years. The questionnaires were also administered to a matched comparison group who had not been bereaved. The study concluded that bereaved PWID experienced complicated grief symptoms following the death of a parent. They found that 33% of the bereaved group experienced ten or more clinically apparent symptoms. This study was unusual in that it revealed that clinical symptoms were more likely to occur with higher rates of bereavement ritual involvement. This is a controversial finding as most of the previous literature (eg Oswin 1985; Kloepfel & Hollins 1989; Blackman 2003) have advocated for PWID to be included in bereavement rituals (that until recently they have often been excluded from) in order to support them in healthier grieving. This would warrant closer study.

The types of concerns raised above have led to the development of a preventative screening tool (Blackman 2008). The Bereavement Needs Assessment Tool (BNAT) is a tool for professionals responding to the bereavement of PWID in order to try to prevent complex grief. It aims to draw attention to the added complicating factors which may be associated with

either an anticipated death, or immediately post bereavement. It is predicted that by assessing some of the complicating factors proactively, in order that they become more visible, this tool will enable professionals to consider how these are then in turn addressed. Currently the BNAT is still in the process of development.

### Bereavement interventions

This author has found that there was a heavy focus on cognition in the literature which manifested in an emphasis on assessing or teaching PWID about the concept of death and knowledge regarding the rituals connected to bereavement (Yanok & Beifus 1993, Read 1996, Mappin & Hanlon 2005). This it would seem, was the case even when an intervention was set up with the intention of attending to the feelings and confusion that arose for PWID at times of loss. Perhaps because of this it was not always clear from the literature when an intervention was set up for education, or when it was set up more as an opportunity for people to reflect on and understand in more depth a personal loss or bereavement experience. This author is more interested in interventions which offer PWID an opportunity to work in depth on resolving some of the difficult feelings connected with grieving, as this is important for comparison and critique of the model that has been developed within this study. However, it is also possible to see that there is value in PWID being able to access loss/death education groups and the author recognises that it is not always easy to make a clear boundary that keeps these two areas completely separate. Therefore some studies which veered more towards education have been included as well.

Most studies have demonstrated that PWID benefited from the opportunity to share and talk about loss and death (French & Kuczaj 1992; Yanok & Beifus 1993; Persaud & Persaud 1997; Read & Papkosta- Harvey 2004). There were also several reports which highlighted how difficult, staff found it to talk about these issues (French & Kuczaj 1992; Persaud & Persaud 1997) which

corroborates the findings described earlier regarding carers in the section above.

One such example, (French & Kuczaj 1992) described a two day workshop for PWID and their key workers on themes of loss and change. The authors were surprised to find how readily the PWID wanted to talk about their bereavement experiences. This contrasted with the staff members, who were more reserved about this subject. They found that the evaluation of the course highlighted the need to allow individuals an opportunity to discuss feelings encountered through loss. Another account by Persaud & Persaud (1997) has also drawn attention to the resistance or reluctance in staff to take on the supportive role for a bereaved PWID. These studies again suggest how the reluctance of care staff to engage in talking about death and bereavement can create barriers that prevent PWID talking about their experiences. These studies also evidence the need PWID have to talk about loss when an opportunity arises. Mainstream bereavement literature (Worden 1991; Parkes & Weiss 1983) confirms the importance of talking about the loss in the grieving process. Persaud and Persaud (1997) also challenged the assumption that other professionals such as funeral directors were not willing to support and educate PWID sensitively, this study suggests that professionals who are more accustomed to talking openly about death are not phased by doing this with PWID as long as they are given access to do so. The study seems to suggest that they rarely gain the access to do this as care staff seemed apathetic or uncertain as to whether they could access this support on behalf of PWID, highlighting yet another way in which bereaved PWID are disadvantaged in their grieving.

Recommendations from another group (Yanok & Beifus 1993) were for future education programmes to include discussion on the different situations that can lead to death (for example not only old age) this backs up the findings of McAvoy (1989) and Kloepfel and Hollins (1989). They stated the importance of introducing clear vocabulary about death, which is important to include in any training for staff as this will form the basis for communicating about death in a helpful way. They also suggest teaching socially accepted displays of grief, it is unclear what is meant by this but it is interesting to consider this in light of the

description in the study by Persaud and Persaud (1997). In their study they attempted to provide an opportunity for the participants of their course to express anger at their loss by throwing wet sponges against a wall and shouting, they realised that this was difficult at first for the PWID to take part in, they then realised that this was because they had learned not to express strong feelings but instead to keep them hidden. However, I suspect that Yanok and Beifus (1993) might mean how to behave at a funeral, as this is often cited as a reason for PWID being excluded at family rituals.

Mappin and Hanlon (2005) have used a repeated measure design to compare understanding of death related topics, the components of the death concept and of emotions associated with grief before and after a bereavement group, which ran for ten one and a half hour sessions over a period of four months. They concluded that the study indicated that the group led to gains in participants' understanding of death, dying and grief reactions. The weaknesses in the study were that they used a very small sample (six participants) and there were no repeats with other groups. This author is interested that this was set up as a bereavement group but that the facilitators only measured the understanding of death concepts of the group members. There seems to be no measure in place to show whether participating in this group meant that group members could now also cope better with the grief they had experienced. The authors of the study suggested that the fact that they were researchers as well as group facilitators could be considered a weakness. Perhaps they were right and it was this fact that meant they were not emotionally distanced enough from the participants to be able to clarify what was needed in the design of their research study. This could be considered another example of how confusion occurs when trying to focus on this subject. Sinason (1992) has stated that the word 'stupid' means literally to be numbed by grief. She relates how hard it can be sometimes to see something when it is too painful. We become literally emotionally and intellectually stupefied or 'stupid'.

A single case study by Campbell and Bell (2010) has described the psychological assessment, formulation and treatment of a grieving woman with

ID who had witnessed the aggressive looking attempts of paramedics to save her mother after a fatal heart attack. This woman had become depressed and stated at the outset of the treatment that she wanted to “not miss Mum as much” and “to stop crying” (p 2). A large part of the report describes the importance of assessing this woman’s concept of death. This seems an odd thing to do when the woman was clearly missing her mother terribly, so was undoubtedly aware that she was no longer around. The assessment seems not only avoidant but also rather a cold and clinical approach towards supporting someone who was obviously struggling with having experienced an extremely traumatic event.

Read and Papkosta-Harvey (2004) have examined group work as a vehicle that promotes learning. The central aim of their work was to identify and clarify the support needs of bereaved PWID through listening and recording the group members’ experience, and built on research previously undertaken (Read et al 2000). The group consisted of ten participants with ID who had each experienced a significant loss or change within the preceding five years. The aims of the study seemed broad; the authors stated that one aim was to ‘...offer a short course of study sessions...’ (p193). They had also built in an evaluation of the group work experience. One of the ways that they planned to do this was to record group members’ personal narratives. They also aimed to offer members ‘...the opportunity to identify and explore issues surrounding loss and change within a safe, confidential and comfortable environment.’ This would also include exploring feelings and discussing loss from a personal perspective. This study seemed unclear as to whether it was offering an opportunity for the participants to study loss or to take part in an experiential group. The result of the study showed positive outcomes for the participants. There was noticeable growth in members self confidence and assertiveness, growth in empathy for others, and an increase in knowledge of, and the normalising of the grieving process. The authors of this study stated that the skills required to effectively facilitate group work are parallel to the skills inherent in counselling, and recommended further analysis of this. This author would not fully agree with this statement as the knowledge and skills needed to

become a counsellor require an intense and lengthy training as well as clinical supervision. Perhaps what is meant instead is that facilitating such a group is complicated and could not be carried out by anyone who has not had some sort of training in active listening and basic counselling skills and who, like a counsellor, would access some sort of clinical supervision. This is possibly why it is not common to see such groups run at centres for PWID by untrained staff.

This last point is inherent in the design of another approach (Blackman and Brookes 2008) to facilitate direct care staff to gain confidence in talking about loss and death with PWID. They developed a programme which used the facilitation of loss discussion groups as an active learning approach during the course of a ten session weekly group. This approach enabled service settings to both offer a supportive group (led by a therapist) to bereaved PWID at the same time as training their staff (who co-facilitate) to gain the confidence and skills to continue to support residents after the group had ended. This is described more fully in chapter seven.

This author noted some confusion in the literature with reference to the meaning of the term 'bereavement counselling.' It would seem that this ranges from the practical and emotional support and acknowledgement of a loss by untrained staff (James 1995) through to bereavement psychotherapy for people with complex grief (Blackman 2002), and a full range in between (Harling 1996, Read 2001, Elliot 2003). Whilst examining this theme in the literature, it has also been important to hold in mind the development in thinking regarding psychotherapy and its application for PWID over the last decade (Beal 1998, Cottis 2009, Frankish 1987 and Sinason 1992). This development has been going on in parallel to the work on bereavement. A further in-depth analysis of this literature will follow this review and can be read in chapter six.

A case study by Kitching (1987) has described how the use of guided mourning suggests that many bereaved PWID need someone to facilitate their grief. The study states that this need not be necessarily a trained member of staff.

However, they should be designated to offer regular and frequent support and to liaise closely with family, and other staff members, and also that this person may need clinical supervision.

With the recommendations from this case study in mind, it is interesting to examine a much later study by Dowling et al (2006) which attempts to compare two bereavement interventions: traditional counselling by volunteer bereavement counsellors, and an integrated intervention delivered by direct care staff which offered bereavement specific support. The study concludes that bereavement counselling by trained counsellors can achieve significant improvements in health and behaviour for adults with ID with relatively little additional training for the counsellors. However, sadly, it also found no positive change among the participants who received the integrated intervention from the direct care staff. The suggestion made from this finding was that it is not a practical possibility for the bereavement needs of PWID to be met within ID services. However, there are significant weaknesses within this study that make these findings questionable, most notably that the carers within the ID services did not receive adequate training or support in order to deliver the integrated intervention, whereas the counsellors had already been well trained (by definition) and therefore the adaptation of their skills was not difficult. The counsellors also already practice within a framework of clinical supervision so would have been well supported to carry out their intervention. It is frustrating that so many studies do not seem to build on findings from previous literature. The study described above is one such example, it has been clearly stated in the literature by Kitching (1987) that in order for care staff to deliver this type of intervention, support and supervision would be needed. Yet this more recent study has not recognised the need to support untrained care staff in taking on this type of work.

In contrast, the impact of a well designed staff training programme (Reynolds et al 2008) aimed at developing knowledge and confidence in carers supporting PWID at the time of bereavement has been described. Thirty three staff participated in a study in which there was a training group and a control group. Both groups completed measures of confidence at the beginning and end of a

four week period around supporting service users through a bereavement survey designed for the study. Over the four weeks there was a significant increase in confidence among the training group with no comparable changes in the control group. This study is important to consider alongside the Dowling et al study (2006) described above, as it highlights the need for adequate training in order for staff confidence to improve.

A couple of studies (Dryden 1994, Read 1996) have suggested there is a need to modify generic counsellor training and/or services to make counselling accessible to PWID. There are recommendations that further research is needed regarding the organisation, management and evaluation of counselling services for PWID, the training and supervision of volunteer counsellors and clarity about the boundary between bereavement counselling and bereavement support.

Different models for making counselling and therapy available for PWID are described. One study (Blackman 1999), has described the development of a specialised bereavement therapy service for PWID and has further described the development of a systemic approach (Blackman 2001) within this service. Another study (Read et al 1999) has reported on a generic voluntary counselling organisation which made itself accessible to PWID.

The effectiveness of individual and group bereavement therapy on PWID was studied in Canada (Stoddart et al 2002). The results showed significant improvement in symptoms for depression particularly in people with a dual diagnosis. However they also found little change in anxiety levels and in knowledge of death or of issues related to bereavement. There were two main weaknesses in the study – the small number of participants and the lack of a control group. A description of the development of a psychotherapeutic bereavement group (Boyden et al 2009) has suggested that even when a group is designed to allow group members to share in a way that they felt comfortable with, it is necessary to actively provide creative ways to stimulate conversation and reflection. They describe how the therapists sometimes had

to take a more directive role than might be expected in a purely psychodynamic group.

Summers and Witts (2003) have described the psychological intervention of a bereaved woman with ID using bereavement and attachment theories. This is one of the few articles which looks towards the individual predisposition of vulnerability to complex bereavement located in ambivalent/insecure attachment and not just at reasons connected to cognitive functioning and communication. They also recognise the importance of simultaneously working with the supporting system. Both of these findings are extremely relevant to this study and reinforce some of this author's findings.

Gault (2003) has described a case study which postulates how, when the grief is complex, support from untrained staff is not enough and specialist professional help from a trained counsellor is needed. This is an important message and signals the differentiation between ordinary grief which demands sensitive support and complicated grief which needs specialised and trained intervention.

### Concluding discussion

In examining more than three decades of literature on this subject, it is immediately apparent that we are still unclear about how best to support bereaved PWID. I have suggested that it would appear that a countertransference response may have made it difficult to think rationally and systematically about this subject.

The review of the literature has highlighted the lack of any co-ordinated or systematic attempt to develop knowledge within this area. There have been a handful of practitioners and researchers such as Blackman, N; Dodd, P; Hollins, S and Read, S who have continued to develop their own paths of interest; this has generated a few seams of richer understanding within small areas of focus. However, overall, few of the studies have built on previous work and there appears to be little investigation as to what the questions that need to be addressed really are.

At the time that Oswin (1985) was writing, her ideas were pioneering and an important contribution to changing the situation. However, many of the issues that she identified continue to arise in papers right up to the present day, without having moved on in any significant way, in particular her concern about how the environment often negatively impacts on the grief experience of PWID. However, two studies (Murray et al 2000; Gilrane-McGarry & Taggart 2007) explored the impact of the environment in some depth. They highlighted the finding that there is extreme passivity on the part of the bereaved person with ID and examined possible causes for this and meanings behind this behaviour; they were also interested in the consequences that this could lead to. I have suggested that it would be useful to design a larger study built on the outcomes of each of these, in order to understand more fully the impact of the care environment on the grief experience of PWID, and to provide specific evidence which could support the need for staff training. The focus in the literature on the environment has however provided greater understanding as to how the environment limits the grieving process, which is crucial for this study.

It seems that it is has been easier to identify the problems than to address them. There is still a tendency to focus on a "homogenous group" or "a race apart" (Mcloughlin 1986), and to forget the early studies that stated that everyone, PWID included, grieve in an individual way, and that there is no 'one fit' solution.

Several studies have focussed on what impact impaired cognition has on the experience of bereavement (McAvoy 1989; Bihm & Elliot 1982; Lipe-Goodson & Goebel 1983; Mappin & Hanlon 2005), without really drawing any firm conclusions. Few considered the role of the developmental conceptualisation of death in PWID. It would be useful to compare and contrast this with findings from the large body of research carried out within the area of childhood bereavement.

The emphasis on teaching and educating PWID in the concept of death and in bereavement rituals could also be seen as an avoidance of having to really see

the painful and often overwhelming feelings that so many bereaved PWID suffer in isolation.

Only one study (Mcloughlin 1986) considered the effects of bereavement and more general loss in childhood and the impact of these accumulated losses on adults with ID, although several studies called for the systematic use of bereavement history questionnaires (Kloepfel and Hollins 1989; MacHale and Carey 2002), which could help this issue to become more recognised. This author would suggest that future areas of research should consider what aspects would be useful to implement within a pre-bereavement screening framework in order to prevent vulnerability to complex grief. Some of this work has been started by Harper and Wadsworth (1993) and Blackman (2008), however, there is still more development needed in this area.

Several authors have made reference to the fact that PWID have an increased vulnerability to atypical or complicated grief (Conboy-Hill 1992; Blackman 2003; Brickel & Munir 2008; Dodd & Guerin 2009) and some stated that further work needs to be done to more accurately describe the nature, time scale, severity and frequency of the symptoms of this in PWID in order to improve assessment and treatment of affected individuals (Dodd et al 2008, 2009; Dowling & Hollins 2006). Only one team of researchers seemed to attempt to address the specific factors that may precipitate this (Dodd et al 2008, 2009). They were specifically interested in understanding the course of grief and in particular complicated grief in PWID and through this to minimise the levels of functional impairment. This is an area which appears to be a main preoccupation and more importantly, which they are carrying out in a more systematic and developed manner than we have previously seen within the general body of work.

Kloepfel and Hollins (1989) have indicated that many PWID might experience death as sudden if they have not understood that the death was expected. This is a significant proposition and needs closer attention. Generic bereavement research highlights that recovering from the experience of sudden death is linked with complex grief.

It would be helpful to find systematic evidence to show whether psychological interventions have proven to be useful for this client group and if so, it would be constructive to map the psychological support for bereaved PWID currently available nationally. If this study were carried out it would be worthwhile to research the orientation and geography of what is currently available and what gaps there are within current provision. In addition, it would be beneficial to carry out an exploration of the barriers to accessing psychological support for this population.

This literature review has identified that there was a strong theme regarding the need for increasing the skills of the work force. A study mapping current training for direct care staff regarding bereavement would also be important and this could lead to national recommendations.

There is little known about how bad news or difficult information is currently communicated to PWID and how, or if, this might affect grieving. A study into this could also result in national guidelines as how best to do this.

There have been a couple of studies (Strachan 1981 and McLoughlin 1986) which consider whether the relationship to the deceased is the factor which really determines the outcome of the bereavement experience, and a few that consider attachment as a more general issue. Only Summers and Witts (2003), McLoughlin (1986), and Brickell and Munir (2008) have discussed this matter in some depth. These are interesting areas for further exploration and are very relevant to this current study since my central argument is that; complicated grief is strongly connected to insecure attachment.

Most studies have been with very small sample groups and none have been replicated. There was little clarity within the research on what has and has not helped the bereavement experience of PWID. Many of the authors simply described the challenges or have focussed on one small aspect of this with a small sample or case study. It is clear that it would be useful for there to be a systematic research approach with multi centre replicable studies in order to build on the body of work laid down over the last few decades. As stated earlier in the chapter this is perhaps because the work has mainly been carried out by practitioners and there is therefore little time or money for research. It

would be interesting for some of the current researchers to join together and carry out some partner research developing the work on a wider scale.

The next chapter will build on what has been understood so far, it will examine what is understood about the state of bereavement currently. It will set a historical context, and trace the development of current bereavement research and practice.

## **Chapter 5 - The search towards understanding bereavement:**

### **A literature review**

#### Introduction

This chapter builds on the last chapter, as it explores the state of bereavement and the search over the last century to understand this process. It incorporates some of the first chapter of Loss and Learning Disability (Blackman 2003), adding updates and focusing in the last part of the chapter on the differentiation between healthy and complex grief. It also includes indicators for resilience in bereavement, all of which have been the main focus of more recent bereavement research.

#### A historical perspective on the study of bereavement.

The Oxford English dictionary (1989) states that the common root of the words bereavement and grief is reave which is derived from the old English word 'reafian' to plunder spoil or rob. This gives us a pictorial sense that when someone is bereaved, something of value has been taken against his or her will and there is a sense of abruptness and that things have been left spoiled.

The clinical study of reactions to loss began in the early twentieth century with Freud (1913, 1917, & 1929). Prior (1989) describes this as the start of the normalising and medicalising of grief and sorrow. She goes on to say;

'...these ideas contrast quite markedly with those of the nineteenth century in which grief, although it was sometimes viewed as a cause of insanity, was never interpreted as itself pathological. Grief, if anything, was a condition of the human spirit or soul rather than of the body and in that sense it could neither be normalised nor medicalised'. (ibid p133-152)

It is important to note this shift in how grief is viewed and to keep this in mind as we come to consider 'complex grief' later on in this chapter. It could be argued that we have moved too far towards medicalising what was once accepted as a normal part of human life.

There are several terms that describe what happens to the surviving people when someone dies, words such as bereavement, mourning and grief are used to describe this state although the meanings of each are not always clearly differentiated. In the section below the literature is reviewed in order to try to gain some clarity.

Freud (1917) gave the term mourning to the behavioural and emotional changes that occur in a person following a significant death. Bowlby (1960) used the term at first to refer to the wide variety of reactions to loss and later argued that there was a difference between grief and mourning. He defined mourning as the public act of expressing grief, which he determined as being an individual's spontaneous response.

A later definition which takes into account cultural, societal and personal variances is that of Averill (1968), who stated that mourning is the conventional behaviour determined by the mores and customs of the society; whereas he sees grief as a set of stereotyped psychological and physiological responses. He views both grief and mourning as depending on the history and circumstances of the bereaved individual. This is probably the understanding which still persists within our society today.

Stroebe et al (1993) have defined the key concepts in the following way: bereavement is the loss of a significant other person in one's life. This triggers a reaction we call grief, which is manifested in a set of behaviors we call mourning. This definition is helpful in its simplicity, however it misses out the important differentiation between grief being the psychological and physiological response to bereavement (including emotional) and mourning being more a set of behaviours and customs as defined by society (according to the culture of the bereaved).

Klass et al (1996) however, have suggested that the mourning period may be the period in which the survivor learns to live with the paradox of allowing the deceased to still be a continued presence in one's life and simultaneously allowing them to be a part of one's past. This is an interesting view and suggests that the rituals and customs of society might facilitate this process.

Freud (1917) was interested in the differences and the similarities between grief and depression, and he offered one of the first definitions of normal and pathological grief. Freud's only explanation for pathological grief was that there must be some ambivalence towards the person who had died and he believed that the aggressive component of the ambivalent state turned inwards and caused depression. He also saw grief as a solitary process, and did not recognize the value of talking and seeking support and comfort from others. His key theory, as described by Payne et al (1999) recognised that people form loving attachments to other people. Love is conceptualised as the cathexis (attachment) of libidinal energy to the psychological representation of the loved person (libidinal energy being positive/loving feelings). When the loved person dies, the person's libidinal energy remains attached to thoughts and memories of the deceased. Freud's early theory stated that grieving throws up the dilemma between the need to relinquish the relationship with the deceased, in order that the libidinal energy may be invested in a new relationship, and a wish to maintain the bond with the love object. Freud did however recognise in his later work (1923) that the withdrawal of 'libido' from the deceased can only occur once the lost person has been 'reinstated' within the ego. Freud's original theory has been greatly challenged in bereavement research (Marwit & Klass 1995; Shuchter & Zisook 1993 and Silverman 1986). But his later ideas have been taken further highlighting that it is possible to both continue to have warm feelings and an 'internalised' relationship with the deceased as well as have strong relationships with others who are still living. A sign of unhealthy grief would be the impossibility of this because the grieving person is consumed by their relationship with the deceased (Worden 1991).

Freud's earlier theory still pervades societies expectations of bereavement and there is therefore ongoing debate over the value of concentrating on the task of relinquishing bonds to the lost 'love object' in order to facilitate grief and whether this is really the purpose of grief at all (Klass et al 1996). This will be discussed in more detail later in the chapter. It is of historical interest to note, however, that later in his life when Freud experienced the death of his daughter and also that of his young grandson, his own experience of grief did

not support his early model. His notion of 'relinquishing the relationship' was something he was unable to do.

What remains of importance to us is that Freud's early ideas stimulated interest in this previously neglected area and provided the foundation upon which many other practitioners and researchers could build their own theories of grief. Klein (1940) for example, extended the theme of pathological grief. She asserted that all grief, is in a sense, pathological in so far as it resembles the manic-depressive state, although for most people it is transitory. Many other studies also involved empirical surveys of the bereaved.

Lindeman's (1944) contribution is important because it was the first time that duration and intensity of grief had been considered. He also acknowledged the importance of verbal expression and highlighted changes in social functioning. It is important, however, to note that some of the features put forward by Lindeman as abnormal grief, such as social withdrawal and hostility, were subsequently found by Parkes (1971) to be universal.

Marris (1958) has described two conflicting states which emerge at a time of bereavement. One is a wish to return to the time before the death and the other is an impulse to deny or forget the whole issue. This theory is interesting and he proposes that recovery depends on working out this conflict. He describes abnormal grief as occurring when the conflict is never resolved. This however seems to make the conflict rather simplistic.

Theorists began to develop frameworks or models from which to try to make sense of the complicated process of grief. One early and important example of this was Bowlby (1960). On the basis of his theory of attachment, Bowlby understood grief and mourning following bereavement to be a form of separation anxiety. His original theory developed to become a four-phase model. He was careful to emphasize that it was not a straightforward progression through four discreet phases but that there would be some overlapping between phases and people may move backwards and forwards between them. It was also anticipated that with time people would move through all phases. Bowlby went on to collaborate with Parkes and they

influenced the development of each others' ideas and jointly developed a phase model of grief (Bowlby & Parkes 1970) as well as continuing to develop their own independent work.

Payne et al (1999) noted that Bowlby's theory (1980) made a number of important points:

- That grief responses are triggered by the loss of an attachment figure.
- The closer and stronger the attachment, the more intense and enduring the distress of grief.
- That during grief work, people cognitively redefined themselves and their situation, and that this was a necessary process of realizing and reshaping internal representations to align them with changes that have occurred.

These points are still valid today, each can be considered against the backdrop of more recent research. The first point is straightforward and apart from cases of certain types of complicated grief known as inhibited grief (Bowlby 1980) this is not disputed. The second point however, could now be added to in the light of new knowledge. We now know that complicated relationships such as those that are incestuous or violent can also affect the distress and intensity of grief (Parkes 2006, Worden 1991). However, the third point is extremely important as it is this point that really breaks away from Freud's (1917) original theory of grief and that has been built on further by others such as Marris (1992, 1986) Silverman (1986), Shuchter and Zisook (1993) and Marwit and Klass (1995).

Bowlby also interpreted pathological grief through attachment theory and made assumptions that it was connected to childhood experiences. He hypothesized that there were disordered forms of attachment in childhood that could increase vulnerability following bereavement. (These are referred to in more detail in chapter 2) These ideas are very important for this thesis, particularly as PWID are vulnerable to disordered attachment (Minnis et al. (2010).

Parkes' theory, as already mentioned, was influenced by Bowlby with whom he worked closely. It differs in that he uses his own extensive data and gives a greater emphasis to the bereaved person's cognitive model of the world and to interventions, (that is; ways of working with a bereaved person in order to support them through complex grief, such as counselling). He proposed that bereavement is a psychosocial transaction (Parkes 1971), which he describes as a "complex interweaving of psychological and social processes" (Parkes 1988 p53-65). Parkes raises an important new point, that the impact of bereavement is not only psychological but he demonstrates through his research how bereavement can also affect how the person redefines themselves within their community and in other relationships and interactions. Parkes suggests that one of the central tasks facing a bereaved person is to integrate the changes created by loss into a new or adapted 'assumptive world'.

Payne et al (1999) have described his central idea in the following way;

"At a time of bereavement individuals are required to modify or change ways of being in the world that were functional before the loss but are now meaningless or redundant without the deceased" (p67). This was a new way to understand grief and these ideas enabled Parkes to develop clinical theories in order to support the bereaved patients that he was supporting.

Parkes (1971) proposed that there is a period of disorganization where people discover that they can no longer continue to function in the way that they did before the bereavement. He describes this as contributing to the distress and disruption of early bereavement. He suggests that people are resistant to change, but that they have to acknowledge the loss and the need for change before the demanding process of adapting can occur. This is helpful information for bereavement practitioners and provides an accessible way to understand the distress that they are faced with when supporting people through bereavement. Parkes continues with practical ideas for supporting bereaved people to adapt which would include the creation of new roles and identities for the bereaved as well as for their relationship with the deceased. This would include elements of identification with the deceased which may include developing skills, or activities that they may have had when alive. He

describes the outcome of successful grieving as gaining a new identity that integrates the deceased into the life story of the survivor.

Marris (1992, 1986) went on to develop Parkes' original ideas, there are similarities between their theories in that they both believed that loss and bereavement challenged the 'assumptive world' (i.e. the way a person has always assumed their life to be). However, one important element that became central to Marris' theory (1992) was the notion that grief was mastered by taking what was fundamentally important in the relationship with the deceased and assimilating this into the new life without them. The importance of this is again the contrast with early psychoanalytic and phase models of grief; all of which emphasized the need to sever emotional ties with the deceased. The observations about the continuing importance of the meaning of the relationship with the deceased have been confirmed by research (Silverman 1986; Shuchter & Zisook 1993; Marwit & Klass 1995).

#### Phase or Stage Models

From Lindemann (1944) onwards most theorists had developed models of grief which followed a general pattern that could be subdivided into 'stages' or 'phases', with the common view that the bereaved needed to work through their grief in order to 'recover'. These phases may include some or all of the following – numbness, denial, yearning, anger, guilt, despair, disorganization and recovery. These models have proved useful for practitioners in providing a description of the major themes of grief over time. However, there is always a danger that they are interpreted too literally and may be used as a model as to how people 'should' respond and although it has always been made clear by theorists that the stages are not a linear process, this may at times be forgotten. Current thinking has challenged these models, defining the grief process as being so individualized and variable and involving so many different facets of the bereaved person, that "attempts to limit it's scope or demarcate it's boundaries by arbitrarily defining grief are bound to fail" (Shuchter & Zisook 1993) (P23). There are also challenges to the theory of recovery. Wortman and

Silver (1989) suggested that for some people grieving may continue for a number of years and that this would not mean that it has become complicated grief.

Worden (1983, 1991) has refined the 'stage' models and drawn on earlier concepts such as Freud's claim that 'grief work' needed to be gone through before an adjustment could be made. He developed a four-task model of grief, which has been very influential and is used by many bereavement workers today. Of all the models of grief that have been developed I believe that this one can be particularly useful due to its focus on activity or 'work to be done' which people can be guided through. This can give people working in this field apparent clarity over a process, which as we have seen is not clear at all.

Worden's (1991) four tasks are as follows:

- To accept the reality of the loss.
- To work through the pain of the grief.
- To adjust to the environment without the deceased.
- To emotionally relocate the deceased and move on with life.

### Contemporary Models of Grief

Two models that look at grief in a multidimensional way rather than the linear approach suggested by the earlier models are Le Poidevin's seven dimensions of loss and that which was devised by Shuchter and Zisook (1993) which has six dimensions.

According to Payne et al (1999) Le Poidevin's model remained unpublished at her untimely death in 1989. She had developed it while working with Parkes at St Christopher's Hospice in the early 1980s (see Parkes et al 1996). It is a useful model in that it prompts enquiry from the bereavement worker as to many areas of the bereaved person's circumstances which may have ordinarily been overlooked or have been assumed known. It enables a much fuller picture to be drawn up of the meaning of this particular loss for this particular

person. The dimensions she considered were: emotional, social, physical, lifestyle, practical, spiritual and identity.

The six dimensions outlined in the later model proposed by Shuchter and Zisook are: emotional and cognitive responses, coping with emotional pain, the continuing relationship with the deceased, changes in functioning, changes in relationships and changes in identity. These models were used as a basis for the design of the Bereavement Needs Assessment Tool (Blackman 2008), because of the diversity of fields that they cover, aiding a full assessment to be made of the meaning and subsequent needs of a bereaved individual.

A significant development in this field has been the 'Dual Process Model' (Stroebe & Schut 1999). They recognized that avoiding grief has its place at times in adjusting to the state of bereavement. They acknowledge that it is important for bereaved people to take time off from the overwhelming roller coaster of emotions that grief can be. This is a very important point and can aid an understanding as to why bereaved people can seem to sometimes disengage with feelings connected to the loss. This behaviour might previously have been considered pathological but Stroebe and Schutt (1999) give a completely new perspective. Their framework builds on traditional models, particularly Worden's tasks of grief, but it introduces a second more proactive concept – oscillation between coping behaviours. They propose that there are two aspects involved in adapting to bereavement: loss orientation and restoration orientation. Loss orientation encompasses all the traditional aspects of grief work. Restoration orientation includes mastering the tasks and roles undertaken by the deceased, making lifestyle adjustments, coping with everyday life, building a new identity without the deceased and seeking distractions from painful thoughts. Many of the elements listed in the Restoration stage are similar to those pointed to earlier by Parkes (1971) and Marris (1992, 1986) The central point to this model is the oscillation between the two states, both of which are necessary for adjustment. The degree and emphasis on each approach will vary for each individual. As Payne et al (1999) stated; "The model implies that judgments about the way a bereaved person is

coping should not be made too quickly” (p86). This is important as there is it implies that healthy grief can take time and that there is not a prescribed time limit.

However, for all the advancements in new models and theories Klass et al (1996) in their book on Continuing Bonds state “clinicians and researchers need to give up the hope of understanding grief in the context of a neat, orderly package that follows a single set of rules” (p351). Some of the earlier researchers, for example Marris 1986; Parkes 1971 & Worden 1983 seemed to be searching for this. Klass et al (1996) described the complex and multidimensional process of mourning as being essentially a unique individual phenomenon, which encompasses the bereaved person incorporating the deceased into their lives while at the same time redefining themselves in the present. They shared the belief that the continued bond with the deceased is a healthy part of the survivor’s ongoing life and that it may continue for the survivor’s entire lifetime.

The continuing bond (CB) theory is still evolving and very recent research has shown that CB can now be described as having two distinct manifestations – a maladaptive form (Field 2008; Fraley & Shaver 1999), which is described as externalised CB involving illusions and hallucinations and the healthy form of internalised CB which involves the use of the deceased as an internalised autonomy promoting secure base. The former, it is thought, could be a risk factor for complicated grief (Field & Filanosky 2010) although this still needs further research and clarity on this would be really helpful in defining healthy and unhealthy grief.

### Resolution of grief

The phase models suggest that there will be an end point to the work of grief and that there is an adjustment to or a resolving of all the issues of bereavement. More recent theorists contest this. They state that mourning is an ongoing process which may or may not have an ending and whose time scale is unique to the individual and their circumstances. Payne et al (1999)

have suggested that grief may not have a definite end point which marks recovery. They suggested that people might adapt to new roles and regain an interest in their life. They add, as Silverman (1986) has pointed out, that in doing so "...people don't give up the past, they change their relationship to it" (p7).

Rubin (1996) has given a new definition to resolution in terms of mourning. He states "Resolution is the process that supplements and continues on beyond adaptation and/or coping with loss. The connection to the representations of the deceased, and to the memories of the deceased continue across the life cycle" (p352 in Klass et al 1996).

### Complicated Grief

Bereavement is a period during which people are often emotionally vulnerable. Without the support of others, or acknowledgment of the state of mourning, it is more likely that a person will experience a problematic bereavement. Unacknowledged grief is an emotional burden that can lead to mental ill health (Worden, 1983, Machin 2003). This is also referred to as Disenfranchised Grief (Doka 1989). Research has highlighted possible links between unresolved, repressed or complicated grief and mental ill health (Zisook & De Vault, 1976. Shorr & Speed 1963).

There is increasing evidence to suggest that at least 10% of the general population will develop Complicated Grief (CG) in response to bereavement (Maccallum & Bryant 2010). There are two main characteristics that can be seen, either the bereaved person appears to be stuck in a chronic state of mourning with intense yearning and longing for the deceased continuing unabated (Prigerson et al 2008) or the person appears to show no emotional response to the bereavement but begins to develop physical ailments or changes in behaviour. The terms used for perceived difficulties with grieving have changed over the years.

Pathological grief (Freud 1917, Parkes & Weiss 1983, Raphael 1984, Stroebe & Stroebe 1987) or abnormal grief (Worden 1982) now tends to be termed

complicated grief (Prigerson, Shear et al 1999) or prolonged grief disorder (Prigerson, Vanderwerker & Maciejewski 2007). The former terms were laden with judgements and as Klass et al (1996) point out these states of mind were not defined by research or clinical experience, but were based on the cultural values from which those models of grief emerged. So it was common (and still is to a certain extent) for someone's grief to be labelled as pathological if it was seen to be excessively intense and lasting for a prolonged period, or if it was too short and there appeared to be an absence of reaction. These diagnoses took no account of the particular individual circumstances, such as relationship to the deceased, spiritual, cultural and family belief system or social and environmental factors. The concept of complicated grief (CG) differs from this. Rather than conclusions being based upon frameworks such as timescale, or concepts such as the ability to sever the bond with the deceased, they are drawn from considering problems for the specific person in the here and now. These might include issues such as not being able to move forward with the rest of their life or difficulties in building other relationships. These problems may be linked to difficulties in the person's continued relationship to the deceased, it may be to do with difficulties in the social environment that surrounds the bereaved person in their daily lives or it may have more deeply seated psychological roots. This concept is of particular importance when we consider the grief of PWID, this group seems particularly vulnerable to CG and it is quite likely that it would stem from a combination of any or all of these causes.

Over the last decade there has been extensive interest in this area of bereavement research, resulting in the proposition of distinct criteria for CG (Prigerson, Shear et al 1999) which have been validated in several further studies (Lichtenthal et al 2004). The distinct cluster of symptoms that characterize CG emerging from the research are; a persistent sense of yearning for the deceased, difficulty accepting the loss, bitterness, lack of trust, and a loss of perceived meaning in life that is ongoing for at least six months after the death (Prigerson et al 1995; Zhang et al 2006). CG is also associated with

distinct negative psychological and health outcomes (Prigerson et al 1995 & 2008; Boelen et al 2003; Boelen & Van den Bout 2008). Emerging models make the proposition that separation distress becomes marked and persistent in CG and as Maccallum & Bryant (2010) state; this is in part "... due to insufficient emotional processing of the loss, which results in a failure to update attachment schemas" (p316). This move towards clarifying healthy and unhealthy grief based on evidence is exciting and will enable scarce resources such as bereavement counselling agencies to focus on supporting people who clearly fall into the CG category rather than people who are grieving healthily.

Efforts are being made towards including CG as a new disorder in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (for current edition see DSM-IV; American Psychiatric Association 2000). There is still some controversy surrounding this with calls for further investigation (Stroebe et al 2000; Goodkin et al 2005) regarding the diagnosis and conceptualization of CG. The concerns are that in order not to pathologise grief, CG needs to be seen to have a unique pathological entity that enables it to be clearly differentiated from normal grief. It is of course important not to 'over medicalise' grief, however, if CG is entered as a new diagnosis this could be helpful for people who are struggling with CG and who really need support to gain access to the counselling support that they need.

An exciting development over the last few years has been the advancement made in the field of neuroscience. It is now increasingly possible to test out psychological hypotheses against what can be learned through neuroimaging techniques (Oschsner & Lieberman 2001). The first study of bereavement and the brain (Gundel et al 2003 as cited by O'Connor 2005) was carried out with a group of eight people who had all experienced the death of a close relative within the past year. The researchers used a particular type of MRI scan on the participants and carried out a number of tests using photos of the deceased along with specially selected words in order to measure the responses of the brain. There are several limitations to this early study, such as the small number of participants and also the fact that the only photo of someone known

to the participant was the deceased, which means that the brain activation recorded could be as much to do with recognition as with feelings connected to the bereavement. However the advancements made in this area of science have begun to open up new opportunities in attempting to clarify what constitutes both normal and complicated grief.

#### Resilience and predictors for risk

Recent bereavement research has been focused on trying to understand the environmental and personal characteristics that affect the bereavement outcome for individuals, in order to identify what it is that increases vulnerability in some bereaved people (Stroebe et al 2006). The findings from this research have significantly shaped the framework of bereavement response (EOLS DOH 2009) in order that those who are at risk of suffering lasting negative health consequences are positively screened and offered appropriate interventions.

One significant study (Van Der Houwen et al 2010) focused on multiple potential risk factors which were simultaneously examined. The study found interesting results on the effects of attachment style. They reported specific differences from previous research, particularly with regard to attachment. Their findings are rich in that they are multidimensional. For example it had previously been considered that; "...attachment anxiety contributed significantly to the prediction of grief and depressive symptoms" however "...when examined within the group of intrapersonal predictors, it failed to reach significance..." (p212) because they found that it disappeared when measured together with social support. This finding is of great significance with regard to PWID who have a high probability of an insecure attachment pattern combined with a lack of social support.

They demonstrated new understanding that both anxious attachment and avoidant attachment are predictors of 'emotional loneliness' - a state which has not previously been considered as a predictor. This is also important when considering the support that might be needed for bereaved PWID who are

known to have anxious or avoidant attachments. Interestingly, however, there is no reference to disorganized attachment patterns.

The key elements described by Palletti (2008: 23) as being integral to healthy adjustment to bereavement are the 'construction of a positive self-concept' the 'effective use of available resources' and the 'maintenance of a positive attitude.'

All of these elements are likely to be areas of vulnerability for PWID, so again this is important to consider with regard to supporting bereaved PWID.

Resilience is also cited as a crucial factor in recovery from bereavement (Benard 1995). The literature on resilience emphasizes the importance of personality characteristics. One particular personality characteristic labelled *trait resilience*, is described as having the capacity to overcome, steer through and bounce back from adversity (Block & Block 1980; Block & Kremen 1996 as cited in Ong et al 2010).

The literature on child bereavement places a strong emphasis on the importance of resilience. Stokes (2009) has written from her experience as the founder of the Child Bereavement Centre - Winston's Wish "The degree of success the child has in overcoming obstacles is a complex combination of personal strengths and vulnerability as well as ongoing interactions with their families, friends and community networks". (p9). She expanded on a shortlist of factors that impact positively on the resilience of a bereaved child (Masten 2001) that include multi factors within the child, within the family, the community and the wider society. These points are extremely important to consider as they are likely to be missing in the lives of many PWID. However, knowing what is needed could be useful in developing supportive work with families with young children with ID in order to foster resilience.

In Canada a unique International long term Research Project (IRP) was set up ([www.resilienceproject.org](http://www.resilienceproject.org)) over 15 years ago. It is described on the website as follows:

The IRP seeks to broaden our understanding of how resilience is conceptualized across cultures and contexts. The IRP uses a unique cross-cultural approach that employs both quantitative and qualitative research

methods to examine individual, interpersonal, family, community and cultural factors associated with building resilience in youth around the world. During the first 3-year phase of the research, the IRP piloted and integrated innovative quantitative and qualitative research methods and collected data from over 1,500 children in 14 communities on five continents.

This research is ongoing in its development and is clearly very important in contributing to our understanding of how people develop resilience. These findings are being utilized in many different ways and are extremely beneficial in building up our sense of what helps people to cope positively during bereavement and even to experience personal growth as an aspect of adapting to the impact of loss.

#### Implications for people with intellectual disabilities

This review of the literature, has highlighted that there are many vulnerabilities that contribute to complex grief that are likely to be present for many PWID. For example insecure attachment patterns which have already been highlighted as an issue of vulnerability for this client group in chapter 3. This is especially important to consider because at a time of bereavement the way in which we have learned to cope at times of stress is likely to determine how we grieve Palletti (2008). The way in which we cope will to some extent be determined by how we relate to others around us and how they respond to us; this response will also be determined, to some extent, by our experience and expectations which are set up within our primary relationships in other words, our early attachments.

Isolation and loneliness are common features for so many PWID and this might in part be connected to insecure attachment patterns but it is also likely to be exacerbated by the environments in which many PWID live. This is another factor that may be likely to make recovery from bereavement more difficult. Bereavements that affect PWID can often be unacknowledged or 'Disenfranchised' (Doka 1989) and their grief can often pass unnoticed or not be recognized for what it is.

The study by Van Der Houwen et al (2010) has reiterated the importance of the 'social network', (which in the case of PWID is likely to be services and/or family), reaching out decisively in order to prevent the 'emotional loneliness' which they have described as a predictor for CG.

Even now with more awareness regarding bereavement within services for PWID it is still easy for people – residential staff, day centre staff, and families for example, not to recognize when a person with ID is grieving. This may be because the person is not expressing themselves in a way that might be expected. PWID do not always find it easy to recognize or to express their feelings; although at a time of bereavement, it is difficult for most people to communicate to others, regardless of whether they are usually good at communicating or not. There is no right or wrong way of doing this, but difficulties in expression may be compounded by the difficulties others have in acknowledging, understanding, or even in listening effectively. It has been my observation that many care staff in residential services are inexperienced and untrained, they may also not have experienced bereavement themselves. It is often my impression that they can have a stereotyped idea of how someone should respond to bereavement and also may think that the person should 'be over it' within quite a short time scale. Staff might also feel frightened of openly acknowledging bereavement for fear of the depth of feelings that could be aroused (Kitching 1987); they may feel that they will be unable to offer adequate support, feel unsure about their own feelings about death and be worried about whether they will be able to cope emotionally themselves. Thus the conscious and unconscious responses of staff can have a significant impact on the PWID who is bereaved.

Few PWID have meaningful roles in society (Harris, 1995; UK. Dept for Work and Pensions 2004) and not many gain the opportunity to develop new skills. This is likely to make the stated need for developing a newly defined identity (Parkes 1971 and Stroebe & Schut 1999) difficult. PWID can remain in their carers' eyes 'perpetual children' and find it difficult to gain any identity beyond being someone's son or daughter. They are therefore more likely to need directive support in redefining themselves in their newly bereaved situation.

Adaptation to the new attachment schema is likely to be difficult because of cognitive difficulties. Rehearsing memories and defining their own bereavement narrative is also likely to be difficult without support. It is important that this support is available in order to facilitate the person to develop an internalized, though redefined continuing bond with the deceased.

The core elements that are needed for resilience, such as a strong sense of self and supportive responses from carers and the wider society are important to focus on strengthening in the lives of PWID.

### Conclusion

This chapter has examined how an understanding of grief has developed within the literature. It has particularly focused on contemporary models of grief theory against a backdrop of the historical development of grief theory, including current research on both complex grief and the building of resilience. The above has been considered with the particular intention of gaining a greater understanding of how the generic bereavement literature can support greater insight into the bereavement experience of PWID. This study has highlighted thus far (in chapter 3) that PWID are vulnerable to experiencing complex grief and this chapter reviewing the generic bereavement literature has aimed to shed some light on the many reasons that may contribute to this. In light of this focus on the vulnerability to complex grief of this client group it is important to consider what psychological interventions are accessible to PWID who experience emotional trauma. The next chapter will examine the literature on the use of psychotherapy and counselling with PWID against a background of the historical context.

## **Chapter 6 - Psychotherapeutic interventions with people with intellectual disabilities: A review of the literature**

### Introduction

This chapter presents the third and final part of the literature review; it considers the history and explores the literature on the use of counselling and psychotherapy with PWID today. It incorporates some of chapter six from *Loss and Learning Disability* (Blackman 2003).

Historically, PWID have not been considered suitable candidates for the 'talking' therapies. This is in part due to the long held assumption that PWID do not experience emotional distress (Davies et al 1997). However this assumption has begun to change over the last couple of decades, Kelleit et al (1999) have stated that "A burgeoning epidemiological research base concerning mental health problems in people with intellectual disabilities has effectively challenged this assumption" (p 324), they go on to say that "Prevalence rates of between 10 and 80% have been reported, depending on the population studied and the definitions and methods employed" (ibid). This is an important starting point for this review and provides evidence that there is a need for counselling and psychotherapy for PWID if it can also be evidenced that they can use such therapies.

It is important to begin by presenting an historical context with which to understand the treatment of PWID and the way in which PWID have been understood at different points in history. Eugenics is a term that was first used in 1883 (Marks 1999). It means to strengthen a biological group such as the human race on the basis of hereditary worth. This was one of the theories that led to many people with ID spending so many years of their lives in long stay hospitals in the early part of the twentieth century (O'Driscoll 2000). It was socially perceived that some control over segregation of the sexes could be maintained inside these institutions. It was also thought that PWID did not have an emotional life or make emotional attachments and therefore would not

find separations from significant others painful (Clark 1933). Eugenics has been presented as having a scientific basis. However, as Marks (1999) has stated:

...the premise that it is a good idea to prevent certain citizens from procreating, even if accepted, would not necessarily have any effect on the gene pool. Further, even if it were possible to remove certain hereditary impairments from the gene pool, we might find that protective functions against certain illnesses (associated with the impairments) would be lost through selection (p34).

However, despite this assertion many PWID remained excluded from the rest of society within institutions until late into the twentieth century when the White Paper 'Caring for people' (1989) was published leading to The NHS and Community Care Act 1990 and the move towards the closure of the long stay hospitals.

In order to understand why PWID remained in this situation for so long it is important to consider how the implementation of the National Health Service Act 1948 and the Mental Health Act 1959 marked the beginning of the medicalisation of intellectual disability. This meant that the emphasis of hospitalisation changed from being one that was purely one of social segregation to being one that was also focussed on treatment. Gates (2007) draws our attention to "...the strong emphasis in the definitions that was placed on treatment (within the MHA 1959)" (p6). The medical perspective that prevailed at this time left little room for thinking further about other disabling affects on people such as secondary handicap (Sinason 1992) as a response to environmental issues which may exacerbate the symptoms of ID. He adds "the Act made extensive reference to the Responsible Medical Officer. It is at this point in the history of mental health legislation that the influence of medicine in defining the nature of learning disability exerted its greatest impact" (p6). With these two frameworks in mind it is easy to understand why, up until very

recently, PWID have not had their emotional needs noticed (Oswin 1991) and also why symptoms were responded to within a medical model of thinking.

### An overview of psychotherapeutic treatments for people with intellectual disabilities

Crick (1988) has documented that when emotional distress has become recognised in PWID the course of action has tended to be medication, cognitive behavioural therapy or a combination of the two. These two methods would be used with the aim of changing the person's behavioural response rather than with a more long-term aim of trying to establish the causes of distress and to then work with this. In contrast a longer-term approach such as through employing the use of one of the arts therapies or psychotherapy, would focus on identifying why the person had become emotionally disturbed. The aim of a longer term therapy would be to bring about a change in managing distress through building a therapeutic relationship, with the possibility of enabling the person to gain insight and understanding into themselves and their responses (Cottis 2009).

It would, however, be fair to say that historically there have rarely been many other options available to PWID because psychotherapy was not advancing as a treatment option for this client group in the same way that it was for the rest of the population (Sinason 1992). A key point in this study is the focus on the therapeutic relationship as a crucial component in bringing about positive changes throughout the course of psychodynamic psychotherapy and it is the development of this treatment for PWID that will be examined next.

As stated above, non behavioural psychological treatments including counselling, psychotherapy and psychoanalysis have, historically, rarely been available to PWID (Kahr 2003, O'Driscoll 2000, Sinason 1992). There were occasional exceptions to this such as Pierce Clark (1933).

Clark was one of the first documented professionals to note that PWID had an active emotional life that was worth exploring (cited by O'Driscoll 2009). He

was the founder of American psychoanalysis and believed that if they received help PWID could be kept out of the institutions. However his views were not widely recognised and they were counter to the general opinion. As Trent stated "This was a rather shocking statement at a time when most psychiatrists regarded mental defectives as unreachable and lacking in feeling" (Trent 1994 as cited by O'Driscoll 2003 p9).

Sinason (1992) has stated that there were a few pockets of interest here and there in the use of psychoanalysis in what was known as 'mental handicap', but she asserts that in the 1940s a divide between psychoanalysis and psychiatry occurred. She wrote "The advent of non-medical psychoanalysts also meant a dramatic diminishing of the number of analysts who worked in long-stay psychiatric or mental handicap hospitals" (p64). She stated that this led to each discipline (i.e. psychiatry, psychology, psychotherapy and psychoanalysis) failing to inform the other of developments. In my experience this segregation of disciplines still exists today and continues to complicate the development of the treatment of the mental health of PWID. America played a leading role in developing psychotherapeutic work with people with learning disabilities in the mid 1940s, although Sinason (1992) reported the practitioners were mainly psychologists working psychotherapeutically rather than psychoanalysts or psychoanalytic psychotherapists; so "...their work did not percolate properly through analytic circles" (p66) meaning that it therefore did not influence the development of psychoanalytic work.

This view, however, would seem to be disputed to some extent by O'Driscoll (2009) who claims from his research that Clark (1933), who was a psychiatrist and psychoanalyst, gave frequent lectures to specialists in this area and published papers and also a book. He has stated that he was "concerned to promote and exchange new ideas in the study and treatment of the feebleminded" (p354) as an alternative to the ideas of that era. O'Driscoll (2009) goes on to say that "In many ways Clark can be seen as a pioneer in expounding ideas and explaining practice that can continue to inform psychodynamic and psychoanalytic treatments in the field of intellectual disabilities today" (p10). O'Driscoll is arguing that Clark's work is still of value

today and this perhaps needs more careful examining. Sadly Clark died in the same year as his book was published, and this also coincided with the economic depression. This combination seemed to limit the potential for developing his work and is perhaps why his ideas did not continue to influence the field.

O'Driscoll (2009) describes how in 1949 Dr Simon Lindsay, a psychiatrist, took up a post at a Mental Handicap institution in Surrey UK. He was a trainee analyst and with the support of his clinical supervisor Dr Clifford Scott, decided to apply psychodynamic ideas to his patients there. He made some interesting findings during this time, noting that when working intensively with a patient over a period of four years and measuring her IQ annually, he discovered that it increased. This is an extremely important finding and it is frustrating that he did not further his work around this outcome. He worked with the founder of attachment theory, John Bowlby and also with Donald Winnicott, the influential English psychoanalyst. Unfortunately Lindsay did not develop this work further, or write about it in academic journals (O'Driscoll 2009), so once again it would seem another opportunity to develop psychoanalytic work with PWID was lost. When pondering on why the psychoanalytic work with this client group has been so slow in its development we could consider the power of intra-psychic influences. This is posited by O'Driscoll (2007), he put forward the suggestion that:

A subtle over identification with intellectual disability may have led some of the early twentieth-century pioneers to hide their work from public view, in much the same way as families have often sought to hide their disabled child from the glare of the community. A complex mix of shame, guilt, rage and hatred may have served to overshadow the attendant feelings of

pride, joy and love that are often also present in the disability transference (p 23).

It seems that this is a very likely explanation and it is indeed sad to think that if this is true that the countertransference has in itself disabled the advance of this work.

However, there continued to be a few accounts of pockets of work, one such example is Linda Mundy (1957), who wrote a positive account of her work with institutionalised children at a hospital in London. An early review of the psychotherapy literature concerning PWID (Neham 1957) concluded that “the weight of evidence presented indicates that for psychotherapy to be effective ...there may be improvement but only within limitations of their mental deficiency” (p7, cited in O’Driscoll 2009). This seems to highlight a confusion at that time in the difference between intellectual disability and mental ill health. Also perhaps a lack of understanding that PWID can experience mental health difficulties that are quite distinct from the intellectual disability and that the signs of intellectual disability could be exacerbated by poor mental health.

In the earlier work of Clark (1933) we can see that he already had this insight, he stated:

...psychoanalysis as a therapy would not claim to remove the fundamental causes of amentia [intellectual disability]. It would attempt, rather, to reduce the amount and depth of fixation so that the excessiveness of retardation may be avoided, even though the innate defect is not curable (cited in O’Driscoll 2009 p15).

Clark seemed to have an in depth understanding of this work, which is extraordinary given the prevailing views of his time, as O'Driscoll (2009) has stated he was indeed a pioneer.

It was not until the 1960s that there were further advances made in France, Canada and the USA, and in the late 1960s and early 1970s there began to be some further interest shown in the UK. Sinason (1992) describes how "In 1968, Anna Freud suggested that psychoanalyst Arthur Couch should visit Harperbury Hospital (a long-stay hospital for individuals with a mental handicap, in Radlett, Hertfordshire) in order to explore how handicap affected ego and psychosexual development" (p 70). She claimed that "there had not been any intention in Anna Freud's mind that such patients could or should be offered psychoanalytic treatment" (p70). This suggests that despite the work of the early pioneers all these years later the prevailing view was still that PWID could not make use of these kinds of therapies.

O'Driscoll (2009) has stated that two notable psychiatrists both trained in psychoanalysis spent their professional careers working in this same hospital – Professor Lionel Penrose and Dr Alex Shapiro who worked at the hospital from 1939 – 1976. O'Driscoll (2009) has continued by reporting that Shapiro "...developed a modified group analysis approach and a version of a therapeutic community in one part of the hospital" (p19). This seems to back up the assertion that Sinason (1992) made regarding the lack of communication between the two worlds of Psychiatry and Psychoanalysis as it seems that Anna Freud did not have knowledge of the work of these two psychiatrists.

Sinason (1992) went on to document a couple of pieces of pioneering work in the 1970s but it was not really until 1979 with the work of the Tavistock Clinic, and at about the same time, Joan Bicknell at St George's University Hospital in South London that there was any significant development in the United Kingdom or Ireland.

Symington (1981) had begun to include a few patients with ID in his clinics and he started the Tavistock Mental Handicap Workshop in order to further develop this work, Valerie Sinason joined him in this and she went on to develop her

own pioneering ideas. One significant idea that Sinason has highlighted in her seminal work *Mental Handicap and the Human Condition* (1992) is the 'death wish' that our society harbours towards PWID, she considered the impact of this on PWID:

Just listening to current discussion about embryo research is experienced differently when you have heard patients who were thought to be 'ignorant and blissful' straightforwardly talk of their knowledge that people wished they were dead and that no-one else like them should be born (p319).

Sinason (1992) writes in such an accessible and straightforward manner about such painful issues. The 'death wish' becomes such an obvious and apparent issue once one reads her description of its presence within our society. However, she describes that because it is so painful to be aware of such deeply seated prejudices we can become unconscious of its very presence, and yet her statement above highlights how many PWID are only too well aware of this issue.

In parallel to Sinason's work there have also been some fine advances in psychotherapy with PWID made by Sheila Hollins (1997) who continued the work begun by Joan Bicknell (1983) at St George's (London) and in the Midlands (UK) by Pat Frankish (1992) and Nigel Beail (1998), including more recently, some of the only research into the outcomes of psychotherapy with this client group (Beail et al 2005, Beail 2003, Beail & Warden 1996, Newman & Beail 2002).

The Institute for Psychotherapy and Disability in the UK of which this author is a founder member was established in 2000 as a way of bringing together the work of many of these pioneers (in particular Beail, N. 1998, Frankish, P. 1992, Hollins, S. 1997, and Sinason, V. 1992) who were beginning to really develop psychoanalytically informed therapies with PWID. The main focus of this organisation is to develop, accredit and regulate psychotherapists who work with people with disabilities. This was as a direct response to the founding therapists' experience that there were significant barriers to PWID accessing psychotherapy and counselling, including attitudes and lack of appropriate training and supervision for counsellors and psychotherapists.

It has established a small but significant change in attitude towards people with disabilities (Kahr 2000a & Kahr 2000b) and has been important in providing support and encouragement to isolated disability psychotherapists through annual conferences and local regional meetings.

Research into the efficacy of psychodynamic or psychoanalytic psychotherapy with this client group is limited, most of it is case-based and qualitative (Cottis 2009). This may in part be because it can be extremely complicated to have such research proposals accepted by ethics boards because the client group are rightly considered very vulnerable. Another factor as suggested by Beail (2005) in terms of randomised control studies, is that it may not be possible or preferable to find matched controls. However, it could also be argued that the people who may be best placed to design research of this sort would be practitioners themselves, as they will be aware of what needs to be measured. But it seems that it is rare to find practitioners who are confident and/or interested in carrying out such research. Beail is one of those rare cases, he is both a practitioner and researcher and is to be commended for his significant contribution to the field. His work has led him to develop validated outcome measurement tools for practitioners which in the current climate of evidenced based practice is significant, it is now important for practitioners to incorporate such tools into their regular practice as this in itself will provide more evidence. One of Beail's early studies (Beail & Warden 1996) focussed on the effect of long-term psychotherapy on both the symptoms and self-esteem of the PWID

referred for treatment. He found in his small study sample that the symptoms had decreased and the self esteem had increased. This was a small study but the results are important, Beail's focus now is to increase the scale of his research, this also indicates the importance of more practitioners using validated outcome measures in order to build up a broad evidence base.

Another important study has shown that defensive behaviour will often stop within the first year of therapy (Carlsson et al 2002). The study highlights that it can take some time for long term defences to come down in order for deeper work to take place. Ending therapy too early can leave a client with ID in the vulnerable position of having recognized 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. This along with Beail's work (Beail et al 2005, Beail 2003, Beail & Warden 1996, Newman & Beail 2002) has important implications in the debate over why long term therapy is often a better treatment model for people with learning disabilities;

The launch of The Royal College of Psychiatrist's (RCP) Working Group in the United Kingdom and Ireland has been an exciting advance in validating the need for, and the ability to use, psychotherapy with PWID. It was set up in May 2000 in order to examine the then current position of psychotherapy in the psychiatry of learning disability and make proposals for future professional and service development, it stated that:

People with a learning disability are now known to have higher rates of emotional, psychological and psychiatric problems and are more likely to be abused than the general population. Yet up until the last 10-15 years the psychological approaches offered to this client group were almost exclusively behavioural (McGinnity and Banks 2002).

It is significant that this work was carried out within the Royal College of Psychiatrists as it demonstrates a coming together of the two worlds that Sinason (1992) had described as having lost communication. Certainly as a practitioner I have found that the subsequent report gave me more credence when I was arguing with psychiatrists on behalf of my clients in order to gain them a referral for psychotherapy.

A key aspect of the work carried out by the RCP working group was a survey and report (Royal College of Psychiatrists 2004) which aimed to capture and describe the developing pattern of the provision of psychotherapeutic services to PWID and identify which professionals provide these services for people with learning disabilities and any perceived obstacles to their work. The results of this survey showed that there are a wide range of psychotherapeutic models already being employed by practitioners from a variety of disciplines, and perhaps most importantly, that there is a significant demand for psychotherapeutic services for this client group. This survey is currently in the process of being updated. One of the leading agencies in this area of work is 'Respond' - a voluntary sector organisation based in London UK and the current employer of this author.

The last thirty years has seen the development of creative psychotherapies such as dramatherapy, art therapy, music therapy and dance movement therapy, these have become collectively known as arts therapies. Because they have become known for not relying on the spoken word, some NHS Trusts employ arts therapists explicitly to work with this client group.

However, there is still the perception that psychotherapy (including arts therapies) is an expensive treatment, especially if it needs to be provided outside of the National Health Service (perspective gained from direct conversation with potential referrers to Respond). This is in part because of the need for the therapy to be long term, this can mean that it becomes a last option choice for treatment. However, according to Chisholm (1998) and Holmes (2000), psychotherapy is cost-effective over a long-term period because it improves outcome in two crucial ways: patients are symptomatically improved, and their need for other services is reduced. These researchers claim

that the amount of psychotropic drugs consumed, visits to the GP, hospital admissions and dependency on benefits are all reduced. This longer-term approach to costing treatment would be a good use of resources providing a better outcome for the patient.

It is well documented that PWID often develop defensive reactions to the insight into their own disability (Bicknell 1983, Sinason 1992, Thomas 1997 & Marks 1999). These defences can then further disable the person, leading to poor mental health.

Bicknell (1983) suggested that insight into having a disability is far more present in PWID than has often been believed. She stated that the insight will be linked to their cognitive ability and also to their life experience and added:

Insight is also linked with failure to reach self-imposed standards. The mentally handicapped child in a large sibship often self-imposes standards that are just above the younger sibling. Somebody must be less capable than him. Families can be warned that there may be problems when the younger sibling of normal intelligence overtakes the handicapped older sibling (p173).

Bicknell (1983) went on to suggest that if we are really to understand the meaning of handicap beyond simply the organic meaning, we need to ask – What does it mean for this person, to have this handicap, at this time in his life, with this caretaker, in this environment, and in this peer group? If we can find answers for these questions for the people with whom we are working, we will have far greater understanding of the insight that they have into disability and what it means for them.

Sinason (1992) described the defensive reactions as a 'secondary handicap', which she suggests manifest in a number of ways. She describes a mild version where the person's defence strategy is to appear more 'stupid' than they really are in order to keep the outer world happy with them. She described how "It can be easier to behave like the village idiot and make everyone laugh than to expose the unbearable tiny discrepancy between normal and not normal on the human continuum" (pp20 -21). This defence is instantly recognisable in many of the PWID that I have met. The secondary handicap being the self imposed limitation on learning or functioning to the persons full capacity. She goes on to describe what she terms 'opportunistic handicap' "where every destructive aspect of the self finds a home in the disability" (p2) she describes this as a "severe personality maldevelopment". A third type of secondary handicap Sinason described as a defence against trauma, she describes how "Trauma can cause handicap (by sexual, physical, environmental, political and emotional abuse); it can exacerbate the experience of the handicap, and the handicap can itself be experienced by the individual and those around as traumatic" (p23). These concepts of secondary handicap as defence now inform the understanding of many psychotherapists who work with PWID and underpin training in this field (Cottis 2009).

It can take a long time to get beyond these defences in order to establish a deeper therapeutic alliance. It is therefore imperative that if someone with ID is given the opportunity of being in therapy, there is provision made to explore thoughts and feelings about living with a disability.

We can see a clear example of defensive coping skills in Neville Symington's (1981), now classic paper, a moving account of psychotherapeutic treatment with a patient whom he calls Harry Smith. In the paper Symington describes Harry's preoccupation with his own intelligence and how he becomes aware of the mixed messages he has received. His father, on the one hand, placed him as extremely able but the manager of his day centre, on the other, thought that Harry was not very capable at all. When asked by Symington how he would measure himself, Harry placed himself just below average. During the

course of the analysis, it emerged that Harry had for the last few weeks been travelling unaccompanied to his sessions, something which he was unable to do at the start of the process. Symington said:

I then acknowledged with him that he was more intelligent than people took him for. I then pointed out to him very firmly that he must be pulling the wool over people's eyes. He agreed with this and wondered why it was. In the same context we got to the fact that he clowned a great deal so that people laughed at him and thought him more of a fool than he was (p191).

This demonstrates exactly the mild version of Sinason's 'secondary handicap' as described above. Symington went on to interpret that Harry felt there was something wrong with him, and that he was extremely anxious in case people did laugh at him because of this. He therefore exaggerated the process, and was then able to feel that he was really perfectly all right. But what caused him pain and anxiety was that there was really something wrong. This type of defensive exaggeration is similar to Freud's (1910) original concept of 'secondary gain.' Freud originally described this as being when a patient exaggerated their symptoms to their advantage, Sinason's concept of secondary handicap has built on this original idea.

One of the most common defences that a person with an intellectual disability will employ against the knowledge of disability is to not think (Simpson 2002), and yet when a therapist enables the client with mild to moderate intellectual disabilities to think, alongside the pain of the insight of the disability, there is room for personal growth (Blackman 2003).

Symington (1981) stated "There is a strong tendency for people to despair as soon as the word organic is mentioned...Neurological growth can be stimulated and is not static. What remains static are people's expectations that change can occur" (p199).

With new advances in neuroscience (Schoore 1994, Siegel 1999 and Schoore 2003) we are now able to see what Symington intuitively discovered for himself; the link between psychotherapy and the development of growth in neural pathways in the brain

### Transference and countertransference

Psychotherapy can offer the client with learning disabilities the chance to be understood through their entire communication. This takes place through; words and sounds, creative responses (if using arts based ways of working), body language, other non-verbal communication and also through countertransference. For people who find communicating through words difficult, being listened to in such a different way and being understood, perhaps for the first time, can be a profound experience.

The status of countertransference as a phenomenon associated with counselling or psychotherapy has changed markedly over the years (Thomas 1997). Formal debate on the difficulties connected to countertransference began with Freud (1910). His original view was that countertransference arises in the physician "...as a result of the patient's influence on his unconscious feelings, and we are almost inclined to insist that he shall recognize this counter-transference in himself and overcome it" (p 144-145). Here he views it as a hindrance to the psychoanalytic process. Two years later, however, Freud (1912) wrote that the analyst must turn his own unconscious like a 'receptive organ' towards the transmitting unconscious of the patient. In other words as Freud's thinking and ideas progressed he came to view the analyst's unconscious response to the patient as an important analytical tool. These two contrasting thoughts have combined throughout the development of psychoanalytic treatment (Epstein & Feiner 1979). In 1950, Heimann declared "the analyst's emotional response to his patient... [is] one of the most important tools for his work." (p81). Certainly when working with a client with learning disabilities and who has very little speech, it can be the only tool one has for trying to understand their emotional state. It is to this which Hollins (1999b) alludes when she states "Sometimes as clinicians we have to create

hypotheses by observing and understanding human nature, but without diagnostic proof" (p7). The only 'proof' we may have is the analysis of our own countertransferential feelings.

Corbett (2007) has described a case where he says "I was aware of holding heavy, dreadful feelings of hopelessness, dread, deadness and fear" (p57). He goes on to say that these feelings can be thought about as part of what he terms the "disability transference" which is when "...the patient projects into the therapist the disavowed feelings that are simply too unbearable to hold" (ibid). This is such an important point to recognise in this work as without understanding this phenomenon it is easy for a therapist to become overwhelmed by the work and perhaps even to burn out. Corbett's eloquent description of this issue highlights the significance of gaining good and regular clinical supervision in order to understand what is happening and to share the 'holding' of the unbearable feelings .

Hollins (1999b) on addressing the value of junior trainee doctors taking a placement in learning disability services has stated that, "...they may have to confront uncomfortable and primitive fears about people who are different from themselves. They may even experience some of the stigma which is so powerfully associated with intellectual disability" (p11). These are two important areas to consider and we may be brought up short by either or both of these experiences at different points in our work with people with learning disabilities.

Linnington (2009) takes this even further in his paper 'Enduring horror: Psychotherapy with Monsters' where he describes the despair often felt in the work and how sometimes this could lead to feelings of wanting to be rid of the patient. This is echoed by Corbett (2007) "Alongside my feelings of curiosity and nurturing for Barry, I was sometimes acutely aware of wishing to abort him from this analytic project that I periodically lost faith in" (p59).

Alvarez (1992) has described her work with psychotic children. "They seem to have gone beyond hope, memory and even fear...there is nothing left on which to leave a trace, no imagined listener" (P13). Although her work is with disturbed children we now know that many of these children grow up to become adults with intellectual disabilities. In fact much of her clinical supervision work more recently includes this adult population.

The discussion thus far provides strong reasons for the benefits of working with a psychodynamic awareness with this client group, which can lead to a deeper insight into the experience of the person with a learning disability through focusing on and understanding our own unconscious responses.

#### Considering the therapeutic matrix

The need to support the care staff whilst at the same time managing the confidentiality of the client is a challenge that runs as a theme throughout the work of many of the pioneers. Clark (1933) wrote that a key clinical point was for the client to enter into a relationship with the support staff, to gain identification with them and he supported this to happen. Corbett (2007) wrote about the links between psychotherapy with PWID and child psychotherapy. In child psychotherapy the parents are often also offered time with a psychotherapist, in order to think and reflect. He highlights the importance of this parallel process and suggests that as therapists working with PWID we also need to assess the psychological capacity of the carers to support the analytic process. This study argues that this is a key factor, as without the ability of the network to support the PWID in therapy, it is impossible to carry out the work.

#### Conclusion

Research has highlighted that PWID are known to have higher rates of emotional, psychological and psychiatric problems and are more likely to be abused than the general population (Royal College of Psychiatrists 2002).

Although it is not always easy for PWID to access psychological therapies, research has shown that defensive behaviour will often stop within the first

year of therapy (Carlsson et al 2002). This has an important implication in the debate over why long term therapy is often a better treatment model for people with learning disabilities. According to Chisholm (1998) and Holmes (2000), psychotherapy is cost-effective over a long-term period because it improves outcome in two crucial ways: patients are symptomatically improved, and their need for other services is reduced.

Countertransference is a key tool within the therapeutic relationship with clients with ID, and can often be an important component of unconscious communication between client and therapist. It is through an awareness and understanding of the countertransference and transference that a change in relational dynamics can begin.

It is imperative when working therapeutically with this client group to develop a framework which includes an alliance with the supportive network surrounding the PWID.

The following chapter examines and reflects on my contribution to this area of work. It describes how my own practice has developed and how I have used my learning to contribute more widely to the understanding of the bereavement needs of PWID.

## **Chapter 7 – A review of the author’s contribution to developing an understanding of bereavement in people with intellectual disabilities**

### Introduction

This chapter charts my contribution to this field from 1996 when I wrote the bereavement training course as part of the ‘resource for opportunity and change training consultancy’ (roc), through to the latest work at Respond - a voluntary sector organisation where I have been the Deputy Chief Executive Officer (Deputy CEO), overseeing the provision of psychotherapy for PWID since 2003. The aim is to critically analyze how the understanding of grief as experienced by PWID has developed within this body of work and how this has informed the study.

### The Beginning

As has already been described my initial professional interest in bereavement and PWID can be traced back to when I was working at ‘roc’ (originally known as Playtrac) which was at that point in time, a training organisation providing courses for health and social care staff who worked with PWID. I had begun to research what resources already existed for supporting bereaved PWID and at that time there was very little. One of the only courses that I found was to be held at St George’s teaching hospital in South London. This was where Professor Sheila Hollins was based. She was organising a study day on the subject and had also produced 2 picture books about parents dying that were specifically aimed at PWID. I attended the study day this inspired me and cemented my plan to set up a training course within Playtrac. In 1996 I had written a new course on the subject and on the first day that I ran this a journalist from the ID journal ‘Community Living’ attended the course in order to review it. (Crowhurst 1996). After I had run the training day I was interviewed for the article which quoted me as saying:

“When I joined Playtrac training consultants in 1994 I was clear that I wanted to write a course on Loss and Bereavement. It seemed to me that this was an area that was not addressed for people with learning disabilities. I researched and wrote the course and quickly discovered that there was indeed a great need for this sort of information; not only were the training courses being booked up quickly but we were also receiving more and more enquiries about consultations focusing on specific bereavement issues. As I took these on, my own learning and creativity in how to support people through the grieving process grew.” (p6).

The article continued by reporting that I would be setting up a new therapy service in April 1997 for PWID who had been bereaved. Re-reading the article for this review it is clear that even in those early days, some of the issues that are key features of this study were present in that early training course, such as relationships, identity and environment. Crowhurst states “Looking at the loss that people with a learning difficulty might experience – especially in moving from an institution into the community – Noelle described how these ‘hidden losses’, for example, the loss of space, community, friends, identity need to be acknowledged” (ibid).

These themes have remained important in the development of the work and begin to be explored further in the publication ‘Loss and learning disability’ (Blackman 2003 p104-5) and again later on, in a paper (Blackman 2008a) where these issues have been incorporated into the early model of the Bereavement needs assessment tool (BNAT), which is still in development. It is interesting to note retrospectively how the early research and experience which

informed the first training course and subsequent early development of the model of therapy, have remained at the core of the work and contributed to my understanding more fully of the nature of grief in PWID.

### Publishing and presenting the work

In 1998 I was commissioned by Pavilion to put together a conference, and edit a publication entitled *Living with Loss: Helping people with learning disabilities cope with bereavement and loss* (Blackman 1998). I took this as an opportunity to bring together many of the people that I had encountered through setting up the NNPCPLD (see chapter 2) to contribute chapters, and to speak and run workshops at the conference. This was an important start to a national collaboration of practitioners, researchers and carers to work together to develop thinking and practice around supporting PWID with issues of death and dying. Although sadly the collaborations which I had hoped for in terms of research and practice development did not really take off in quite the way I had envisaged. Looking back retrospectively I think that professional rivalries prevented many truly collaborative partnerships. In my naivety I had not realised how competitive the research world can be. However many of us went on to develop our work independently and we then published and contributed collectively to conferences, often under the banner of the NNPCPLD and met together regularly to discuss the issues. So the development of the work was shared on many levels; we were continually discussing and influencing each others contributions.

In the same year I was also invited to contribute to a conference within the Health Trust where I was based, which focussed on assessment and evaluation within the Arts therapies. This was a great opportunity to reflect in detail on the methods of assessment and evaluation I had been using and to write these up more formally. It was also the first time that I had experienced questions from the floor from other professionals, some of these felt quite a challenge to me as a new presenter. It was a valuable experience in learning to defend and argue my thinking and was helpful in consolidating the early shaping of my

model. All papers from this conference were put together into a monograph entitled - Assessment and Evaluation in the Arts therapies which was edited by Dr Tony Wigram (Blackman 1999). These two publications were important in establishing the documentation and development of the therapeutic model that I was creating within the 'roc' loss and bereavement service.

The following year I had several papers accepted for the 11<sup>th</sup> World Congress of The International Association of the Scientific Study of Intellectual Disability (IASSID) which was held in Seattle, USA. Following the congress, I was invited to publish in an American journal called The Journal of Gerontological Social Work. This was a paper which focussed on the systemic way of working that I was developing as the model within the bereavement service (Blackman 2002). Writing up the model more formally from this systemic perspective was a further consolidation for me of how the model was shaping up. It was a chance to explore how the theoretical frameworks I used came together with the experience I was building up of bereavement and PWID and how each had informed me in developing my therapeutic model.

During congress there was an opportunity to make a connection with some of the other presenters who were interested in this research area. Some important connections were formed, notably with Stuart Todd whose work was from a sociological perspective and with Professor Sheila Hollins and Sandra Dowling who were embarking on a research project comparing two different approaches to bereavement support for PWID. This led to collaborations to write the two following publications; 'When Somebody Dies' (Hollins et al 2003) and 'Caring for People with Learning Disabilities who are dying' (Blackman & Todd 2005).

The first book (Hollins et al 2003) is part of the Books Beyond Words series and uses a picture based narrative to explain the role of bereavement therapy. It is used as a resource directly with PWID and at the back of the book there is information to support carers. This process was once more an important stage in consolidating some of my thinking and experience so far. In order to devise the picture based story book, I had to step into the perspective of the bereaved

PWID who would be using this book as a resource. This was an interesting experience and helped me to reflect on what I had learned from my clinical practice. Another key part of this process was that we worked closely with a small group of PWID testing out the story and pictures as we devised it in order to evidence that the book was able to convey the story that we hoped that it did. This was the first time that I had discussed the issues of death, grieving and psychotherapy with PWID who were not in therapy with me and I found this very useful as I was able to speak more freely with them.

The second book; (Blackman & Todd 2005) began as an information booklet which I was commissioned to write by Todd, as part of the dissemination of one of his research projects. We met regularly in order that I was able to share my ideas as to where I had got to in researching what I thought needed to go into the booklet. During my research for this booklet it became clear to me that there was a big gap in resources for supporting carers of PWID who were dying, and that it would be difficult to put all that I felt was needed into a small booklet. Our 'booklet' grew to become a small book which we co-wrote and we were able to interest my publisher (Worth Publishing) to take it on, and I am excited to report that, last year it was translated into Polish, and Stuart and I were invited to run a symposium on death and dying in Warsaw. The book was aimed at untrained residential support staff in order to provide easily accessible information enabling them to support PWID who are diagnosed with a terminal illness and also to enable them to support the other residents living with them including supporting them in bereavement after the death. There are still few resources which address this palliative care need. Although it has been joined more recently by an excellent, comprehensive and up to date publication on the NHS End of life care website by Linda McEnhill which is part of the series of resources 'The Route to Success' (2010).

During this time I was very involved with the National Network for the Palliative Care of People with Learning Disabilities (NNPCPLD) that I had co-founded in 1997, and with others from the network I attended the European Association of Palliative Care conference in Sicily in 2001 and the Congress in The Hague in 2003. It was at these events that I was able to develop a more generalised

understanding of current palliative care by attending presentations of papers and studying poster presentations as well as meeting with mainstream palliative care experts from around the world. This helped to shape my broader knowledge and interest in palliative care and bereavement research and its relevance to PWID. Following these events I was invited along with some of the other NNPCLD members to publish a paper in a special edition of the European Journal of Palliative Care (Blackman 2005). Up until this point the care of PWID had not featured as a topic of interest at these conferences and now our presence had led to a special edition of a specialised European journal focussing on the palliative care needs of PWID. This was a demonstration to me that gathering together as a network had been a positive thing to do in shaping the collective thinking and in raising the profile of the needs of this population. Although there was initially resistance towards recognising this client group and we often felt quite shunned, the network's role in raising the issues of PWID persistently at each conference had been important in ensuring that this had become an issue that could no longer be ignored by professionals in the field of Palliative Care.

In 2003 *Loss and Learning Disability* (2003 Blackman) was published, this publication enabled me to bring together findings from the six years of running the loss and bereavement service alongside a scholarly review of the literature. This book marked the beginning for me of critically engaging with all that I had discovered so far, through my practice and through my encounters with others. As I struggled to write this book my own developing ideas began to take shape particularly around the importance of early attachment relationships. I also began to formulate ideas for a bereavement needs assessment tool. On reflection this would have been an ideal time to have embarked on a PhD study. This might have provided me with more structure and guidance at this earlier stage. However, I was not at a point in my own development where I could have envisaged that I was capable of such an academic task.

In the same year I reduced my hours from full time to part time in my role as director of the loss and bereavement service, and joined the therapy service

'Respond' as Assistant Director. Respond had formed in 1991 in response to the widespread recognition that many PWID were the victims of sexual abuse, and they were an organisation that I had often looked to as I developed my ideas and models of therapy in the Loss and bereavement service. This new role at Respond provided an opportunity to work alongside many of the pioneering disability psychotherapists already working there and to be supervised by Anne Alvarez who had led the Tavistock's clinic for children with autism and who had published extensively in this area. Alvarez was very keen for the Respond therapists to publish their own book to add to the very small literature on psychotherapy with PWID and with her encouragement and patience the book 'Intellectual Disability, Trauma & Psychotherapy' was eventually published (Cottis, T. 2009). My chapter entitled 'Therapy for Life and Death' (Blackman 2009) focuses on my therapeutic work with older PWID it discusses clients' struggles with the concept of mortality (their own and others') and the sadness of people who have struggled to gain independence throughout their lives as they face becoming more dependent again as their bodies become frailer as they grow older.

The interest which had begun earlier (Blackman 2003) to develop a Bereavement Needs Assessment Tool (BNAT) continued and I have presented early drafts of this at several conferences and training events. This has led to several different teams across the country trying out the tool and feeding back their experience of using the BNAT, these developments were written up (Blackman 2008a). The interest that has been generated by this article has demonstrated that there is a clear need for a resource such as this; therefore I intend to continue to refine and develop it in the future in order that it can become widely used to support PWID.

I was invited to contribute to a book on the clinical supervision of dramatherapy (Jones & Dokter 2008b), a chapter entitled 'Making Space for Thought'. Clinical supervision is a subject which is of great interest to me, I think that it is an important resource for people in many roles from care worker to psychotherapist, especially when working with PWID. In this chapter I highlight the importance of addressing the attacks on thinking that can occur in

the therapy with PWID and I also flag up the importance of noticing and working with the often hidden losses in the lives of PWID. I believe that it is imperative that psychotherapists working with this client group have clinical supervision with supervisors who really understand this area of work. Without knowledge of some of the core transference issues already discussed in this study it is easy to become lost in understanding the issues that are being presented.

Since September 2010 I have been involved with the Department of Health as part of a small focus group of experts in the review of the End of Life care Strategy and the national bereavement guidelines, in order to ensure that all guidance includes the needs of PWID who have been bereaved, this work is still ongoing. This marks a significant turnaround in the recognition that PWID really do have bereavement needs that need to be clearly understood and met. However it is still a constant battle to get a real understanding of the changes that need to happen in order to bring about significant change.

#### Working at Respond

Since 2003 I have been working at 'Respond' and in my role there I have been able to broaden the brief of the organisation to include trauma and bereavement as criteria for referral. In 2004 I developed a specific project within the service that focuses on ageing for PWID and incorporates loss, bereavement and palliative care, which later became known as The Respond Elders Project. This project provides psychotherapy to PWID both one to one and in groups, and training and consultancy to families, paid carers and professionals. As part of this project I developed a six week Action Learning Course (ALC) for staff in ID services on loss and bereavement. The literature reviewed earlier in this study highlights conflicting evidence regarding care staff's recognition of grief in PWID and barriers to their ability to provide adequate support after bereavement. Some studies (Hollins and Esterhuyzen 1997, Dowling et al 2006) have highlighted that staff attributed anxiety, depression and changes in behaviour as intrinsic to the intellectual disability rather than recognise these as reactions to grief. However, other studies

(Murray et al 2000, Reynolds et al 2008) have demonstrated that staff seem to have a good knowledge of the grieving process and how to recognise this in PWID. Yet even though staff seem to be better informed than they were a decade or more ago, there still seems to be a lack of confidence in carrying out the tasks needed in providing adequate support to PWID who are bereaved (Murray et al 2000, Dowling et al 2006) and an inability to indicate a willingness to talk about death or just to listen attentively (Murray et al 2000). With all of this in mind the ALC was designed with the aim of passing on to staff, the skills and confidence to talk comfortably and supportively with PWID about issues of loss. Below is a description and evaluation of the development of this work.

#### The Pilot project - Action Learning Course (ALC) on loss and bereavement

The ALC began as a pilot project which I first ran in October 2006. This was aimed at staff working in an organisation that provided residential care for PWID. The pilot project consisted of half a day's training for all staff. Plus six, one hour, weekly loss discussion groups with PWID, which also included two co-facilitators from the residential setting who co-ran the group alongside me. The group consisted of five PWID who had all been bereaved (all over one year previous to the start of the group). Every week on the day that the group was held, I held pre and post session meetings (15 mins) with the co-facilitators in order to develop the theory delivered in the first day of training into practice, to support emotional learning and to ensure that the passing on of group skills was identified. The evaluations from this pilot informed the decision to develop this model further.

#### Lessons learned from the pilot

It became clear through the evaluation that six weeks was not long enough for the co-facilitators to gain enough confidence to continue the work without a lot of support from myself. It also highlighted the importance of preparation work with an organisation at the point of setting up the project. In particular, the engaging of interest and support of senior management in order that they fully

understood the process and utilised the process strategically into the whole organisation.

The pilot also highlighted refinements to the model that were needed. The findings pointed to the following changes:

- Before groups began there would be a half day training with the whole staff team which should include managers as well as care staff
- There would be eight sessions instead of six
- The pre and post meetings would last for half an hour instead of 15 minutes
- The Co facilitators were to keep reflective journals in order to maximise the learning and other evaluation measures needed to put in place
- That there would be a final one hour supervision session after the project had finished to consolidate learning and to plan for how to continue the work

#### Setting up a funded project to develop the work further

In June 2007 funding was secured from Lloyds TSB for a project to develop this work over the next 3 years enabling Respond to advertise for and recruit a therapist to become the project worker. Her task would be to encourage ID organisations to host an ALC. In the first year of the project, she ran five ALC in different organisations.

The following reports on the findings from the first ALC held as part of the TSB funded project.

#### The Evaluation Process devised for the ALC

A robust evaluation system was put in place in order to learn from each ALC that took place. This provided Respond with a tool with which to make continual refinements to the model, enabling the team to learn as much as possible about how, and in what ways this model might go towards fulfilling

the need to equip care staff to provide a higher level of loss and bereavement support to PWID.

Permission was sought from all participants to share the information gathered as part of the evaluation and dissemination of this project, this was done in an accessible format for the group participants who had ID.

The evaluation of each programme of training consisted of the following:

- The senior manager was asked to fill in a pre and post evaluation form regarding the expectations and the outcomes for the project
- The delegates on the one day course filled in pre and post evaluation forms
- The group members (PWID) were supported to fill in pre and post project questions
- Co facilitators were asked to keep reflective journals
- Respond worker kept a reflective journal

#### The setting for first ALC

This was a Campus style setting which had originally been set up by parents. The group members consisted of eight PWID (four men and four women). They were aged between late 40's and mid 60's and had various different abilities ranging from mild to moderate ID.

#### The co-facilitators:

A man in his early thirties who had been working with PWID for around ten years mainly in this campus as a support worker.

A woman in her early fifties who had also been working in the campus for many years and who had been a home manager for some time.

#### Questions asked of co-facilitators to guide their reflective journals

What did you find interesting or puzzling in today's session?

a). in the facilitation?

- b). in things said or done by group members?
- c). in things you thought or said?

What if any changes did you notice?

- a). in yourself?
- b). in your partner?
- c). in the group?

The following quotes are taken from one of the co-facilitators reflective journals within the first couple of weeks of running the group:

*"I was interested in the way the (Respond) facilitator was able to enhance service users' willingness to open out to each other"*(week 1)

*"I was quite shocked by some things said and that some people had no objects to remember with and some no photographs"*(week 2)

These quotes illustrate the ability of this style of training to help participants to learn in a very immediate way, the same information that is contained within a one day training course and yet seen 'in action' it can be understood much more deeply .

These next quotes are taken from the same reflective journal towards the end of the group:

*"I found it difficult to manage the session on my own and felt a little lost but input by M (the Respond facilitator) helped and I now know how to steer group better"*

(week 7)

*"At the beginning of the course I was unsure of how it would progress and whether it would help service users. However I now feel that having watched and learnt from M I will be able to run the group following her guidelines"* (week 8)

The extracts above indicate how the ALC has supported this participant to feel confident enough to now facilitate a group without the 'expert' input. This is an important contribution, the literature confirms that staff generally find it difficult to talk about and indicate a willingness to listen to PWID if they need to talk about their loss (French & Kuczaj 1992, Persaud & Persaud 1997) this evidence suggests that the ALC has brought about a significant change in the skills and confidence of its participant.

The following quotes are from the other co-facilitator's reflective journal early on in the group:

*"...Puzzled that D appeared to be able to manipulate the group & irritated by her constant interruptions".* (week 2)

*"More relaxed attitude towards participant who inadvertently dominates session"*(week 4)

*"Feel more confident in talking in the group, bringing attention to individuals who quietly mention something"*(week 6)

These quotes demonstrate how through the co-facilitation of the Respond 'expert' facilitator this participant has learnt to understand and work with some of the complex dynamics of the group participants. This is something which can best be taught through an action learning model of training as the 'expert' facilitator can highlight the dynamics within the group within the feedback sessions, and can suggest ways to manage these. The success or failure of these 'management techniques' can then be discussed at following feedback sessions.

The evaluation of the group by the participants with ID

The participants were asked in the first and last session the question - How do you feel talking about people you have lost? They were supported to write down their response (the wording has been transcribed exactly as it had been spoken).

The table below shows how they felt before and after the ALC:

<b>Feedback from participants with ID</b>	
<b>Before the ALC</b>	<b>After the ALC</b>
I just lost my mum. I find it hard to cope. Its hard to talk about	It was useful I liked it. I found it easier to talk in this group. I wanted to talk. I want to come back again. People listen to me.
I feel upset	Very helpful to when I lost my mum two years ago. It was very helpful to remember you lost. It changed the feelings because other people lost parents and animals, mums and dads
It hurts when I talk about my mother and father and grandparents	I like it so much here because it makes me feel better here talking about my family and everyone who passed away
I feel upset. I need help	I found I could talk to people about my feelings but it was hard.
Sad. It makes me cry	It's changed (My feelings) because you talked to me. It helped me quite a lot. Seeing the pictures was sad

Table II

Before the ALC the participants found that their feelings connected to the losses were very painful and their statements show how difficult they had found it to talk about their feelings or their losses. This appears to echo a similar theme to the studies which highlight how difficult it is for PWID to share their feelings when staff do not have the skills to indicate that they can listen (Gilrane-McGarry & Taggart 2007 and Murray et al 2000). It was therefore positive to see that by the last session, the same participants demonstrated that there had been a change in the way that each of them now talked about their losses and their feelings. The participants mention how they valued being listened to, having had an opportunity to remember the deceased, normalising their experience through hearing other people's stories and that although talking about the loss was hard it made them feel better. These are all very valuable outcomes from the group experience and confirm the findings of French and Kuczaj (1992); Yanok and Beifus (1993); Persaud and Persaud (1997) and Read and Papkosta- Harvey (2004).

The Respond project worker noted in her reflective journal towards the end of the first group:

"As the group grow more trusting and confident so do the co facilitators. The group space provides the time and conditions for PWID to learn to express and explore their experience of death and loss within a group and willing to witness their pain. Ultimately this instils a greater resilience so that the next encounter with loss can be borne more easily. Because Staff only slowly take on the facilitation they are freed to listen and witness the reality of peoples lives and to learn from this". (MB 2008)

Here we can see from the experience of the Respond facilitator that one of the most valuable qualities that this model of training offers both the group participants and the facilitators is time; time to slowly learn from each other on many levels.

#### Reflection on the project

Although there is a big investment of time for each service provider that signs up for the opportunity to take on an action learning course (ALC) within their organisation, the benefits are multi layered. The evaluations from the group participants (PWID) were very positive - there were tangible changes in such a short time. The learning for the two co-facilitators has been practical but has also taken place on a deeper psychological level. They now have a commitment to continue to run similar groups and to cascade the learning within their organisation.

The evaluation of each of the other ALCs that have been run during the first year of the project has been similar to this first one. The evaluation of the ALCs has demonstrated that there has been a rise in confidence within the individual staff members who have taken part. They were able to demonstrate that they could confidently provide support to PWID who had been bereaved and felt comfortable in facilitating conversations about issues of loss. The wider aim to bring about fundamental changes within each organisation in their support of PWID around issues of loss has yet to be seen, this needs further research and I have yet to write up the findings from the whole project. However this model does have weaknesses, in particular the time and resources that are needed, few services are willing to invest so much in order to build up the skills and confidence within their service. It is my hope that if I can build up more evidence and write it up in an accessible way aimed at providers they will recognise that this would be an investment well worth taking.

#### Developing a new approach to psychotherapy with PWID

As already discussed in chapter six, in my experience there are difficulties in working in a classic dyadic way in psychotherapy with PWID. With every client it feels as though there are always more than just the two people in the room (Corbett 2009). This is true on many different levels, for example PWID are almost always dependent on others for travelling so there is often an escort involved in bringing a client for a session, and this can often bring about complications that can threaten to compromise the confidential nature of the

therapy, as they are there at the beginning and end of the therapy session and often try to have some sort of communication with the therapist (Blackman 2003). Another factor which can become a challenge in the psychotherapeutic work with PWID, is that it can be difficult for many clients to have a sense of their own life story (Blackman 2003). Many PWID have fragmented thinking and memory can be difficult, so in order to support the therapeutic work it is important to find ways to fill in the gaps in knowledge and this usually means speaking to staff and/or family.

When I first set up the 'grief loss and bereavement service' (1997) as well as providing psychodynamic therapy to bereaved PWID, the service, also used elements of systemic and psychodynamic thinking to inform the way it thought about and supported the people working with the referred clients. Systemic psychotherapy is a model which takes account of the network around the individual which it sees as influencing, holding and reflecting internal parts of the client (Baum and Lyngaard 2006). The reason for incorporating this way of working was that my experience had demonstrated that unless I built into the practice a way of working closely with the supportive network surrounding each client, the psychotherapy would have less of a chance to work well for the client. I therefore devised a model which at the start of therapy offered a day of training (when the service first began this was two days but eventually became refined to just one day) for the staff who supported the client who had been referred. This had as core components – an introduction to loss and bereavement, an opportunity for the staff to ask questions about the therapy process and also a chance for everyone to piece together as much as possible about the life story of the client. The training had three main functions – firstly to build a relationship between the therapist and the support network, secondly to enable the support network to understand more about the therapeutic process in order to get them on board to fully supporting the importance of the therapy and thirdly to enable the therapist to learn more about the client. At the end of the training day I encouraged good channels of communication between myself and the supportive network in order that they could support

the changes that the client was experiencing in therapy and also inform me of any significant issues occurring in the client's life.

In order to demonstrate why this way of working is important, a description of work with a client who will be known as Paul is outlined below.

### Case study

Paul worked hard in therapy to show the 'able' side of himself, this often felt like a defensive action (Sinason 1992). He was very numeric and often impressed me with his skill in this area. Meanwhile the staff team supporting him and on whom he was very dependent, often got the dates of sessions wrong, arrived late and through my psychodynamic lens I understood this as them holding the dysfunctional part through the transference in their relationship as supporters of Paul (Obholzer, A. & Zagier Roberts, V. 1994). This could also be understood as the staff perhaps not believing that he could make use of such a therapy or even feeling envious of the attention he received and therefore sabotaging the sessions either consciously or unconsciously (Menzies-Lyth 1960). I was able to work with the staff team in order to help them to recognise what was happening and this enabled them to support him in a less disabling way. As Paul felt more empowered by this change of attitude, the staff began to see him in a different light, he became less defensive in being able to think about how it was to have a disability, and became more able to express his anger and frustration at this rather than at them. He also became more able to think clearly about the changes in his life since his bereavement, and to make choices about how he would like to be living both in the present and the further future. This is an early example of how the therapeutic model I was developing worked. However, one of the weaknesses in this way of working was the challenge for me as the therapist of holding the confidentiality and loyalty of the therapeutic relationship at the same time as working in alliance with the supportive network.

### The development of the attachment based systems approach

As has been clearly demonstrated above and in other cases throughout this study, one of the key things that this author discovered whilst at 'roc' was that in order to enable long term change for a client with ID in therapy, a therapeutic service needs to be able to communicate and think about the client with the whole 'system' and include the supportive network as part of the treatment.

When I moved to take up the post at Respond in 2003 I was able to build on the model first created within the roc loss and bereavement service and incorporate the 'case management system' that was already in place at Respond, integrating and developing the two models. The 'case management system' was similar to my model but it differed in that the communication with the team around the client was carried by somebody separate from the therapist. At this point in history Respond did not provide training to the team, the case manager was simply the person who supported the setting up of the referral, who attended any meetings about the client and who attended to any other communication. I have been instrumental in designing and implementing the sophisticated model that Respond now has in place by introducing an inclusive therapeutic package. The therapeutic package is as follows - all new referrals to Respond are now commissioned with the following as a basic minimum - one year of therapy, one day of induction training with the staff and four hours of consultation with the staff spread throughout the year, carried out by a 'case manager' for each client who is separate from the therapist and who can provide a bridge between the confidential therapeutic work and the client's supportive network and everyday life. This enables the network to become a very real part of the transformative process of the therapy at the same time as keeping the therapeutic relationship 'safe'. This is a real development of my original model and has overcome the original challenge of maintaining the loyalty of the therapeutic relationship whilst at the same time building a 'therapeutic alliance' with the support network.

The aim of this 'therapeutic alliance' is to bring residential staff on board as a part of the therapeutic team, to enable them to recognise the part that they

play in supporting the therapy but also the part that they play in their everyday relationship with clients. During the induction day, staff members are taught some basic information about attachment and about transference and together with key points from the client's specific history they are enabled to understand that how they relate to a client can make a huge difference to the client's recovery. This is supported through regular telephone and e-mail contact with the home and through the face to face consultation sessions. The result of implementing this model has been evidenced by the positive response we have seen in a greater commitment from many of the staff teams in supporting the therapy. Previously, we would often have to work with staff's ambivalence towards therapy. This could be seen played out when client's sessions were missed because they were not put in the diary or another appointment had been made which clashed or they would arrive consistently late. This is difficult for people who are dependent on others to get them to their psychotherapy sessions. Respond has seen an increase in attendance and punctuality. Case managers have also reported more positive working relationships with the referring staff teams. These developments in the work at Respond have yet to be written up but there are plans to do this in the near future. It has been an important part of this research to continue to refine and develop this model of psychotherapy.

### Conclusion

This chapter has described my contribution to understanding and responding to the bereavement needs of PWID. This has been a two fold development, firstly in raising the confidence of care staff to provide bereavement support, and secondly in developing a new therapeutic model.

This chapter has highlighted my response to the complexity of developing the skills and confidence of direct care staff in order that they can support PWID through a period of bereavement. I have adopted a multi layered approach to meeting the perceived needs of care staff, through developing an action learning model of training and also through engaging them as part of the treatment process when the grief has become complex and there is an added

need for psychotherapy. I have highlighted the importance of enabling care staff to listen attentively to the loss stories and experiences of PWID, and have demonstrated how they can learn through modelling how to respond appropriately and helpfully. I have also described the development of a long term model of psychotherapy that includes the supportive network as a part of the treatment model in order to best meet the needs of PWID who experience complex grief.

The following chapter is the final one, in this chapter I clarify my thesis and draw together what has been learned through examining key examples from my clinical practice together with the most relevant literature. This chapter also makes recommendations for future policy and practice both for PWID who have been bereaved and also for PWID more generally.

## **Chapter 9 – Conclusion and recommendations**

### Introduction

This study has examined what can be learned through grief therapy with PWID from a psychodynamic perspective, alongside a critical examination of the most current and relevant literature. It is argued that through this exploration, a clearer understanding of what contributes towards complicated grief in this client group has been gained. The uniqueness of this research study has been its focus on the effect of insecure attachment on PWID who have been bereaved. The study has also provided evidence as to how this information can be used to design and provide services which can better support PWID.

On examining over three decades of literature on bereavement and PWID, it became apparent that at the start of this study there was a lack of clarity about how best to support bereaved PWID. The review highlighted that this subject has been difficult to think about rationally and systematically; it has been easier to identify the problems rather than to address them satisfactorily. There has been a tendency to focus on a “homogenous group” or “a race apart” (Mcloughlin 1986) and to forget the early studies (Emerson 1977; Oswin 1985) that state that everyone, PWID included, grieve in an individual way and that there is no “one fit” solution. The key finding from the literature however, is that PWID experience a high percentage of complicated grief (Conboy-Hill 1992; Blackman 2003; Brickel & Munir 2008; Dodd & Guerin 2009).

The review on the generic bereavement literature has shed some light on the many reasons that may contribute to why PWID may experience such a high proportion of complicated grief (CG). We have learnt that CG may be linked to difficulties in the person’s continued relationship to the deceased, it may be to do with difficulties in the social environment that surrounds the bereaved

person in their daily lives, or it may have more deeply seated psychological roots such as unhealthy attachment patterns.

One significant study (Van Der Houwen et al 2010) which focused on multiple potential risk factors, found interesting results on the effects of attachment style. They found that attachment anxiety was a significant factor in complicated grief symptoms when examined on its own. This is an important finding in view of my study. However, interestingly, when this was examined within the group of intrapersonal predictors, they found that it disappeared when measured together with social support. This finding is of great significance with regard to PWID who have a high probability of an insecure attachment pattern combined with limited social support. This observation also re-enforces the suggestion raised in McLoughlin's (1986) study, that a greater investment in a few highly significant relationships may make the breaking of these bonds catastrophic. He suggested that this may mean there is less opportunity for PWID to access support from such a limited network resulting in extreme isolation during bereavement. Many studies concluded that unsupportive environments exacerbated the grief of the individual. The combination of these findings confirms that there is a need to find ways to both address changes in the environment as well as consider how to work with unhealthy attachment (Brickell & Munir 2008).

The literature points to an over-emphasis on teaching direct care staff about bereavement rather than addressing staff confidence in applying knowledge (Kitching 1987 & Reynolds et al 2008). This indicates that different models of training and support for staff are needed and has implications for future training of the work force. This study has addressed this finding in a number of ways. The origins of the study were in addressing the skills and confidence of direct care staff. Latterly the 'Action Learning Courses' (ALC) described in chapter seven highlight the significance of developing confidence in direct care staff. They have demonstrated that there is value in learning through 'doing'. The ALC project has shown the importance of providing care workers with the time to rehearse skills safely and the opportunity to be facilitated in a

supportive manner. However what has also been learned is that providers can be reluctant to invest in such a resource intensive intervention and that more evidence is needed in order to highlight the value of such an investment.

This study progressed from focusing originally on educating the workforce to having a direct focus on addressing the therapeutic needs of PWID who had been bereaved in combination with supporting the care staff.

#### Limitations of this study

This study has been unusual in that it has been carried out alongside the development of my practice over the course of 15 years. I did not plan originally to be carrying out research and the methodology has therefore been applied retrospectively.

The study used qualitative methods based on a phenomenological position (Maykut & Morehouse 1994). The observations and reflections that have informed the research have been made from the perspective of a psychodynamically informed dramatherapist. Although there are strengths in that this provides a specific way of interpreting the material gathered, there is also the possibility that this particular way of viewing the world means that other possible interpretations have been missed.

My retrospective collecting together of information may have sometimes been a weakness, it has meant that I have had to look to documented evidence of the development of the work. Sometimes this has been work that I have already published but at other times I have had to rely on the quality of notes written before I had officially become a researcher. I have also sometimes had to rely on the fallibility of my own human memory with all of the inherent biases which can colour this and the challenge of remaining objective.

I have applied reflexivity to the best of my ability and this has enabled me to be aware of the many influences that I bring to the research as well as the effect of the research on me. I know for example that as a practitioner researcher I am by definition already convinced of the value of therapy, and

that this will have an influence on the outcome. It would therefore be unlikely that this study would find that psychotherapy is not a positive intervention for this client group and that nothing important about the issues that the client brings could be discovered. This has meant that my starting point already has a particular slant and I have remained aware of this particularly when reviewing the work of other authors, doing my best to not be over critical of others' work in the light of my own ongoing work. Added to this is the fact that the research question has been designed by me and I am therefore, likely to hold an underlying wish to find a positive outcome to the question that I have set myself, however objective I try to remain. I have also been aware all through the writing up phase of this study that I have been holding my peers in the field of bereavement and ID in mind, I have been aware of them judging the quality of my work or the view that I have taken in my critique of their work. I have tried to remain conscious of this and endeavored not to allow these factors to influence me, however they have been present and this in some small way, may have affected the study.

As stated earlier, it was not until I came to write up this study that I made connections to themes of loss in my own life. These connections have been unconscious, and yet have informed my professional path of inquiry. The underlying mirroring of my childhood loss is likely to have made me at times over identify with the situation of some of my clients and to lose my objectivity. I am aware that the focus that I have taken at times on wishing to develop ways to skill up the workforce in order that they can feel confident to do 'the right thing' at a time of bereavement is likely to some extent to have been unconsciously driven by my own experience of exclusion and confusion during my childhood bereavement.

In writing up and analyzing this study retrospectively, I have been aware that there is a danger that I may be so close to the work that I could lose my critical subjectivity (Reason 1986 as cited in Payne 1993). I have done my best to be vigilant about this, however, my passion for the work and personal

involvement have at times been a hindrance to this. For example, it has been exciting to bring together all the work that I have developed and examine it closely in order to make sense out of what has happened, and it has not been possible to do this without feeling a sense of pride. But I am aware that pride can be a dangerous thing if one is not very careful, it can blind one to the weaknesses that are bound to be inherent in any personal investigation. I have done my best to remain as objective as possible and to be aware of the judgments both internal and external that could influence this study, and yet I know that there are limitations to what I have presented.

#### Contribution to knowledge

This study has highlighted that there are both internal (McLoughlin 1986; Sinason 1992; Strachan 1981) and external reasons (Hoover & Markell 2004-5; Murray et al 2000; Oswin 1981) as to why grief might become complicated for people with ID. The critical review of the literature on bereavement and PWID has found that the focus has been mainly on the external reasons and to some extent on cognitive ability (Bihm & Elliot 1982; Lipe-Goodson & Goebel 1983). This thesis has demonstrated that many PWID will experience complex grief that is not only linked to environmental factors but also to psychological issues. The internal factors which affect bereavement in this client group have been examined in some detail through the analysis of clinical examples (chapter 3). It has explained the significance of understanding how the trauma of disability (Sinason 1992) affects attachment in people with intellectual disabilities, and has focussed on the meaning of this in connection to bereavement.

This study has demonstrated the importance of providing access to a psychodynamic form of bereavement psychotherapy when a person with ID is struggling with complex grief. As the work has progressed, the main argument has become clear; that through psychodynamic psychotherapy an understanding of the attachment pattern of the bereaved client with ID can be developed. Through this insight a greater awareness of how the grief has become complicated can be reached. This study has demonstrated that with this insight it is possible to use the therapeutic relationship as a means of

supporting the bereaved client to find some resolution to the complex grief. This has been demonstrated through case studies and has been supported through examining the examples against the literature.

I have described the gradual development of a new model of disability psychotherapy which has emerged during the study, this has an attachment based systems approach. My model includes the supportive network as a component of the therapeutic treatment.

This study has also described how the attachment perspective, and the insight gained from bereavement psychotherapy have been employed to inform new models of training and support for staff. It has become apparent during the course of this research that it is important for direct care staff to understand the significance of working relationally, this can contribute to a restorative model of support. My new therapy model offers direct care staff a relational framework with which to understand their role and provides them with an ability to understand some of the behaviours in PWID that previously had no meaning to them. This has been demonstrated through the case studies, in particular, the case of Maureen in chapter three. This thesis aimed to address the question as to whether or not the insight gained from the practice of psychotherapy could contribute to supporting people with intellectual disabilities who have experienced bereavement. The above has demonstrated that this insight can be used in many different ways to support this need.

#### Implications for future research

Given that this study has underlined that PWID are vulnerable to CG, and also that the literature review concluded that unsupportive environments exacerbated the grief of the individual, I propose that screening should be introduced for all PWID who are either facing bereavement, or who have been bereaved. This would mean that some of the predictive factors of CG would be identified and a pro-active approach could be applied in order to support the person to grieve healthily. I therefore plan to continue to develop the Bereavement Needs Assessment Tool or BNAT (Blackman 2008) further. The

BNAT is designed to identify factors of vulnerability that are present in the environment rather than internal factors

Brickell & Munir (2008) suggested that all PWID should be considered as potential candidates for targeted bereavement interventions. However the review of research seems to indicate that if we educate and support care staff as suggested (Oswin 1981; Kloepfel & Hollins 1989 and Reynolds et al 2008) in being able to provide appropriate support we might see more clearly which individuals really have complicated grief as opposed to grief exacerbated by external factors such as lack of support. Implementing such support for staff alongside a proactive bereavement needs assessment would be more appropriate, in order that only the PWID who are likely to be vulnerable to CG are provided with specific bereavement interventions.

The aim of the BNAT is that it will support PWID and their carers to identify areas of vulnerability to CG. The idea being that consideration could be given to the identified factors and that these issues could then be addressed before they affect the grieving process. The aim would be that once the BNAT has been refined and its design is completed it could be produced as a national and accessible resource.

However, with regard to the key finding from this study regarding internal factors influencing CG, the indication that there is likely to be a high incidence of insecure attachment amongst PWID (Clegg & Lansdall-Welfare 1995 and Larson et al 2011) needs to be tested more robustly. I propose that it is important to carry out a large scale research study to examine this possibility in more depth. Such a study would be useful in building up an understanding of the attachment patterns of PWID more clearly. This is important because if, as suspected, there is an abnormally high percentage of PWID who have insecure patterns of attachment, the evidence would support some of the broader policy recommendations that I have outlined below. The BNAT combined with an understanding of the individual attachment pattern would be the best approach to proactively support someone with ID who is facing bereavement.

Building on the last statement, I also propose that a new psychotherapy outcome measure should be considered for development, which could evaluate

changes in attachment pattern. This could be used at the start and end of a course of psychotherapy. Such a tool would be important in gathering evidence to demonstrate whether psychodynamic psychotherapy can bring about a change in attachment pattern.

Another key finding from this study is the importance of the practice of long term (minimum of one year) psychodynamic forms of psychotherapy with PWID who experience complex grief. In the current financial climate securing funding for long term psychotherapy is a challenge. It is therefore imperative to gather further evidence to demonstrate the effectiveness of this approach. Chisholm (1998) and Holmes (2000) have suggested that to take a short term outlook of the cost implications of long term psychotherapy may be inadvisable. They have stated that psychotherapy is cost-effective over a long-term period. This is because it improves outcome in two crucial ways: patients are symptomatically improved, and their need for other services is reduced. Carlsson et al (2002) have made a further point regarding long term therapy; they have demonstrated that defensive behaviour will often stop within the first year of therapy. This would make it advisable to employ a long term model of therapy with this client group. However, having this knowledge is not enough, it is crucial to build up systematic evidence to demonstrate that psychological interventions can be proven to be useful for this client group. I therefore propose that services offering all forms of psychodynamic psychotherapy (including arts therapies) need to be working together to develop and validate useful outcome measures. There are some tools that are being created and adapted (Beail et al 2005) and these need to be employed more extensively by services.

I have suggested that the findings from Murray et al (2000) and Gilrane-McGarry and Taggart (2007) are important in respect of highlighting the impact of an unskilled workforce on the grieving of PWID. Both studies have been carried out with small samples. I would therefore suggest that it would be useful to design a larger study built on the outcomes of each of these, in order to provide clearer evidence on the impact of the care environment on the grief

experience of PWID which could help to place more importance on the need for training staff.

### Recommendations for policy and practice

Having demonstrated that there are both internal and external causes for CG, I propose that it is important to find ways to reduce the external factors where possible. One course of action that has been highlighted in the literature (Kitching 1987 & Reynolds et al 2008) is to develop confidence within staff teams to facilitate PWID to 'express' their grief, and for staff members to demonstrate their ability to properly listen. Two successful models have been highlighted to address this need. Firstly the review of literature highlighted Reynolds et al (2008), this study has suggested an alternative approach which has also shown evidence of success (Blackman & Brooks 2008). Training, however, needs to be established as an affordable option for services to use in order to develop confidence within their staff teams. This study has also demonstrated the need for ID services to invest in training their care staff to understand the significance of working relationally, this can contribute to a restorative model of support. Offering direct care staff a relational framework in order to enhance their understanding of their role in relation to the PWID that they are supporting, provides them with an ability to understand some of the behaviours that previously had no meaning to them. A national and strategic implementation of such approaches, supported by empirical evidence would be necessary to bring about any real change.

This study has also identified the risk of CG in all new babies born with a disability. This therefore, highlights the need for families of new born babies with ID to be better supported. Families need supportive care both immediately after the birth and also during the early months, in order that healthy attachments might be made. For example early interventions such as support with breast feeding in babies born with ID through an inclusive and positive approach (Sooben 2010) may enable a healthy attachment process.

There will however, be some families where insecure attachments are connected to generational neglect and abuse. In these cases a recognition of the life long complications caused by such an environment should be recognised and action taken early on in order to minimise the damage.

Finally, the new model of disability psychotherapy that has emerged from this research study needs to be evaluated and the findings disseminated in order to provide better understanding and support for PWID.

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