

**SAYING GOODBYE:**

***how people with learning disabilities and staff experience the end of  
key working relationships***

Victoria Mattison

University College London

D.Clin.Psy.

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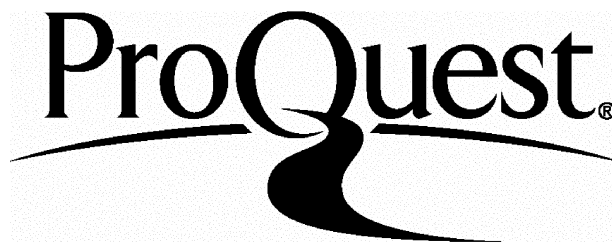
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.....

## ABSTRACT

This research, structured as two parallel and complementary studies, explored how people with learning disabilities and staff experience the ending of key working relationships. Twelve residents and 18 staff were interviewed about their previous experiences of such separations. The interviews were conducted and analysed using a grounded theory approach. The interviews focused on three areas: residents' and staff's perceptions of their key working relationships; preparations and adjustments at the end of those relationships; and the emotional impact of separation on both parties.

The main analysis identified a six-part 'typology' of psychological processes describing the experiences of residents and staff: 'loss and grief'; 'attachment'; 'denial'; 'helplessness'; 'self-devaluation'; and 'acceptance and acquiescence'. This typology was then incorporated into a final grounded theory account, drawing on two core concepts termed 'dependency' and 'fear of dependency'. The findings are discussed in relation to literature from indirectly related areas: the termination of therapeutic relationships, models of grief and loss, and social processes relating to residential care staff and people with learning disabilities respectively. The implications are considered for residential services for people with learning disabilities, researchers and clinical psychologists.

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## CHAPTER ONE: INTRODUCTION

### Overview

*'Grief results from the severance of bonds.'* ( Murray Parkes, 1991, p.269).

People with learning disabilities in residential care are regularly faced with the impact of separation and loss when their key workers move away. Supportive relationships with staff are essential to this client group, many of whom have spent a lifetime in institutional care, and the majority of whom will never become fully independent in daily living. The widespread organisational difficulties relating to staff retention in residential services can have devastating effects on the lives of residents (clients). As yet, no study has addressed the impact of ending staff-client relationships. The present research, structured as two parallel and complementary studies, will examine the experiences of both care-staff and people with learning disabilities. It will focus on the nature of the key working relationship, the process of separation and the impact on everyone concerned.

The first chapter reviews the literature currently available in the area of staff-client relationships, theories of attachment, and models of grief and loss. The implications of the literature review are then discussed in the context of the rationale and the methodological approach of the present research. The second chapter describes the method of data collection and analysis, using a Grounded Theory approach. The third chapter presents the findings from interviews with residents and staff respectively. In

the fourth and final chapter the results of these two separate studies are combined and related to the literature, with the aim of developing a deeper theoretical understanding of the impact of ending key working relationships, and practical guidelines for services.

## **Background**

The problem of staffing residential facilities is not a modern phenomenon. In the early nineteenth century with the opening of the first mental handicap institution at Adenberg, the staffing situation became so bad that it was later to be described as having been run by two “uneducated peasants” (Kanner, 1964). More recently, one British hospital ward for 20 children with severe learning disabilities was reported to have had 89 different members of nursing staff providing care over a three year period (Stephen & Robertson, 1972). Therefore, one could argue that the staffing of residential services does not facilitate the emotional development of those people with learning disabilities who have spent most of their lives in institutional care (Clegg & Lansdall-Welfare, 1995).

The issue of rapid staff turnover is fundamental and has only briefly been addressed in the research literature (Zaharia *et al.*, 1978, George & Baumister, 1981; Allen *et al.*, 1990). These studies have focused mainly on measures of staff stress and job satisfaction. Certain factors have been associated with people leaving posts. These

include: lack of integration of staff members; low pay; and lack of training and support systems to deal with the behavioural difficulties of clients. Allen *et al.*, (1990) compared staff working in a long stay hospital with those working in new local authority community housing. Surprisingly, the closing institution was found to have greater staff stability than the developing community service. This finding was linked to an uncertainty around staff roles within the community, indicating the relevance of the present research to modern services.

In the current climate of inevitable staff movement, the clients’ need for support must take priority when the person who has worked with them is leaving. The literature hints at the difficulties arising for clients around the unexpected loss of relationships with individuals in their environment. These difficulties include depression, behavioural symptoms and psychiatric problems (Harper & Wadsworth, 1993; Clegg & Lansdall-Welfare, 1995).

In a paper by Emerson (1977), it was claimed that 50% of crises in the lives of people with learning disabilities involve the loss of a close relationship. For example, Sinason (1992) describes her contact with “Maureen” a young woman with learning disabilities which highlights this phenomenon. This extract encapsulates the potential impact of losing a key worker on the emotional life of the client:

*Over the next few months, there was a deterioration. Teresa, Maureen's excellent key-worker, was leaving. Maureen reverted to her old modes of false comfort. Her crying returned to biting. She started spilling her drink and the only toy she touched was the fire engine. She was full of burning feelings about the loss. Teresa's thoughtfulness extended to her leaving plans. She was carefully handing over care of Maureen to Tom, a sensitive young man. Tom said that although Maureen had been wailing and biting, there was a new quality of sadness that had never been there before... with Tom understanding Maureen's grief so well she began to recover, and not only did she recover, she made a further step forward... Tom, Maureen's new key worker is now leaving. He has not told Maureen verbally yet, but she has picked it up emotionally. There has been a return to crying, biting and wetting...the new residential staff feel despair (p249).*

Before presenting this study in depth, it seems important to clarify my own perspective on the issue of ending staff-client relationships. The impetus behind this research arises from personal clinical experience, initially as an Assistant Psychologist and subsequently as a Trainee Clinical Psychologist on placement with two specialist teams for adults with learning disabilities. It became apparent that many of the referrals coincided with the time of a sudden and unprepared-for loss of key worker. Over the course of a valuable experience of individual psychotherapy with one client, I learned from the experiences of a woman who had spent a life time in residential care, with multiple changes of key workers. This client gradually revealed her reluctance to become attached to the staff working at her home for fear of being rejected and abandoned without warning. It may be necessary to consider this research in the knowledge that I am approaching this subject from the perspective of residents who have been emotionally damaged by the departure of those staff who have occupied a central role in their lives.

### **Conceptualising staff-client relationships**

Developments in the community support of people with learning disabilities have specific implications for the roles of staff employed as 'carers', (Abraham *et al.*, 1991). Indeed there are widespread responsibilities for those who become involved in residential care work. According to Hastings and Remington (1994), the daily contact of staff is central both to the development and socialisation of residents. Staff behaviour has been extensively studied for this reason, especially the interactions between staff and clients (Felce *et al.*, 1991; Clegg *et al.*, 1991;1996). The degree of learning disability obviously determines the work of the staff member (Twigg & Atkin, 1994). When the resident has a profound learning disability for example, caring may involve considerable amounts of physical support. It can involve lifting, washing and dressing the person, dealing with incontinence, feeding and caring for them throughout the day. Most carers of people with learning disabilities however describe physical care as relatively untaxing (Twigg & Atkin, 1994). The impact of behavioural problems is often perceived as more stressful. Generally the staff face a very demanding role, and often with minimal support.

#### ***Perceptions of staff's roles***

A study by Allen *et al.* (1990) explored staff's own perceptions of their roles within community homes. They asked the staff as part of a wider study, whether they saw their job as most similar to the role of a nurse, teacher or carer. They found a great

diversity of responses dependent at least partly on the professional backgrounds of the staff. Only a minority of these staff used the term carer, less than half adopted the label of nurse alone, almost the same proportion avoided the term nurse altogether, and the rest described their job as a mixed role. This study concludes with strong indications that role ambiguity and uncertainty about the responsibilities of the job are linked to high rates of staff leaving post.

More recently Clegg and colleagues (1996) have suggested that interpersonal dynamics between staff and residents are more complex in community group homes than in the old institutional settings. This study asked staff from four units for adults with profound learning disabilities to describe their key working relationship with a particular client. The key worker was identified as the person on the staff team who is particularly assigned to plan that client's overall welfare. Four types of relationship were identified. The 'provider' relationship was defined as most instrumental with a focus on meeting the client's needs. The 'meaning maker' relationship was characterised by efforts to engage with and understand the client; a 'mutual' relationship was identified, which consists of shared joy around development; and finally a 'companion' relationship suggests more of a friendship, which evolves with trust and emotional comfort. In this study the client's level of ability or disability was related to the relationship type. For example, the more able clients were found to be classified under a companion relationship. Perhaps most interestingly for the purpose of the research at hand, this study found the key working relationship to be working least well for residents in situations of high staff turnover, and few staff with

vocational qualifications. Staff in this study felt that it was irresponsible to create close relationships which were likely to be broken to the detriment of the well being of clients.

This consideration of the role of staff would be incomplete without reference also to the residents’ own interpretations of their key working relationships, and in the absence of such research with people with learning disabilities it is helpful to turn to another client group. Powers (1993) explored the relationships of institutionalised older adults and identified various types of network patterns. Notably, residents with well integrated and balanced networks were found to interact with and receive support from a wide range of relationships. They relied mostly on their own resourcefulness and connections, with staff attending to formal roles and allowing for more personal interactions outside of the home. In contrast, residents with institution-centred networks (who are more likely to reflect the experiences of people with learning disabilities) emphasised reliance on a small number of network members and seemed to have become increasingly isolated and depressed. Informal and social relationships with staff were found to be particularly important to these residents, whose ties with the outside world tended to be weak or absent. The residents in this study seemed to actively engage staff in ways that shaped the staff’s roles in individual networks, and their wishes for autonomy or attachment differed. However, both types of networks were vulnerable to loss and change.

***The Friendship needs of people with learning disabilities***

According to Firth and Rapley (1990) the impoverished upbringing or life history of a learning disabled person can often lead to that person having especially strong dependency needs. These can be considered by addressing some of the literature on the effects of relocation from institutions. The available research (Landesman, 1987) suggests that of the people with severe learning disabilities, those who were most “passive” in their social behaviour were the most vulnerable to the negative effects of relocation. Although they had shown less ability to initiate social relationships with others, many had clear ties to staff or residents in their previous homes. When these ties were broken, their social interaction was reduced in consequence. Unlike people who were more able to initiate contacts, not only did they not replace their lost relationships, but they were at risk of being overlooked and ignored by others.

There is indeed much evidence to suggest that a significant proportion of people with learning disabilities do not participate in satisfying social relationships - one cause of their deep loneliness and isolation (Flynn, 1987; Atkinson, 1989). A comprehensive review of the descriptive research into friendships and social relationships of this client group (Landesman-Dwyer & Berkson, 1984) indicates that friendships are among the most valued aspects of their lives. These studies are consistent in showing that a substantial minority of adults, whether living with family, or in residential establishments, lack close friends altogether. In the context of the present research one effect apparent from this review which deserves particular reference is the finding in some studies that larger residences appeared to facilitate the formation of



friendships, whilst people living in smaller community residences experienced greater isolation.

*Implications for staff-client relationships*

In the light of this research pertaining to their poverty of relationships it is perhaps unsurprising that residents may interpret their relationships with staff members as friendships (Firth, 1986). Such relationships may meet their individual needs for a close emotional attachment in the absence of anyone else in their lives with whom an intimate exchange of feelings can take place. In some situations there may be a genuine commitment on the part of residents and staff which lasts beyond the termination of the key working relationship. However, the nature of these relationships is not always clear to either party. Each may have a different perception of the relationship. This can cause great distress and loss if the worker moves away, or if the client has perceived the relationship as a friendship, but this has not been understood by the staff member (Firth & Rapley, 1990).

In a study of relationships between social workers and people with learning disabilities Atkinson (1989) identified the discomfort and ambivalence experienced by the professional when clients appear to become over-dependent on her. The professional can feel “drawn in” by the client’s needs. Atkinson argues that it is important for professionals to understand the nature of such relationships from their own point of view, to communicate this with clients, and not to raise false expectations or misunderstandings which may ultimately cause greater distress. In

this situation it can be especially important to clarify the nature of the relationship. This may prevent the staff or professionals from holding responsibility for a person's welfare in a way which makes total escape from the relationship the only eventual coping strategy. Such a cycle of involvement and rejection can lead to greater harm by increasing the client's insecurity. These issues are considered more closely below in the context of theories of attachment.

### **Attachment: a framework for understanding staff-client relationships**

According to Bowlby (1988) care-seeking and care-giving are basic components of human nature, and the ability to offer effective care is often dependent on the degree to which individuals have received it themselves. Bowlby distinguished attachment theory from other psychodynamic models of development with his emphasis on the social environment. His theory claimed that we construct and reconstruct ourselves and our relationships from experiences of interactions with significant people.

Schaffer (1992) later criticised attachment theory for assuming that the responsibility for the parent-infant relationship rests completely with the parent-figure in their history. This criticism is particularly relevant to learning disability where research shows that many factors influence the attitudes which parents develop towards their disabled child (Goldberg *et al.*, 1995). These factors include: the severity of the child's disability and the presence of additional life-threatening illnesses; the lost hopes and expectations of parents and the way in which the news of the disability was

broken; and the child’s reception by the family and the outside world. A cycle of rejection is commonly experienced by the learning disabled child, and is likely to result in growing insecurity and continuing difficulties with forming attachments in later life (Gallimore, 1989).

Heard (1982) reported a study of attachment in older children and adults, describing responses people make to experiencing ineffective care on such a long term basis that they have given up hope that attachment could ever be achieved. The first response, ‘Increasing Demand’ to having attachment needs met is expressed by pleading and protest behaviours which can escalate to violence. It is not continuous and might alternate with periods of withdrawal which can include self harm. The second, ‘Avoidance’ is expressed by compliant behaviour which avoids situations which arouse psychological threat. The third, ‘Withdrawal’ is observed when the person attempts to meet their own attachment needs either by self cossetting (with food for example) or by excitement seeking. ‘Withdrawal’ is described as the most maladaptive form. This model may be useful for understanding some of the difficulties which carers face in supporting people with learning disabilities in residential services

According to Allen *et al.*, (1990) recent service developments are looking to increasing staff stability, which would present a greater opportunity for people with learning disabilities and poorly developed attachments to work on relationship building. However, increased staff stability may also put staff under greater pressure to work at a more personal level. In the past staff have been constantly moved around

services to break up relationships which were becoming enmeshed (Allen *et al.*, 1990). The question of whether residents are having their "needs met" more effectively will depend on whether the evaluative criteria concern independent living skills, relationship development or the absence of behavioural problems (Clegg *et al.*, 1995). Frankish (1989) argues that if the emotional needs of clients can be addressed effectively, clients and staff can be assisted towards greater emotional growth, which is likely to benefit the whole service.

### ***Application of a model of attachment***

Clegg and Lansdall-Welfare (1995) provided an application of attachment theory as an explanatory model for making sense of the enmeshed relationships between three adults with learning disabilities and their care workers. This intervention-study emphasised the importance of creating secure attachments in a clinical setting. It reported at least a partial resolution of problems relating to the residents' limited exploration of the world, their intermittent patterns of intense anger and their fixations on individual carers. Support was most effective when it separately addressed the different elements of the enmeshed relationship. Clegg and Lansdall-Welfare suggest that a staff member may have worked with a client for a number of years, and that helping the client towards a more constructive relationship is central to their emotional well-being. New staff need to understand the client's potential for becoming enmeshed and to be alert to signs of inappropriate attachment developing. The negative experiences originating in the staff's working relationships must be addressed before services can develop greater sensitivity to the emotional needs of

clients. This study therefore advocated support for the enmeshed care staff early in the intervention with the provision of outside psychotherapy for residents and staff. The intervention was found to help the resident towards a more secure perspective on her life. Clegg and Lansdall-Welfare conclude this study with an acknowledgement of the potential difficulties for carers in facilitating secure attachment relationships for distressed clients. However, an appreciation and recognition of their attachment needs is advocated as a realistic goal.

### Separation

This discussion of attachment leads also to a consideration of the impact of separation. In Clegg and Lansdall-Welfare’s (1995) study the eventual separation of two of the enmeshed staff-client relationships was found to be necessary but “brutal” for both parties. This was handled with a commitment to preparation and support to staff and clients, and the identification with the client of an alternative person who might become a replacement attachment figure. In these relationships the separation was not permanent and informal contact was later introduced with positive results. However loss of relationships with staff is a major issue and can be considered by looking at this phenomenon with other dependent relationships, especially with children and older adults.

Swanson *et al.*, (1988), and subsequently Lanyado (1989), have explored the experience of separation and loss in residential placements for children. Lanyado

considered the possibility that the child who really cannot cope with the loss of her care worker may start to ‘disintegrate’, perhaps because she has suffered many previous losses in her life and had finally found someone in the original care worker who could tolerate her. Swanson and colleagues claim that children who enter residential care are confronted with issues of separation and loss before, during, and after their stay. Their experiences of separation and loss in that setting may be exacerbated by their having endured other losses prior to their placement in care (rather like the impoverished histories of some adults with learning disabilities). This study also considered Bowlby’s (1969) theory of attachment and loss to explain this phenomenon. Bowlby suggested that children who have formed an anxious attachment with their primary attachment figure, and who then experience other significant losses, may become sensitive to any kind of separation/loss, displaying reactions of protest and despair. Swanson recognised that children may manifest their feelings about loss quite differently, but that they are generally acutely sensitive to such feelings. They argued that professionals and staff must acknowledge and express their own feelings of loss in order to be accepting of similar feelings expressed by children in their care.

### ***The emotional impact on staff of separation from clients***

The importance of staff’s acknowledgement of their own feelings of loss (referred to above) reinforces the need to address the issue of terminating relationships directly from the perspective of those who are leaving. Lanyado (1989) suggests that whilst there is usually an awareness of the significance of loss or separation from a loved

adult for a child, there is little consideration for its counterpart. She asks what it means to the adult to give up caring for a loved child. 'When the child moves to another care group - part of growing up - the original worker is likely to miss him, to wonder if his new care worker can understand him as well and handle him as 'carefully' as she did. At times she may well feel critical of how he is treated, feeling she could do it better' (p.139). Lanyado identified feelings of loss and anger which may then be powerfully experienced by the care worker, and which will be heightened if the child is also finding it hard to cope with the change.

The impact on professionals of ending working relationships with clients is also discussed by Rosenberg (1990) in his reference to the 'personal-professional connection' between disabled older adults and their carers. "When we work with disabled clients, we naturally become attached. We care not only for them but about them. Our work requires that we form attachments for brief periods of time and then let them go... we find ourselves suddenly separated from people we have grown to care about" (p.77). Rosenberg argues that carers do not receive adequate support, or time, for grieving over lost relationships. When the role changes, the carer must let go and become attached to the next client to begin the helping process all over again. Without grieving for the lost client, it might be difficult to begin and maintain new supportive relationships.

*Facilitating separation*

Rosenberg (1990) also identifies the carers' responsibility for deciding how much to allow the clients' physical and emotional dependency to develop, and how and when to let that dependency shift to another carer, or to greater independence for the client. For these reasons, he described helping relationships as having the unique quality of beginning (and ending) unequally, which can evoke a range of feelings in the carer and resident alike. When a client faces adjustments of loss and change, there might be a tendency for staff to avoid confronting the painful reality. This may arise as a result of the staff's own feelings and fears about being disabled, or perhaps from their need to protect or shield the disabled client from emotional pain. Often the result is that the staff and the client will avoid certain tasks necessary for successful adjustment. This is referred to as 'co-conspiracy for denial' (Rosenberg, 1990).

As a final thought on the process of facilitating separation, it might be helpful briefly to refer to the literature on terminating therapeutic relationships. In an article about ending therapy, Zinkin (1994) states "What perhaps we might all agree is that a good and successful ending is never without pain. If there is no pain, the work and the relationship cannot have been of much value" (p.22). However, he later points out that there is simply no agreed way of ending, especially because the work on psychoanalysis is replete with conflicting opinions about preparation.



### **A bereavement model of separation and loss**

According to Oswin (1981), many of the difficulties encountered by people with learning disabilities arise because they are treated differently from the “normal” population and as a result their needs are not met at crucial periods in their lives. In the absence of any research which relates specifically to the event of ending relationships with staff, it seems appropriate to consider available models of the mourning process, which may equally be applied to other losses experienced by people with learning disabilities (Cochrane, 1995). In fact the available research on bereavement in the lives of people with learning disabilities is also sparse, but recently there has been increasing recognition that this is an area to be addressed through careful preparation (Wadsworth & Harper, 1991; James, 1995).

It seems appropriate to begin this section by describing a framework for thinking about loss and grief. Bowlby’s (1969) model of grief is based on Attachment Theory, and focuses on the adaptive nature of behaviour. It refers to the multifaceted, intense internal and external responses (emotional, behavioural and psycho-physiological) to perceived and observed losses in a person’s life. According to Harper and Wadsworth (1993) this model is particularly applicable to understanding the grief processes in learning disabled people. “Bereavement includes the process of coping and experiencing a response to a significant loss or separation. It often includes changes in behaviour, thoughts and feelings. Operationally it becomes apparent when the

individual displays behaviour that implies that they are “upset” over the separation from a person, object or situation” (p.314).

***Emotional and behavioural disturbance arising from grief reactions***

Emerson (1977) was instrumental in highlighting the impact of bereavement on the emotional lives of people with learning disabilities. In her clinical consultancy role to emotionally disturbed learning disabled adults, Emerson reported frequent contacts by group homes or institutions because a client who had previously shown few problems had suddenly “for no apparent reason” started presenting emotional and management difficulties. The symptoms included verbal or physical aggression, or extreme withdrawal. Emerson described crisis intervention approaches which searched for a precipitating stress and found that in half of the referred cases the death or loss of someone close had occurred. This led to a consideration of the events surrounding the bereavement and the manner in which it was handled (discussed below).

Ghazziudin (1988) suggests that the challenges that face people with learning disabilities living in the community can be complicated by the fact that their symptoms are often viewed in isolation and the effects of their total life situation are ignored. Their means for communicating personal distress are limited, and unusual or “challenging” behaviours make it difficult for them to share their experiences. This study explored the role of life events in the psychiatric disorders of learning disabled people, and their referrals to specialist services for behavioural reasons. Most interestingly for the purpose of the present research, grief and reactions to loss of

relationships specifically were identified as significant precipitants of overt behavioural difficulties and psychiatric disorders.

Harper and Wadsworth (1993) surveyed staff supporting adults with moderate to severe learning disabilities about their assessment of the clients' difficulties and behavioural reactions in the event of loss or bereavement, and their needs for additional resources to cope in this area. This study was unusual and invaluable in its inclusion of interviews with clients about the types of losses they had experienced as well as their reactions to those losses. The clients in this study were able to identify a broad range of reactions to loss, including a mixture of sadness, anger, anxiety, confusion and physical pain. The researchers attributed these behaviours to a depressive response that is common to individuals (with or without learning disabilities) at a time of intense personal loss. It became clear from the staff's responses that those clients who have difficulty with verbally expressing their emotional pain do often express their distress through more concrete and overtly behavioural strategies, such as hitting out or withdrawing completely. The inability to use appropriate communication strategies to empathise with people with learning disabilities makes it difficult for staff and professionals to be supportive.

These studies indicate a need for future research to more fully explore the social origins of disturbed behaviour in people with learning disabilities. Sinason (1992) supports this intention, urging staff and clinicians alike that "If we do not try to make sense of behaviours such as head banging and self injury, we can be accused of

joining in the conspiracy of silence” (p.223). Sinason argues that managing to be aware of the meaning of behaviours can offer a way of helping clients, staff and professionals.

***Staff’s perceptions of the impact on clients of loss and bereavement***

Historically it has been felt that people with learning disabilities do not have the capacity to form strong emotional bonds and intimate relationships that ultimately could culminate in feelings of personal loss or mourning, and that they will be unable to feel grief (Yanok,1993). Clients may be prohibited from coping with and expressing the grief process by well-intentioned carers who wish to spare the individuals from “upsetting events” (Seltzer, 1985). Displays of grief are often misinterpreted and thus discouraged, particularly when the emotional and behavioural manifestations are intense or disruptive. According to Day (1985) medications or behaviour modification strategies may even be used within services to decrease the clients’ symptoms of emotional pain.

In a study by Strachan (1981) a group of nurses working in an institutional setting were interviewed about their observations of potential bereavement reactions displayed by people with learning disabilities in their care. Despite reports of having observed a wide variety of commonly understood responses to bereavement, a common observation was “no response to the death”. In his critique, Strachan noted that the reliability of data collected was dependent on the nurse’s ability to observe

and recall and, perhaps, on their expectation of little response to bereavement by people with learning disabilities.

Building on her observations of the links between emotional 'crises' and loss of relationships in the lives of people with learning disabilities (cited above), Emerson (1977) identified certain patterns of staff behaviour that seemed prevalent in the context of the bereavement process. These included the staff's denial of the significance of the loss and inappropriate emotional responses to the client after the event. There seemed to be no support for the client's emotional reactions, and almost no time for facilitating adjustment to the changes in the client's life. Emerson advised that the staff should consider the extent of the client's disability, in order to determine how many times the message must be repeated for the client to really understand. She concluded with the message that care staff must come to terms with their own embarrassment and fears about bereavement and loss, so that they can ask appropriate questions and offer support and understanding to residents. In the context of the present research it is useful to consider that these guidelines might generalise readily to the endings of relationships with staff.

In summary, whilst it must be acknowledged that many people with learning disabilities may be able to negotiate an experience of loss or bereavement and transition into a life without the lost person, for some people this transition is managed unsuccessfully. As a result they may manifest ongoing emotional turmoil or behavioural difficulties. Further research is needed to determine those factors which

contribute to successful coping (Harper & Wadsworth, 1993). This might enable the development of supportive communication techniques in anticipation of separation or loss for people with limited cognitive and verbal skills.

### **Aims and rationale of the present study**

The primary aim of this research is to explore and describe the process and impact of ending relationships between care-staff and people with learning disabilities in residential services. This is an important area to consider in view of the present climate of high rates of community-staff turnover, and the lack of available literature relating to the potential effects of separations on the lives of residents.

This research aims to address two connected preliminary questions in order to provide a context for the focus of study. These questions are concerned with how staff and residents perceive the key working relationship. These perceptions are then related to their respective experiences of separation.

The literature reviewed above has indicated a lack of research which directly addresses the experience of ending key working relationships between care-staff and people with learning disabilities. A literature is developing on the importance of attachments and relationships with carers to the lives of this client group (Clegg,

1995; Firth & Rapley, 1990). Various studies have also referred to the impact of loss and grief on the clinical presentation of clients (Emerson, 1977; Stack *et al.*, 1987; Harper & Wadsworth, 1993). However, there is no study to date which combines these areas for a consideration of the effects of losing a key worker on the emotional world of a learning disabled person. These areas are drawn together in the present study.

This overview of the literature has also examined the experiences of staff working with different client groups, in order to consider the impact of ending dependent relationships from the perspectives of those who are leaving (Lanyado, 1989; Rosenberg, 1990). The importance of sensitivity to grief reactions has been outlined by Swanson *et al.* (1988) who suggest that carers must acknowledge their own feelings of loss in order to be accepting of the feelings of their clients. As yet, this issue has not been researched with care-staff in the field of learning disabilities. The present study addresses how staff prepare residents when they leave. It also explores the emotional availability of the staff in responding to the reactions of residents.

Finally, while there is a growing literature on staff’s descriptions of their key working relationships (Harper & Wadsworth, 1993; Clegg & Lansdall-Welfare, 1995), there is limited knowledge of residents’ perceptions of the key worker’s role. This study attempts to build on the findings of previous research, with an analysis of key working relationships from the perspectives of both parts of these dyads.

The literature indicates that people with learning disabilities often lead complex lives, with intimate involvement in a range of different support networks (Twigg & Atkin, 1994). According to Potts and Howard (1986, cited in Clegg *et al.*, 1996) the historical trend of behaviourism and later of normalisation philosophies have meant a limited role for clinical psychology in working with this client group, with an over-emphasis on people's skills and deficits. Clegg and colleagues (1996) therefore turn to ideas from social constructionist theory to consider the support of clients, especially with its emphasis on switching from an individual to a social orientation. These ideas are relevant to the nature of the present research and the methodological approach selected. Social constructionism (which originated with Mead, 1934) focuses on what occurs between two people. It suggests a reappraisal of psychological knowledge away from considering individuals on the one hand and social environments on the other towards comprehending the exchange between them. Personal history (and people's construction of it) will contribute to difficulty in social relationships. This construction of life events is relevant to both parts of the key-working relationship. According to Clegg (1994) it is necessary for researchers to overturn the judgmental culture that has dominated the last few years and to address a mutual involvement in the staff-client dyad. It is important to explore the difficulties of staff and clients alike. This ethos of understanding relationship dynamics from both perspectives suitably sets the scene for the present research.



***Background to the methodology***

This is a new area with limited and indirectly related research and theory. It requires a 'discovery-oriented' approach which enables the generation of theory from the data. Grounded theory advocates such an approach with its concern for describing processes, and for investigating subject areas that are difficult to access with traditional research methods (Glaser & Strauss, 1967; Rennie & Phillips, 1988; Pidgeon, 1996). The term 'grounded theory' has two meanings associated with the original work of Glaser and Strauss (1967). The first refers to the idea of grounding theory in experiences, accounts and local contexts. The second is used to describe a method involving specific analytic strategies for making sense of qualitative data. This approach originated in the field of social psychology, but more recently it has been applied in clinical settings (Clegg, 1996).

Grounded theory aims to capture the complexity of real life phenomena (Strauss, 1987). Its approach is particularly appropriate for exploring endings of relationships between care staff and learning disabled residents, because it places value on the experiences and perspectives of participants, and allows access to an area of study that has not previously been considered.

## **Research questions**

This research consists of two parallel studies: Study One considers the process of ending key working relationships from the perspectives of residents in learning disability services. There are three broad research questions:

### ***Preliminary questions***

1. How do residents experience and describe their relationships with key workers?
2. How do residents recall the process of ending previous relationships with key workers?

### ***Main question***

3. What were the residents’ feelings about separation from key workers?

Study Two explores residential care-staff’s experiences of leaving and ending relationships with clients with learning disabilities. There are four broad questions:

### ***Preliminary questions***

1. How do staff describe their relationships and interactions with residents?
2. How did staff prepare clients for when they left?

### ***Main questions***

3. What were the staff members’ feelings about ending relationships with residents?
4. How do staff conceptualise the potential impact of the leaving process on clients?

## **CHAPTER TWO: METHOD**

### **Overview**

Semi-structured interviews were conducted with 12 residents with learning disabilities, focusing on their experiences of separations from key workers (Study One). In a parallel study 18 residential care staff were interviewed about their experiences of ending key working relationships with clients with learning disabilities (Study Two). A grounded theory approach was used to guide both the data collection and analysis in each study. This chapter begins with an outline of the recruitment process for both studies. The measures and procedures for data collection are then described for each study in turn. Finally, the grounded theory approach to qualitative research is summarised.

### **Recruitment procedure**

The participants in the resident and staff studies were recruited from residential services for adults with learning disabilities in the London borough of Harrow.

Ethical approval for this study was granted by the Harrow research ethics committee in March, 1997 (see Appendix 1). Recruitment then took place in a series of stages. First, the overall residential service managers of local social services and voluntary sector organisations under the remit of the Harrow Learning Disability Community

Team were contacted by post. They were sent an introductory letter explaining the purpose of the research, with a cover letter from the consultant clinical psychologist (see Appendix 2). At a follow up telephone call, those who expressed interest were offered a presentation by the researcher. At this stage, I was invited by Harrow Social Services and Harrow Mencap to their respective management meetings. These meetings provided a forum for further discussion and clarification of the research plan with individual home managers within the two organisations. Each of the home managers present at those meetings was then given a plan of the research process and information sheets for prospective participants (See Appendix 3). The home managers then presented the idea at their resident and staff house meetings and generated lists of potential participants. Each of the identified homes was then contacted again by telephone. The managers provided names of interested residents and staff, and individual interviews were arranged for the willing respondents

In the early stages of contacting homes there was a shortage of participants, so the recruitment process was broadened to include a local Not-for-Profit organisation and a second voluntary sector organisation.

## **STUDY ONE: RESIDENTS**

### **Participants**

Residents who were receiving a 24 hour staffed community residential service in Harrow participated in Study One. The residents came from three out of the four organisations described above. There were three criteria for inclusion in the study:-

- 1) Residents must be able to give informed consent to participate.
- 2) Residents should have verbal communication.
- 3) Residents will have had experience of a previous key working relationship wherein their identified key worker has left the service and moved away.

The six individual units agreeing to take part included a total number of 34 residents. (Four additional units were identified at a preliminary stage, but unit managers were unable to identify residents from those units who were either willing to participate, or who would fit the criteria above). A total of 15 residents were interviewed and 12 were included in the study. Three participants were excluded from the analysis due to communication difficulties during the interview. Information about the organisations represented in this study is presented in Table 1.

**Table 1.** Resident participants - organisations and units ( $N = 12$ )

Service	Organisation	Number of Participating Units/Homes	Total Number of Residents	Number of Resident Participants
A	Social Services	2	16	5
B	Mencap	3	15	6
C	Not-for-Profit <sup>a</sup>	1	3	1

**Note**

<sup>a</sup> Not-for-Profit denotes a registered charity organisation which provides services within the health service

***Characteristics of the sample***

The resident sample consisted of seven women and five men. They ranged in age from 34 to 72 years, with a mean of 44.5 years ( $s.d.= 12.2$ ). The ethnicity of all participants was identified by staff as White UK. The residents' key workers indicated that the participants had a range of learning disabilities. Four participants had a diagnosis of Down's Syndrome, two participants had a diagnosis of Cerebral Palsy, two were described as having physical and learning disabilities (wheelchair users); and four participants were categorised as having a general learning disability. The latter two groups were identified as having an unknown diagnosis. Information for the remaining two residents was missing (due to incomplete demographic forms). The length of time they had been living at their current placements ranged between 1.5 and 7 years, with a mean of 4.8 years ( $s.d.=1.7$ ). Five participants had resided in long-stay hospital/institutional care since childhood, and seven participants had grown

up with their families. A review of information about residents’ daily activities indicated that seven participants attended day-centres, three participants worked in sheltered employment placements, and two combined working and attending a day-centre. Finally, according to the Degree of Dependency Rating Scale data (explained later in the description of Measures), the sample can be described according to the following criteria of dependency.

**Table 2.** Dependency ratings of resident participants

Dependency Ratings <sup>a</sup>	Number of residents
Low Dependency	7 <sup>b</sup>
Medium Dependency	1
High Dependency	0
Total	8

Notes

<sup>a</sup> Information is missing for four residents, because two managers felt that this measure was inappropriate and too basic for use with their clients.

<sup>b</sup> This figure includes 1 resident with mobility problems.

There is also a separate scale within the Degree of Dependency questionnaire for assessing speech, which rates clients according to four possible dimensions. These range from ‘never a word’ to ‘sentences and normal’. All of the residents were rated at the highest level for speech, which is unsurprising, since verbal communication was one of the criteria for participation in this study.

## **Procedure**

Initially, key workers at the residential homes were asked to present the idea of the research interview to their key clients. Those residents who were able to give informed verbal consent were then contacted by telephone to arrange an appropriate meeting time. One statutory home with a large number of residents invited me to a client-led house meeting to present the plan for this research. This allowed residents to hear about the study at first hand, and to make informed decisions about participation. In the majority of cases however, staff approached residents individually and discussed the proposed interview.

Prior to each interview, I met each resident with his/her key worker to reiterate the interview plan and to go through the resident information sheet. A request for tape recording interviews was made and then consent forms were given in two stages. Initially the resident was asked for consent, and then the key worker was asked to give further consent on behalf of the resident (see Appendix 4). At this stage I spent some time with the resident alone, as an opportunity for us to get to know each other, and to address any questions or concerns which may have arisen. Each interview lasted approximately 35 minutes. At the end of the interview the questionnaires were completed with key workers.



## **Measures**

### ***Interview***

A semi-structured interview protocol was constructed based on the growing literature on methodological issues in interviewing people with learning disabilities (Sigelman *et al.*, 1981; Flynn, 1986; Chapman & Oakes, 1995). A useful consensus has developed about types of questions, how to ask them, the most appropriate setting for the interview and certain safeguards which can be built in to the data collection (Atkinson, 1988). These findings are summarised below.

First, Sigelman *et al.* (1981) suggest that open-ended questions should be favoured, as they avoid problems with acquiescence and over-reporting associated with yes/no questions. They also avoid a reported tendency for this client group to display “recency effects”, i.e. choosing the second option in either/or questions. Wyngaarden (1981) also advocates unthreatening, relaxed, conversational-style interviews, with a preference for individual interviews in order to maintain privacy and confidentiality. Flynn (1986) adds to these suggestions by urging the researcher to check out the respondent’s level of communication in advance as far as possible. He also suggests that tape recording interviews can make the procedure seem less test-like. The preferred setting for these interviews seems to be the person’s own home (Flynn, 1986), as this may allow for a more relaxed interview process. Finally, Wyngaarden proposes starting with easier questions to establish some rapport, keeping the more difficult or emotional questions until the middle or end of the interview. He suggests

beginning with closed questions, and following on with more open questions to assist this process.

These guidelines were incorporated into the design of the resident interview protocol. Residents were interviewed about their experiences of separation from previous key workers. The interview covered four areas which initiated the grounded theory study:-

- What do you remember about that key worker?
- What kinds of things did you used to do together?
- What happened when your key worker left?
- How did you feel at that time?

The interview protocol comprised a set of questions which served as a guide, or were used as probes, but not all questions were asked in every interview. These questions evolved over the course of the study as a result of a merging of data collection and analysis. This was in keeping with the grounded theory approach as described in the section on data analysis below. (See Appendix 5 for a copy of the final interview protocol).

### ***Demographic questionnaire for key workers***

A brief form was constructed for completion by the participant’s present key worker. As well as providing demographic information, this form served as an indicator of the reliability of the participant’s communication (see Appendix 6). The importance of

involving informants who do not have a learning disability, and who know the respondents well, to act as a check on the information collected, is highlighted by Sigelman et al, (1981).

***Degree of Dependency Rating Scale (Kushlick et al, 1973).***

The Degree of Dependency Rating Scale was originally developed by Kushlick, Blunden & Cox (1973) and is one of the most well-known dependency rating scales in current use (Caddell *et al.*, 1984). It was developed as a means of assessment to relate to issues of management of people with learning disabilities, rather than to clinical syndromes. It is designed for completion by carers and staff. In the original version, two scales were constructed for the measurement of relevant behavioural characteristics. One scale (Social and Physical Incapacity Scale, SPI) rates according to continence, ambulation and the presence of specified problem behaviour. The other (Speech, Self Help and Literacy Scale, SPI) reflects speech, self help and literacy abilities of identified clients. Evans *et al.*, (1981) later amended the scales, by combining scores on the sections dealing with continence, mobility, problem behaviours and self-help ability to derive a single degree of dependency rating for each client. This combined scale has been used in many large scale surveys and has some universality in the UK (Humphreys *et al.*, 1984).

It is the single dependency rating, using combined SPI/SSL data, which is used in the present study (see Appendix 7 for a copy of the questionnaire). Three basic categories of dependence are generated (with variations to account for age and mobility). These

categories are labelled as Low Dependency; Medium Dependency and High Dependency. This information as it relates to the present sample is described in Table 2 above. A separate scale within this questionnaire is completed for an assessment of verbal communication. The information from this scale is also summarised above.

## **STUDY TWO: STAFF**

### **Participants**

The 11 individual units agreeing to take part in this study represented four organisations in Harrow, and comprised a total of 74 staff members. There were two criteria for inclusion in the study:-

1. The staff should have previous experience of key working a client(s) with learning disabilities in a residential service.
2. The staff member will have ended the identified key working relationship.

Twenty one staff volunteered to participate, but three of those did not meet these criteria for the study. A total of 18 staff was finally included in this study. Information about the participating organisations is presented in Table 3.

**Table 3.** Staff participants - organisations and units ( $N=18$ )

<b>Service</b>	<b>Organisation</b>	<b>No. of Participating Units/Homes</b>	<b>No. of Staff in Total <sup>a</sup></b>	<b>No. of Staff Participants</b>
A	Social Services	3	19	4
B	Mencap	3	21	7
C	Not-for-Profit <sup>b</sup>	2	15	2
D	Voluntary Sector	3	19	5

Notes

<sup>a</sup> Due to staff turnover the membership of the staff teams actually changed over the period of data collection.

<sup>b</sup> Same note as in Table 1 above.

***Characteristics of the sample***

The sample consisted of 11 women and seven men. Their ages ranged from 25 to 55 years, with a mean of 32.7 years ( $s.d.= 0.6$ ). Sixteen participants described their ethnicity as White UK or English, one as Irish, and one as Afro-Caribbean. The length of time that each participant had been employed with people with learning disabilities ranged from 2.5 to 29 years, with a mean of 8.2 years ( $s.d.= 5.7$ ). In regard to their current employment, ten participants described themselves as Residential Support/Care Workers, two as Senior Care Workers, three as Deputy/Assistant Home Managers, and two as Home managers. The vocational and training experiences of staff were quite varied. Six staff reported receiving 'on-the-job training' and relevant brief courses, four had a RNMH qualification (Registered Nurse in Mental Handicap), three had gained a diploma in social or community care,

one was a psychology graduate, two were in the process of part time Social Work Training (DipSW), and two had received no training at all.

***Characteristics of residents described by staff for the purpose of the interview***

Each staff participant identified a particular key-client for discussion in the interview. The sample of key-clients discussed consisted of five women and 15 men. The length of time as key worker to those clients ranged from three months to six years, with a mean time of 2.5 years (s.d.=1.6). Participants were also asked to identify the length of time that had passed since ending that relationship. Time elapsed ranged from one week to five years, with a mean time of 2.1 years (s.d.=1.9). Two staff had returned to previous work settings, but with different roles and client responsibilities. Finally an overall degree of dependency rating was obtained for all residents discussed during the staff interviews. This information is presented in Table 4.

**Table 4.** Dependency Ratings for those residents described by staff participants

<b>Dependency Ratings</b>	<b>Number of key clients</b>
Low Dependency	8 <sup>a</sup>
Medium Dependency	9
High Dependency	3
<b>Total</b>	<b>20<sup>b</sup></b>

**Notes**

<sup>a</sup> This category includes one client with mobility problems.

<sup>b</sup> The number of residents discussed exceeds by two the number of staff interviewed. This is because two participants chose to compare their experiences with two different residents, and therefore completed two separate scales.

**Table 5.** Verbal communication ratings for those residents described by staff participants

<b>Communication Ratings</b>	<b>Number of key clients</b>
Never a word	2
Odd words only	5
Sentences and normal	12
<b>Total</b>	<b>20</b>

### **Procedure**

Staff interviews were arranged in the homes themselves. The participants identified a suitable time when there were enough staff to cover the shift. The plan for the interview was reiterated with each person individually. The information sheet and consent forms were given out (see Appendix 8), and permission was requested for tape recording the interviews. Participants were invited to ask questions before they agreed to take part. The interview was conducted after each participant had completed the demographic form and questionnaire. This order was chosen so that discussion could be focused around the process of separation specifically, thus avoiding repetition of basic information that could be summarised briefly in writing. Each interview lasted approximately fifty minutes.

## **Measures**

### ***Interview***

The interview was constructed on the basis of literature on the semi-structured interview technique. Notably Burgess (1984) highlights the potential within the semi-structured interview method for gaining access to situations that are otherwise “closed”, or not witnessed by the researcher. A sensitively constructed interview can enable the researcher to understand important phenomena in the participant’s own words. Burgess stresses the crucial goal of establishing trust and developing the confidence in those with whom the interviews are used. The respondent should be allowed to talk freely and with minimal constraint. Burgess advises the use of an “aide memoire” to clarify the agenda with participants and to ensure that similar topics are being addressed in each instance. More specifically, Robson (1993) suggests a sequence of questions that should emerge in a logical progression. This sequence allows for more straight forward introductory and descriptive questions at the beginning. These are followed with the main body of the interview, and the more difficult (or threatening) questions will fall much later on in the sequence. At the end of the interview the subject will be drawn to a careful close with more straightforward questions to diffuse possible tension at the end.

The semi-structured interviews conducted with staff in the present study drew on the guidelines suggested by Burgess (1984) and Robson (1993), and focused on staff’s experiences of ending previous key working relationships. Each participant was



asked to choose a particular client for whom they had stopped being a key worker. Usually this meant a client from a previous employment setting (unless the staff member had left and returned to the same service). Staff were given prior notice of the topics for discussion, both verbally over the telephone and in writing (in the information sheets). The interviews covered a core set of topics which initiated the grounded theory study:-

- Describe your role and relationship with the key-client.
- What happened when you left your post as key worker?
- What might have been the impact on the resident of your departure?
- What were your feelings at this time?

As in Study One, the interview protocol developed and changed in order to address emerging issues reported by participants over the duration of the study (see Appendix 9 for a copy of the final protocol). This was in keeping with the grounded theory approach to data collection. The interview questions provided a framework for conducting the study, but the structure was flexible in order to allow respondents to describe their experiences with minimal constraints.

In addition to the interview protocol, two questionnaires were used to obtain background information about the staff and the residents whom they discussed in the interview.

***Demographic forms***

Two brief forms were constructed for staff participants in order to collect basic demographic information about the participant, and about the client(s) she/he identified for the purpose of the interview (see Appendix 10).

***Degree of Dependency Rating Scale (Kushlick et al., 1973)***

This form (see Measures in Study One above) was completed by each participant, to provide an overall indication of the level of ability of residents they discussed. This information is presented in Table 4 above. The results of a sub-scale for assessing verbal communication within the Degree of Dependency rating scale are also presented (see Table 5 above).

**Data analysis**

The data from both studies were analysed separately, but in the same way using the Grounded Theory approach to data analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1990; Henwood & Pidgeon, 1994; Pidgeon & Henwood, 1996; Clegg, Standed & Jones, 1996). This approach to qualitative research is described briefly below, but is considered in greater depth in Chapter Three.

### ***Grounded theory***

Grounded theory describes a method of simultaneous data collection, coding and analysis. The data collection is driven by theoretical concerns, and involves active *theoretical sampling*<sup>1</sup> of new cases as the analysis proceeds (Henwood & Pidgeon, 1994). A key orienting method of this approach is *constant comparative analysis*. This urges a constant alertness to the similarities and differences which exist between instances, cases and concepts to ensure that the full complexity of the data is explored (Strauss & Corbin, 1990). The process of *open coding* gradually compares new data to emerging categories or themes. If no categories fit the data then a new one is developed to represent it. At a point of *saturation* (when no new categories or themes emerge from further data), the analysis shifts to relationships between categories and the creation of *researcher categories* for the beginning of a grounded theory account. By a process of category integration, or *axial coding* (Strauss & Corbin, 1990) the researcher categories can be compared and combined to form a hierarchical structure in which *higher-order categories* are developed. It is at this final stage of the analysis that the interrelated concepts are further reduced to a grounded theory account based on more theoretical ideas (Henwood & Pidgeon, 1994).

In the present study the collection, coding and analysis of data from the resident and staff interviews was conducted simultaneously. The data analysis proceeded as soon

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<sup>1</sup> In this summary of Grounded Theory, the terms presented in the language of the approach are in italics. Some of these terms are explained in more detail in Chapter Three, with examples from the data.

as sufficient material had been collected from both studies, i.e. when repetition began to occur. There were three phases to the data collection and analysis in each study, and the semi-structured interview schedules for each one were revised as the data collection proceeded.

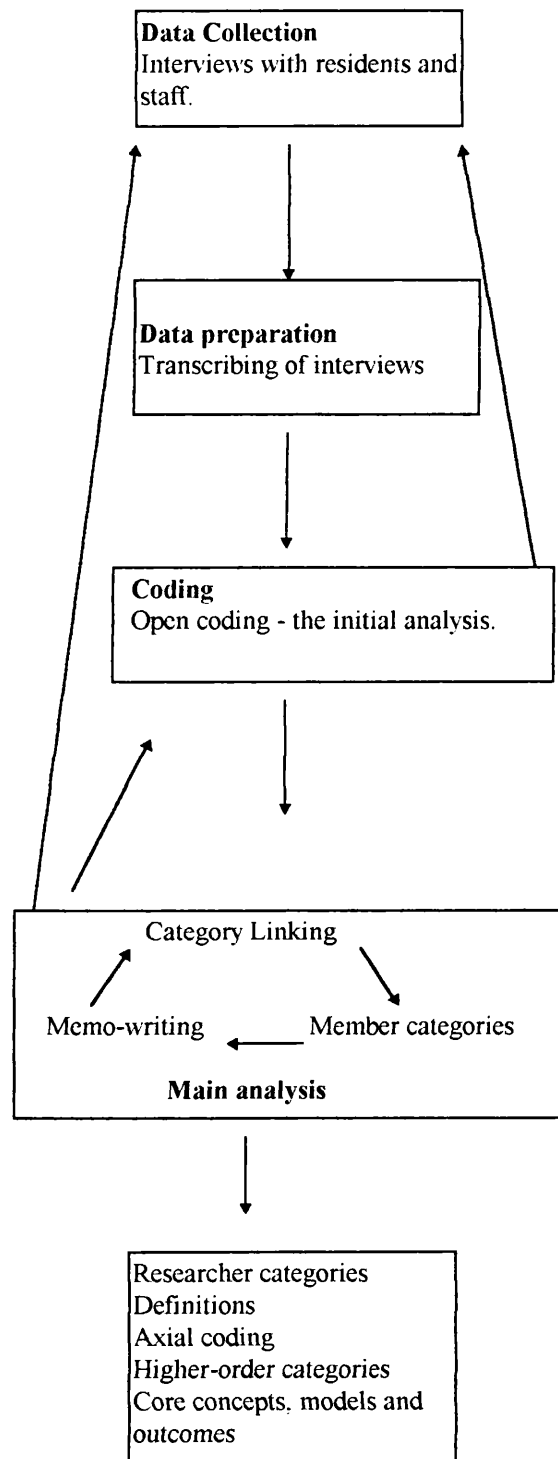
The process of conducting the two studies in parallel meant that theoretical sampling resulted from some analysis and linking between the studies. For example the impact of changing roles of key workers within the same unit was discussed initially in the resident interviews. A subset of staff who had changed roles was then interviewed to consider their perspectives on this process.

A final stage of this method of analysis suggests that the *theory* must be seen to 'fit the data' as a measure of the validity of interpretations (Glaser & Strauss, 1967). A process of *respondent validation* has been considered for both studies. This is captured by the notion that the analysis should be recognisable and of relevance to those studied (Henwood & Pidgeon, 1996). This process is more fully discussed in Chapter Four.

There are various ways of addressing reliability in Grounded Theory research. One of the methods adopted in this study was by replication, where the process of assigning member categories to researcher categories was independently replicated by a psychologist experienced in the grounded theory approach.

I was also fortunate to have been given the opportunity to meet twice with a team of psychologists currently working with people with learning disabilities, for a consideration of the researcher categories in Study One. These *consensus meetings* offered valuable opportunities for in depth discussion of the overall findings, justification of the linking of different categories, and consideration of the associated and available literature. (See Fig.1 for a diagram summarising the grounded theory approach).

**Figure 1.** Grounded theory approach<sup>2</sup>



<sup>2</sup>This figure is adapted from Pidgeon and Henwood’s (1996) representation of grounded theory.

## CHAPTER THREE: RESULTS

### Overview

This chapter presents the main findings from the interviews with residents and staff (Study One and Study Two) respectively. Before considering the results, an overview of the grounded theory method of analysis applied to both studies is described in detail. In the present research, the analysis goes in full circle from the research questions, to an overall coding and categorisation of interviews, and returning to a delineation of areas for grounded theory analysis based on the original research questions. The result is three separate grounded theory accounts relating to the role of the key worker; the process of separation; and feelings about the loss of the key working relationship. The results of these grounded theory accounts are then presented in the form of *researcher categories* defined and elaborated with examples from the data. These accounts are then discussed in relation to developing theoretical ideas.

### The grounded theory account

The mechanics of Grounded Theory analysis of data varies among researchers. In the present research I have used Pigeon and Henwood’s (1996) systematic method for creating categories, which allows for the generation of theory based on a hierarchy of themes in the final analysis. This approach moves from the transcript data to the final

grounded theory account in stages. In order to illustrate the analytic process, I will present in detail the process of developing a single *researcher category* in Study One. This type of category is created at the final stages of analysis, raising earlier descriptive categories of data to a higher analytic level by incorporating more interpretative ideas.

For the initial analysis Pidgeon and Henwood (1996) suggest the development of a clear and permanent record of the pertinent data. This requires a detailed processing of the transcripts as the data collection proceeds, with early identification of relevant material. The data in the present study was thereby sorted into clusters based on the shared meaning of extracts from the participants’ own words. These groups of related extracts were then labelled and numbered on individual cards. This marks the first stage of *open coding* (for an example of this process see Box 1 below).



**Box 1.****Extracts from resident interviews which relate to worrying about losing key workers in the future.**

*I was worried that my key worker was going to change (again) that I was going to lose one key worker then getting another one, then getting a new one...cause D. (key worker) did the same thing when she did that in April to August. She went on holiday around the world (R4) <sup>a</sup>.*

*It does worry me (losing a key worker) because it means having to make a fresh start with someone else, and I don't know their philosophies. They may have other ideas as to how to go around the problem - I don't know(R8).*

*I get worried - I don't want staff leaving here (R6).*

*If I haven't got a key worker I have to find a new one (R5).*

*It is difficult when someone leaves - it means there's a gap to fill, and it may take some time to fill the gap. And it's hard - it's hard because in theory it will all deject on to the clients I suspect (R8).*

*She's my co-worker, she's going to stick my co-worker. She tells me what do every day(R7).*

*I would be very sad if C (key worker) left (R3).*

<sup>a</sup> See Appendix 11 for a copy of the original interview with R4, presented for an example of resident interview transcripts.

In a second stage of open coding, these extracts were summarised to create a second version of the data, allowing an indexing system of *meaning units* to emerge. In Study One 224 separate meaning units were identified from the residents' transcripts. These meaning units were re-grouped to create a collection of *member categories*, derived directly from the content of interviews and labelled according to a common theme. (See Box 2 below for an example of member category development including meaning units which describe the data in Box 1 above). This began the process of categorisation and involved a search for similarities and diversities within the material. A number of indicators were collected which point to different facets of the same concept. The number of member categories increased as the data collection continued and when some data emerged which did not fit an available category, a new

one was created. This process finally condensed the vast number of meaning units into 78 member categories labelled according to their content.

### **Box 2**

#### **Member category 31 - Worry about change in the future. (Meaning units identified within the extracts shown in Box 1).**

Anticipation of future loss  
 Uncertainty about stability of key worker's position  
 Worry  
 Repeated experiences of loss  
 Sense of abandonment  
 Fear of being left  
 Having to build new relationships with staff  
 Unfamiliarity of a new key worker  
 Clients suffer as a result of staff changes  
 Denial of the inevitability of saying goodbye  
 Expectation of painful feelings about the loss

The open coding procedure was interrupted twice by the collection of further interview data. As the number of member categories increased, it became necessary to refine, extend and relate them to each other. This was the beginning of *category integration* and the development of researcher categories. At this stage in the analytic process I met with a clinical psychologist experienced in the field of learning disabilities for a *consensus meeting*. It was then decided that the 78 member categories could be logically divided according to the content of the questions asked. This consensus meeting identified three distinct areas in the data which can be addressed in order to answer the research questions. These were statements relating to the following topics:

- **the role of the key worker**, which refers to the residents’ varied perceptions of staff, and their different experiences of the key working role and relationship;
- **the process of separation**, which relates specifically to the residents’ accounts of how their relationships with key workers ended; and
- **the emotional impact of separation**, which forms the main grounded theory account, addressing the residents’ experiences of the impact of separation from key workers.

What followed therefore can best be described as three separate grounded theory analyses of residents’ responses. The member categories were clustered and either split or re-combined to fall within the three areas described above (although there were instances of linking between these areas, which are referred to later). *Theoretical memos* (comments and hunches) that had been recorded throughout the data collection and initial coding stages were drawn on to refine the indexing system and to develop 19 *researcher categories*. These researcher categories were re-labelled and are presented in three sections below, with definitions and examples from the transcripts.

In order to complete the example of this grounded theory account from transcript data to final analysis, the pathway of the member category ‘worry about future loss’ (see Box 2 above) was later combined with other related member categories and then subsumed under the researcher category: ‘the inevitability of loss’ (defined below).

It was at this third stage of the analysis that a process of inter-rater reliability was carried out by another researcher experienced in the grounded theory approach. Independent allocation of the 78 *member categories* to the *researcher categories* outlined below obtained 83 per cent agreement initially. Complete agreement was obtained by discussion and clarification of category boundaries. The agreed grounded theory account for each of the three areas respectively is outlined below.

Each researcher category is explained by a definition of its content, with examples from the data (quotes) to support its main themes. The more variable categories are either split to account for opposing within-category dimensions, or they are reported with a definition and elaboration of terms and examples. (This format of presenting the results is the same in both studies). The participants’ words are reported in italics, and the residents are identified in terms of subject number (e.g. R3) to give some indication of the distribution of responses within each category. The key workers are referred to as s/he or sometimes by initial (changed for reasons of confidentiality).

## **STUDY ONE**

The analysis of residents' interviews is based on three broad questions: how the residents describe their relationships with key workers; what the residents recall about the preparation for ending previous relationships with key workers; and how the residents felt about losing the key working relationship.

### **The role of the key worker**

The following classification of residents' accounts of their experiences of (and interactions with) key workers are glimpses of previous and/or ongoing relationships. The transcript material changes accordingly between references to past and present experiences. Six distinct types (or researcher categories) of role definition have been identified in the data. These are as follows: 'provider'; 'nurturer'; 'companion'; 'partner'; 'co-dependent'; and 'constant'. However, it is clear that these roles are not mutually exclusive, and that residents have sometimes identified one particular relationship according to a number of definitions.

#### ***1) Provider***

This relationship type refers to the residents' experiences of instrumental responsibilities of the key worker, as someone who has a fundamentally supportive role. Within the 'provider' relationship the residents' primary care needs are

acknowledged, and their sense of physical dependency on staff is recognised: *Even now I can't go out on my own without staff support, because I might fall over or something like that (R8)*. Many participants seemed to have formed a perception of their own dependency, and to have developed a strong reliance on the key worker for activities of every day living: *She bathed and dressed me and now I'm on my own (R2, whose key worker had just left)*. In some cases this reliance on staff suggests the residents' fears about their potential to harm themselves without the supervision of someone in a more 'responsible' role: *He looks after me. He has to keep an eye on me (R12)*. In an extreme case this could suggest the resident's idea that she cannot function without this basic support: *She tells me what to do every day (R7)*.

## 2) *Nurturer*

There are different facets to the category of 'nurturer', and the definition is split to reflect its two main themes.

### 2a) *Calming Influence*

This aspect of the key working relationship refers to the residents' experiences of the staff taking away their worries and concerns. There were many references to the nurturing, calming role of the key worker, almost as a container for their anxieties: *She told me not to worry. She used to say "come over to me, I'll cheer you up", and she put her arms around me and said "never mind"(R2)*. This sub-category also reflects a lack of sense of self efficacy in some participants, and an uncertainty about their ability to take care of themselves: *I feel more relaxed when I have someone to*

turn to (R12). *He used to calm me down (R1).* Despite the basically one-sided nature of this relationship, there is a reality that in the absence of wider social contacts and friendships the resident may rely on the key worker as a confidante: *Well she (key worker) is a friend that you can turn to and it's a friend who I can talk to when I've got problems (R8).* Intimacy can be part of a more reciprocal relationship, and this category overlaps with ideas of the key worker as a companion.

### 2b) Validator

This part of the nurturing role of staff relates to their capacity to validate residents. Many participants displayed gratitude and appreciation of the staff's kindness and affirmation of them: *I'm going to stick with D (key worker) because he's nice and he's kind, and he's very kind to me (R7).* Sadly, in some cases it felt almost as though this kindness was something very new and unusual in their interactions and relationships with others: *I liked her when she talked nicely to me in the car and all that (R3).*

### 3) Companion

The ‘companion’ role incorporates ideas about the social function of the key working relationship. It includes references to the enjoyment of shared interests: *We went on holidays together (R11).* It also reflects participants' appreciation of their key workers' unique and personal characteristics and attributes: *I liked his jokes and his company... I miss his jokes and company and drums. I just miss him as a good, good key worker (R1).* This category also displays the depth of feeling that some clients

have towards staff: *She was my closest friend (R2)*. The key worker’s role as a social link for residents, providing access to wider relationships outside of the home through their own relationship networks, is also represented in this category: *He took me out with his friends (R5)*. Overall, many of the accounts represented here relate to the residents’ trusting and enjoyable experiences of a familiar relationship, with a shared-friendship status, which has developed gradually: *It was more like a friend - it was over a course of time that we got to know each other (R8)*.

#### 4) *Partner*

A small group of residents referred to their more intense and sometimes sexual feelings towards key workers: *I still love him because he is a nice man, he’s good looking. He loves me and I love him (R4)*. These are grouped together in a category relating to ideas of staff fulfilling the role of partner: *It’s hard because it’s like losing a relationship (R8*, who compared the impact of losing his key worker with breaking up with his girlfriend). There is an element of fantasy about these accounts, where residents seem to be wishing for more intimate relationships with their key workers. However, a variation within this category is represented by the recognition of boundaries, suggested by one client in particular: *It wouldn’t be allowed if I cuddled her (R3)*. This idea arguably reflects a sense of frustration and temptation experienced by this client who has strong feelings for his key worker.



**5) Co-dependent**

Another representation of the key working relationship relates to the residents' perceptions of reciprocity and co-dependency in their contacts with staff: *We used to get on well together. It was a good relationship between the two of us. We got on, we shared our problems out (R8).* Many participants described a mutual experience of giving and receiving care in the key working relationship, and almost an equal share of support: *Yes we got on together. She looked after me and I looked after her... I looked after her because she wanted me to, and I sat with her in the dinner hour (R11).* In these instances there was a different kind of fantasy underlying the residents' accounts, one of sharing and equality within the relationship. This category can also be linked to the perceptions of the key worker as a companion (described above). However, the emphasis of accounts in the category of 'co-dependent' is on the residents' implicit recognition of the needs of both parties.

**6) Constant**

This category relates to the residents' appreciation of constancy, with staff having a long-term perspective on their care: *She's been there from the start (R4). She knew my old key worker (R6).* In one instance, the key worker had instigated the resident's change of placement, rescuing her from a difficult environment and enhancing her quality of life. *He (the key worker) came to the hostel and he saw me there and he took me here (to my new home) (R5).* This is the smallest category in the relationship typology, but is crucial for a wider understanding of the importance of stability in the

overwhelmingly transient lives of people with learning disabilities. It represents the residents’ appreciation of having an attachment with someone who seems to be ‘holding them in mind’.

### **The process of separation**

The residents described various aspects of the events surrounding the endings of their key working relationships. These include:

- the actual preparation for ending the key working relationship (where it occurred);
- events occurring in the aftermath of the event;
- the residents’ strategies for coping;
- experiences of ongoing contact (whether or not this was maintained); and
- the residents’ reasons and explanations for their separations from staff.

#### ***1) Sudden endings***

##### ***Definition***

This category relates specifically to the experience of a sudden and unprepared for loss of key worker. Each of the participants was able to comment on his or her recollection of the presence or absence of preparation. This issue provides much of the impetus behind the present research, and it therefore seems appropriate to comment on the frequency of ‘unprepared for’ endings as reported by residents; two thirds of

participants described an abrupt ending with little or no chance to say goodbye: *It was very sudden - she just went- like that (R9). He gone off - and that's it (R5).*

### *Elaboration*

Many participants were able to clearly recall the events surrounding the day they were told (perhaps suggesting the traumatic impact of this news), and they could often identify the limited time between being told, and the key worker actually leaving: *She took me to the pub and that, and she told me she was going the next day (R2).* In some cases there was even a sense of not knowing about the impending separation, not being prepared and being faced with a sudden loss: *I didn't know - she just stopped working here (R2).* These experiences were recalled with a sense of confusion about the process: *I said goodbye and she was gone (R11).* A small group of participants reported their discovery that their key worker was leaving as accidental: *Until that very day she told us, N. (a co-resident) found out (R4).*

## **2) Keeping in touch**

### *Definition*

The question of keeping in touch with key workers generated two main types of response in residents. These relate to the desire for ongoing contact, and the lack of personal control over seeing key workers again. This category is therefore subdivided to reflect these two issues.

2a) *Just wanting to say ‘hello again’*

Many participants described their wish to see key workers again: *It would be nice to see them again, just to say hello and how are you and to see briefly what they’re doing (R8)*. In most cases, they seemed satisfied with even the briefest contact: *She sends me post cards. I like that (R6)*. One participant looked happy and excited as she talked about her key worker: *Then I saw her again, twice in church and she looked me up and down, and she wanted to know where I lived and I told her (R11)*. There was a certainty in the accounts of many participants that the opportunity to see the staff again was to be taken: *Most people who have left I have seen again. I think that’s a good thing (R12)*.

2b) *Keeping in touch goes both ways - the residents’ lack of control over contact*

Some residents reported their failed attempts at keeping in touch with key workers. One participant explained, *I’ve got her telephone number. (I asked whether she ever rang her old key worker), no, because there’s no answer - I do try (R4)*. Sometimes the residents described their longing to see staff again, but they seemed to recognise their lack of control over contact in reality: *Can’t get in touch, don’t know where she is (R2)*. There was also a sense of residents having to rely on other staff to support this contact: *I can’t go on my own - I would if I could (R8)*. This idea of dependency on staff links to the role-category ‘Nurturer’ described above. However, a small group of participants indicated their fantasy of control over seeing the key worker again: *She (the key worker) will return if I want her to (R9)*.

### 3) *Goodbye pleasantries*

A small group of participants described how their experiences of saying good-bye to key workers had been marked by pleasant rituals or 'happy events' in the home. In some cases the residents had received gifts from staff: *She said I'll give you something to think of me...she gave me soap and that, but I can't get in touch (R2)*. In other cases they were encouraged to provide the leaving presents. One client described her plans for saying goodbye to her current key worker, *I'll buy some flowers for J.(key worker) some chocolates. Will miss her (R9)*. There were also reports of meals out and parties: *We did have a leaving party, but that was besides the point you know (R8)*. However, underlying all of these pleasantries, there seemed to be questions about how far these events can assist with the pain and inevitability of separation: *Well I know it's not a question of shaking the hand and saying goodbye. It's something more emotional than that I think (R8)*. These residents were able to show their insight into the reality of saying goodbye which cannot be masked by 'quick-fixes'. This category links also with responses referring to residents' feelings, and what often presents as their very painful insight into the finality of separation.

### 4) *Appreciating the needs of staff*

Many residents showed a depth of insight into the limitations of the key working role, and an appreciation (or justification) of their decisions to leave. One participant's account movingly reflects this level of understanding of the staff's needs, explaining why his key worker had decided to leave: *She wanted to do a job where she didn't*

*have to do shifts - because when she was doing shifts she was getting very tired. Then it's not a good idea to drive a car - can't concentrate (R3).* A group of participants also displayed their ability to acknowledge the reality of having to share the key worker in the face of the wider family obligations of staff: *She (the key worker) has maternity leave - she will need to feed her baby (R11).* This appreciation of the personal lives of key workers was sometimes extended to an acknowledgement of losses in the lives of staff: *He has got a mother and son. Then his mum passed away. Very sad. He wasn't happy here. He was all right and then he left after that (R5).*

This category also relates to the residents' awareness of the distinction between the staff and themselves dependent on their relationships with key workers: *What I'm saying is that it's their job which is the main thing, isn't it? (R8).* It may have been difficult for the residents to appreciate this wider role, and they may have had angry or envious feelings when they considered the different lives and opportunities of key workers. These emotions were not expressed, but may have contributed to their ensuing distress.

### **The emotional impact of separation**

The emotional impact on residents of separation from staff is a central tenet of this research. This part of the analysis refers to:

- the residents' feelings about past experiences of loss;

- their fears about losing key workers in the future;
- their means for expressing more painful feelings; and
- their perspectives on both other residents and staff who have been affected by this process.

### ***1) Facing the pain***

#### *Definition*

This category refers to the theme of emotional pain, often expressed poignantly by residents, following the end of the key working relationship. It is clear that many of the extracts incorporated within this category link with other researcher categories concerned with the impact of loss on the residents’ lives. Nevertheless, it is interesting to note that every one of the residents in this study identified feelings of hurt and sadness in the event of saying good bye to their key workers.

#### *Elaboration*

Some residents clearly articulated their feelings about separations from key workers:

*I felt gutted - lost from hereon....hurtful, very hurtful (R8).* A few talked about more hidden expressions of mourning: *When I was alone, I laid down and cried my eyes out (R1).* One participant suggested that he was grieving the loss, even though it was sometimes difficult to express, *sometimes it gets all bottled up (R1).* Others commented on the impact of saying good bye as though they recognised that others might not see their real and painful feelings: *You can be sad without crying actually*

(R3). Indeed one participant grieved openly over the loss, *I loved A... I can't stand it* (R6), indicating her sense of injustice that someone so special to her had been taken away.

## **2 ) Associations with bereavement - memory of loss**

Many residents made a link between experiencing the loss of a key worker and their reactions to wider experiences of loss and bereavement. In fact, at an initial meeting with a group of residents to explain the purpose of this research, one person shouted out, *should we talk about people dying too?* This comment encouraged other residents to start recounting their experiences of family and friends dying. In a telephone conversation to organise a time for the interview, one resident asked, *will I be talking about funerals?* (R1). This almost automatic association with death was also apparent in the content of the residents' interviews. When asked about her experiences of losing key workers, one participant said: *It makes me feel like I'm never going to see them again. It gives me that feeling* (R12). Another explained: *It made me think of my friend dying* (R6). One participant described her experience of seeing her key worker again after a long time, and when asked to describe her feelings at the time she said, *I was sad because I lost my mum* (R11). This participant (R11) cried for the remainder of the interview and wanted to describe her memories of her mother's death. There is a clear sense of residents' experiences of the finality of ending relationships with staff, and their experiences of bereavement being equated in their minds.



### 3) *Somatic reactions to loss*

This category relates to the physical representation of emotions presented in the accounts of many participants. There was a tendency towards describing feelings about losing a key worker as concrete physical reactions: *It feels inside you. I feel not that here inside me (R1)*. A few participants related their sadness about separations to sleep problems: *I can't sleep because J. has gone (R5)*. This finding (in the first wave of interviews) led to an adjustment of the interview schedule, with the addition of a question asking participants to identify specific areas in their body where they located their painful feelings. In response to being asked where they felt the pain, two participants responded with certainty: *Upset stomach, pains in stomach (R5)*. *I feel it in my eyes (R4)*. One participant reported feeling tired and having a headache just thinking about saying goodbye.

### 4) *The inevitability of loss*

This category was developed to reflect the residents' repeated and cyclical experiences of losing key workers: *I was worrying that my key worker was going to change (again) that I was going to lose one key worker then getting another one, then getting a new one (R4)*. It addresses their struggle with having to begin new relationships with staff: *You have to make a fresh start - it's a worry (R8)*; and displays their insight into the potentially adverse effects on themselves: *Sometimes, if I haven't got a key worker, I have to try and find a new key worker (R5)*. There is a sense of inevitability and helplessness in the residents' repeated experiences of being

‘abandoned’: *She did it (left) before, she went around the world.. I thought what’s going on? (R4)*. However, in common with a theme of coping (described below), the participants also displayed their experiences of becoming accustomed to the process of loss and change: *It was hard for me, but I got used to it (R2)*. This seemed to have developed after repeated experiences of loss resulting in their withdrawal from the possibility of being hurt again in the future. In general, many of the participants were aware of the possibility of key workers leaving, and their reactions were a mixture of anticipation, worry, fear and a requirement to become numb to the whole experience: *I don’t cry anymore (R6)*.

## 5) *Coping*

### *Definition*

This category incorporates the residents’ identified strategies for coping with the impact of separation from key workers. Many of these accounts indicate the participants’ perceived lack of self efficacy and personal resources for coping, and their reliance on the availability of others (usually staff) for managing the loss.

### *Elaboration*

This category links with the role of the key worker as ‘nurturer’ described above, and the residents’ needs for emotional support from staff: *I might talk to staff about J. (key worker) coming back (R5)*. For one participant, this reliance on staff was extended to a point of needing someone else to identify her own distress about the

loss: *The staff told me (I was upset). I get the staff to calm me down (R7)*. Another participant described her dependence on family outside of the home to help her to cope with her difficult feelings: *My mum told me not to worry (R2)*. Occasionally participants displayed their capacity to draw on inner resources and private memories of relationships with staff, to assist them in coping with their loss: *I have a picture of her... I think what she was like (R2)*. However, a striking technique for surviving the pain of repeated experiences of separation from key workers is presented in the accounts of two residents: *You get used to it having someone new... I still get on, we're getting some new staff soon (R4)*. *I don't cry my eyes out now - I used to (R6)*. These extracts relate to the idea of residents becoming ‘numb’ to the experience of losing someone, and perhaps defending against their more painful feelings by ‘getting on’ and not surrendering to the pain. These responses seem to link also with aspects of the ‘the inevitability of loss’ category.

## 6) Lack of control

There was a recurring theme in the residents’ accounts of their lack of control over retaining relationships with staff: *I don't know why they have to leave when I don't want them to - they have to (R2)*. One participant referred to this experience as though he felt invisible in the process, *I feel lost out. I feel I'm not that there (R1)*. A group of participants described their longing for staff to return: *I wish her back (R11)*. This but this longing was often expressed with a painful realisation that there was nothing they could do to change the situation. It was out of their control: *She can't come*

*back - can't make it (R5).* However, a small group of participants seemed to have developed a ‘fantasy of control’ over what is, in reality, an inevitable process of eventual separation from staff: *He's my key worker and he's going to stick with me all the time, and he's not going to leave me. No - I like him very much (R7).*

### 7) *Dangerous feelings*

Some residents indicated a perception of danger surrounding their own sad and difficult feelings about losing a key worker: *My sadness might hurt her (R12).* This may suggest their fear that their own feelings might be too upsetting for staff. One participant replied to a question about telling his key worker that he was sad she was leaving, *I didn't want to because it would make her sad, because I just want to enjoy - I can still be her friend and write to her... I didn't talk too much about it because I think if you go on about something, it upsets the person (R3).* Another more explicitly displayed her sense of her own feelings being potentially damaging or destructive to staff, *It's hard, but I'm not nasty (R5).* Overall these accounts seem to represent a sense of the residents’ compliance and need to please the staff: *I don't feel sad because I like her.* Taken to an extreme this wish to please and pacify seems to negate the residents’ realisations of their own rights to experience sadness.

### 8) *The ‘pass the parcel’ effect*

A small group of residents described their experiences of ending relationships with key workers who had remained in their homes, but with changed roles, and sometimes as key workers to different clients. One participant clearly described her sense of not knowing what was happening, and being passed around the staff team, *my key worker couldn't cope with me. It felt embarrassing when she said she couldn't cope with two of us (R4)*. This account reflects the resident's sense of being a burden to staff. Another participant reflects his confusion arising from his change of key worker, *I can't confide in my old key worker. It's a different relationship. He'll pass it on to my key worker...it is hard to understand (R8)*. This process of staff change within the same setting clearly evokes a different catalogue of repercussions for residents. In fact it led to a separate sampling of staff who had experienced this change to their key working role (see Study Two).

### 9) *Empathy with the key worker*

This category refers to instances where the resident displayed an ability to take on the perspective of the key worker who had left: *It was hard for us both to express at the time...it's hard for them (staff), there is nothing easy about saying goodbye (R8)*. Many participants showed their empathy for the situation of staff, both in their roles as key workers: *He wasn't happy here (R5)*, and after leaving post: *I just know she's missing me - she'll be upset (R9)*. This capacity for understanding was sometimes

extended to a consideration of the staff’s feelings about saying goodbye: *She felt sad to leave (R5)*. However, it remains difficult to discern whether these considerations were based on real insight, or whether they were projections of the residents’ own feelings about saying goodbye to key workers.

## Summary

The essence of this research is concerned with exploring the impact on residents of losing their relationships with key workers. The first two sections of this analysis are more descriptive accounts of relationship-types and events surrounding ending relationships. These elements are inextricably linked with the emotional aspects of separation, but it is the third section relating to the impact of separation which forms the main grounded theory account.

The final stage of this analysis of residents’ interviews involved category integration, or *axial coding*. By drawing links between categories the last nine researcher categories have been synthesised to generate three higher-order categories as follows:

1. **Loss and grief:** facing the pain; somatic reactions to loss; associations with bereavement.
2. **Helplessness:** inevitability of loss; lack of control; coping (by reliance on staff); pass the parcel.

3. **Acceptance and acquiescence:** coping (by accommodating to staff changes and 'moving on'; dangerous feelings; empathy with the key worker.

### *Elaboration*

The first higher-order category refers to the participants' overwhelming sense of loss and grief in their accounts of separation from key workers. These feelings were manifested through open expressions of tears and sadness, or in quieter, more private moments of reflection. However, sometimes residents were less able to give words to their reactions, but rather felt their grief in more physical (somatic) representations, as though it was more explainable to them in their concrete expressions of emotional pain. Finally, in the process of reflecting on separations from staff, the participants made automatic associations with people dying. This suggests that the experience of losing key workers was represented and grieved for as if the residents had been bereaved.

The category of 'helplessness' reflects the residents' experiences of cyclical processes of staff change and movement. There is an inevitability about their separations from key workers, and they described their anxieties about having no one left to care for them. However much they wanted to hold on to these relationships, the residents were powerless in the face of staff's decisions to leave, often without much warning, and sometimes never to return again. There is a central theme of passivity about their experiences, which is represented quite clearly in the process of being 'passed around' by the system, even when the key workers had changed role but were physically on

site, it was no longer appropriate for the residents to approach them. Moreover, even their strategies for coping with these losses were often dependent on staff - for reassurance, care and support.

The third higher-order category, ‘acceptance and acquiescence’, refers to the implicit sense of compliance about the residents’ accounts. They expressed their own ways of accommodating for the departure of staff, often showing empathy and offering reasons for their key workers’ decisions to leave. As well as displaying sensitivity to the staff’s needs, or a fantasy that the key workers would be experiencing similar feelings of grief to their own, this empathy is significant in the absence of residents’ anger. There is a sense that residents ‘can’t bite the hand that feeds them’, a fear perhaps that if they do get angry, they might not receive any support. This links also with the category ‘appreciating the needs of staff’. In some cases the residents felt compelled to mask their hurt and pain in order to protect, or appease, the staff. Overall, this category refers to the finding that residents may sometimes deny their real feelings, not giving themselves permission to express their less accepting reactions to separations from staff.

In the final stage of a grounded theory analysis it is possible for a single category to emerge from the data, if such a step is meaningful and appropriate. **Dependency** is a theme that seems to underpin these three categories relating to residents’ experiences of separation from key workers. This dependency is reflected in their emotional attachments to staff, the reality of power imbalance in these relationships, and their



anxiety about being abandoned, with no-one to look after their needs. There is also an implicit requirement for them to quietly tolerate their painful feelings for fear of otherwise repelling those on whom they depend. The residents' dependency is often lifelong. The cyclical event of staff leaving differs even from experiences of bereavement in that it is not just a single goodbye. Rather than moving on themselves when staff leave, the residents are forced to turn to replacement, dependable relationships, and subsequently to future separations and losses.

These higher-order categories will be returned to later in Chapter Four.

## **STUDY TWO**

The analysis of staff interviews is built around three broad questions: how the staff describe their relationships with residents; how staff prepared residents for the end of the key working relationship; and what staff considered to be the impact of separation on the emotional lives of residents. The results of this study are organised in the same way as Study One.

### **Analytic process**

The development of each *researcher category* followed the same process as described in Study One. In Study Two a total of 259 *meaning units* were identified in the 18 transcripts. These were coded and grouped to generate 80 *member categories*.

As with Study One, the results of this study are presented as three separate grounded theory accounts, based on the content of the following topics:

- **the role of the key worker**, which reflects the staff’s perceptions of their roles in the key working relationship and includes aspects of their understandings of the residents’ views of their roles;
- **the process of separation**, which refers to the staff’s accounts of how their relationships with residents ended; and

- **the emotional impact of separation**, which forms the main grounded theory analysis, including the staff’s own feelings about separating from residents and their perceptions or interpretations of the impact of this event on residents.

These grounded theory analyses combined led to the development of 16 researcher categories. At this stage, a process of inter-rater reliability was carried out with the same researcher as in Study One. The independent assignment of the 80 member categories to the researcher categories outlined below obtained 94 percent agreement. Once again full agreement was obtained by discussion and clarification of the category boundaries. Below are the three final grounded theory accounts of staff interviews. The role of the key worker is described briefly to give some sense of the diversity of the key working relationships described. The preparation for ending the key working relationship is then reviewed for an insight into processes of separations. However, the main analysis is based on the impact of leaving on both parties. Within each section there are some categories which correspond to the categories in the resident study (for example ‘Goodbye pleasantries’). The participants (staff) are identified in terms of subject number (e.g. S12), and the residents are referred to as s/he or occasionally by (changed) initial.

### **The role of the key worker**

This classification of staff’s descriptions and definitions of their relationships with residents extends Clegg *et al.*’s (1996) classification. Indeed three of the four researcher categories (‘provider’, ‘meaning maker’ and ‘companion’) are developed from the ideas of Clegg and colleagues. The fourth researcher category (‘family’) is added in the present research, and replaces Clegg’s category ‘mutual’. However, a more important point of difference is that whereas Clegg’s typology of relationships assumes mutually exclusive categories, in the present analysis it is clear that there are overlaps within the most of the accounts of individual participants. Notably, one key worker’s (S17) description of his role as a key-worker falls within each of the categories, indicating the potential diversity of this role even within one relationship.

#### ***1) Provider***

The ‘provider’ relationship is identified in terms of the practical, instrumental role of the key worker, in supporting the resident with activities of daily living. A relationship “where clients basic needs are met” (Clegg, 1996 p.254). It reflects quite a one-sided relationship, and is possibly the more commonly perceived role of staff in their capacity to support residents to live in the community. One key worker succinctly encapsulates this dimension of the key working relationship: *Basically things that I would do for myself, but that he either couldn’t, or wouldn’t do (S2).*

Many participants described the ‘hands-on’ practical caring role: *It was very hard work - also because I was doing a lot of physical stuff for him.. and he was incontinent of both urine and faeces, and I might spend a morning cleaning him up - you would feel quite drained (S16)*. There was also a general representation of the expected duties and responsibilities of the key worker: *It was the usual key-worker-type stuff - making sure toiletries were bought.. clothes were done and whatever else (S17)*. The theme of responsibility recurs within this category, and is often combined with ideas about general supervision and overall care of the resident: *Lots of supervision - he could never see a task fully through to bathe himself - he might forget to put the plug in the bath and then he would come and say “There’s no water” (S13)*. Generally the key worker who falls into this category can be considered as the resident’s ‘primary carer’.

## 2) *Meaning Maker*

The category of ‘meaning maker’ encompasses ideas about engaging with the residents, and endeavouring to make sense of their communications. Again it extends Clegg *et al.*’s (1996) ideas of interpreting residents’ feelings. It refers to the staff’s capacity to spend time with the resident, slowly building up the relationship and supporting her. The essence of this role is based on understanding the person: *You know - when someone is feeling something and they can’t communicate it to you. So I spent quite a lot of time with him - he was quite depressed and that, so I would try and find out the cause of things. I don’t know whether I ever did fully (S16)*. The key

worker in this category is literally attempting to make meaning out of the resident’s communications. A group of participants took on the responsibility of extending this process to ensure that other staff took the time to engage with, and understand the resident: *Considering C’s feelings in what was going on, and making sure that other people were aware of - this is why we are doing this.. It was an advocacy role I think in a lot of ways (S17)*. Some staff expressed the sentiment of things being *dumped in your lap (S18)*. However, many participants described their efforts to work with residents towards processing their feelings and developing personal coping strategies: *Part of our relationship was about.. just trying to get her to express herself for whatever reason (S12)*. In a few cases, staff described a reciprocal development of understanding in the key working relationship: *It ended up with us having an understanding of each other, and the way each other operated (S17)*. In this case ‘meaning making’ was operating as a two way process.

### 3) Companion

The ‘companion’ category relates to the enjoyment of the key working relationship. It includes accounts of joint activities, common hobbies, and mutual appreciation. In some ways this aspect of the relationship was described with surprise, as though it is an unexpected bonus for staff to experience pleasure within the relationship. It refers to shared excursions including holidays and shopping trips, and generally going out socially together - ‘highlights’ of the key working relationship: *We’d go out for dinner, or we’d go to the cinema - just little things like that you know.. we’d go out*

*shopping for clothes together. So the relationship did build up because of the things that we'd done together (S11).* Implicit in this relationship-type is a recognition of the individuality of the resident, and an appreciation of her character: *With me and H. there was a definite click, just because of musical interests and he loved going to the theatre (S2). He appreciated my sense of humour (S3).* Clegg *et al.* (1996) refer also to quiet components of shared-time. *Just sitting - having a drink - watching the world go by - chatting with each other and things like that (S17).* However, this reference to companionship is qualitatively different in some ways from residents' accounts. There is an implicit recognition of the relationship as only comparable to friendships experienced outside of work.

#### **4) Family**

There is a general idea, in the minds of both parts of the key working dyad, of the staff-client relationship replacing a particular family dynamic. The category of 'surrogate family' has two components:

##### **4a) Surrogate parent**

The sub-category of 'surrogate parent' relates to staff's experiences of residents responding to them as a child would respond to her parent. This suggests a parental transference, with the resident seeking closeness and protection from the key worker: *He (the resident) saw me more like a mother figure, like he does his older sister (S13).*

There is a sense of familiarity in that relationship, with staff feeling bound to behave

as a parent would: *He knew how I would react - in the same way as there are times when my little girl says to me “Thanks for stopping me for doing whatever”... B. needed the control aspect of the relationship sometimes (S17).*

#### 4b) Surrogate child

Under the sub-category of ‘surrogate child’, the staff member feels like a child in the key working relationship: *Because she mothered me a bit.. every time I wasn’t well, it would be her that comforted me and stuff - looked after me (S6).* This reverse parent-transference was especially evident in the accounts of staff who were much younger, with residents being of the same generation as their own parents. It may suggest the key worker’s role as the child that the resident has never had: *I mean it felt sort of like talking to someone almost like your dad at times. It felt like sort of an older person.. he was in his 50s and I was in my late 20s... so there was that big sort of thing- the protective thing (S18).* However, this description is qualitatively different from the residents’ accounts of staff being experienced as family to them. The staff were able to identify the resident as ‘acting like’ a family member: *Really it’s like my family. You know I spend more time with the guys here than I do with my family, because my family live away - but deep down you know that the guys aren’t your family, and eventually you will have to move on (S14).*

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### **The process of separation**

The area of ‘process of separation’ deals specifically with the question of how staff prepared residents for the end of the key working relationship. It includes a number of categories relating to different aspects of this process. These include:

- the staff’s actual preparation plans;
- saying good-bye (or not) to residents;
- marking the occasion;
- support from management; and
- contact with clients after the working relationships ended.

Within each category there are variations in the processes reported and differing accounts. The summary below incorporates the pertinent features described.

#### ***1) Explanations for not saying Goodbye***

##### ***Definition***

A substantial minority of staff participants reported not having said goodbye to their key clients on separation, and they recalled various reasons for their abrupt departures. Some attributed this to external factors beyond their control while others professed this to have been the result of uncertainty as to the correct approach to be taken.

*Elaboration*

A number of participants described their own grievances with management, and their decisions to leave suddenly and without warning: *I actually walked out (laughs) - personal reasons with the unit. I took a grievance up against the manager and I just walked out (S3)*. Others reported not having been given the opportunity to say good-bye due to perceived “dangerous implications” in the home: *The client asked me, looking very worried and upset and said "You're not leaving are you?" and somebody dived in and said "No, he's going on holiday", which I felt quite awful about. I could see why they said it though. So as far as I know, they were told I was going on holiday, just to tide the situation over for a few days, because it was a really dangerous situation in that home. I said bye bye to him, but I never said I'm not coming back (S5)*. Two staff had been involved in difficult incidents with residents, and had been encouraged by management to leave immediately, for their own safety: *I wasn't even allowed to say good-bye - even to the other clients (S14)*. There was also a sense of not having had personal responsibility for preparing the key-client, but rather anticipating that other staff members would take over: *The day I left, the people I was working with didn't know that was my last shift. But the understanding was that the care manager was going to tell everybody. The clients were like "where are you going?" and I was like "I finish at eight tonight you know". I felt gutted (S12)*. Others had not realised that they would not be seeing residents again: *When I left I didn't realise it was my last shift working there. It was only a matter of days before they wanted us to go on training...To think that we never had the chance to say good-bye. One day we were there and the next we were gone (S9)*.

There was also a small group of staff who attributed their not having said goodbye to their uncertainty with regards to the correct course of action to be taken: *We did speak about things, but not a great deal. Not really about me leaving.. so I didn't really know how he felt about me leaving (S6)*. Finally, some participants considered that not saying goodbye was in the best interests of the residents: *I tried not to deal with the end. Because I was leaving, it wasn't for me at that point to give him messages he couldn't handle... he was happier to avoid that side of things (S8)*.

## 2) Gradual Preparation

### Definition

This category refers to the staff's thinking processes around saying good-bye, including advance planning for the ending and gradual build up towards leaving. It also incorporates: strategies for reminding the residents in stages; organising a hand-over that ensures continuity of support for the resident; ideas for a more considered end to the key-working; and finally regrets about previous experiences.

### Elaboration

It is interesting to note that the participants had very different ideas about what constitutes 'gradual preparation'. Some felt that a few days or a week's notice was sufficient preparation time for residents: *We had to build up for it. If he needed a haircut, you had to give him a day's notice, and keep reminding him. So we decided it would be best if we built it up over a period of about a week - to get used to the idea*

(S10). However, others had different concepts of what constitutes ‘gradual’ and felt that a longer period was necessary for the residents to adjust to the loss: *I actually started telling her about two months before. When I first told her she would totally switch off, so it had to be a long gradual process of telling her you were actually leaving (S1).* A few participants also revealed their strategies for gradually supporting the resident through this process: *Being quite honest with them...helping them work through their own feelings about that, and helping them to share that, and tell people "I'm really naffed off". And for the last few weeks we sort of planned things like "Good-bye sessions" (S12).*

Finally, a small group of staff went further to reveal their preparations for handing over their role as key worker in a way that would ensure continuity: *I did shifts with the new key worker for three months before he became key worker, so he would get to know the client before he key worked him and stuff. (S11)*

### 3) Goodbye pleasantries

The importance of marking the end of the key working relationship was expressed by many participants. However, the nature of these endings is sometimes difficult to discern. The majority of staff described their attempts to create a ‘happy ending’. This category mirrors the residents’ accounts of meals out, parties and visits to the pub - various attempts by the staff to ease the painful transition: *There's always an event for the person who leaves, whether we go out for a meal or a party or stuff. It*

*has always ended on happy terms. There's never just a good-bye at the end of a shift. There's always a happy ending. I think people rely on having a nice memory and a happy memory (S7).* This marker was considered sufficient by some participants for recognising the ending: *There was general chat about me leaving, we had the party, which gave people a chance to say good-bye, and I took him out. I don't think there would have been anything in addition that I would have done (S11).*

However, a small group of staff described the importance of recognising the pain around saying good-bye, which could not necessarily be papered-over with pleasantries: *I think when I was working with her (key client) at the end it was acknowledged not that everything was going to be of a social content, you know make it all happy, because that would be pointless (S12).*

#### **4) Lack of support**

There was a recurring theme of lack of support for staff in the event of ending their relationships with key clients, and leaving post. Some participants reported being made to feel guilty about leaving, and being pressurised by their managers to stay: *What support? Constant wanting me to change my mind before I left.. Making me feel guilty.. I think they also said "You can't leave now when people are so attached to you" (S6).* Others described the lack of policy and guidelines for staff about preparing residents: *I was having quite a dilemma about how long before I was actually leaving that I should be letting people know. I mean there were no guidelines*

*or anything within the organisation.. it was very much left down to me. I had to create a kind of wind down for myself (S8).* A group of staff actually referred to minimal general supervision in their role as key worker, which impacted also on the end of their posts. There was an awareness that this lack of personal emotional support would have affected their relationships with residents: *I didn't have any (support). None at all. I didn't get any in relation to ending relationships or finishing relationships with key clients - things like that. I don't think I had had supervision for six months by the time I left.. but the support for me would have carried down to the residents, because I was supporting them (S16).* This often led to a sense of isolation in staff, who felt misunderstood, with little opportunity for processing their own feelings about leaving: *The only person who really gave me any support was my partner, but it was hard for him because he doesn't understand - he couldn't understand how hard it was for me to leave these people who I've worked with - day in and day out for two and a half years (S11).*

### **5) Keeping in touch**

The question of keeping in touch with residents at the end of the key working relationship led to a range of opinions about the merits and drawbacks of promising ongoing contact. This category is therefore sub-divided to reflect the two main opposing schools of thought relating to this issue.

## 5a) Clean Breaks

Many staff were clear about their wish to make a clean break from residents, and not to give false hopes of future contact: *I didn't want to have her phone me up at home or anything like that, as far as I'm concerned that's work.. but I'm not prepared to commit myself to her, knowing that I couldn't do it regularly and I don't think she would have benefited from that... It has to be very clear cut with J. (S12)*. There was a sense that the ending had to be very final also for the sake of the staff: *I had tell him I was leaving, and that would be it, because obviously for me I didn't want any other contact (S7)*. Some staff clearly wanted to avoid confronting a potentially painful reunion: *Probably part of the reason that I haven't gone back as well as the aggro. with the staff, is the fact that I don't really want to know whether or not it had a negative effect - me going (S17)*.

## 5b) Maintaining the relationship

A group of staff was keen to develop new forms of relationships with residents after leaving post. These were described in terms of friendships as well as advocacy roles. These staff were hoping to preserve the relationship, but in a different capacity: *It's nicer now, because I know I'm not his key worker, I don't have to worry about all the rubbish - you know - all the paper work and documentation. I can just treat him like a friend - it's a lot more relaxed (S9)*. A smaller group of participants recognised their own need to maintain their relationships with residents: *I rang regularly, and I was attached as probably she was... I think it was for both really, because I felt "oh gosh, I'm going off to a strange country" (S6, who was moving abroad)*. One participant explained that she visits regularly, because she misses her old job and all of the

residents, *I pop in on my day off (S11)*. Others expressed their wish to see residents again, but felt that this was not encouraged by the units: *I think that the other problem is that many organisations make it hard for you to go back - they (residents) are still very protected by the people who have responsibility for them (S17)*. However, a small number of staff had managed to develop regular contact with previous clients: *I see him every couple of weeks (S9)*. This contact was reported to be appreciated by both parts of the relationship.

### **The emotional impact of separation**

The emotional impact of separation is the focus of this study. This topic includes:

- the staffs' own feelings about leaving; and
- their perceptions of the feelings of residents, including both:
  - their actual observations of residents' reactions; and
  - their thoughts about how they imagined residents to be feeling at the time.

Ideally, for the purpose of this research, it would be useful to be able to categorise the views of participants as clear-cut descriptions either of themselves or of residents. However, at times it is difficult to disentangle the ownership of the feelings identified. There are some clearly identified feelings which can be attributed to staff, or to residents, or to both, but there is also an element of ambiguity, with the ownership of some feelings being quite difficult to discern.



**1) Observable impact of separation - on residents***Definition*

This category relates to reports by staff of the observable reactions of residents to anticipating, or experiencing, separations from key workers. These include: the residents’ clear communications of emotional distress; their implicit behavioural responses to grief; and the staff’s observations of regressive or withdrawn behaviours in residents in response to loss.

*Elaboration*

A group of participants identified the overt emotional responses of their key-clients, whilst informing them about their plans to leave: *She yelled, and yelled - and screamed out, and I mean screamed as though someone had hit her from behind or whatever. But it was totally unexpected (S4).* Some staff expressed their surprise and disbelief at the extent of residents’ reactions. Even within the accounts of individual participants there were splits in the interpretations of residents’ feelings, almost a denial of the observed effects: *When I told him I was going he sort of went "Oh no - don't want to talk about it, don't want to talk about it - and he reverted to that sort of child-like behaviour... He cried a couple of times on the day that I was leaving, but again it's hard to know whether it's sincere crying because that's the thing to do, or whether he does really have feelings and emotions (S15).* A group of participants referred to the withdrawn behaviour of residents in reaction to hearing about staff’s departure: *His behaviour changed. Throughout that week he never opened his mouth. He used to sit in the corner and have his lunch on his own (S7).* Others recognised the

residents’ regression in response to hearing the news (and in the aftermath of being told): *Apparently she became very withdrawn, repetitive speech became more. A very articulate lady, but when people spoke to her she would switch off, and start doing all the repetitive stuff (S1).* A group of key workers also noted a combination of responses in key clients: *I remember her crying an awful lot, and she actually detached herself from me before I left. She didn’t want to talk to me and really reverted back to how she had been (S6).* Finally, one participant described the resident’s shock and surprise, *T. was just really shocked - and she said to me “I’m really shocked” (S18).* This suggests that, for the client, the news of the key worker’s imminent departure was completely unexpected.

## **2) Perceived impact of separation on residents**

There are variations in staff’s perceptions of the impact of their departure on residents. This category is therefore sub-divided to reflect two opposing dimensions of the staff’s accounts.

### **2a) Minimising the emotional responses of residents**

#### *Definition*

A central and recurring finding in these results was the perception of the majority of participants that residents were almost unaffected by the loss of their key working relationship. There were various reasons given for this assumption. These include: the staff’s difficulty with discerning the feelings of residents; their assumptions that

people with learning disabilities may not have the capacity to grieve; their underestimation of their own importance to residents; and their belief that people with learning disabilities become 'numb' to the experiences of loss in their lives.

### *Elaboration*

Many staff expressed a sense of disbelief that residents may be emotionally affected by losing their key working relationships: *I don't see it (grief) and they don't verbalise it - you know you don't see people going through this process of grief (S4)*. Even in the light of evidence of residents' manifestations of distress, the staff sometimes found it difficult to attribute emotional reactions to clients: *He went down hill after that (after the key worker left). He was putting on weight just as I left and his epilepsy got worse. He probably had two bad years after I left ... his mum connects that with me going. But I mean it (epilepsy) always gets worse for a while and then you change the medication and it gets better again (S3)*. Some participants seemed to simply underestimate their own importance to key clients: *I don't think he missed me. Em I honestly, all my experience of working with clients, I don't think any client has ever missed me (S3)*. Others appeared to have difficulty acknowledging that people with learning disabilities could experience grief. In fact a small group of staff related the resident's 'diagnosis' or 'syndrome' to a lack of emotional insight or experience: *He probably won't be bothered like that - I could have been anyone. I did tell him I'm going, but he just carried on licking his fingers and staring at the wall... I'm not sure he would have understood the concept of going. He was in his Autistic world (S2)*.

Finally, many of the participants ‘explained away’ the emotional impact of separations with the suggestion that the residents had become used to the process of separation: *You see her kind of adapt when staff come and go, and it’s like “OK here’s another person”... but she’s probably just become accustomed to it all (S12).* These staff were indicating a sense of residents becoming hardened to the impact of losing key workers, having experienced many losses in their lives.

This discrepancy between the observable impact (category 1), and the perceived lack of impact on residents (category 2a) to separations from key workers, is clearly demonstrated in the example below (Box 3). Two staff (S9 and S10) were interviewed about their respective interpretations of one resident’s (T) reactions to losing the key working relationship with S10. At the time of interview, participant S10 had recently left T, and was employed in a new unit. Participant S9 had remained with this resident and was therefore able observe T’s reaction to losing his key worker.

### Case Example

#### **Box 3.**

#### **Two staff describing the reactions of the same resident (T) to separation from his key worker.**

The perceptions of key worker who had left T.

*I knew that T. (key client) wouldn't be affected emotionally. I knew that it might stress him out a bit, but as for kind of feeling a loss, he wouldn't really feel a loss. I really felt that he would only really miss the fact that there was something there for two years, and now it was gone...It was kind of a comfort thing, there was something missing, and that was me - I could have been an object. I knew that he didn't really understand emotion (S10)<sup>a</sup>.*

The observations of the staff member who had observed T's reaction.

*T. became really quiet. It became really noticeable that he was really unhappy. He completely withdrew from what was going on. It was unbelievable. He was unhappy all the time. He wouldn't eat at the dinner table. He would throw his plate on the floor. We couldn't believe it (S9).*

#### Note

<sup>a</sup> See Appendix 12 for a copy of the original full transcript of the interview with S10, as an example interviews with all staff participants.

#### **2b) Interpreting the painful reactions of residents .**

A few participants did interpret the more difficult and painful feelings of residents in the event of separation: *She was quite sad - she knew I was going. And sometimes I think she was quite angry as well, because she knew she was a resident and I was a staff member and it was going to happen - but it had happened so many times (S12).*

In fact, a small group of staff (including S9 above) were asked specifically about their

observations of residents who had lost key workers in the past: *She used to get very attached to members of staff, and she used to mention members of staff who had left years ago (S1)*. These staff seemed able to use their experiences of being around residents in the aftermath of a previous change of key worker, to understand their less obvious expressions of grief.

### **3) Diminishing the key working role**

#### *Definition*

The theme of diminishing the key working role does link to category 2a (above) relating to the staff’s perceptions of little impact on residents of ending their key working relationships. However, it is reported separately in its capacity to reflect the lack of awareness of some staff about their own importance to residents.

#### *Elaboration*

Many of the participants’ accounts reflect a sense of them ‘depersonalising’ themselves in their key-working relationships, describing themselves in terms of their roles rather than their personal characteristics: *The clients might miss the times, but I mean they might not relate the times to the people (S3)*. Some staff felt that they were filling a gap in the resident’s life, which anyone could fill: *You felt that someone else could fill your shoes very easily, it wasn’t necessarily that he would miss you as a person at all (S5)*. In fact over half of the participants suggested that it was the times, or the activities (rather than themselves as individuals) which the residents missed: *I*

*mean he reacted to it the same as if anything was missing. I mean if you took away his old shoes because they were knackered and had holes in.. he wouldn't like it (S10).*

There was an implicit message in many of these accounts that anybody could fulfil the 'functional' role of the key worker.

Occasionally, participants actually described their sense of being devalued at the time of leaving key-clients: *A hole in his life - can be filled by someone else. It felt as if I was on a conveyer belt, and someone else was going to come behind me and go through the exact same process. It was horrible (S7).* This was particularly the case when there was no opportunity to mark the end of that relationship: *I felt very undervalued ..I think how other people react to that sort of change as well - it's like you're nobody, well not necessarily that you're nobody - but no-one's (S12).* In the absence of an observable reaction in key residents at the time of saying good-bye, some participants reported 'discovering' the impact of their departures from other staff who had witnessed the residents' reactions: *I heard (from the remaining staff) that they (the residents) were very sad, and it made me feel quite good actually. Everyone needs a bit of appreciation don't they? (S16).* These comments reflect the staff's reliance on others to remind them of their own value to the resident, as though they were unable to grasp an idea of their own worth without some clear evidence, or obvious acknowledgement.

#### 4) Guilty feelings.

##### *Definition*

Many participants communicated their regrets about ending relationships with key clients. There was an overwhelming display of guilt about 'abandoning' residents, and breaching promises of ongoing contact. There was also a wider expression of concern about relinquishing the team and the 'sinking ship' at a time of mass staff turnover and little continuity of care.

##### *Elaboration*

One participant explained the demands of the context of residential care-work, and his awareness of a 'disservice' to residents: *I think that it is one of the greatest failings of the community care system is the staff-turnover. I mean in the first two years of that organisation we had over 300% turnover of staff. We had a staff team of 11, and we had something like 78 different members of staff in three years - for five residents (S17).* Indeed many staff communicated their feelings of personal responsibility for supporting residents. Those who recognised the impact on residents of the news of their impending separation indicated their remorse: *That made me think "Oh gosh, I shouldn't be going, I'm letting her down - she's gone backwards and it's all my fault" (S6).* Some staff displayed their own sense of indispensability, describing their concerns that replacement staff would perhaps fail to recognise the residents' needs: *I worry about her maintaining her skills (S4). I worried that the next person to step in to my shoes would not be so patient (S10).* These concerns contrast with the



sentiments described above (category 3) suggesting that anyone could fulfil the key worker’s role.

Finally, a small group of participants displayed their guilt about letting the residents down after they had left: *I’d promised I’d take him out regularly, but even now I haven’t and I still feel guilty when I see him (S3)*. It was implied that for these participants the relationship had terminated when they had left post - physically and emotionally.

### 5) *Missing the residents*

#### *Definition*

This category was developed to elucidate the painful feelings identified by some staff in response to separations from key clients. In many ways these sentiments mirror the feelings expressed by residents in Study One, and yet the staff’s accounts suggested that they had not anticipated their own painful feelings.

#### *Elaboration*

This group of participants often described their feelings in terms of difficulties for both the residents and themselves: *It’s a bereavement in a way - for T it’s a bereavement and for myself as well really, I mean you’ve lost a good friend haven’t you? When I saw her afterwards, I was really choked up (S1)*. Some staff explained their comforting associations with past residents and homes: *I really do miss him and*

*I have found that after a horrendous day here, my automatic reaction will be to go there (to the staff member’s previous workplace). I don’t even think to myself that I’ll just pop in. I’m just driving and then suddenly I find I’m on that road (S11).* There is a sense of staff sometimes not wanting to close that chapter of their lives: *A lot of me is in the home, and I don’t want to cut off completely (S15).* One participant reflected on his own delayed reaction, and his inability to process his own feelings at the time. *It does sound sad doesn’t it when you think about it (laughs nervously). You don’t think about it as much when you re working though (S16).*

Finally, one participant’s account powerfully communicates the tangled grief of staff and residents as a result of losing a reciprocally important relationship. The reaction of each one mirrors the feelings of the other. This participant described her visits to the day-centre to collect her new residents, where she often saw her old key client from a previous work place: *I would pick our clients up to bring them home, and he would automatically pick his coat up, and take his bag and want to come with me... So it was very, very hard from my side because I would still see all of them, and like I would walk in and W. would follow me around and then I’d say “Bye then”. And I’d drive home and think “I want to go back”(S11).*

## 6) *Dangerous liaisons*

### *Definition*

The theme of danger relating to over-involvement with residents developed from the accounts by many staff of the detrimental impact of key working on their own lives. These participants referred specifically to the all-encompassing nature of residential care-work, which has forced them to protect themselves. However, there was also an element of uncertainty about how close to allow oneself to become to residents.

### *Elaboration*

One participant described her lessons from experience of 'getting your fingers burnt': *You have to be very clear where the boundaries are - and not to get swallowed up by the client... I had a very bad experience where I became far too involved with just one person a multitude of reasons meant that I took four months off work (S12)*. Many staff described their difficulties maintaining boundaries within the key working relationship, and their almost involuntary attachments to residents: *It's hard to be distant (S16)*. However, a group of participants were very clear-cut about their distinction between work and developing relationships: *Key working is a piece of work. It's not supposed to be fun... I think part of the job is not to get too attached (S3)*. There was a sense of effective practice being the result of emotional distance from residents: *You need to be more professional - less involved (S5)*.

Nevertheless, one key worker expressed her uncertainty about developing relationships with residents in the knowledge of real issues of staff turnover, and

repeated losses in the lives of people with learning disabilities: *It's very difficult because you don't know how close to get to people and you think about moving on in a few years time, and should you constantly give that closeness, and then take it away, or should you be quite distant and be there for every day things and keep your distance? ... I think you can't be distant in this work, because it's their home and you can't just push someone away, and be distant - you have to be close (S6).*

### **7) Passing the parcel**

#### *Definition*

An important area of this research relates to the impact of staff's role changes due to team restructuring in the units. In Study One, this has been referred to as 'pass the parcel'. The present category explores the experiences of those staff who have been asked to 'pass on' their key-client to another staff member. This process seemed to impact on staff in various ways, ranging from difficult and jealous feelings to thoughts about the positive effects of change.

#### *Elaboration*

A group of staff described their sometimes jealous feelings about new staff taking over and making decisions for the resident: *It was quite difficult seeing P. go to his new key worker instead of me - I'd be thinking "I want you to come to me - it's not fair". But obviously I had to accept that (S11).* Sometimes they wondered whether the new key worker was doing the job properly: *You'd see his room sort of change around, and you'd be thinking - did he want that? (S16).* This concern about the

capabilities of new key worker even resulted in some cases in the staff unthinkingly continuing to do parts of their old jobs themselves: *It was strange - little things like haircuts. It was almost like I would just do it, and then I would think “oh no, I’m not supposed to do that” (S11).* One key worker talked about her own feelings of failure arising from being asked to change role: *I suppose I was disappointed, and maybe I felt a bit of a failure too at the time, I thought maybe you know - it’s through me that I’ve got to move on, although I knew at the time I was asked by the manager - but you do feel a bit of a failure, you feel perhaps it could have been somebody else that could have done it - although in my mind I wasn’t ready to move on (S13).*

However, many participants did feel that change was positive and healthy for all concerned (including some of those who had more painful reactions). It was suggested that this process allows for new influences and fresh ideas, and prevents over-dependence in residents. There was also a view strongly held by some of the staff that this process eased the experience of eventual separation at the end of the key working relationship: *It’s much better if people know from the outset that they are going to be with a key worker for eighteen months - and everyone knows then everyone is going to swap (S18).*

## Summary

A central consideration of this research concerns the emotional impact of ending the key working relationship. The final analysis therefore draws together the last seven *researcher categories* relating both to the feelings of staff, and to the staff’s perceptions of residents’ reactions to separations. By a process of *axial coding* those seven categories were linked and combined to generate three *higher-order researcher categories*, as follows:

1. **Attachment and separation** - missing the residents; guilty feelings; observable impact of separation; passing the parcel; dangerous liaisons (referring to difficulties maintaining boundaries at work).
2. **Denial** - minimising the emotional responses of residents; dangerous liaisons (relating to denial of emotional involvement with residents).
3. **Self-devaluation** - diminishing the role of the key worker; passing the parcel.

## *Elaboration*

The first higher-order category, ‘attachment and separation’, indicates the reality of a situation wherein, despite the boundaries and limitations of their roles, the staff do often develop very strong attachments to residents. These attachments may differ in form and intensity from the experiences of residents (as indicated by their descriptions of the key working role), but they are nevertheless evident. They seem to result in the staff’s sentiments of loss and guilt in the event of saying goodbye to key clients; their

open appreciation of residents’ reactions to separations; and their difficulties with standing by to watch as someone replaces their role.

The second higher-order category, ‘denial’, refers to the various methods adopted by staff to defend against the painful reality of their importance to key-clients, and the grief reactions of residents to repeated experiences of loss. This leads to a process of ‘splitting-off’, or denying the evidence of residents’ distress, and failing to acknowledge their less obvious communications of grief. It also accounts for the efforts of some participants to uphold a clear definition of key working as ‘a job’ with a clearly defined aim of emotional distance.

Finally, the category of ‘self-devaluation’ relates to the staff’s tendencies to minimise their roles and responsibilities in relation to clients. The participants made repeated references to their basic roles, and to their beliefs that anyone could take their place. Often they suggested that their departure would not have mattered to the client, as long as their (the clients’) needs were met. This lack of value attached to their personal contributions to relationships, may also reflect a process of internalising the devalued nature of their roles (they too are sometimes unthinkingly passed around the service), in the face of limited expressions of appreciation by clients, and little recognition of their contributions to the wider service.

An underlying theme or *core category* which emerges in the staff’s accounts parallels the concept of dependency, described in Study One. There seems to be a **fear of**

**dependency** which forms the basis of many of the staff’s interactions with residents. The staff are constantly faced with the painful discovery that is inherent in their work with clients and is no-one’s fault - people who cannot look after themselves need other people to look after them. The permanent needs of people with learning disabilities mean, in the majority of cases, that they will never live independently as adults. In many cases the staff have developed a sense of indispensability in relation to key-clients, which is often too unbearable to manage. This can lead to their development of defensive techniques which serve to mask the reality of their importance to the residents for whom they care.



## CHAPTER FOUR: DISCUSSION

### Overview

The aim of this research, structured as two parallel and complementary studies, was to explore the impact both on people with learning disabilities and staff, of ending key working relationships. A sample of 12 residents and 18 staff was interviewed about their previous experiences of separations. The interviews were analysed using a grounded theory approach. This chapter discusses the findings from both studies in relation to the three main research questions. These comprise:

1. How do residents and staff describe their key working relationships?
2. What were the processes involved in ending previous key working relationships?
3. What was the emotional impact of separation on residents and staff?

The main analysis identified a six-part 'typology' of psychological processes describing the experiences of residents and staff: 'loss and grief'; 'attachment'; 'denial'; 'helplessness'; 'self-devaluation'; and 'acceptance and acquiescence'. This typology was then incorporated into a final grounded theory account, drawing on two core concepts termed 'dependency' and 'fear of dependency'. The nature of residents' life-long dependency needs was considered, and the staff's attempts to defend against this dependency were explored.

The findings of the present study are discussed in relation to the literature reviewed in Chapter One. However, in the absence of previous research relating directly to the experiences of people with learning disabilities and staff at the end of their relationships, the discussion also draws on literature from several related areas: the termination of therapeutic relationships, models of grief and loss, and social processes relating to residential care staff and people with learning disabilities respectively. The chapter ends with a review of the methodological limitations, suggestions for further research, and an outline of the wider research, clinical and professional implications of this study.

### **How do residents and staff describe their key working relationships?**

Perhaps one of the most surprising results of the present research is the finding that the residents’ accounts of the key working role and relationship correspond quite closely with those of staff. The staff’s interpretations of relationships with clients do to some extent match the findings of Clegg *et al.*’s (1996) study, which generates a four-part classification of key working roles. This includes the ‘provider’, ‘meaning maker’ and ‘companion’, terms which match the data from the present study. However, Clegg’s fourth category ‘mutual’ is replaced here by the role type ‘family member’. The present research does differ from Clegg’s findings in that participants defined their key working relationships according to a number of dimensions. This indicates the dynamic nature of the key working role, which incorporates a variety of

roles, responsibilities, and interactions at different times. In contrast, Clegg found that these role types fell neatly into mutually exclusive categories.

Another important element of the present research arises from the examination of residents’ own interpretations of their relationships with staff. The residents were realistic in acknowledging their dependency on staff. Their awareness of their own needs is reflected in their descriptions of the ‘provider’ and ‘nurturer’ roles of staff. The former provides practical and physical support, the latter provides emotional support. These categories almost match the staff’s descriptions of the ‘provider’ and ‘meaning maker’ roles. Arguably the residents’ dependency on staff is reinforced by the setting, wherein people with learning disabilities are often not encouraged to depend on themselves or on each other (Clegg, 1993).

One of the more telling findings in the residents’ accounts is their appreciation of being treated ‘*kindly*’ by staff, referred to in the ‘nurturer’ category. Sadly, the significance for the participants of being treated with some sensitivity may reflect a very poor sense of self, and a history of impoverished care (Bicknell, 1983).

Both residents and staff referred to the companionship element to their relationships. There was evidence of appreciation on both sides of the relationship, of each other’s personal attributes and characters. Many residents described their experiences of staff by drawing on superlatives. There were references to the key worker as ‘*my best*’ or ‘*closest*’ friend. This finding supports the literature on the paucity of social

relationships for people with learning disabilities, and the importance of staff as friends providing intimacy in their otherwise isolated lives (Firth & Rapley, 1990). However, the staff's interpretations were qualitatively different from those of the clients. In the staff's accounts there was only an implicit recognition of the key working relationship as comparable to friendships outside of work. This lends support to Atkinson's (1989) contention of the importance of clarity and realism about staff's relationships with clients, to avoid later misunderstandings.

The residents' experiences of isolation and lack of close personal relationships is also apparent in an analysis of their accounts of the role of the key worker as 'partner'; as 'co-dependent'; and as 'constant'. These categories relate to the idea of staff replacing absent relationships, and enabling the residents to experience a form of intimacy, often otherwise missing in their lives. Perhaps the most poignant description falls into the category of 'partner' role. This description reflects the residents' fantasies of more intimate liaisons, or sexual relationships, with staff. These thoughts might arise out of their confusion about the closeness of the key working relationship, which may be experienced through the physical or emotional care provided by key workers. It is important to state that the sexual feelings of clients are generally often feared and repressed in services for people with learning disabilities (Craft & Craft, 1981). It is often the case that clients are not encouraged to develop relationships even between each other. This suggests that these desires for staff may arise from attempts to repress the resident's normal, human urges for closeness and intimacy with any other person, including fellow residents.

The category of 'co-dependent' also indicates perhaps a different kind of fantasy, one of reciprocal support, and sharing of problems - a wish to feel needed and to be appreciated for looking after the staff. However, the residents' ideas about familiarity and reciprocity in key working relationships mirror, to some extent, the accounts of staff who describe the key working role as 'family'. Some staff indeed made references to their experiences of clients '*almost*' replacing their own (the staff's) family members. Interestingly, these accounts of family roles were interchangeable, with staff taking on the role either of child or of parent in these relationships. In the 'child' role the staff experienced being looked after, particularly by older residents. This can be explained as their powerful counter transference feelings towards clients who wish to parent the staff. In the parent role, by contrast, the staff were aware of the more dependent needs of clients. Perhaps this was all too painful in its reality that these are adults who will almost never gain independence, and break free from their primary care needs.

Finally the 'constant' role of the key worker is expressed with gratitude and appreciation of someone having a longer term perspective on the residents' lives. The importance of this constancy is perhaps unsurprising in view of the abundance of literature relating to high staff-turnover and transient relationships for clients living in residential settings (Allen *et al.*, 1990; Clegg & Lansdall-Welfare 1995).

Since the staff in this study chose to describe relationships predominantly with more able residents, it is difficult to discern the potential association between the client's

level of disability and the key working relationship type, as Clegg *et al.* (1996) suggest. This could be explored more closely in future research by careful examination of the disability and drawing links with staff's accounts. There may also be a conditioning influence of institutional backgrounds affecting clients' views of the roles of staff.

### **What were the processes involved in ending key working relationships?**

The residents' accounts were replete with recollections of sudden and unprepared-for endings of key working relationships. There was a sense of the unexpected nature of those endings leading to shock, confusion and bewilderment. One could argue that the ending may have appeared even more sudden to the residents because of their particular need for lengthy preparation and the provision of repeated and clear messages over time (Emerson, 1977). However, these references to unforeseen separations are supported by the accounts of those staff who reported either not having said goodbye at all to clients, or described a 'gradual preparation' with varying ideas about what constitutes gradual including, in some cases, giving only a few day's notice.

Experiences of unanticipated separations from staff will arguably have had a significant effects on residents. As Zinkin (1994) suggests, "there is a difference between bringing something to an end and just stopping" (p.18). According to

Wortman and Silver's (1992) model of factors relating to adjustment after loss, the impact on clients will depend largely on whether it can be incorporated into their 'view of the world' and their expectations of events. The suddenness of loss and the conditions under which it is perpetrated can contribute to the shattering of this 'world view' about the predictability of events. Those losses which are perpetrated 'carelessly' or without time for processing will be especially likely to violate assumptions of predictability. People may come to see the world as uncontrollable. This model can be related to a theory of helplessness in clients, discussed in more detail below.

The issue of sudden endings links also with the ideas of both staff and residents about ongoing contact, or 'keeping in touch'. The residents in this sample seemed satisfied with even the briefest contact. However, a painful reminder of the imbalance in the key working relationship emerges in their realisations that it may be beyond their control to renew contact. The staff will usually be able to locate the residents, but the residents will often have no knowledge of the whereabouts of staff after their departure. In fact the staff in this study displayed their uncertainty about ongoing contact with clients. There was an ambivalence about the correct procedures, represented in the dichotomy of responses described as 'clean breaks' versus 'maintaining contact'. Some staff had thoughts about moving the relationship to a different level, referring to plans for developing friendships with clients. In their study of enmeshed key working relationships, Clegg and Lansdall-Welfare (1995) endorsed a plan for informal ongoing contact to ease the process of transition. However,

Siebold (1991) describes separation at the end of therapy, relating the wish to maintain relationships to powerful ‘counter-transference’ feelings experienced by the therapist. This could be interpreted to suggest that the staff in the present study were sensing the residents’ needs to hold on to their key working relationships. Nevertheless, Zinkin (1994) suggests that even if there is some form of ongoing relationship with clients after terminating therapy, a process of mourning is still needed because “something is indeed lost forever” (p.20).

The issue of deciding the status of potentially ongoing relationships between staff and clients can be related to the reality of residents’ lack of control in this decision. Rosenberg (1990) points out that the staff take the lead in establishing the structure of the relationship - deciding what will be done, when it will be done, and how it will be done. It is the key worker who must also decide when, and how, to move away from that relationship. This imbalance may lead to feelings of failure and hopelessness in the client. Conversely, the staff member may feel drained, imposed upon, and manipulated; and yet both may feel that neither could function without the other.

Many of the staff reported their attempts to ‘mark the end’ of the key working relationship. However, for some of those staff, there was perhaps an avoidance of addressing the pain involved in saying good-bye. For example, a clear pattern in their accounts relates to the brief and often ‘pleasant’ or ‘happy’ nature of those marked endings. There were parties, gifts and meals out. In some cases these markers were considered to be ‘*enough*’. Arguably, some of the staff had been drawn in to creating



jokey, cheery atmospheres in an unconscious attempt to defend against the impact of loss, and the feelings that working with handicap arouses (Sinason, 1992).

Residents did often report a happy end, but clearly this did not mask the pain of separation. There are certainly questions around the effects on residents (and staff) of avoiding addressing the more painful aspects of separation. Again, in discussing the termination of therapy, Siebold (1991) refers to anticipatory grief theory to suggest that the environment in which loss occurs will influence the way the individual processes the event. This theory suggests that the process preparatory to mourning is significant, and that mourning may not begin until after the loss has occurred. This theory therefore emphasises the importance of assisting the patient to face the painful reality of ending: a process which can obviously take a great deal of time. According to Siebold, one way of helping the patient to accept this reality is to give her sufficient facts so that she can master the news, and then to allow her as much time as possible to process the information. Interventions should include sharing facts about the staff's departure and exploring the clients' less conscious feelings about the event. Anticipatory grief theory can be applied to the context of ending key working relationships, with the implication that planned ending procedures would be important not necessarily to mask the pain, but rather to encourage the beginning of a process of adaptive grieving.

Kauffman (1994) looks more specifically at the management of grief in residential settings, and indicates the importance of a 'supervisory process' for departing staff.

He suggests that there should be a procedure for handling the staff's leaving, requiring a routine based on agency policy and protocol. This would facilitate appropriately planned endings. However, the staff in the present study reported little or no support from supervisors or service managers. In some cases this lack of support and the ensuing experiences of isolation in the event of ending key working relationships seemed to reinforce the participants' feelings about the devalued nature of their work. Numerous studies have related staff stress and lack of support to staff behaviour in residential settings, reflecting the importance of special attention to adequate supervision for key workers (Rose *et al.*, 1994). Indeed, as George and Baumister's (1981) study of staff stress suggests, this lack of support inevitably leads to excessive rates of staff-turnover in residential settings.

According to Rosenberg (1990), support in terms of facilitating grief for lost relationships assists in the development of new ones. The staff have personal needs of their own, some of which must be met in the work setting if they in turn are to meet the needs of residents.

Ironically, in some settings the clients had taken it upon themselves to 'appreciate the needs of staff'. Many residents displayed their readiness to take on the perspectives of their key workers, offering valid explanations for their decisions to leave. However, it may be necessary to take caution in interpreting these reactions, especially in light of research which has shown that people with learning disabilities are often likely to give socially desirable responses to questions about their own experiences (Zetlin *et al.*,

1985, cited in Barrett & Jones, 1996). It is possible that the participants in this study did not feel able to express their true feelings or knowledge, but rather that they felt able to express what they believed was wanted of them.

### **What was the emotional impact of separation on residents and staff?**

The present study identified a six-part ‘typology’ of psychological processes describing the impact of separation on residents and staff. Two core concepts: dependency and fear of dependency seem to underpin these processes, and form the basis of this grounded theory account. Each of these aspects of the analysis is discussed in turn below.

#### ***Loss and Grief***

Many of the residents were articulate and open in their expressions of loss and grief arising from the departures of key workers. Every one of the participants described feelings of sadness, hurt and pain arising from this event. Furthermore, the residents’ automatic associations between separations from key workers and experiences of people dying confirm Cochrane’s (1995) suggestion that these losses may evoke bereavement responses. The finding of ‘grief reactions’ in residents is also supported by the staff’s accounts of their observations of residents either on receiving the news of impending separation, or in the immediate aftermath of losing those relationships.

The contention that people with learning disabilities are treated differently from the 'normal' population during critical life events is outlined by Oswin (1981). It therefore seems important to review the grief reactions of clients to losing their key workers in light of an available model of 'normal' grief. According to stage-theories of grief<sup>3</sup> such as Bowlby's (1980) model, the first stage of grief is described as denial of the loss and numbness to the impact of grief. This stage is perhaps evident in the staff's accounts of residents not showing their grief, just 'carrying on' as though unaware of what was happening. The second stage is described as searching, where there is a strong urge to re-unite with the lost person. In the present study, this may partly account for the finding that the residents wanted to make contact with their key workers, even briefly, just to see them again. Bowlby suggests that the individual may experience anger during this phase, as a result of the loss. However, the residents' accounts are perhaps significant in their absence of any anger directed towards staff. This may be linked to Sinason's (1992) suggestion that people with learning disabilities must put on a 'happy face', be pleasant for fear of being rejected otherwise by those on whom they depend. Bowlby's third phase of grief is characterised by mourning and depression. This is supported by the residents' own accounts of crying, not being able to stand the pain; or as staff point out, regressing and withdrawing into silent worlds.

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<sup>3</sup> In the past, stage theories of grief have been referred to quite rigidly, with an expectation that a person will move sequentially through the stages. However, they are more often referred to today for an understanding of the range of possible feelings which someone may experience as a result of loss or grief: . . . . .

There was an awareness by some residents that others might not necessarily recognise their pain, especially if they were not grieving in the usual way. Perhaps it was difficult to express in terms of abstract feelings, but the residents were able to draw insightful links between their physical or somatic symptoms and their reactions to separations.

This finding links with the literature which refutes suggestions that people with learning disabilities do not have a complex emotional world. Barrett and Jones (1996) highlight the differences between their inner worlds and those of their non-disabled counterparts. Abstract concepts like time and future may not make sense to clients, and distinctions between reality and fantasy may be harder to make. The effect of these cognitive limitations might even result in more frightening and impoverished inner worlds. Barrett and Jones also suggest that the quality of early social interactions will impact on the clients’ readiness to share their feelings with others. Those who have developed a sense of being wanted may be more ready to share. Generally, residents may be using qualitatively different emotional processes to other people, so it can be more difficult for them to share their feelings with others, and for staff, therefore, to understand their grief. These ideas overlap with Sinason’s (1992) description of emotional intelligence - where a person can be emotionally aware and knowledgeable, despite major deficits in cognitive intelligence.

According to Bowlby’s (1980) stage-model of grief, individuals will hopefully enter a final stage of grief, referred to as ‘acceptance’. At this stage they will be able to break

down their attachment to the lost person and start to establish new relationships with others. This final stage of grief is crucial. Whether or not the residents will enter this stage is arguably contingent on the way their grief is handled by those who surround them. It may be a function of the way the good-bye process is handled as 'anticipatory grief theory' suggests (Siebold, 1991). Nevertheless, it is important to state that although so much of the residents' recollections and reflections were painful and poignant, they also demonstrated resourcefulness: they often found their own ways of moving on, and were able to develop new relationships with staff.

### *Attachment and separation*

The staff's reactions to separation sometimes paralleled those of clients, although they were usually presented as less severe and frequent. These include: sadness; missing the residents and reluctance to hand over responsibility of clients to their new key workers. Some staff also described their 'guilty feelings' and regret about abandoning needy clients. There were also concerns that the residents would regress as a result of their departure, indicating those staff's feelings of indispensability. This finding is supported by Lanyado's (1989) study of the impact of separation on staff caring for children who move on to new placements. These feelings combined display the reality of the staff's attachments to key-clients, despite their attempts to sometimes minimise those relationships.

Siebold (1991) describes the impact of separation from clients focusing specifically on the therapist's response at the end of therapy. She argues that leaving can evoke a sense of missing out on the future development of patients. Therapists invest time in enabling the patients to achieve greater satisfaction from life. The therapist not only struggles with omnipotent and sad feelings relating to ending treatment, but with role credibility as well. The feeling that you are the only one who can help the patient is a common transference experience. According to Siebold, the process of handing over the patient to someone else may also may cause anxiety in the new therapist, particularly when developing a relationship with a patient who has only recently ended work with another therapist. Presumably these insecurities may arise when residents move between key workers.

### ***Denial***

There is a clear discrepancy between the residents' accounts, the observable impact of separation, and many of the staff's misperceptions of clients' grief. This discrepancy forms one of the central findings of this research. Although a small group of staff clearly noticed and acknowledged the painful reactions of clients to losing their key working relationships, many greatly underestimated the residents' grief. It has already been suggested that it is possible that the staff were sometimes unable to recognise the resident's grief because they may not verbalise it. However, the finding that even within the account of one individual staff member, there were variations in their thoughts about the impact of separation on residents, does suggest an element of

'splitting off' the more painful parts of their experiences and recollections - a defence mechanism described by Menzies (1970) in her description of social defence systems in nursing staff. This denial was also apparent in staff's accounts of limited emotional involvement with clients, and the purely 'job-status' of residential work, contrasting with the theme of attachment described above.

What influences this denial in staff? It may be a case of an attitude towards people with learning disabilities that "they do not have the same feelings as the rest of us" (Oswin, 1991 p. 26); alternatively, grief and disability create fears and uncertainties in people, leading to 'sweeping under the carpet'. Either way, it means that people with learning disabilities are not always appropriately supported through their grief (Oswin, 1991). This supports Rosenberg's (1990) 'co-conspiracy for denial' theory, whereby staff seem to avoid confronting the painful reality of residents' grief, by avoiding the tasks necessary for successful adjustment, such as preparation and an opportunity for residents to reflect on their feelings. This may also explain the finding in the present study that some staff did not even say goodbye to clients before they left.

Lack of sensitivity to the grief of people with learning disability does not arise necessarily from unkindness, but perhaps more from a denial of feeling (Oswin, 1991). The denial or repression of one's feelings commonly occurs amongst staff who work in emotionally stressful institutions and can result in staff ignoring the grief of the client, or subduing their own rising feelings of tenderness. Menzies' (1970)



account of defensive techniques in the nursing service highlights both the pain and distress of breaking relationships, and the importance of stable and continuing relationships, so often implicitly denied by the system. The characteristic feature of the 'social defence system' described by Menzies, is its orientation towards helping staff to avoid the experience of guilt, anxiety, doubt and uncertainty of working within an institution. Arguably, these defence mechanisms assist the staff in their avoidance of the basic anxieties evoked by their contacts with clients, and they therefore bring us back to the roots of excessive staff turnover. According to Bion (1955) an understanding of defence mechanisms in the functioning of a social institution is an important diagnostic and therapeutic tool in facilitating social change. There is a need to understand these unconscious processes in the pursuit of facilitating organisational change.

### ***Helplessness***

The residents reflected on various aspects of their separations to suggest their often underlying sense of helplessness and 'lack of control' in their experiences of 'inevitability' about losing staff. This helplessness was apparent also in their accounts of being passed around the service, and of not being able to renew contact with key workers. Even some of their reported coping processes relied on staff, as though they had internalised a dependent view of themselves as clients. There are many facets to this helplessness, some of which have been referred to briefly already, but the

literature identifies a number of psychological processes which lend themselves readily to these findings.

According to Swain (1989) the ‘learned helplessness’ model (Seligman, 1975) can be drawn on to explain the psychological consequences of powerlessness as important dimensions of the roles imposed on oppressed groups - the feeling that things are the way they are and that one simply has to accept them because one does not have the power to change them. Swain contends that helplessness is a psychological state that can result when events and outcomes are uncontrollable, that is, independent of a person’s responses and behaviour. This model suggests that helplessness should be viewed as an aspect of social relationships and power imbalance between people.

This model of helplessness indicates a need for careful consideration of the conditions which deny people with learning disabilities even elements of control and predictability over their own lives. If ‘learned helplessness’ can be viewed as a social relationship, then it is surely reinforced by a setting which accepts lack of preparation and warning about events which will impact on the lives of residents.

Another potential contributing factor to this condition of helplessness is suggested by Perske (1972, cited in Craft & Craft, 1981), who claims that systems of residential care are not good at enabling people to become more self-sufficient and to assume more personal responsibility. This idea is supported by the finding in the present research that clients were very dependent on staff for support, comfort and

reassurance. Although people with learning disabilities spend much of their time in the company of large groups of people, the nature of the service setting can create an isolating environment. In their analysis of staff-client interactions, Clegg and colleagues (1991) strongly question how much encouragement is given to residents to support one another rather than to seek help and support from staff.

### ***Self-Devaluation***

There is a recurring theme of self-devaluation in the staff’s representations of their own roles and responsibilities in relation to clients. This was represented in many of the structures and processes of the different services. Staff seemed to feel that anyone could ‘*fill my shoes very easily*’; that they wouldn’t be missed. Many of their clients were apparently unable to show appreciation of their key workers, or to display their feelings of sadness at the end of these relationships. In these cases, some key workers relied on the reports of other staff to prove that they had indeed had an impact on their former clients. A group of staff participants indicated that the absence of appropriate goodbyes, their sense of being ‘passed around the service’, and the lack of support for their own feelings all fuelled their feelings of insignificance to clients. Interestingly, these accounts also parallel the experiences of residents who had felt embarrassed to be passed around services, with little opportunity to say goodbye, and a sense that they did not matter in the process.

It may be argued that the finding that many staff seemed to 'diminish the role of the key worker' can be understood also as a defence against the pain of knowing how important they do become to residents. In this case it would fit with the theme of denial represented above. However, there does seem to be something additional to this strategy of denial, which is explained by Menzies (1970) in her analysis of the roles of nursing staff, as a sense of general devaluation of the staffs' roles and contributions to patients. Menzies suggests that this lack of value results from a combination of factors: lack of an appropriate training orientation; dissipation of success with clients and satisfaction with jobs; dissipation of people's gratitude; being taken for granted; lack of value attached to their own work in hospitals; and a general lack of support and disregard for the staff's own needs and capacities.

These factors can arguably be applied to care staff working with people with learning disabilities. Indeed, there were numerous references by staff to their absence of support, their inability to recognise their own impact on clients, and to generally demanding work conditions with minimal recognition and encouragement. A simple explanation of this self-devaluation of staff may be that those who choose to work with people with learning disabilities become as devalued as the client group itself, and ultimately separation can become equated by both parties with rejection.

*Acceptance and acquiescence*

A noticeable absence of anger towards staff has already been mentioned in relation to clients' reactions to separations. However, this merits further attention in relation to the central theme of compliance and acquiescence implicit in the residents' accounts. The level of 'empathy for the key worker' was a striking facet of residents' responses. One important indication of this acquiescence lies in the category pertaining to the residents' suggestions of 'dangerous feelings'. Comments from clients such as: '*my sadness might hurt her*' (the key worker), suggest the residents' fears that there may be something damaging to others about their own verbalisations of grief.

These fears can perhaps be partially explained by Kauffman's (1994) theory on 'the psychological state of helplessness', which suggests that the client's sense of helplessness in the event of loss (also referred to above) can lead to an anxiety about abandonment. The client will therefore be afraid, not only of being hurt by others, but also of the power of her own words to hurt staff. In people in whom helplessness and abandonment predominate, language may become charged with the emotional significance of the loss.

The finding that it is difficult for people with learning disabilities to have and express feelings such as rage or frustration is not a new phenomenon. Sinason (1992) relates this finding to the client's reluctance to feel consciously how unfair it is that she has learning disabilities. This is explained by Sinason as one of three forms of secondary handicap, referred to as 'mild secondary handicap', where a person with an already

existing handicap exaggerates that handicap to make themselves as inoffensive and easy going as possible. Its most distinctive feature is the handicapped smile - “for fear of offending those they are dependent on” (p.21). It can form the so-called friendly happy demeanour of handicapped people - their uniform - disguising their underlying sadness and insecurity. As Bicknell (1983) suggests, the self-esteem of people with learning disabilities has often been so damaged by repeated experiences of separation, failure and rejection that a sociable persona is almost unthinkingly developed.

***Core concepts: dependency and fear of dependency***

Dependency is a central and underpinning theme in the residents’ relationships with staff. Whilst much of this discussion has drawn on the available literature relating to the termination of psychotherapy, there is a marked distinction between ending therapy with a healthy patient and separation at the end of the key working relationship. The healthy patient will move on and gain independence from the clinician, perhaps internalising much of what she has learned. However, the client with learning disabilities will remain dependent and her dependency will shift to the next staff member, only to be shifted again and again and again.

The nature of the client’s dependence on the staff member was referred to in Chapter One, with Clegg and Lansdall-Welfare’s (1995) description of the key working dyad. The structure and status of those relationships dictates that one member will be permanently in need of the other. This characterisation of dependency surrounding staff-client relationships is supported by the residents’ descriptions of the key worker

as their provider and nurturer - their lifeline. It is also suggested by their fantasies of more intimate relationships with key workers, mostly to replace the absence of family, friends, or partners in their lives. This dependency is also indicated by the residents’ grief over separations from staff; their need to cling to those relationships; their internalised views of themselves as helpless; and their compelling acceptance and acquiescence in the event of loss, for fear of otherwise repelling the contact of those on whom they so desperately depend.

For the healthy patient, part of the adjustment to termination of therapy will often be about developing new skills to deal with the loss. Sadly, residents will be unable to do this, because the reality is that they will always be dependent. This reality is perhaps too painful for everyone concerned and may lead to the staff’s avoidance and denial of those issues.

A central tenet of the staff’s descriptions of relationships and accounts of separations is the aspect of fear surrounding the knowledge of themselves as depended on by clients. The staff seemed to use various strategies for defending against this aspect of their relationships. They sometimes minimised their importance to clients, with reassurances that they were not emotionally involved. However, this suggestion of detachment is difficult to accept in the light of their accounts of the reciprocal nature of those attachments, and their sadness after the severing of key working relationships.

The staff’s tendencies to often avoid the tasks necessary for preparing residents for their departure seemed to arise not from their malevolence, but rather from their struggle to acknowledge their importance to clients. Defensive techniques such as devaluing their roles and responsibilities and denying the residents’ grief may be mobilised by individual staff, or collectively utilised by services to survive their otherwise unbearable fears of being depended on. As Rosenberg’s (1990) ‘co-conspiracy for denial’ theory suggests, the staff may avoid emotionally painful issues, some of which may relate to their own feelings as they fantasise about what it might be like to be disabled like the client.

### **Methodological limitations of the study and suggestions for future research**

The limitations of this study and suggestions for future research are discussed in relation to four areas: generalisability, design, measures, and method of analysis.

#### ***Generalisability***

A central limitation of this research concerns the extent to which the sample of resident participants is representative of other clients with learning disabilities. Due to the requirements of the interview, one of the criteria for participation in Study One was that the residents should have verbal communication skills. Since verbal ability often corresponds quite closely with the overall functioning of people with learning



disabilities, it is perhaps unsurprising that, in the majority of cases, the residents were also identified as able according to the dependency rating scale. Thus, the sample was biased towards clients with mild learning disabilities.

Future research into the impact of separation from key workers could be focused on more effectively involving a wider range of clients, to enable them to express their views, and to report these views as accurately as possible. For example, there should be less reliance on verbal speech, and more use of symbols, pictures and other communication aids for a more representative reflection of clients’ experiences.

In addition, most of the clients discussed by staff participants in Study Two were described as having low dependency needs and, in the majority of cases, as having speech. The staff may have elected to talk about separations from more able clients because they were more ‘favourable’ experiences. One should be cautious therefore in extrapolating the findings to staff’s experiences of separation from less able clients. Although this study attempted to conduct balanced interviews and to address staff’s experiences with a range of clients, future research could invest more time in establishing greater trust in interviews to enable participants to discuss any aspect of the ending process, however favourable. Staff who agreed to be interviewed may also have differed from those who did not, because they were self-selecting: they may have been more reflective and more prepared to talk about their experiences.

A final point about generalisability relates also to methodological issues, and the role of theoretical sampling. If early analysis can prompt further data collection, as grounded theory suggests, then fewer time constraints on the recruitment of participants could allow the research to be extended to participants with experience of different aspects of this process. For example, clients who have experienced lengthy and clear preparations for separation; or a group of staff who may have struggled to build new relationships with residents after taking over from a valued key worker could be interviewed. An analysis of these samples would broaden this account. In addition, theoretical sampling could be extended to different settings, cultures and contexts to explore a wider range of experiences of ending key working relationships.

### ***Research Design***

The extent to which the cross-sectional design of this research was sensitive to different aspects of separation at the end of key working relationships remains questionable. Both staff and residents were asked to talk retrospectively about their experiences, and in some cases it seemed difficult for participants to accurately recall the processes and feelings involved. Ideally, a longitudinal design would be needed, to follow the experiences of residents and staff before and after separation, with participants being interviewed at different points in time.

Furthermore, whereas this study extrapolated basic themes in order to highlight the overall phenomenon of separation, within a different design it may have been possible

to have compared those residents and staff who had been through a process of preparation prior to separation, with those who had not. The design of the present study limits what can be concluded about the causal relationships between different aspects of the ending process and the impact on everyone concerned.

The subject of this research lends itself readily to a more focused and systematic consideration of potential factors relating to the facilitated grief and adjustment (of both parties) to the loss of key working relationships. Perhaps future studies could benefit from the model provided by Clegg and Lansdall-Welfare (1995) in their study of attachments between clients and staff. Their study was conducted over one year and followed the relationships between key working pairs, working with clients and their staff around ongoing concerns. Such an approach would enable us to explore the perspectives of both parts of the same relationship (as opposed to exploring the separate experiences of residents and staff about retrospective relationships). It could be more clinically based, providing interventions and support for staff and residents leading to the time of the staff's departure. This may clarify some of the causal relationships between aspects of process and emotional reactions of staff and clients alike.

It is interesting to note that one of the most telling findings in the present research arose in an examination of the discrepant accounts of two staff's descriptions of the same client's reactions to separation (see Study Two: Results, Box 3). It was only by chance that both participants had decided to refer to the same client, but this allowed

for a consideration of the different perspectives of participants, unearthing information which would not have come to light through one perspective alone. Perhaps this model of investigation could be intentionally incorporated into the design of further investigations of key worker-key client separations.

Finally, this was designed as a descriptive study to explore a previously neglected area of research. The process of describing people’s experiences is an important first step. This research has highlighted some of the difficulties experienced by residents and staff at the end of key working relationships, and has considered ways of dealing with these separations in the future. This study can suggest hypotheses for future studies, which could attempt to quantify different aspects of separation experiences. The present findings could thereby be taken and examined in large scale surveys of clients and staff. Within an empirical framework, it may be possible to examine whether teaching the importance of preparation makes a difference to the ending process. This could be designed as an intervention study, looking at the causal relationships between intervention and outcome in residential services for people with learning disabilities.

### ***Measures***

There are difficulties inherent in using interviews as the sole method of data collection in any research. Indeed the unstructured interview is rarely conducted in isolation, but is more often used as part of a broader research programme (Burgess, 1984). It can

complement a battery of methods to allow a more in-depth observation of the subject under investigation. This issue is relevant to interviewing both residents and staff, as the interpersonal dynamics of interviews are important but elusive. The feelings, expectations and perceptions of researchers and respondents alike are in operation, and these colour the interaction between them (Atkinson, 1988).

Future studies could look at the subject of ending key working relationships from other perspectives. These could incorporate reports of participant observations of the period surrounding the key-worker’s departure; or the inclusion of data from referrals to specialist learning disability services which coincide with the loss of a key worker. These techniques could provide some perspective also on the experiences of less able clients.

The limitations of using interviews to explore the experiences of people with learning disabilities have been referred to briefly above, in terms of generalisability issues. In addition, learning disabled clients may experience difficulties with expressing themselves in a consistent fashion, and may be susceptible to certain response effects, such as acquiescence (Chapman & Oakes, 1995). It is also possible that the negative experiences of clients, as people who had been segregated and stigmatised, might influence their perceptions of the research. They may have felt obliged to participate, or they may have attempted to cover up their more painful experiences by putting on a brave face (Atkinson, 1988). In the present study, one attempt to address these issues was made by building in opportunities for brief meetings with residents prior to the

start of the interviews. Ideally, it would have been preferable to have had two meetings with each participant, one as an opportunity to get to know the client, and the other to conduct the interview. On the few occasions where this happened, the clients were clearly more familiar and relaxed about the interviews.

Clearly, much work is needed for developing ways of interviewing clients sensitively if we are committed to allowing people with learning disabilities a voice (Chapman & Oakes, 1995). A future study could make steps towards creating a trusting, understanding and safe setting for interviews with clients. The 'Getting to know you' approach has been devised by Brost and Johnson (1982) as a way of allowing frequent, regular and close contact between researchers and respondents over a gradual time period. A well-resourced study in the future could employ a range of opportunities for enabling clients to talk about themselves and their lives, and for the researcher to hear the clearest possible account of people's experiences.

Finally, it is worth noting the limitations of the Degree of Dependency Rating Scale (Kushlick *et al.*, 1973) as a measure of the overall ability of residents. A small group of staff refused to complete this form, understandably, due to its arbitrary measures of competence, and the crude nature of its assessment capacity. However, in the absence of other measures which are quick to complete and represent an overall level of dependency needs (including verbal communication), it was perhaps sufficient, when completed, for an overall description of the sample.

*Method of analysis*

The qualitative data arising from participants' interviews were analysed according to a grounded theory approach. The limitations of this method of analysis and suggestions for future studies are discussed within the framework of 'standards of good practice' for qualitative research (Stiles, 1993). These standards refer specifically to the reliability or 'trustworthiness of the data'; and to the validity or 'trustworthiness of the interpretations'.

*'Trustworthiness of the data'*

According to Stiles (1993), a central criterion for judging the trustworthiness of the data involves repeated cycling between data collection and interpretation. In the case of grounded theory, 'theoretical sampling' offers a means for ensuring an iterative process between the data and the researcher's conceptualisations (Pidgeon & Henwood, 1996). This means that early analyses should prompt further data collection. Sampling concerns are driven by the need to test emerging theory. This process was incorporated into the present study as far as possible. For example, a small sample of staff was interviewed about their change of role within the same service, on the basis of information from interviews with residents (as discussed in Chapter Two). However, given the time constraints of this study, participants had to be recruited over a short period of time, prior to the data analysis and after the initial few interviews. As the study developed it would have been helpful to have referred

back, either to the original participants, or to different sub-groups of residents and staff, to further explore aspects of the emerging theory.

A second indication of the trustworthiness of data outlined by Stiles (1993), relates to ‘procedural trustworthiness’ - the issue of whether the study is replicable (after allowing for contextual differences). The main question concerns whether another researcher would conduct the interviews differently and therefore find different results. I have tried to address this issue in the present research by remaining close to the data, typically using the participants’ own words for developing categories. I have also tried to make the analytic process as transparent as possible. The transparency of this study should enable the ‘grounding of interpretations’ as Stiles suggests, i.e. there should be a clarity about the links between concrete examples from the data and more abstract interpretations in the analysis.

Another important consideration relating to ‘procedural trustworthiness’ (and to ‘the trustworthiness of interpretations’) concerns the subjective bias of the researcher. Whilst subjective bias is always a concern in qualitative research (Knox *et al.*, 1997), Stiles (1993) recommends that the researcher should disclose her preconceptions or values relating to the area of study. It therefore seemed important to make my personal starting point explicit in presenting this research. My clinical experience provided the impetus for the study and this clearly shaped and influenced the analysis.



The issue of subjectivity in this research was also partially addressed by having another researcher provide an independent check on the allocation of member categories to researcher categories. However, there are two further concerns relating to the subjectivity of this study. First, there was no opportunity for an independent coding of the transcripts. This would have provided a greater opportunity for scrutinising the data (and analysis). Second, this research consists of two separate studies and two sets of data, and ideally there should have been two separate researchers doing the analysis for each one. Inevitably the process of analysis was influenced by my having coded and categorised both studies, drawing links between the experiences of residents and staff.

The issues of subjectivity could be more fully addressed by involving a team of researchers in future studies. The sharing of tasks could allow for the transcripts to be coded by someone who is independent of the main analysis. A combined approach to the analysis would also provide some consensus in the development of themes for an overall grounded theory account.

### ‘Trustworthiness of the interpretations’

According to Stiles (1993), one way of assessing the trustworthiness of interpretations in qualitative research is addressed by the concept of triangulation: gathering information from multiple perspectives and multiple methodologies. A convergence across several perspectives should represent a stronger claim than any one alone. In the present research there has been an attempt to represent the perspectives of both

staff and residents in their experiences of separation. This goes part of the way towards meeting the criteria for multiple data. However there has only been one methodology of data collection used, this being the unstructured interview.

Perhaps this study could be viewed as a first step of ‘theoretical sampling’ of this grounded theory account, towards the ultimate aim of a general theory about ending relationships. There are ways of ‘looking at the mountain from different angles’. Indeed, Glaser and Strauss (1967) explicitly encourage the use of archival and other textual materials and a combination of sources and data types as part of the final grounded theory account. Suggestions for complementary methodologies in the future, such as client referral audits and participant observations have already been made.

Another assessment of the trustworthiness of interpretations is described by Guba and Lincoln (1989, cited in Stiles, 1993) as consensus among researchers. This involves presenting the analysis to other investigators for discussion and clarification of emerging themes. This process offers reassurance that others have found the proposed interpretations convincing, and reflects the researcher’s judgement of a fit between observation and interpretation. I was fortunate to have the benefit of feedback on the researcher categories from Study One, from a team of psychologists who met to discuss the results on two separate occasions. The team endorsed the main researcher categories, and agreed with the generation of the concept of dependency which underpins this grounded theory account. Unfortunately, due to time limitations of the

team, I was unable to repeat this process with the findings from Study Two. This would have been a useful assessment of the links drawn between both studies.

Finally, one check on the accuracy of interpretations is to ask the people whose experience they purport to represent. This is referred to within grounded theory analysis as respondent validation (Pidgeon & Henwood, 1996) and serves as a check that the participants agree with the interpretations made. Unfortunately I have been unable to include this stage within the time limits of this research. However, I plan to incorporate a measure of respondent validation through a series of presentations of results to interested units where interviews have taken place. At the present time, three staff teams and two groups of residents have shown their interest in this process. Hopefully these presentations (planned for July, 1998) will also generate useful discussion about future codes of practice for the preparation plans for staff and residents in the event of saying goodbye. Future studies could allow time after completion of the analysis for the design and production of a suitable, easy to understand account of the findings, with illustrations which could be distributed to all respondents (Atkinson, 1983) - staff and clients alike.

### **Implications of this research**

The implications of this research are presented in two parts. First there is a consideration of the academic and research implications. Second there is a discussion of wider service, clinical and professional issues.

#### ***Academic and research implications***

##### **' New directions'**

This study points to the relevance and importance of the impact of ending key working relationships on residents and staff. Previously, anecdotal reports of reactions to the key worker's departure have been the sole source of information about this subject. If this can be seen as a clinically relevant area, worthy of future investigation, then there are exciting possibilities for further research in the field of learning disability.

The discussion of the present findings (arising in a new area of investigation) has indicated the potential for drawing on indirectly related studies with other client groups, for the development of conceptual frameworks of analysis. However, the support of people with learning disabilities surely warrants its own body of literature, if we are committed to the empowerment of a client group who have historically been marginalised and neglected.

'New approaches'

More recently, there has been a growing awareness within clinical psychology of the need to engage specifically with developments in qualitative research. Postmodern challenges to psychological theorising emphasise that people's experiences are socially constructed within relationships and contexts, thereby disputing the possibility of absolute objectivity in research (Henwood & McQuen, 1998). This brings us back to the aim of the present research (outlined in Chapter One) as understanding the exchange between individuals and their social environments, whilst being aware of our personal perspectives on the investigation. Hopefully, the present study indicates the relevance of a grounded theory approach to clinical research, with its intention of developing a close fit with the data, being meaningful to participants and leading to new conceptual developments based on personal experiences. This approach suggests exciting ways of bringing participants' responses into research design, with an alertness to the differences between their perspectives (Clegg & King, 1998).

'New Voices'

The value and importance of including the views of people with learning disabilities in all areas of research has only recently been recognised (Atkinson, 1988). Although interest is growing and experience is accumulating about how this client group can be included in studies of their lives, the literature relating to effective and accessible interview techniques remains sparse. The present study supports Atkinson's plea for researchers in this field to share their experiences. The challenge remains for

researchers to allow people with learning disabilities to have a ‘louder’ voice in studies of their experiences.

### ***Clinical and service implications***

The present study has attempted to go some way towards understanding reactions to the ending of key working relationships between staff and residents with learning disabilities. In setting these in the context of typical and normal reactions to grief and loss it is hoped that this may illustrate the importance of preparing for such separations where possible, and also of recognising the special nature of the key worker-client relationship and the specific needs of both parties. This study has important implications for the support of residents and staff, in the context of overall service provision for people with learning disabilities.

Drawing on suggestions from ‘anticipatory grief theory’ (Siebold, 1991), the present study has suggested that planned endings and facilitated grieving will have a significant impact on the later adjustment of residents. The clients can be helped to identify and express their feelings, and this process might promote their emotional recovery. These ideas can be extended to suggest further development of non-verbal ways of supporting clients with severe and profound learning disabilities who are grieving.

The residents' lack of control when separations occur has been discussed in relation to 'learned helplessness' (Swains, 1989). In the present study this model has been applied to the residents' discovery that their key worker is leaving unexpectedly, and without warning. The reality of staff movement and change will clearly never allow for a full process of consensus over the long term support needs of clients. Nevertheless, this research suggests that actions can be taken to allow residents to feel included in future plans for their care, rather than these plans being unilaterally decided by others. These actions would include honest discussion, careful planning and lengthy preparation for the departure of staff. Residents can have only partial control in this situation, but what is being suggested here is more dialogue between everyone concerned.

A focus on the significant role that relationships play in the experience of clients is crucial. The residents' accounts of their attachments to staff, and their wishes to maintain relationships lend support to Atkinson's (1989) plea for honesty about ongoing contact with staff. Perhaps services would benefit from the ideas of one resident participant, who clearly articulated how preparation could take place:

*It (discussion with the key worker) would have had to be on our own... I wanted privacy on our own. It would help to have lots of time, to explain why they were leaving and where they were going to, and whether I would be seeing them again.*

The impact on staff of separation from dependent clients has also been addressed in this study. Staff are often left alone to contend with their feelings of loss, guilt and

uncertainty about ending key working relationships, as well as their own helplessness in the face of working with disability. Without support to process these feelings, staff may resort to their own defences, often denying their importance to residents and failing to acknowledge the impact of their departure.

Kauffman (1994) provides a summary of guidelines for services faced with the event of staff leaving. These include: a 'supervisory process' for the key worker, with clearly defined strategies for preparing clients; affirmation and support of their relationships with clients; and recognition and acknowledgement of the mutuality of loss in parting. The present study supports these suggestions of guidelines and policies for services, not only in the event of staff change, but also in the ongoing supervision and support of the demanding role of the key worker.

### ***Professional implications***

The professional implications of this research must be considered in the context of limitations on the resources of clinical psychologists employed in the field of learning disability. The availability of clinical input does not begin to match what is needed, and psychologists are increasingly required to share their skills with others. There is a need to further demystify professional knowledge, enabling the models usually drawn on in the process of direct client work, to be made more explicit to services (Davis & Butcher, 1985).



Services for people with learning disabilities have had a long history of providing skills training and behaviour modification, and the emotional needs of clients (and staff) have often been overlooked. Clinical psychologists can combine work with clients, staff and organisations, intervening directly or indirectly to facilitate more adaptive transitions at the end of key working relationships.

An important consideration for clinical psychologists arises from the unintentional therapeutic effects of the present study. In some ways the process of being interviewed allowed staff some time to reflect on the meaning of their separations from clients. It is possible that allowing more time for staff to have focused discussion about endings may in itself alter the way they plan for their departures. This is quite a simple intervention plan, based on encouraging managers to have these sorts of discussions with their staff teams.

According to Sinason (1992), the provision of psychotherapy can encourage clients to ‘lose’ their smiling masks and appeasing behaviour, and become more in touch with their losses and with the reality of their disabilities. A psychodynamic framework for discovering some of the meaning behind clients’ behaviours can also be useful in helping staff to better orient themselves towards their residents.

The present research has suggested that an understanding of models of separation and loss can help staff to appreciate the dynamics of the parting process, and the transference and counter transference issues that may arise when saying goodbye to

their key clients. This understanding can develop at a service level through consultation to staff teams. Through the provision of psychological support to residential learning disability services, it may be possible to shift emphasis away from locating difficulties in clients on the one hand and environments on the other, towards thinking about reciprocal staff-client relationships and whole social contexts of care. Effective ways of supporting services have yet to be evaluated, but an awareness of the value of consultation, education and training is steadily developing. However, as Miller (1969) suggests, the onus remains with the profession 'to discover how best to give psychology away' (p.1074).

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## APPENDICES

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**HARROW RESEARCH ETHICS COMMITTEE**

(Chairman: Dr David Lubel)

Room 6BB 014

Northwick Park Hospital

Tel: 0181-869-2688

Fax: 0181-869-2174



NORTHWICK PARK & ST MARK'S  
NHS TRUST  
WATFORD ROAD HARROW  
MIDDLESEX HA1 3JJ

10 March 1997

COPY

Victoria Mattison  
Top Flat  
111 Iverson Road  
LONDON NW6 2RA

Dear Ms Mattison

**Ethical Submission No. 2306: Terminating relationships between care staff and people with learning disabilities**

The above project has been considered and approved by the Harrow Research Ethics Committee. It would be appreciated if, in any future correspondence relating to this project or in any entry made in case-notes about procedures undertaken in the course of this study, you would refer to it as **EC 2134**.

The Committee wishes to remind all investigators of the importance of keeping General Practitioners informed of research work affecting their patients particularly when the patient's involvement continues after discharge from hospital.

Your sincerely

Brian Saperia  
Secretary



Mary Kay, Director of Social Services and Housing  
Elizabeth Reed, Chief Executive Harrow Community Health Services  
Marketa Chy, Executive Northwick Park Hospital



# Harrow Learning Disability Team

Contact Address: Orme Lodge  
Gordon Avenue, Stanmore, Middlesex, HA7 3QD  
Tel No 0181 954 8885  
Fax No 0181 420 7476  
( Answerphone Outside Office Hours )



Middlesex  
HA7 3QD Tel. 018 954 8885

Information for unit/house managers

Contact

March, 1997

Our Ref. Dear Manager,

Your Ref.

Date.

CR/MM

3 April 1997

Dear

I am writing to you about a research project which will be undertaken as part of her Doctoral degree in Clinical Psychology by Victoria Mattison. She will be looking at the important area of staff/client relationships and the effect on clients when staff move.

I am delighted to be able to supervise and support original research at this advanced academic level, and that the area of learning disabilities is being focussed on. I am hoping that you will be able to support this research by agreeing that we can approach the managers of the residential units within your service in Harrow.

I enclose copies of letters and a description of the research, prepared by Victoria, which give the background and the practical implications of participating in the project. Please get in touch if you would like further information or would like to discuss any issues. I will be back from annual leave on 10th April, and hope to speak to you then. We will be planning to write to unit managers after 14 April.

Yours sincerely

Chris Roberts  
Consultant Clinical Psychologist



**NP**  
NORTHWICK  
PARK  
HOSPITAL  
TRUST

Mary Ney, Director of Social Services and Housing  
Elizabeth Heyer, Chief Executive Harrow Community Health Services  
Michael Cole, Chief Executive Northwick Park Hospital

**HC**  
**HS**  
NHS TRUST

HARROW  
COMMUNITY  
HEALTH  
SERVICES

**Contact Address and Number:**

Learning Disabilities Team,  
Orme Lodge,  
2 Gordon Avenue,  
Stanmore,  
Middlesex,  
HA7 3QD      Tel. 018 954 8885

**Information for unit/house managers.**

March, 1997

Dear Manager,

I am conducting a study to explore the process and impact of the departure of staff from services for people with learning disabilities. I will be focusing on the experiences of staff and residents who may be able to reflect on previous key working relationships.

The study will involve a semi-structured interview with each participant lasting between 30 minutes and one hour. If possible, there may also be a subsequent interview at a later stage to revisit certain responses. Staff will be requested to complete a form relating to the dependency needs of the client on whom they decide to base their interview. For those residents who participate, present key workers will be asked to complete the same form. The information about clients' dependency needs will be used only for describing the sample in the study.

The participants will be drawn from a cross section of units in the borough of Harrow. At the end of the study, there will be an opportunity for verbal or written feedback of the overall findings, to the whole unit/home. This is optional and is for you to think about.

The study is being supervised by Chris Roberts (Principal Clinical Psychologist, Harrow LDT), and is being carried out in partial fulfilment of a Doctoral qualification in clinical psychology. An overview of the study plan has been sent to the Harrow Research Committee for ethical permission and review. It is important to note that any personal information about participants will be treated as confidential, and the identities of the respective units or houses and of the respondents will be protected at all times.

There is no obligation to participate, and those staff or residents who do decide to do so, may withdraw at any stage of the study - without giving reason. I enclose information sheets for prospective participants to explain the purpose and process of the interviews.

.....

Please feel free to ask any further questions that may not have been addressed above, and to request any further information that you may require. I will follow this letter with a telephone call in a few weeks, so please take your time to consider.

Thank you very much for your time.

Yours sincerely

Victoria Mattison  
Clinical Psychologist in Training

Supervised by: Chris Roberts  
Principal Clinical Psychologist

.....

## **An overview of the study**

This study will consider a previously neglected area of research, relating to the experiences of staff and residents with learning disabilities at the end of key working relationships.

Approximately 20 members of staff and 10 clients in the borough of Harrow will be interviewed. The interviews will last about one hour at a time, and will be semi-structured to explore the process of ending significant staff-client relationships. At the start of each interview, the researcher will check with the participant that the aims are understood, and that s/he has agreed to take part. The interviews will be taped and transcribed for the purpose of the analysis. The tapes will then be destroyed and the transcripts will be presented in a way that ensures participant confidentiality.

Staff (specifically key workers) will be asked to reflect on their experiences of a previous relationship with a client. They will therefore be responding retrospectively. They will be asked to complete the Degree of Dependency Rating Scale (Kushlick et al., 1973), to give a measure of the dependency needs of the clients they discuss in the interview. Residents will be asked to describe their experiences of ending a past relationship with a key worker. For those residents, the present key workers will be asked to complete the same Dependency Rating scale. This is required for a description of the sample. Once again, this information will remain confidential to protect the identity of individual clients.

The data from this study will be analysed and later presented as a summary of the main findings. These results will be made available to those services who request a written or verbal feedback of the findings. The completed study will be submitted by the researcher as part of the Doctoral requirements for clinical psychology training.

.....

**Contact Address and Number:**

Learning Disabilities Team,  
Orme Lodge,  
2 Gordon Avenue,  
Stanmore,  
Middlesex,  
HA7 3QD      Tel. 018 954 8885

**INFORMATION SHEET****For: Staff Participants**

Please Read Carefully.

March, 1997

Dear Participant,

This study is being conducted to explore the nature of staff movements within and between services and the resulting changes on relationships with clients. It will focus on your own experiences and perceptions of this time as a staff-member, or more specifically, as a key worker.

The study will involve a semi-structured interview lasting approximately one hour. Twenty key workers from a cross section of settings will be interviewed. Please read carefully the following points, and then take some time to decide whether or not you would like to participate.

- 1) This research is being conducted in fulfilment of part of a Doctoral qualification in clinical psychology. It is being supervised by Chris Roberts (Principal Clinical Psychologist, Harrow LDT). It has been sent to the Harrow Research Committee for ethical permission and review.
  - 2) Participants will be kept informed (as far as possible) of themes that emerge from the study as it progresses. However, any personal information will be treated as confidential and kept secure. The identities of respondents will be protected at all times.
  - 3) In addition to the individual interviews, you will be asked to complete the Degree of Dependency Rating Scale. This scale will be completed in relation to the overall dependency needs of the particular client on whom you base your discussion in the interview.
  - 4) The study will be carried out in the borough of Harrow over the next six months. At the end of that time, you may choose to have a feedback session to discuss the findings. This is entirely optional.
  - 5) There is no obligation to participate, and if indeed you decide to do so, you may still withdraw at any stage of the study - without giving reason.
- .....



Please feel free to ask any further questions that may not have been addressed above, and to advise me if you would like any further information. Please read the consent form carefully, before signing.

This information sheet need not be returned and can be kept for your own reference.

Thank you very much for your time.

Yours sincerely,

Victoria Mattison  
Clinical Psychologist in Training

Supervised by: Chris Roberts  
Principal Clinical Psychologist

.....

**Contact Address and Number:**

Learning Disabilities Team,  
Orme Lodge,  
2 Gordon Avenue,  
Stanmore,  
Middlesex,  
HA7 3QD      Tel. 018 954 8885

**INFORMATION SHEET****For: Resident Participants**

Please Read/Listen Carefully.

March, 1997

Dear Participant,

This interview has been set up to talk about changes that happen in your life here, especially when staff move on or leave. The interview will be a place to think for a short time about what has happened in your life at those times.

We will talk for about half an hour. I will talk to you and to a few other people living in support homes like this one. I will try to explain things as much as possible, and then you can have some time to think about whether or not you would like to take part.

- 1) The interview is part of a study, which I will write up as part of my training to be a clinical psychologist.
- 2) I needed to get permission from a committee in Harrow who decide whether or not this research can happen.
- 3) We can talk together about the things that you say. Any personal information about you will be kept confidential. This means that it will not be known who has said those things.
- 4) It is completely your decision about whether or not you want to take part. Also, if you do decide to take part, you can leave the study or stop the interview at any time.

Please feel free to ask any questions, and let me know if there is any more information you would like. This sheet is for you to keep.

Thank you very much for your time.

Yours sincerely,

Victoria Mattison  
Clinical Psychologist in Training

Supervised by: Chris Roberts  
Principal Clinical Psychologist

Victoria Mattison (Clinical Psychologist in Training)  
Chris Roberts (Consultant Clinical Psychologist)

Learning Disabilities Community Team  
Orme Lodge  
2 Gordon Avenue  
Stanmore  
Middlesex  
HA7 3QD

## **RESIDENT CONSENT FORM**

I have been through the information sheet about the study to be done.

I have had a chance to ask questions and talk about the study.

I have received enough information about the study.

I understand that I can decide not to answer questions, or not to carry on with the interview at any time. I don't have to give a reason for this.

I agree with what has been said on this sheet - YES/NO (please underline yes or no).

I agree to take part in this study - YES/NO (please underline yes or no).

Signed.....

Name in block letters.....

.....

Victoria Mattison (Clinical Psychologist in Training)  
Chris Roberts (Consultant Clinical Psychologist)

Learning Disabilities Community Team,  
Orme Lodge,  
2 Gordon Avenue,  
Stanmore,  
Middlesex,  
HA7 3QD.

## **STAFF CONSENT FORM ON BEHALF OF RESIDENT PARTICIPANTS**

I have been through the information sheet about the research to be undertaken.

I have had an opportunity to ask questions on behalf of my key client, and to discuss the study.

We have received enough information about the study.

I understand that the resident is free to withdraw from this study at any time and without giving reason.

I agree with what has been said on this sheet - YES/NO (please delete as necessary)

I agree to consent to the interview on behalf of the resident provided s/he can give informed consent in addition - YES/NO (please delete as necessary)

Signed.....

Name in block letters.....

Name of key client/resident.....

.....

### **Additional Information about the Client/Resident**

Please complete this form on behalf of your key client. This information will provide a useful addition to information provided during the interview. It will remain completely confidential - the anonymity of the client will be preserved at all stages of this research.

- 1) Client's name:
- 2) Age:
- 3) Name of Support home:
- 4) Number of residents:
- 5) Number of staff in the full staff team:
- 6) Staff:client ratios during a typical shift:
- 7) Length of time that your client has lived in this particular residential home:
- 8) Previous Residency:
- 9) History of Institutional/Long stay hospital care from childhood - Yes or No?
- 10) Please give an indication of the nature or known diagnosis relating to the client's learning disability.
- 11) Please provide a brief overview of the client's daily activities:

Thank you very much for your time!

Please return to Vicky Mattison  
(Clinical Psychologist in Training)

.....

## THE DEGREE OF DEPENDENCEY RATING SCALE

(Kushlick, Blunden and Cox, 1973)

### Notes of guidance for completing this form.

It is requested that one of these forms be completed by every member of residential care staff interviewed for the purpose of this study. Respondents are required to complete this form with the relevant information pertaining to one particular previous key client. This client will then be referred to in the context of the interview. The aim is to collect a brief description of the client's capacities and behaviour.

The form has been designed to collect the necessary information as accurately as possible with (we hope!) the minimum of inconvenience to staff.

### GENERAL INSTRUCTIONS

1. Please complete both pages of the form and be sure to fill in *every* item.
2. Please write as legibly as possible.
3. Please write in pencil, so that any alteration can be made easily.
4. For sections 2 and 3 please circle the appropriate code (1 - 3).
5. If you are uncertain about any part of the form do not hesitate to seek guidance from the researcher.

### SPECIAL INSTRUCTIONS

#### Section 2

(a - d) **Wetting and Soiling.** *Frequently* - more than once a week.

Wetting or soiling which occurs during an epileptic fit should be recorded in the same way as wetting or soiling of any other kind.

(e - f) **Walking.** This question aims to assess only whether the person is ambulant and to what degree. Thus, if he or she needs help with walking because of blindness, or because of the danger of fits, this should not be recorded as an incapacity of walking.

(g) **Feeding.** A person is able to feed himself *Without help* if:

(1) S/he does not require careful monitoring due to especially messy eating, not take an unreasonable time to finish eating if left without assistance.

(2) S/he does not need to have food specially prepared after it has left the kitchen.

(h) **Washing.** If a male can wash himself, but only requires help with shaving, this should be scored *Without help*.

(i) **Dressing.** If your key client is unable to tie his/her shoe laces, this should be scored *With help*.

(j) **Speech.** This question on speech is a measure of the ability to use language, it is *not* a measure of a speech disability. Thus if a person uses sentences s/he should be scored on Sentences and normal even though the speech may be difficult to understand.

(k) **Reading.** Score *Nothing* if this person is unable to read or recognise his own name.

Score *A little* if this person can read or recognise his own name.

Score *Newspapers and /or Books* if he or she is able to read and understand a newspaper or simple book. (A person who only looks at pictures should be scored as reading *Nothing*).

(l) **Writing.** Score *Nothing* if this person is unable to write his own name or is only able to copy it.  
Score *A little* if this person can at least write his own name without copying.  
Score *Own Composition* if s/he is able to write brief letters without help in composition or in the actual process of writing.

(m) **Counting.** A person would score *Nothing* if s/he was quite unable to count or, even if s/he can count, e.g. 5 - 10, cannot make use of this skill.  
A person who scores *A little* would be able to recognise small values, e.g. would be able to sort out 4 sheets or 5 pillows or 3 spoons etc.  
A person who scores *Understands money values* would be able to make small purchases at a shop and give and receive correct change.

### Section 3

Please code behaviour irrespective of whether or not the person was taking medication.

**Marked.** If the behaviour had occurred during the last month of your key working relationship.

**Lesser.** If the behaviour appeared to be between Marked and No

**No.** If this behaviour never occurred or if it occurred so seldom that it was difficult to remember when it last occurred.

Please return completed forms to Victoria Mattison (Clinical psychologist in Training).

Thank you very much for your time.

.....

## CONFIDENTIAL

### Section One:

#### GENERAL DETAILS

A. Name of key client

B. Sex

C. Date of Birth

### Section Two:

#### 1) CONTINENCE

a. Wetting (nights) 1 Frequently 2 Occasionally 3 Never ----

b. Soiling (nights) 1 Frequently 2 Occasionally 3 Never ----

c. Wetting (days) 1 Frequently 2 Occasionally 3 Never ----

d. Soiling (days) 1 Frequently 2 Occasionally 3 Never ----

#### 2) MOBILITY

e. Walk with help 1 Not at all 2 Not up stairs 3 Upstairs and elsewhere ----

f. Walk him/herself 1 Not at all 2 Not up stairs 3 Upstairs and elsewhere ----

#### 3) SELF HELP

g. Feed him/herself 1 Not at all 2 With help 3 Without help ----

h. Wash him/herself 1 Not at all 2 With help 3 Without help ----

i. Dress him/herself 1 Not at all 2 With help 3 Without help ----

#### 4) SPEECH ABILITY

l. Speech 1 Never a word 2 Odd words only  
3 Sentences and normal 4 Can talk but doesn't ----

#### 5) LITERACY

m. Reads 1 Nothing 2 A little 3 Newspapers and-or books ----

n. Writes 1 Nothing 2 A little 3 Own correspondence ----

o. Counts 1 Nothing 2 A little 3 Understands money values ----



## BEHAVIOUR PROBLEMS

- Please return completed schedule to Victoria Mattison (Main Researcher).

## **Interview Schedule for Resident Participants**

### Explanation

I would like to do a study about what happens when key workers leave - about saying good bye to key workers. I will ask you to think about a key worker who you have had in the past, who has now left. Perhaps you can think about how you felt when s/he was leaving.

Before we start, I just wanted to ask you a few questions about yourself and your life.

### **Section One**

- 1) What is your name?
- 2) How old are you?
- 3) What have you been doing today?
- 4) What do you like doing with your time?
- 5) Who do you spend time with in the house?
- 6) What do you normally do during the week?
- 7) Who is your key worker at the moment?
- 8) Have you had lots of key workers?

### **Section Two**

- 8) Can you remember a key worker who has now left?
  - 9) What was his/her name?
  - 10) Can you tell me a little bit about what you remember about that key worker?
  - 11) What kinds of things did you used to do together?
  - 12) What made your key worker different for you from the other staff in the house?
  - 13) Did s/he know you/understand you well? In what way?
  - 14) Did you like that key worker?
- .....
-

### **Section Three**

- 15) Can you tell me about when s/he left - what happened?
- 16) How did you know s/he was leaving?
- 17) Why did s/he leave? Was it something to do with you? Did she have her own reasons (job, moving away)?
- 18) How did you feel when s/he left - (Angry, Sad, Happy)
- 19) What happens to you when you feel sad/angry? (Did you feel it anywhere in your body)?
- 20) Did you talk to anyone (your key worker) about your feelings at that time? (If not why?)
- 21) How would someone know if you were upset? - (What makes you feel better)?
- 22) How did your key worker feel about saying goodbye to you?

### **Section Four**

- 23) Where is that key worker now?
- 24) Will s/he be coming back ever?
- 25) How would you feel if you saw him/her again? (What would you say to him/her)?
- 26) Then what happened? Did you get another key worker?
- 27) How did you feel about the next key worker?
- 28) Do you think your key worker will leave? - Do you think about it?
- 29) General closure questions - For example: What are you doing this evening?  
What are you doing for Christmas?
- 30) Check on how the resident is feeling at the end of the interview. (Would you like to ask me any questions?)

Thank you very much for being interviewed.

.....

Victoria Mattison (Clinical Psychologist in Training)  
Chris Roberts (Consultant Clinical Psychologist)

Learning Disabilities Community Team  
Orme Lodge  
2 Gordon Avenue  
Stanmore  
Middlesex  
HA7 3QD

## **STAFF CONSENT FORM**

I have been through the information sheet about the research to be undertaken.

I have had an opportunity to ask questions and discuss the study.

I have received enough information about the study.

I understand that I am free to withdraw from this study at any time, and without giving reason.

I agree with the above statements YES/NO (please delete as necessary)

I agree to take part in this study YES/NO (please delete as necessary)

Signed.....

Name in block letters.....

.....

## **Interview Schedule for Staff participants**

### Explanation

I would like you to think back about your relationship with a particular key client, to reflect on your role in that relationship, and the time of moving away. The interview is not very structured, in order to allow you to talk about what you feel is most relevant, but hopefully we can focus on particular themes which I will identify. As my letter states, your identity will be protected for reasons of confidentiality.

The issue of ending relationships can be a difficult subject and people can feel criticised, and sensitive. I just want to find out how key workers experience this process themselves - there is no right or wrong way. The interview will last for approximately fifty minutes. I would like to record for the purpose of my analysis, after which the information will be deleted. Do you have any questions at this point?

### Questions

- 1) Can you tell me a little bit about the key client identified for the purpose of this interview?
- 2) What was your relationship with this client like (quality of relationship). How did you see each other?
- 3) How would you define your role in that relationship?
- 4) What happened when you left the post?

(Prompt: How did s/he find out? Can you say something about what happened?)

- 5) If you hadn't told your client that you were leaving - how do you think she would have responded?
- 6) What went in to your thinking process around deciding to tell/ not to tell?
- 7) What do you think might have been the impact on your key client?
- 8) Can you think about your own feelings around this time?
- 9) What kind of support did you need around leaving? What do you think the client needed? Did you receive any direction/guidance around this process?
- 10) I wonder whether you might do things differently, if you had the opportunity to go back to that time?
- 11) Have you had any comparative relationships?
- 12) General Closure Questions - For example: Do you intend to remain in the field of learning disability?

Thank you very much for your time!

### **Brief information about Staff Participants.**

Please complete this form as fully as possible. This information will provide a useful addition to the content of the interview. The questions consist of standard demographic facts points to describe the research sample. It will remain completely confidential. The anonymity of participants will be preserved at all stages of this research.

- 1) Name:
- 2) Sex: male/female (please circle):
- 3) Age:
- 4) Current Occupation:
- 5) Ethnic background ( as you would define it):
- 6) Length of time in employment with people with learning disabilities:
- 7) Professional qualification or previous relevant training:
- 8) Description of current work place (Total number of staff members \_\_\_\_ . Total number of residents \_\_\_\_ )

### **About your key client**

- 1) Name of key client(s) identified for interview:
- 2) Level of disability: mild/ moderate/ severe (please circle the appropriate one).
- 3) Length of time as Key worker:
- 4) Length of time at that particular residential home:
- 5) Number of concurrent key-clients
- 6) Time elapsed since leaving post:

.....

**Interview with R4: "Heather"**

Note. All names have been changed for reasons of confidentiality.

V. Well Heather, perhaps we can start with just a few questions about you. Is that all right?

H. Yes.

V. Great, so how old are you?

H. 29.

V. Really- and when are you 30?

H. Next year.

V. And do you know what date?

H. 1st of June.

V. Right, so you've not long been 29 then?

H. No.

V. I see, and Heather, can you tell me a little bit about what you like doing with your free time?

H. Spend a bit of time in my bedroom.

V. In your bedroom?

H. Yes

V. And what do you do in your bedroom?

H. I can see lots of videos.

V. So you like watching videos?

H. Yes.

V. Anything else?

H. Tidy my room

V. Gosh, you're better than I am. I can see looking around this room. And who do you like spending time with in the house, I wonder? Any of the residents here?

H. One of the boys and one of the girls.

V. Right, so two people. And who is your key worker at the moment Heather?

.....

H. Well, it used to be Lisa, then Mary was my key worker for a little while, and now it's Denise.

V. Now it's Denise - so you've had three key workers here?

H. Yes.

V. And before you lived in this house, I was wondering whether you had any key workers anywhere else?

H. No.

V. I see, so where were you living before here?

H. With my mum

V. So it's quite new to you to have a key worker?

H. Yes.

V. So when I talk to you now Heather, if I ask you if you can talk a little bit about a key worker who has left, who would you be thinking about? Someone who you have said goodbye to.

H. Well - there were two left earlier this year, Jane and Kate, and another one left about a couple of weeks ago, Sam.

V. And was Sam your key worker Heather?

H. No - Lena's

V. I see - and did you like Sam?

H. Mm

V. And was it hard to say goodbye?

H. Yes. And we've got another one leaving a week this Saturday, who's Neil's key worker - because he's on holiday at the moment.

V. Gosh, it sounds like there are a lot of comings and goings at the moment. I wonder how that feels for you Heather?

H. Bit strange

V. And do you remember when your own key worker left too?

H. Yes.

V. Who was that?

H. Lisa - she left before the end of last year. . . . .



V. And is she the one who you said you got a post card from?

H. Yes.

V. Would you like to talk about Lisa and when she left, or would you like to talk about Denise?

H. Denise came up to me one day when she was doing a sleep in and I didn't even realise until she told me that she was going to be my key worker.

V. So Denise is your key worker at the moment?

H. Yes, 'cause Mary couldn't cope with two of us, I mean me and Chris, so Mary's only Chris's key worker now.

V. So Mary is still here and you still see her, but she's not your key worker anymore?

H. Yes.

V. And can you remember how that felt Heather?

H. A bit embarrassing.

V. Can you explain in what way perhaps?

H. When she said she couldn't cope with two of us residents.

V. Right, I understand. So that made you feel a bit embarrassed.

H. Yes.

V. That sounds very hard (pause). I'm wondering whether you think that it was because of you that she left, or because she had too much work on?

H. Too much work on, because of too, because she couldn't cope with two clients.

V. I see, so it feels perhaps a bit embarrassing because she is still here, even though she's not your key worker any more.

H. Yes.

V. And you've mentioned Lisa, was she your key worker before Mary?

H. Yes.

V. And did she actually leave the house?

H. Yes.

V. So you don't see her any more.

.....

H. No.

V. Can you remember what happened when she left.

H. Before she left she told me that she was going around the world.. and that was last October.

V. And can you remember what she was like? Can you tell me a bit about her?

H. She had short dark hair

V. And what was she like also as a person?

H. Nice.

V. She was nice - and what kinds of things did you used to do together?

H. Went up town last year, and went to the cinema down here in Harrow, to see the film Mission Impossible, with Tom Cruise.

V. Oh yes - and did you enjoy that?

H. Yeah.

V. So you used to go out with her sometimes?

H. Yes.

V. And what else did you used to do with her?

H. Cause most of us went on a day's outing last August Bank Holiday to Chessington.

V. I see - and did Lisa come with you?

H. Yes.

V. So was Lisa your key worker for a long time?

H. Soon after when I moved in last year.

V. So she was here when you moved in?

H. Yes.

V. And for how long, do you remember?

H. She was there from July till October.

V. July, August, September, October (counting on my fingers), so she was here for about 4 months?

H. Yeah.

.....

V. Right. And you liked Lisa?

H. Yes.

V. And can you think - I mean I don't know Heather, you might have ideas about this, but what makes a key worker different from the other staff in the house?

H. Because they've got different personalities.

V. Different personalities?

H. Yes.

V. And is there something that makes a key worker special to you?

H. Yes.

V. It can be difficult to think about, but mainly what kinds of things might you do with a key worker that you don't do with any other member of staff perhaps.

H. Em, you get more time to answer the telephone.

V. You get more time to answer the telephone?

H. Yes.

V. And anything else?

H. No.

V. No.. so you were saying that Lisa left because she went round the world - is that right?

H. Yes.

V. And can you remember how you found out she was leaving?

H. Until that very day she told us, Neil found out so all of us got together to but her a card and a present.

V. I see, so the day that she told you, you got her a card and a present?

H. Yes.

V. And how long after that did she leave?

H. Same time I went on holiday with two of the other key workers and Lena.

V. I see - so did you have a little bit of time after she was leaving?

H. Yes.

V. Was it a couple of weeks? .....

H. No.

V. More than that or less than that?

H. Less.

V. So was it more like a week or a few days or..

H. Few days

V. It was a few days - so one of you found out. Did you say Neil found out - or all of you did?

H. All of us.

V. All of you. So she said she was leaving because she was going round the world?

H. Yes.

V. And I wonder if you can remember how you felt when you found out?

H. Upset.

V. In what way?

H. That she wasn't going to be my key worker for very long.

V. And were you able to tell her, Heather.

H. Mm

V. You did, and can you remember what she said?

H. No.

(Note: It felt very painful at this point in the interview).

V. I was wondering whether you felt anything else apart from upset?

H. No.

V. Did you feel angry?

H. No.

V. Or em - did you feel worried?

H. Mm.

V. Can you remember what you were worrying about?

.....

H. Em - cannot remember.

V. Yes - it's difficult to think about these things isn't it? Does it feel all right talking like this Heather?

H. Yes.

V. Are you sure?

H. Yes.

V. I was wondering Heather, you know when you were upset, did you feel it anywhere in your body?

H. Mm.

V. Where did you feel it?

Long silence

H. Can't think.

V. I think it's very hard to think about it and remember.

H. Yes.

V. When you get upset, how do you know I wonder? Do you feel it in your body?

H. (Nodds).

V. Do you know where you feel it then?

H. Feel it in my eyes.

V. Like tears maybe?

H. Yes.

V. I see, and I think that's how people can see when we're upset sometimes too -when we're crying.

H. Yes.

V. And did you talk to anyone about being upset that Lisa was leaving?

H. Yes.

V. Do you remember who you talked to?

H. Can't remember.

V. So, how does someone know if you are upset sometimes? . . . . .

H. By telling them.

V. Aha, and who do you normally tell?

H. One of the other staff.

V. Do you? And is it your key worker or anyone?

H. Anyone.

V. So where is Lisa now?

H. Last post card we had from her is from Australia, then New Zealand.

V. Gosh - that is far away isn't it. Do you know when she's coming back?

H. Don't know.

V. And do you think you'll see her again ever?

H. I don't know when I'll see her again.

V. I see. That sounds hard (pause). So Lisa left, and then what happened Heather?

H. Mary took over.

V. And how long was she your key worker for?

H. Since before the end of last year, until a few weeks ago.

V. Oh, it was only a few weeks ago. So you may still have lots of feelings about that. Perhaps we can think about those.. you talked about being embarrassed.

H. When she told me that Denise was going to take over as my key worker, cause I didn't even know until after when I came back off my holidays.

V. So you didn't know till then?

H. Cause Denise did the same thing when she did that in April till August.

V. Denise did the same thing - I wonder what you mean by that Heather?

H. She went on holiday around the world - Thailand.

V. Oh Denise did that as well?

H. Yes.

V. Whilst she was your key worker?

H. Before she was my key worker. . . . .

V. I see - so because she'd been round the world what did that make you think Heather?

H. I thought what's going on.

V. So you felt a bit confused maybe?

H. Yes.

V. I wonder how you felt about Denise being your new key worker?

H. I was worrying about that my key worker was going to change.

V. You thought she was going to change again?

H. Yes.

V. And what made you think that Heather?

H. Can't think (pause) That I was going to lose one key worker, then getting another one, then getting a new one.

V. Yes, so you did feel worried about things?

H. Yes.

V. And is Denise still your key worker now?

H. Yes.

V. And do you still feel worried about it?

H. No.

V. How come?

H. (Pause) I think it was about a few weeks ago until Denise told me.

V. So Denise told you, not Mary?

H. Mary told me at first, and then Denise told me soon after.

V. Right. So it sounds like it was a bit of a shock to you.

H. Yes.

V. It seems like it's difficult to think and talk about isn't it, Heather?

H. Yes.

V. And are you all right thinking about it?

H. Yes.

V. So you were a bit worried when you started with Denise that perhaps she would leave?

H. No.

V. Were you worried that you might have to change your key worker again?

H. Yes.

V. And are you still worrying about that?

H. No.

V. What makes you less worried about that Heather - can you say?

H. Not worried no.

V. Do you know if there is something that makes you feel a little bit better about it?

H. You, you get used to it - having someone new.

V. And do you think that makes it easier?

H. Yes.

V. You know you said you felt worried about losing Denise when she started?

H. Yes.

V. Did you tell her?

H. No.

V. Did you tell anyone you were worried?

H. No.

V. But when you do worry about things normally, who do you tell then?

H. The staff.

V. So it was a bit upsetting when Mary left?

H. Mary is still here, won't see her until the day after tomorrow when she's sleeping in.

V. Sorry - I was talking about when she stopped being your key worker, not when she's left. I'm making things very confusing. When you see her now, do you still speak to her?

H. Yes.

V. And does it feel a bit strange speaking to her sometimes? . . . . .



H. Yes - she's no longer my key worker.

V. So how is it different now that she is no longer your key worker?

H. Well, I still get on, but - we're getting some new staff soon.

V. Right, so lots of changes are happening in the house aren't they?

H. Yes. Before I came here, Mary had long dark hair, but now she's got short dark hair.

V. Right - so she looks different?

H. Yes.

V. Heather, have you got anything you want to say to me, that I've forgotten?

H. No.

V. That's fine, I've just got one more question - is that all right?

H. Yes.

V. I wondered how you felt when you got the post card from Lisa?

H. Happy.

V. Were you? And do you write to her?

H. Don't have the time.

V. It can be hard to find the time can't it? Well, Heather, Eastenders is on at the moment - are you waiting to watch it?

H. Yes.

V. Thank you very much for talking so honestly.

STOP TAPE.

.....

## Interview with S10: "Matt"

Note: All names have been changed for reasons of confidentiality.

(Memo: On the telephone before the interview, Matt said that he couldn't understand what we might talk about for 50 minutes, because 'there wasn't that much to saying goodbye').

V. I'm going to ask you to think about you're relationship with one particular key client. I don't know how many clients you had as a key worker?

M. Just one.

V. So have you got someone very definite in mind who you want to think about?

M. Very definite, yes.

V. Right - that's fine. So can you tell me a little bit about your client?

M. Em yes - I was the key worker for just over two years. I think he was about 54 when I left the unit. He had Autistic tendencies, which means that he wasn't really Autistic severely. But he fulfilled some of the criteria of Autism - em what can I say?

V. Well -what was his name, or what are you going to call him for the interview?

M. His name is "Keith".

V. Keith - right. Em so he was about 54, and had he been living there for a long time?

M. The organisation started about five years ago, and they started up north, and they started in this borough five years ago, and then the clients were dispersed in the area.

V. So Keith had been with them from the move?

M. Yes, he was in the old hospital for about 30 years, and then he moved to this house.

V. So he's had a pretty long history of institutional care?

M. Yes.

V. Since childhood?

M. No I think his parents managed to look after him till his 20s. I think - the details are a bit vague now, but that's as far as I know, and when they couldn't cope with him any longer he went in to the hospital, and he was there for years.

V. I see - and in the time that you knew him - did he have contact with his family?

M. Oh yes - lots and lots - they were very close?

V. And are his parents still alive?

M. Yes - I mean they are very very old, and they are falling to bits, but they're still alive. . . . .

V. Right - because that can be important in thinking about relationships with key workers, the impact of having other family contact.

M. Yes - it's rare I think.

V. Yes (pause) I guess I 'm wondering whether you liked him.

M. Yes - he was em a really nice bloke. The thing was he was very endearing because he em - it's difficult to find the proper lingo to describe, but em he was like em - I don't want to say a child, but he had a very immature way about him. It was funny because he was this huge man, you know he was very big, and yet he was you know like a youngster. And em he had some very funny ways about him. And he could be very hard work in that he had a lot of tantrums - tantrums is a bad word as well, but he would throw a wobbly often, and even that was quite amusing because it was like em, he was so immature it was amusing. I'm not laughing at him, it sounds like I was laughing at him, but it wasn't like that.

V. Sometimes it's difficult nowadays, because it feels difficult to say anything correctly.

M. Yes exactly. I mean he was great fun, because he would smile and laugh a lot, and that was hilarious.

V. So what was your role in the relationship as a key worker?

M. Well - I would just look after his file, and there were things in his file like his personal future plan - where we would map out his next six months and think about his development. Em and his finances. Make an appointment to see the doctors - checking to see if there was anything wrong with him. Going with him to buy his clothes and em.. and although I didn't have a lot of contact with his family. They didn't take me very seriously, because I am a bit of a youngster in their eyes. They would pay me lip-service, but the manager would be the one who would speak to them.

V. Right - and was that difficult?

M. No - I didn't find that difficult at all, because they were hard work. I mean it wasn't interfering, because they only wanted the best for Keith, but they would make life difficult. They couldn't see both sides of the argument, because they were so set in their ways. And rather than to let Keith develop as a person, develop as an individual. They would do anything to calm him down, but they just wanted him to stay as he was - no hassle, just to plod along. And to kind of go against that was very hard work.

V. I see -so you didn't have direct involvement, but you allowed him to have it.

M. Oh yes, at one point Keith was going home every weekend to see his family, and to stay with them for a night or two, and then we cut it down to every two week, because they were so old that they couldn't manage every weekend. But on the weekends that he didn't go home, they would come and visit the house.

V. So other than looking after his file as you say, how was your role different as his key worker from the other staff in the house?

.....

M. Because you spend that little bit more time with someone, and you kind of endeavour to get to know them just that little bit more, because I mean you are looking out for anything that is wrong with them as a client, especially because there were only two male staff at the house - there were only two male clients as well. So we were with one male each. So I was with Keith, and so because of the male ratio of the place it was always well - if there was a problem with Keith, then Matt would sort it. That was good, I preferred it that way, because then you know exactly what's going on.

V. And was it a lot of hands on care, personal care stuff, or was he able to care for himself?

M. Em no - there was a lot of personal hygiene, stuff like that.

V. And em, how do you think he related to you? Do you think he related to you as a key worker?

M. I think so. It was difficult to really know what Keith understood by a relationship. He didn't have - he wouldn't really know what a friend was. He couldn't really understand emotion and relationships. So, I don't think he would really understand the kind of link there. But I do know that he would understand that Matt was the person that was with Keith a lot of the time - more so than other members of staff, and it got to the point where I think he could trust me, and if there was a problem he would ask me.

V. Right - and em did he communicate with you verbally?

M. He did yes, but because of his Autism, it was difficult having a conversation with him. You couldn't have a conversation with him - you would be struggling. You would have to initiate 90% of the conversation. And Keith wouldn't say more than a few words unless you coaxed a sentence out of him..

V. And em did you do activities together?

M. Yes, a lot of the time, I mean if he needed a pair of shoes we would go out for the day shopping, and we would go out to the pub and have lunch and em, yes we spent a lot of time together. We went on holiday together with other staff and clients, but we were there together.

V. I see, so Matt what happened when you were leaving I wonder?

M. Well em, because of the way Keith is, he finds it very difficult to deal with change. I mean if there's something in the living room - he knows exactly where everything should be - so if there's a vase which is not where it should be on the mantle piece, then that can really throw him, and can really set him off. Em that's what made it so difficult with Keith to kind of further his development, because he was so against any sort of change in his life, and em I've forgotten the question.

V. It was about what happened when you were leaving.

M. Right - that was a big deal, because if Matt - if I wasn't around, it happened with lots of members of staff - he knew people's names, and so he would say "Where's Beth? where's Matt? where's Kate? But if Matt wasn't around anymore, he would ask and ask and ask, and it would go on. I think it still does go on actually. I mean I see him occasionally. I've been to visit a couple of times, but I see him at the day centre anyway. And he's always got something to tell me, yes.

V. So did you have the chance to tell him you were leaving?

M. Well, that was the thing. We had to build up for it. I mean if Keith needed a haircut, you had to give him a day's notice, and you had to keep reminding him throughout that 24 hour period. You'd say "now you know Keith, you're going for a haircut tomorrow - you know what that means don't you? And as long as he had time to get used to the idea, then he would be fine with it. But if you sprung anything on him, like "You're going to have a haircut now", then he would just go ballistic. So we decided it would be best if we built it up over a period of about a week, because if we told him any sooner than that - say a month, then for that month you would get nothing more than "When's Matt leaving? When's Matt going?"

V. Aha

M. And you could tell him one hundred times, and he would ask the question again and again and again. So we thought "Well, give him a week - a week to get used to the idea, and we said you know "Matt's going to work in another house", and he knows some of the clients here anyway, so we said "Yeah - Matt's going to work with Will, and Andy and Jack at their house, so over the period of a week he got used to the idea and then I was gone, and so yes - that's really how we did it.

V. Right - when you say we..

M. All the staff were involved.

V. All the staff were involved, I see. So when you actually told him, I wondered whether it was just you and him or..

M. No other people were involved.

V. And how do you think he felt about it?

M. Well, em I don't know - I mean I really don't know how Keith feels about anything. I mean if there is something out of place, it gets him very annoyed - well not very annoyed, but very flustered and disorientated. But as far as emotion and em you know feelings and stuff, I don't really think that that affected him. I think he was affected more by the fact that there was something around that was around all the time, and now it wouldn't be around. And there would be someone else to look out for all his needs - you know, like the doctor and his finances and shopping and stuff. Because it was always, it was usually down to the key worker to see if, if your key client needed any clothes you'd go out with your key worker to get them. And only on the odd occasion would it be any other member off staff that he would go out with to buy these things.

V. So did you feel that it was about missing more the things that you did than you as a person?

M. I really feel that he would only really miss the fact that there was something there for two years and now it was gone, on a regular basis. I mean I popped around occasionally, and I do see him sometimes at the day centre, and he still remembers me, he still knows my name. He'll tell me what's been going on, like recently he went on holiday to Spain, and he had lots to tell me about that, he couldn't wait to tell me, and he was overjoyed to be telling me, but really I don't think that emotionally it affected him. It was kind of a comfort thing, there was something missing, and that was me - I could have been an object: . . . . .

V. I see -so did you feel that someone could slip in to your shoes pretty easily, or did you feel worried about the person taking over from you perhaps?

M. Em, well I worried about the person who would be taking over, because you had to be very careful and patient with Keith, especially when he's having a tantrum, because there's no point in - you have to be firm, but there's no point raising your voice and you'll only make him worse if you do things the wrong way, and I was worried that the next person to step in to my shoes would be em not so patient maybe. But that's just wanting the best for Keith, because I do have a high regard for Keith, and I think he's a top bloke. But em I think I did things pretty well as far as Keith was concerned. I just wonder if anyone would have the patience to.. you know I really put a lot of work in to it. So that's the only thing I was worried about.

V. So how were you feeling I wonder about the whole thing?

M. Well I felt pretty good. I felt bad for leaving all the clients, and all the clients at the house were just brilliant - just really really fantastic people. They were so funny and so interesting and em - so I felt bad because I was leaving the clients, and I felt bad for leaving the staff - although not as bad as I felt for leaving the clients to be honest with you. But I felt good because I had done two years there and I felt it was time for change, to work with a new client group. And that's what I got when I moved here - plus more money.

V. Right - and did you think you might miss Keith.

M. Yes - well yes, I think you can become complacent with that sort of relationship - where you know someone so well, you know exactly what's going to trigger them, you know what makes them happy and so you can become very complacent - like everything's just so easy, it's boring. So I think having said that I didn't know whether someone stepping in to my shoes would be as good as I was, sorry that sounds a bit big headed...

V. No..

M. Having said that someone new going in to the job would go in to it with as much kind of vigour as, you know, a new person going in to a new job - getting to know someone. The client can get a lot out of that, providing that it's the right sort of person.

V. So perhaps you are saying that change can be quite healthy?

M. Yes definitely.

V. Do you think key working relationships should be limited in time?

M. Yes I do, definitely, because there is nothing saying that if you leave this person that you can't still be friends with them, that you can't visit them. So I think change is healthy, as long as it's not every five minutes. As long as you've built up a good relationship with the person. Like I consider Keith as my friend..

V. So you manage to maintain contact with him?

M. Yes - I do. Yes, Keith is still my friend, and even though I've left the house - even if I left the organisation, I could still go and visit Keith any time I wanted. So I do think as far as key working goes, a change is as good as a rest.

V. Aha - so how often do you manage to see Keith?

M. Em - every couple of weeks, I mean that may be just at the day centre, or I have to go over to his house to pick something up maybe. Or I have done occasional bank shifts to help them out, so I've seen him then. So yeah, I would say that it works out at about every couple of weeks.

V. Aha - and em, when you told him you were leaving, I was wondering whether you told Keith that you might carry on seeing him..

M. Yes - I did, I said that I would be able to see him - whenever. I mean he's been over to this house a couple of times to see me. Em, so yeah, yeah - I did say that.

V. So is he pleased to see you?

M. Yes, he gets excited - it's nice.

V. And I wonder how you feel when you see him?

M. It's nicer now, because I know that as I'm not his key worker, I don't have to worry about all the rubbish - you know, all the paper work and documentation. I can just like treat Keith as a friend you know - it's a lot more casual, a lot more relaxed - knowing that I'm not forced to be kind of.. You're not forced to be someone's friend when you are a key worker, but it is kind of like, em a business thing. It is very much a client service worker thing, so now I'm just like a friend.

V. I see - and when you were his key worker did it feel like you were his friend then?

M. Yes it did, but it felt very much like "Sorry Keith, but I'm being paid to be here, and I'm being paid to see you. So, I did feel like his friend definitely, and you know - we got on quite well, but that's always at the back of your mind. I fee! like he is more of a friend now than he was then.

V. I see, that's interesting. So, Matt, I was wondering how things might have been, do you think, if you hadn't told Keith that you were leaving?

M. Well, it depends. If I hadn't told him, and I had just left and that was it, there would be all sorts of questions, and he would really hound the other members of staff there as to "Where's Matt" and all that. And it's always short statements with Keith, and he will ask things over and over again throughout the whole day: "where's Matt, where's he gone" and you'll answer, and that won't satisfy and he will just ask and ask and ask. I think that's actually his kind of way of initiating contact, between him and the other person. But unfortunately, it can ware you down a bit, and that's where the patience comes in.

V. Yes - I'm sure. So you think that if you hadn't told him, he might have just carried on asking and asking questions?

M. Yes, although he was when I left anyway, but I think it would have been worse, and I think the main reason for giving him that kind of week to get used to it was so it was fair on him. Maybe he wouldn't have reacted any different, but it was just so that it was fair that, someone

who had been his key worker for two years a privileged position - and for them to just leave would be rude. You wouldn't do that to anyone.

V. No. And how long had you known, longer than that?

M. Yes, I'd known for a couple of months.

V. Aha - and I'm wondering about any support - did you have any support around ending that relationship?

M. Em, not really, but there wasn't really any need for it, because as far as I was concerned, Keith was still going to be my friend - in a really better way I see, and I was going on to something - I could go and refresh myself, you know - because a change is as good as a rest.

V. Yes. So you didn't feel any lacking in that area?

M. No not at all.

V. So did you get any advice around handling the move?

M. I actually got advice from my manager, who was a very dynamic person there. You could ask her anything and she was very dependable. And she was a constant source of like wisdom really. And so she advised me as to how to take it, and I felt good with that. And she offered me support in like - well, I don't know, she was just great so.

V. OK. that's good. So I was going to ask you whether you had heard or imagine that there may be any change in Keith's behaviour after you left, or in his emotions. Do you imagine there would be?

M. No.

V. No kind of difficult behaviours or anything?

M. No.

V. And did you hear anything about his behaviour after you left.

M. Yes, I mean people would say that he was asking "where's Matt?" quite a lot. But that's petered out now".

V. So there was in not a change in him so much, or a decline?

M. Oh no - I mean he reacted to it the same he would if anything as missing. I mean if you took away his old shoes, because they were knackered and had holes in, you would take them away, and go with Keith to buy a new pair. And you'd say to him "Keith we've got to throw these shoes out because they're all knackered". And he wouldn't like that, and buying new things for Keith was difficult - especially shoes for some reason. But you would give him a while to get used to the idea. You wouldn't chuck them out straight away. You would give him a while to get used to the idea and then you would throw them away. And for a while afterwards he would ask "Where are the brown shoes?" And he would ask that - for I don't know - a few days or a week, and then that would be it, he'd get used to the new ones (laughs nervously).



V. So you think it's the same with people?

M. Yes - I do.

V. Had you ever seen him upset about anything?

M. Oh yes - I mean not crying, not emotionally - just that there's something not right in his routine - or his system and that would completely throw him, and he'd get very - how would you describe it? I would say worried, but I never kind of worked him out completely, because you couldn't because the conversation was difficult. You know - I tried and I remember asking him about friendship and does he think of me as a friend and stuff, and he would just say yes to everything. And I would say - "You're my friend because I like you Keith, do you think I'm your friend?" And he'd say yes, and then I'd say are apples pink - sorry, I'm taking out my arse, but he could talk about friendship, and he'd say "yes, yes, yes", and then you could talk about something ridiculous and he would still say "yes, yes".

V. I see, so he is quite compliant - agreeing with things?

M. Yes.

V. Aha - so I'm wondering - do you think he did see you as his friend Matt?

M (Pause). No - I think he thought of me as someone who was around and was part of his kind of world - an object really..

V. Perhaps it would be interesting to ask you whether you have had any comparable relationships where you have spent an intense time with someone and then had to leave them. Whether it is through work or in any context, and if that's had any impact on the way you think about Keith.

M. Well - my current girlfriend - I was seeing her about three years ago, and we'd been out with each other for about four months, but all through that time I knew she was going to Australia for a year. So that was a real wrenching apart. But as for how I was with Keith I knew that - because it was really emotional between me and my girlfriend. But it wouldn't be between me and Keith because I knew that he didn't really understand, you know, emotion.

V. Right - so you are making a comparison because of the separation, but perhaps saying that it was a different relationship with your girlfriend, so it was difficult to compare - is that what you are saying?

M. Yes.

V. OK, so it was difficult to predict how he was feeling about things?

M. yes - I mean it's difficult to know - no one knows really I don't think, how emotional Keith would be about anything. Sorry was your question about if I had ever left anyone and whether that affected the way I said good bye to Keith?

V. Yes - did that impact on saying goodbye to Keith in any way?

M. No - not at all.

V OK - I was wondering whether there anything that I haven't asked about?

M. No.

V. Because what I do remember is that when I said to you on the phone that it might take about 50 minutes, you said "What am I going to talk about for 50 minutes?"

M. (Laughing) yes - I've done all right haven't I?

V. Yes you've done fine. But I suppose I thought that well - because for some people that actual saying goodbye can be like a non issue really - it's part of the course really. And I don't know if it did feel like that?

M. I think the bottom line really is that I knew that Keith wouldn't be affected emotionally. I knew that it might stress him out a bit, but as for kind for feeling a loss, he wouldn't really feel a loss, he'd just see that the old brown shoes again - the old brown shoes have been chucked out, they're gone. But that doesn't bother me because that's just the way he is. You know there's a lot about Keith that I like and that makes me laugh, and I've got a lot of affection for him. The way he deals with it - I know that it wasn't going to upset him terribly, so I was never that worried - you know? But with clients that can understand their feelings a bit more, and they're more able to converse with you. Keith was verbal, but he couldn't hole a conversation, so there was no way that he could kind of glean any sort of information out of you - other than the bare facts.

V. Right - so you think perhaps that the more able clients might have felt the loss more?

M. Yes - definitely.

V. I see. Well Matt, there was just one question that I forgot to ask earlier. That was about whether you ever went on holiday when you were working with Keith and whether that had an impact on him?

M. Yes - same thing, he would just say. I was saying to Keith I remember, I'm going on holiday soon - I'm going to be away for a couple of weeks, and when I was gone he was asking the other members of staff "Where's Matt? Where's he gone?" And that lasted for a little while and then I was back.

V. So perhaps it was an extension of that leaving permanently?

M. Yes.

V. It sounds like it feels difficult to know how important you are to people when they can't communicate verbally so well.

M Yes - but I firmly believe that it was the object thing rather than the emotional thing.... maybe I've misunderstood but, anyway..

V. Perhaps it is just a different way of looking at things. Another way. Thank you very much Matt.

STOP TAPE .....