The Experience of Dual Diagnosis in Learning Disability:
An Exploratory IPA Study of People with a Learning Disability and their Core Family Members

By

Joanne Coombs

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Department of Psychology
Faculty of Arts and Human Sciences
University of Surrey

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Adult Mental Health Essay

Can the experience of hearing voices (auditory hallucinations) be considered an ordinary part of human experience? What implications might such a conceptualisation have for the ways that clinical psychologists respond to service users to hear voices?

December 2005

Year 1
Introduction

I will begin this essay by outlining my reasons for selecting this particular question. Firstly, it is important to note that I have not worked with clients who have heard voices in my previous clinical experience. The topic of hearing voices is one that initially struck me as intriguing and perplexing and one that I was keen to learn more about. Moreover, the stance of the question allowed me to challenge my own preconceptions of the experience of hearing voices by exploring alternative frameworks of understanding such a phenomena. I have adopted an enquiring, reflective and open minded approach to this question which is in part reflective of my status as a Trainee Clinical Psychologist at this stage of training. I have chosen to use the first person narrative throughout this essay to provide opportunities for reflection and the integration of academic literature into my training and perspective as a Trainee Clinical Psychologist.

In initially conceptualising the first part of the question; that of whether auditory hallucinations can be considered an ordinary part of human experience, I began to search for literature pertaining to whether hearing voices was a sign of mental illness. Upon reflection I realised that implicit within this conceptualisation of the question was my own assumption that the experience of hearing voices was not in fact ordinary. That is, replacing the concept of ‘ordinary human experience’ with that of ‘mental health’, and by default relegating the experience of hearing voices to the realms of ‘mental illness’ and implicitly defining mental illness as ‘extraordinary’. Upon reflection, my original assumptions were based upon stereotypes of auditory hallucinations derived in part from the dominant psychiatric view of such experiences as symptoms of mental illness. However, this initial assumption has provided the basis for the structure of the essay. I will consider the experience of hearing voices in the context of the mental health - mental illness paradigm and whether there are more helpful alternatives to the pathologisation of such experiences which may support the view of voice hearing as an ordinary experience. In the second part of the question I outline the implications for clinical psychologists of considering voice hearing as an ordinary experience. In particular, clinical psychologists should encourage the client to explore the meaning of such experiences within the context of their life. I also explore some contradictions within mental health law and services that may serve as barriers to the conceptualisation of voice hearing as an ordinary part of human experience.
Defining Auditory Hallucinations

The term 'auditory hallucination' can encompass a variety of experiences such as hearing music, noises and voices. For the purposes of this essay, the term 'auditory hallucination' refers only to voices and therefore is considered synonymous with the term 'hearing voices'.

According to the Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition (DSM-IV; APA, 1994), auditory hallucinations are the most common type of hallucination and are usually experienced as voices that are perceived as distinct from the person's own thoughts. Within the DSM-IV, auditory hallucinations are most fully described in relation to psychosis, in particular, schizophrenia. The APA considers hallucinations with little insight into their pathological nature as a prominent symptom of psychosis (Wise, 2004). Broader definitions have focused on the presence of impairment (such as hallucinatory experiences) that significantly interfere with the ordinary demands of life. Interestingly, what is considered to be the 'ordinary demands of life' is neither further qualified nor considered in the context of social, cultural, individual or personal factors. Though psychiatry does not consider hearing voices to be associated with psychosis alone, auditory hallucinations are classified as positive symptoms of schizophrenia in that they are amplifications of normal perceptual experiences. The emphasis on defining auditory hallucinations in diametric opposition to normal human experience firmly places the experience of hearing voices in the mental illness paradigm.

Slade and Bentall (1988, p.23) advocate a broader definition of hallucinations as "any percept like experience which a) occurs in the absence of an appropriate stimulus, b) has the full force or impact of the corresponding actual (real) stimulus and c) is not amenable to direct and voluntary control by the experiencer." I have found this conceptualisation of hallucinations more helpful as it focuses on the pragmatic aspects of the hallucination and does not define the experience of hearing voices in relation to mental illness.

The History and Development of the Concept of Hearing Voices:

The experience of hearing voices is not a new phenomenon. Many historical figures such as Socrates, Moses, Jesus, Mohammad and Joan of Arc claimed to have experienced
both visual and auditory hallucinations. How, then, have we moved from a conceptualisation of such experiences as signifying divinity and wisdom to one of mental illness? An examination of the slow paradigm shift in the historical conceptualisation of auditory hallucinations reveals the role of psychiatry in shaping such connotations of auditory hallucinations. However, more recent research findings suggest that alternatives conceptualisations of the experience of hearing voices may be more appropriate than that provided by the dominant psychiatric narrative.

The ‘daemon’ or voice of Socrates is well documented (Leudar & Thomas, 2000). Although the degree to which the voice of Socrates was similar to contemporary accounts of voice hearing is questionable, Leudar and Thomas (2000) argue that it is likely that the voice of Socrates could be considered an auditory hallucination. It was not until the nineteenth century that the term ‘hallucination’ was formally adopted to describe perceptual experiences occurring in the absence of appropriate stimulus (Leudar & Thomas, 2000). It was also in the nineteenth century that the term hallucination was inextricably linked to mental illness by psychiatrist, Henry Maudsley. Subsequently, historical visionaries became ‘hallucinators’ and were retrospectively diagnosed as suffering from a mental illness. The association between voice hearing and mental illness was further compounded in Schneider’s First Rank Symptoms (FRS) of schizophrenia. This framework outlined a number of ‘symptoms’ considered to be pathognomonic of schizophrenia, of which auditory hallucinations featured prominently. FRS of schizophrenia include three types of auditory hallucinations, including hearing voices speaking personal thoughts out loud, hearing two or more voices discussing the individual and hearing voices giving a running commentary on daily thoughts and actions. These ‘symptoms’ still feature in current psychiatric classification systems such as the DSM-IV.

What Constitutes ‘Ordinary Human Experience’?
Is hearing voices a sign of mental illness?

As delineated above, the experience of hearing voices is traditionally associated with a diagnosis of mental disorder. The DSM-IV is perhaps one of the most influential and authoritative texts on ‘mental illness’ in contemporary western society (Crowe, 2000), therefore it is necessary to consider in more depth how this manual contributes to the construction of contemporary depictions of mental illness. Crowe (2000) conducted a discourse analysis of the DSM-IV to examine the ways in which the construction of mental
illness in the DSM-IV serves to create conceptualisations of normality. From a social constructionist perspective, classifications of mental illness are not true representations of reality, rather they are a function of the historical and cultural context and the limits of the linguistic codes used to define the boundaries of 'reality' (Burr, 2003).

Crowe states that diagnostic manuals such as the DSM-IV diagnose mental disorders by grouping a constellation of behaviours which are which are considered symptomatic of the illness. Symptoms such as hearing voices are considered to be part of a larger syndrome occurring within the individual and ignores the possibility that such experiences may be a response to external life events. In the quest to assign an overarching label to a constellation of symptoms, the meaning of experiences such as hearing voices in the context of the individual's life is perhaps lost. The psychiatric meaning attached to experiences such as auditory hallucinations constructs these experiences as abnormal and outside the range of 'ordinary human experience'. The discourses of mental illness outlined in the DSM-IV play an active role in constructing the experiences of mental health service users and serve to trap people in identities that are limiting for them. Moreover, the negative connotations attached to the psychiatric view of auditory hallucinations may serve to detriment the experiences of service users who hear voices. For psychiatry, the idea that someone could hear voices but not have a severe mental illness is an oxymoron (Wise, 2004).

The purpose of such a critical examination of the DSM-IV is not to advocate the abandonment of some form of normative classification in clinical practice. My experience of working in several mental health teams indicates that to some extent, mental health professionals, including clinical psychologists have co-opted the psychiatric classification system into their clinical practice and can be a useful tool to facilitate communication between professionals (Lemperiere, 1995; cited in Crowe, 2000).

Alternative frameworks for understanding voice hearing

Several researchers have begun to advocate alternative frameworks of understanding auditory hallucinations in opposition to the traditional psychiatric view. For example, Leudar (Leudar & David, 2001) has proposed that hearing voices under the guise of a 'symptom' is not so much an indication of mental illness as a cause of psychological distress to a voice hearer. Rather than considering auditory hallucinations per se as a sign of mental illness, Leudar suggests that the clinical significance of hallucinations should be considered
in terms of their consequences for life. He proposes alternative criteria to distinguish between problematic and non-problematic auditory hallucinations. These criteria are firstly if the hallucinations are out of touch with mundane reason, secondly, if it stands apart from the remainder of personal experience, and thirdly, if the hallucinations are a source of unreasoned and impulsive action. However, Leudar's criteria would require further qualification to be considered useful in clinical practice.

As delineated above, auditory hallucinations are not always associated with mental illness and other researchers have asserted that the experience of hearing voices occurs in a wide range of contexts. For example, voice hearing may indicate a number of non-psychiatric medical conditions such as left temporal lesions, speech-related cognitive deficits and most ironically as side effects of psychiatric medications (Boyd-Ritsher et al., 2004). Furthermore, a number of studies have highlighted similarities between the auditory hallucinations of psychiatric and non-psychiatric clients. Honig et al. (1998) concluded that the physical characteristics of auditory hallucinations experienced by both patients and non-patients were similar, but that mental health service users generally experienced more negative voices. Johns et al. (2002) compared the auditory hallucinations of clients with Tinnitus and schizophrenic patients. Consistent with Honig et al. (1998), the physical characteristics (volume, clarity and frequency) of hallucinations were similar between the two groups, however, the Tinnitus patients predominantly heard music and voices which they described as pleasant, whereas schizophrenic patients described their voices as negative. People may also experience voice hearing in response to normal life events such as bereavement, sexual abuse and trauma. Ensink (1993, cited in Thomas & Leudar, 1996) found that 28 per cent of a sample of 97 women who had been sexually abused in childhood had experienced auditory hallucinations. Moreover, such hallucinations were very similar to those described by Schneider as First Rank Symptoms of schizophrenia (Thomas & Leudar, 1996).

If we are to consider 'ordinary human experience' as synonymous with the experience of the majority, then it is noteworthy to consider the prevalence of auditory hallucinations in the general population. Historically, the incidence of hearing voices in the general population has been estimated at approximately one per cent (Sidgewick, 1894, cited in Thomas & Leudar, 1996). Although this study was conducted over a century ago, the substantial sample size of 17,000 people provides a very representative sample. More recent
epidemiological studies (Tien, 1991) estimate the incidence of auditory hallucinations in the population at two per cent. Reports of hallucinatory experiences in the general population provide evidence that such experiences are on a continuum with ordinary human experience and may help to bridge the gap between mental health service users and non service users.

*The Roles of Culture and Religion in the Experience of Hearing Voices*

Further evidence that auditory hallucinations can be considered an ordinary part of human experiences comes from cross-cultural studies indicating that such experiences are common and often positively valued in some cultures and societies. Johns, Nazroo *et al* (2002) conducted a study to examine the prevalence of auditory hallucinations in Afro-Caribbean, South Asian and White samples and whether such experiences were linked to a diagnosis of mental illness. Reports of hallucinations varied across the ethnic groups, with prevalence rates of 9.8% in the Afro-Caribbean group, 2.3% in the South Asian group and 4.0% in the white group. Of those reporting hallucinations, only 1.9% of the Afro-Caribbean group, 6.7% of the South Asian group and 11.4% of the White group met the criteria for a diagnosis of psychosis or were on anti-psychotic medication. These findings indicate that there are differential prevalence rates of hallucinations between cultures and that the incidence of hallucinations is not always associated with a diagnosis of mental illness. However, it is unclear why the ethnic minority groups in this study had lower rates of psychotic diagnosis. It is possible that ethnic minority groups did not consider hallucinatory experiences as an indication of mental disorder. Interestingly, Bhugra *et al* (1999) found that Asian people living in London were more likely than their white counterparts to conceptualise symptoms of first-onset schizophrenia in religious or magical terms and were less likely to describe the symptoms as mental illness. While the research described is not representative of the diverse range of ethnic and cultural backgrounds that clinical psychologists may work with, it does lend credence to the view that it is important to be mindful of the differential prevalence rates of hallucinations between cultures and the belief systems used to explain such experiences. The implications of such cultural differences for clinical psychologists are discussed further in part two of the essay.
Hearing voices: In Search of a Paradigm Shift?

Challenges to the traditional psychiatric view have typically been met with some resistance. Ryle (1949, cited in Chadwick et al, 1996) has argued that psychiatry and psychology are fundamentally different disciplines and are therefore equipped to address different questions and aspects of clients' lives. Voice hearers typically lose much control of their lives in the context of a diagnosis of 'mental illness', so perhaps part of the paradigm shift should be for psychiatry and psychology to loosen the diagnostic reigns and enable service users to reinstate some control and ownership over their own experiences? A number of psychologists have begun to move away from the traditional psychiatric diagnostic categorisation towards a conceptualisation of experiences such as voice hearing as being on a continuum with 'normal' functioning and ordinary human experience. Such a conceptualisation may help to promote a move towards an open-minded approach to hearing voices. As stated by Krishnamurti (1991, cited in Romme & Escher, 1999, p.10) “The problem is not how to end disorder but whether the mind can look at it freed from tradition”. An awareness of the historical status of auditory hallucinations as a symptom of mental illness is useful and with this knowledge in mind, we can move towards a new conceptualisation of the experience of hearing voices that will be more helpful for the client.

Part Two: Implications for Clinical Psychologists

New Approaches to Understanding and Managing Auditory Hallucinations

Traditionally, clinical psychologists have worked with people who present to services in distress and therefore the contrasts between the 'normal' and 'abnormal' are likely to appear significant. Such an exposure bias has led some clinicians to use exclusively pathological models of voice hearing (Cohen & Cohen, 1984). The work of Romme and Escher (1993) suggests that the degree of psychological distress experienced is linked to the extent to which the experience is viewed as normal. These findings provide the impetus for the conceptualisation of hearing voices as an ordinary experience and have important implications for the ways that clinical psychologists respond to service users who hear voices. Previous treatment approaches have been based on the assumption that eradication of the voices is the best outcome for patients. However, there is an increasing evidence base demonstrating that the presence of voices is not so much a problem as the inability to cope with them (Romme & Escher, 1993). It is this body of evidence pertaining to the empowerment of service users and the meaning of such experiences for the individual that I
will now examine in reference to the ways that clinical psychologists should respond to service users who hear voices.

The Government's Expert Patient initiative (Department of Health, 2001) recognises patients living with long-standing illness as experts in understanding and managing their own conditions. Such an initiative will help to promote mutual rather than didactic learning between the client and therapist and go some way to bridging the gap between client's experiences and academic theory. Validation of the clients' experiences has significant therapeutic potential in terms of helping the client to understand and gain control and ownership over their own experiences. I feel that an emphasis on really listening to and learning from the patient as the expert may foster greater curiosity in myself as a therapist and hopefully in turn a feeling of acceptance and containment for the client. There is significant therapeutic potential in conceptualising the experience of hearing voices as an ordinary part of human experience in that such a view may serve a normalising function that can be extremely validating for the client. Furthermore, encouraging the client to share experiences with other voice hearers and directing them to supportive self-help organisations such as the Hearing Voices Network may be very normalising and supportive.

There is much to be gained from listening to service users experiences of their recovery from psychosis. Thornhill et al (2004) conducted a study analysing the narratives of people recovering from psychosis with a focus on how the meaning inherent in people's experiences are linked to the recovery process. Three very different genres of experience were uncovered; escape, enlightenment and endurance. People within the escape genre described recovery as a need to escape from the imposition of a certain belief system about their condition and from the perceived hopeless prognosis from professionals. This narrative echoed the need to escape from a feeling of imprisonment within mental health services and from the identity of a chronic mental health patient. Narratives of enlightenment described recovery as a quest for growth, often encountering discordance between the meaning of the experience for the client and how the experience is viewed by professionals. A theme of control strongly underpinned such narratives, as did a conviction that voices had meaning. Narratives of endurance described the recovery process as an ongoing struggle to retain a sense of self. People within this category were less likely to experience the helpful or liberating effects of psychosis.
The range of experiences encountered by clients delineate that recovery from psychosis may take different forms. This reinforces the importance of listening to the client’s reflections on their experiences and building such beliefs into the individual formulation. Narratives of enlightenment in this paper echo similar narratives of normalisation and acceptance found to be therapeutically effective in previous health research (Crossley, 1999, cited in Thornhill et al, 2004). The authors conclude that all narratives identified suggest the need for a genuine collaboration between client and therapist to enable clients to define their own recovery and to foster mental health services which are genuinely healing (Roberts & Holmes, 1999, cited in Thornhill et al, 2004). Research such as this delineates firstly that recovery from psychosis and from other forms of ‘mental illness’ is possible and secondly that recovery may be different for each individual client depending on the meaning attached to and their understanding of their experiences.

Consistent with this line of reasoning, Jones et al, (2003) conducted a Q-methodological study of voice hearers understanding of their experiences and identified six distinct theoretical frameworks of understanding voice hearing. These were positive spiritual perspective, personal relevance perspective, resigned pessimist perspective, pragmatic response perspective, passivity to forces perspective and generic mental illness perspective. A detailed consideration of the treatment implications of each of these frameworks is beyond the scope of this essay, but such research highlights that voice hearers explanations of and beliefs about the meaning of their experiences rarely fit into one explanatory model. Indeed, attempting to fit the client’s experiences into one theoretical paradigm may actually serve to detriment therapeutic engagement. Clinical psychologists can encourage service users to find meaning and adopt frameworks of understanding that are concordant with their experiences which will reinforce the conceptualisation of voice hearing as ordinary for that individual. Implicit within such an approach is the message that the beliefs and views of the service user are valued and of worth which can be extremely validating and empowering. Recent recommendations from the British Psychological Society (BPS, 2000) suggest that clinical psychologists should adopt a more individual and holistic approach to working with service users who hear voices and this approach is discussed below.
Towards a ‘Reconceptualisation’ of Mental Health Services

The new approach to understanding mental illness and psychotic experiences advocated by the British Psychological Society’s Division of Clinical Psychology (BPS, 2000) represents a shift away from the traditional psychiatric model of such experiences to encompass issues of diversity pertaining to the experience of hearing voices. The report acknowledges mental illness and psychotic experiences as relatively commonplace and espouses the view of a continuum between mental health and mental illness. The report also acknowledges the limitations of the narrow confines of psychiatric diagnosis and subsequent treatment by medication that has traditionally underpinned mental health services. Clinical psychologists are encouraged to adopt a more holistic approach to treatment in which the service user and clinician develop a collaborative relationship that respects the individual’s own understanding of their experiences.

Clinical psychologists should recognise that not all voice hearers will want or need help from mental health services (BPS, 2000). For example, if a person is hearing voices but is not distressed by them and posing no risk to themselves or others, then mental health services may not be required. Refusal of the client to engage with services should not be taken as a sign of non-compliance or disengagement from services, but the reasons for this explored with the client. Furthermore, it is important to acknowledge that some people may find the ‘illness model’ of their difficulties helpful or containing and may not be ready to or lack the insight and motivation to consider the meaning of their experiences or to conceptualise them as ‘ordinary’. Interestingly, my only experience of working with a voice hearer provided a stark example of this. At the beginning of the essay I stated that I had not worked with voice hearers in my past clinical experience. However, during the course of researching the essay question I was fortunate enough to shadow a member of my team covering ‘duty’ – the crisis drop-in service provided at the service. A gentleman diagnosed with paranoid schizophrenia and experiencing command hallucinations from his voices presented to the service. Though I only observed the assessment, I was struck by this gentleman’s apparent reliance on medication for the voices and his reference to the ‘safety’ of an acute inpatient psychiatric ward. It was at this point I realised that such academic theorising about a new approach to understanding and managing the experience of hearing voices may be somewhat idealistic and it is necessary to remember that this approach may not suit all clients. An awareness of the challenges of implementing such a new framework
within mental health services is important and the implications of such difficulties for clinical psychologists are discussed below.

**Wider Roles of a Clinical Psychologist: Social Inclusion**

The traditional psychiatric model of mental illness has expanded into increasingly everyday realms. The mental health - mental illness paradigm serves to create barriers between groups seen as falling at either end of such a continuum. If indeed the experience of hearing voices continues to be viewed apart from the ordinary experience of the majority, it is possible that service users who hear voices will continue to be segregated, stigmatised and demoralised. Such consequences support the need for a paradigm shift within psychology.

Changes in attitudes towards mental illness within professional bodies such as the BPS do not run parallel to those of society. A recent report by the Social Exclusion Unit (SEU, 2004) identified that stigma and discrimination against people with mental health problems continue to permeate society. Furthermore, certain groups such as ethnic minorities may face additional stigmatisation and feel alienated from predominantly white mental health services and are more likely to disagree with their diagnosis, particularly if they hold specific religious or cultural beliefs about their experiences. It is notable that the DSM-IV acknowledges that hallucinations may be a part of normal religious experience in certain cultural contexts. However there is no further explanation of in which cultures and circumstances voice hearing is considered normal. Therefore, important decisions about the 'normal' or 'pathological status of the hallucinatory experience is left to the clinical judgement of the individual clinician. There are two dangerous consequences associated with making clinical judgements of this kind without recourse to specialist knowledge. Shashidharan (1993) has argued that misinterpretations of a clients' lifestyle and cultural practices can lead to clients from ethnic minority groups being misdiagnosed with psychotic disorders such as schizophrenia. Alternatively, a lack of cultural awareness may lead the clinician to feel deskilled in dealing with the experience of hearing voices in cultures different from their own (for clinicians of all ethnic backgrounds). This highlights the importance of education for clinicians about the prevalence and type of hallucinatory experiences in different cultures and the need for professionals to consult with cultural advisors about the nature of the experience rather than relying on stereotypical conceptions of hallucinations in different cultures.
The SEU report also highlighted that health and social care professionals often have too low expectations of what people with mental health problems can achieve. However, such pervasive pessimism is often unwarranted and the report acknowledges that the advice received by people with mental health problems from professionals can set the tone for the course of their illness and the impact on their social functioning and quality of life. This finding has important implications for clinical psychologists in that the portrayal of the experience of hearing voices as an ordinary part of human experience may be conducive to empowering service users and to helping them reintegrate back into the wider community.

While efforts to promote social inclusion are valuable, it is equally important for clinical psychologists to maintain a sense of reflective realism about what level of attitudinal change in society can be attained and the timescales for achieving this. Such transformations would require change in cultural, contextual and structural systems. Similarly, while it is unhelpful to label all auditory hallucinations as symptoms of mental illness, it may be equally unhelpful to simply try and reverse current conceptualisations of such experiences within society without any level of discrimination between severity and risk. Some forms of auditory hallucination such as command hallucinations are more highly associated with risk to self and to others. The approach adopted should fit with the client, and as previously outlined by Leudar (Leudar & David, 2001), the experience of hearing voices should be judged according to their consequences for the life of the client and for others.

Learning curves and contradictions

While I find it intuitively attractive to view the experience of hearing voices as an ordinary experience, there are certain practices within mental health law and services which act as barriers to the implementation of such a conceptualisation. The fact that clients may still face compulsory detainment under the Mental Health Act (1983) undermines the view of the experience of hearing voices as ordinary. Although sectioning under the Mental Health Act is beyond the role of clinical psychologists, this may serve to detriment the therapeutic relationship between service user and therapist. Furthermore, the proposals by the government to introduce Community Treatment Orders that will force people in the community to take medication against their will is in diametric opposition to efforts to promote the social inclusion of people with mental health problems such as those outlined by the Social Exclusion Unit (2004), which ironically is also a government-driven initiative. May et al, (2003) argue that such proposals are counterproductive and will not enable people
with mental health problems to recover a sense of social value and purpose. Moreover, the authors concede that such compulsory treatment is a violation of Article 5 of the United Nations Declaration of Human Rights. Such proposals contradict the view of auditory hallucinations as an ordinary part of human experience. Clinical psychologists may find it difficult to reconcile the disparities between new approaches to understanding mental illness and practices such as sectioning and compulsory drug treatment to provide a coherent and consistent treatment approach for clients who hear voices.

Conclusion

In conclusion, there is a growing body of evidence supporting a move away from the traditional psychiatric view of auditory hallucinations as a sign of mental illness towards the conceptualisation of such experiences as lying on a continuum with normal human experience. Furthermore, the significant therapeutic potential of helping clients to find meaning in their experiences and to define their own recovery provides the impetus for clinical psychologists to embrace a more holistic and individualised approach to client care. However, as clinical psychologists, we need to be mindful of the challenges of implementing such a new approach to understanding and managing the experience of hearing voices.
References


Professional Issues Essay

Using illustrative examples, discuss the advantages and disadvantages of formulation to clinical psychology practice

January 2007

Year 2
Introduction

I will begin this essay by outlining my reasons for choosing the essay on formulation and the structure of the essay. Firstly, as outlined later in the essay, formulation is one of the key skills in clinical psychology practice according to the Division of Clinical Psychology. Furthermore, formulation is one of the skills that as a trainee clinical psychologist, I am still in the process of developing. At this stage of my training, there is still a lot of anxiety surrounding the process of formulating, therefore this essay also served as a useful tool to help consolidate my understanding of the theory and difficulties surrounding formulation. I have chosen to use the first person narrative throughout the essay to provide opportunities for reflection and integration of the issues and debates discussed into my own practice as a trainee clinical psychologist. With regard to illustrative examples, I have chosen to provide anecdotal examples from my personal clinical experience rather than provide formulations to illustrate 'correct' and 'incorrect' formulations, as this is not the stance I have chosen to take with the essay. Rather, the illustrative examples from my clinical practice serve to highlight some of the dilemmas inherent in formulating in everyday clinical practice.

In reading for this essay, I had struggled with attempting to answer the essay question by making a dichotomous divide between the advantages and disadvantages of formulation to clinical psychology practice as this division obscured the complexities of the debate surrounding formulation. I was particularly influenced by an article by Harper & Moss (2003) in which the authors postulated a number of questions about formulation to help clinical psychologists think more critically about the use of formulation in clinical psychology practice. I have structured the essay around a selection of these questions. The aim of the essay is not to answer the questions posed by Harper and Moss, but rather to use the questions to critically reflect on the issues pertaining to the use and role of formulation in clinical psychology practice. The following key questions provide the structure for the issues to be discussed:

- What are formulations for? What do they enable us and our clients to do that we were unable to do before the concept was in common use?
- Who are formulations for? Us as practitioners, our clients or others? Do clients come to us asking for formulations?
By what criteria do we judge the quality of formulations?

Defining formulation

Within the clinical psychology literature, various authors have proposed definitions of formulation, though there is currently no agreed global definition of formulation either within or between specific therapeutic traditions (Sim, Peng-Gwee & Bateman, 2005). The Division of Clinical Psychology (DCP, 2001) state that "formulation is the summation and integration of the knowledge that is acquired by the assessment process (which may involve a number of different procedures). This will draw on psychological theory and data to provide a framework for describing a problem, how it developed and is being maintained". The different therapeutic traditions within clinical psychology, namely, Cognitive Behavioural Therapy (CBT), Psychodynamic and Systemic all adopt a slightly different stance with regard to the definitions and purpose of formulation. It is beyond the scope of the essay to provide a detailed account of the differences between the definitions of formulation, and it is perhaps more important to consider the common elements that connect them. All traditions state that a formulation should summarise and connect a clients core problems, draw on psychological theory to form hypotheses about a persons difficulties and guide the selection of a suitable intervention for the client. Moreover, Johnstone (2006, in Johnstone & Dallos, 2006) states that formulating is a dynamic process and should be open to revision and reformulation as the work progresses and more information about a clients difficulties becomes available. The flexibility of formulations allows clinicians to make intervention decisions based on theory and the clients idiographic presentation (Persons, 2006), though other authors argue that the flexibility of formulations is also a weakness as it can lead to clinicians becoming complacent about the evidence base underpinning their formulations.

The Division of Clinical Psychology (DCP) of the BPS espouse formulation as one of the four key skills of a clinical psychologist which enable them to meet the aims of the profession. In the document “Core Purpose and Philosophy of the Profession” (Division of Clinical Psychology, 2001) formulation is said to be the summation and integration of knowledge and information gleaned from the assessment process. This document states that the formulation draws on psychological theory to inform hypotheses about how a particular problem developed, is maintained and may be helped through intervention (if appropriate).
In order to fully understand the definitions of formulation, it is helpful to have an understanding of the context surrounding development of the concept of formulation within clinical psychology.

**History and development of the concept of formulation**

A critique by Crellin (1998) tracks the use of the term ‘formulation’ within the socio-political contexts surrounding clinical psychology and subsequently its inclusion as a central defining skill of clinical psychologists within training programmes. Crellin noted that the term formulation began to appear in clinical psychology texts in the 1950’s at a time when, according to the British Psychological Society’s (BPS) review of training (BPS, 1956; cited in Crellin, 1998), the key responsibilities and job roles of psychologists working in the NHS pertained largely to objective assessment as an aid to diagnosis, with a partial role in informing treatment planning, though such treatments were typically conducted by psychiatrists.

In 1969, the BPS regulations on training in clinical psychology espoused formulation as a key part of the process of assimilating assessment information and as an important element to be included in clinical case reports. In 1977, the Trethowan Report (cited in Crellin, 1998) acknowledged the changing role of clinical psychologists, particularly with regard to professional and clinical responsibility. This report identified the fact that clinical psychologists were consulted on issues of assessment and treatment formulation as a key factor in clinical psychologists taking responsibility for their own work. Crellin states that by the 1990’s, the term ‘formulation’ was “enshrined” in BPS regulations on the training of clinical psychologists.

In reviewing the history and development of formulation in clinical psychology practice and training, Crellin casts a rather sceptical eye over the rise of the concept of formulation as the pinnacle of clinical psychology practice. Similarly, Harper and Moss (2003) reflect on the absence of the concept of formulation in their training in the late 1980’s and early 1990’s and question the motives behind formulations ‘rise to the top’ within clinical psychology. In my previous experience as an assistant psychologist, my supervisor
echoed the sentiments of Harper and Moss by citing the distinct absence of the concept of formulation in her training during the early 1990’s and had raised the issue of how to evaluate this skill in her trainee’s with the university. Indeed, until writing this essay, I had not questioned the pivotal role of formulation in my practice as a trainee clinical psychologist and had assumed that it had always been a cornerstone of clinical psychology practice. However, this essay has led me to question and think more critically about the concept and use of formulation in clinical psychology practice, and indeed about the wider socio-political implications of the construction of formulation as a key skill of clinical psychologists, as is explored below.

The role of formulation within clinical psychology practice: What are formulations for? What do they enable us and our clients to do that we were unable to do before the concept was in common use?

In examining the role of formulation in clinical psychology practice, it is important to consider this issue at both the wider socio-political level and at the level of clinical practice. In the same way that our formulations often help us to consider what functions a certain behaviour or pattern of relating may serve for a client, it may be useful for us to ask ourselves as clinicians and as individual people what function formulation serves for us at both the professional and individual levels.

The wider socio-political functions of formulation: Formulation as a political tool

Since its inception and introduction in the 1950’s, the concept of formulation has rapidly developed. Crellin speculates that the growth of formulation as a key skill for clinical psychologists served to carve out the professional identity of clinical psychology by promoting formulation as a unique area of expertise exclusive to the profession. Therefore, formulation may have played a pivotal political role in establishing clinical psychology’s professional identity and independence from psychiatry at a time when clinical psychology was struggling for autonomy and influence. In examining the functions served by adopting and clinging to formulation as one of the central defining skills of a clinical psychologist, I have found Yalom’s view very interesting and perhaps applicable to one of the functions of formulation (Yalom in Dumont, 1993: 203). Yalom states that our theories (i.e. formulations) are “self-created wafer-thin barriers against the pain of uncertainty”. In the same way that
any practitioner can identify with the feeling of relief at arriving at a formulation that seems to make sense of a client's difficulties (Johnstone in Johnstone & Dallos, 2006), it may be that clinical psychology's adoption and construction of formulation as a key skill to define the profession arose at a time of professional unrest and served the political purpose of distinguishing clinical psychology as a unique profession from psychiatry and as such served a defensive function against system-wide feelings of inadequacy.

Formulation and diagnosis

In the same way that clinical psychology has used formulation to carve out its identity as unique and separate from that of psychiatry, some of the main concepts underpinning the process of formulation have developed as the antithesis of diagnosis used in psychiatry. Blatner (2006) warns against being lulled into a false sense of security by categorising a client's symptoms according to criteria outlined in the Diagnostic and Statistical Manual of Mental Disorder (DSM-IV) (American Psychiatric Association, APA, 1994) and argues that offering a diagnostic label is not an explanation of a person's difficulties. Rather, a formulation should provide an explanation of a person's difficulties in the context of their lives and if diagnostic labels are borrowed from psychiatry, the implications of such diagnoses for clients should be outlined and linked to the intervention plan. This is a lesson I had learned while on my learning disability placement in constructing a formulation that incorporated a diagnosis of an autistic spectrum disorder. I had struggled to reconcile the differences between diagnosis and formulation and to ensure that the formulation placed the autistic spectrum disorder in the context of the client's life by making links between his behaviours and the implications of these for both him and his carers. For example, the formulation took into account staff frustration at the repetitive questions asked by the client and incorporated strategies for staff in how to respond as well as some education about the nature of autistic spectrum disorders to place the behaviour in context. This illustrative example highlights the dilemmas associated with the use of diagnostic labels within psychological formulations, and this issue is discussed further below.

Different therapeutic traditions hold diverse views on if and how formulation and diagnosis can co-exist. For example, systemic therapists may be less likely to adopt a
psychiatric framework for understanding a person's distress as such medical approaches locate distress as inherently within the individual rather than as serving a function within a system. However, some cognitive-behavioural therapists such as Tarrier and Calam (2002) believe that it is possible to use case formulation within a disorder-based classification system. This was largely my experience on the adult mental health placement in that clinical psychologists constructed formulations around one or a number of psychiatric diagnoses such as health anxiety or obsessive compulsive disorder. At first, I had struggled to fit the implications of such diagnoses into formulations and to reconcile the two approaches. For example, one lady had a 'diagnosis' of health anxiety (hypochondriasis) and while she found it comforting to know that there was a recognised 'diagnosis' that fit her experiences, she became very anxious and concerned that people in her system would think she was 'making up' symptoms. This was linked to her beliefs about the nature of the word 'hypochondriac' and the social stigma attached to that label. Therefore, part of the formulation and intervention plan included addressing these beliefs, normalising her experience and discussions of the meanings attached to mental health diagnoses. This example highlights how formulations may have a broader scope than a diagnostic label in that formulations can and should take account of the social context within which 'diagnoses' are made.

While the above example highlights both an advantage and disadvantage of using diagnosis and formulation concurrently, Pilgrim argues that the use of a dual system only serves to highlight clinical psychologists' ambivalence towards psychiatry in terms of campaigning for full professional independence but also selectively co-opting a medical knowledgebase when it suits. It is important for clinical psychologists to remain mindful that formulations may be open to the same criticisms as the profession has levelled at psychiatry and psychiatric diagnosis. For example, as discussed in the section 'By what criteria do we judge the quality of formulations?', in the same way that the profession has been rightly critical of the low reliability and validity of psychiatric diagnoses, the relative paucity of research into the reliability and validity of formulations mean that formulation could be exposed to similar criticisms.
Formulation in clinical practice

In considering the question posed by Harper and Moss 'what are formulations for?', it is helpful to consider the purposes of formulation within clinical psychology practice. For clarity, I have considered the general purposes of formulation rather than exploring the purposes according to different therapeutic traditions. Sim, Peng-Gwee and Bateman (2005) identify five main functions of a formulation under the headings of integrative, explanatory, prescriptive, predictive and therapist. The integrative elements of formulation allow the salient features of a case to be summarised and brought together which is particularly helpful with more complex cases where there may be a number of presenting problems interlinked. The formulation should also provide insight into the inter as well as intra-individual aspects of a case and help to explain the evolution of the problem within the context of the life of the individual/couple/family. The formulation should also function as a blueprint guiding therapy and Sim et al state that this function may be particularly helpful for trainees as they may feel the need to change course with the intense and changing moods of some clients or if therapy becomes 'stuck'. I learnt the importance of having a comprehensive formulation to follow in therapy on my adult mental health placement. I had been working with a female client who presented with a number of difficulties which I considered to be quite complex and interlinked and for several sessions I had difficulty constructing a formulation to guide therapy. This lady often presented with intense changing moods both within and between the sessions and I had found myself changing my approach each week which left both myself and the client feeling confused and disorientated with the work. The lady disengaged after five sessions and began to see a local private counsellor. Sim et al state that the formulation should also have a predictive function in being able to shed light on the prognosis of the case and can serve as a useful baseline marker for reformulation of the case as therapy progresses and more information becomes available which can be used to form alternative hypotheses. The final function of a formulation as outlined by Sim et al pertains to helping the therapist understand the nature of the therapeutic relationship and ultimately to experience greater empathy for the client.

In summary, the purposes and functions of a formulation as outlined above mainly seem to be aimed towards helping the therapist to make sense of and plan effective
treatment interventions. This leads to the next question posed by Harper and Moss: Who are formulations for?

Who are formulations for? Us as practitioners, our clients or others? Do clients come to us asking for formulations?

Formulation and practitioners

As highlighted above in considering the purposes and functions of formulations, the majority of the functions seemed to be aimed at clinicians in helping the clinician to make sense of the case. Indeed, as espoused by the DCP, formulation is one of the four key skills of a clinical psychologist and therefore does play an important role in our professional lives. However, it is also important to consider the more subtle role that formulation may play in our personal and professional lives. Reflective practice is a very important aspect of clinical psychology practice and we are required and encouraged to remain mindful of our own beliefs, motives, expectations, experiences, cultural attitudes and interpretative lenses and seek feedback about practice. However, there is a danger in that seeking feedback, we may seek to confirm our own formulations and discount evidence that contradicts the hypotheses we have constructed in order to meet our own competency needs. This is particularly salient considering my status as a trainee clinical psychologist and I am very aware of often feeling incompetent due to my level of training and lack of experience in many areas. In working with a female client with a diagnosis of health anxiety, we had jointly constructed a formulation incorporating her experiences into the cognitive behavioural model of health anxiety (Wells, 1997). Constructing and sharing a formulation that fit the clients experiences made me feel competent, particularly as the clients experiences fit the model of health anxiety which formed part of the formulation though I remained open and reflective about this in supervision. This example illustrates how the use of formulations in clinical practice may meet our own needs, whilst also highlighting the importance of reflexivity in being able to recognise when our clinical practice serves our own needs.

Formulation and clients

Formulations are ultimately ways of conceptualising clients difficulties, but it is useful and necessary to consider the benefits, limitations and implications of constructing formulations with clients. As highlighted by Johnstone (2006), clients do not come to clinical
psychologists seeking formulations, therefore in what ways are they helpful? Clients do, however, seek help in making sense of their difficulties and in finding more adaptive and helpful ways of coping, relating and functioning and if, as is constructed within the clinical psychology paradigm, formulations are useful in helping therapists to understand a clients difficulties and plan appropriate interventions from them, then surely they serve a useful function? A key question pertains to if, when and how formulations are shared with clients and whether this is helpful for the client. There is a dearth of research into both clients views of formulations and the effects of formulation on outcome in therapy and the small amount of research that has been conducted has yielded more questions than answers (Kuyken, 2005 in Tarrier, 2005). Research within the psychodynamic traditions showed that interpretations that adhered to a clear formulation produced more symptom change than those interpretations that did not adhere to the formulation (Crits-Christoph, Cooper & Luborsky, 1988, cited in Kuyken, 2005 in Tarrier, 2005). A more recent study that examined the impact of sharing a cognitive-behavioural case formulation on symptoms of anxiety and depression (Chadwick Williams & Mackenzie, 2003) showed no significant effects either way. Similarly, there is a paucity of research into clients views of formulations and the research that has been conducted has yielded some conflicting results. In the study by Chadwick, Williams and Mackenzie (2003), nine clients found the formulation helpful in enhancing their understanding of their difficulties, six clients felt reassured and comforted whereas six clients also found the formulations worrying, saddening or upsetting with the emphasis on childhood experiences forming core beliefs which had been so pervasive throughout their lives. The sharing of formulations may lead to some clients feeling weighed-up, evaluated and Rosenbaum (1996) warns against fitting a clients difficulties into a pre-determined formula and adopting a ‘cook-book’ approach which may not pay significant attention to the complexity of an individual case. Indeed, in my adult placement, one of the learning needs that arose from my placement review was the need to move away from a ‘cook-book’ approach to therapy to adopting a broader framework and to begin to feel comfortable with uncertainty in the therapeutic relationship. On reflection, with formulation being espoused as a core skill of clinical psychologists, using such a structured approach to formulation was a way of feeling competent in being able to formulate a clients difficulties and also was symbolic of my need for structure at that point in my training.
Formulation and collaboration

In the clinical psychology literature, there is a substantial emphasis on the importance of the therapeutic relationship between the client and therapist (Bordin, 1975; as cited in Horvath, 2000) and this ethos has filtered through to an emphasis on the importance of collaboration between clients and therapists in jointly constructing and working through formulations. Dallos, Wright, Stedmon and Johnstone (2006 in Johnstone & Dallos, 2006) underscore the importance of the client having a role in choosing the treatment offered. However, the issues of adopting a genuinely collaborative approach raises interesting dilemmas in terms of how much, when and in what ways aspects of the formulation are shared with the client. This may be particularly difficult if the formulation is incongruent with the view of the client or of other people and professionals within the network of concern. This raises the ethical dilemmas of power and control that are inherent within the therapeutic relationship in terms of the therapist holding information or hypotheses about the client and holding the power to disclose that information as and when they feel it is appropriate. This is a difficult ethical dilemma that needs to balance the client's rights in terms of access to information and the duty of care we have as clinicians not to unduly increase distress and to minimise the risk of harm or abuse arising from our interventions.

While it is an ethically sound concept to make our practice genuinely collaborative, in reality, this is sometimes less straightforward than the guidelines suggest. For example, I have recently struggled with the issue of constructing genuinely collaborative formulations and in sharing those formulations with clients who have a learning disability. For example, one client I have been working with has a profound learning disability and is blind and deaf and only responds to touch which makes communication with him very difficult. In terms of sharing the formulation of the challenging behaviours for which he had been referred to the psychology department for with him, I have struggled with an internal ethical dilemma about how to follow the recommended guidelines of being genuinely collaborative with clients. This dilemma underscores the importance of consulting colleagues, supervisors, other professionals and family members in informing how to move forward in being genuinely collaborative while protecting the best interests of the clients.
By what criteria do we judge the quality of formulations?

In the same way that formulation is espoused as one of four key skills fundamental to clinical psychology practice, evaluation also forms part of the core skills of a clinical psychologist. The DCP state that "All activities and interventions need to be evaluated both during their implementation and afterwards to assess the stability and security of change". Evaluation is a central tenet of the scientist-practitioner ethos that has formed part of the identity of clinical psychology practice. If, as clinical psychologists, we choose to work within a scientist-practitioner framework, then it follows that our work, i.e. formulations, should be subject to scientific investigation – that is, demonstrate adequate reliability and validity (Bieling & Kuyken, 2003). However, there are tensions inherent in applying a positivist model of science to the complex study of human problems and this leads to the question of how we evaluate our formulations: In terms of truth or usefulness?

Evaluating formulations as truths: reliability and validity

In order to evaluate the concept of the 'truth' of formulations, they must be proved to be both reliable and valid. Johnstone (2006, in Johnstone & Dallos, 2006) highlights that the current evidence for the reliability of cognitive case formulation is modest at best. Persons, Mooney & Padesky (1995) asked 46 practitioners to identify the presenting problems and core beliefs from two audiotaped initial assessment interviews and found that though there was good agreement between judges in identifying the presenting problems, there was less agreement regarding the hypothesised underlying core beliefs. A more recent study into the reliability and quality of cognitive case formulation found the same pattern of results with good levels of agreement between clinicians on the descriptive aspects of the formulation but relatively low for the inferential elements (Kuyken, Fothergill, Musa & Chadwick, 2005). The psychodynamic literature cites slightly higher levels of agreement between clinicians in using the Core Conflictual Relationship Theme (CCRT) model as a framework for formulating. Kuyken (2005, in Tarrier, 2005) cites that the results of eight different studies investigating the reliability of the CCRT method yielded agreement within the moderate to good range. In comparing the cognitive-behavioural and psychodynamic orientations, Eells, Lombart, Kendjelic, Turner and Lucas (2005) found very few differences that could be attributed to therapeutic orientation alone. Though these few studies do not fully represent the evidence base on the reliability and quality of formulations across all therapeutic
traditions, they serve to highlight some of the problems inherent within trying to measure formulations as 'truths'.

In considering the concept of validity, it is important to ask the question of what is validity as applied to formulation? The lack of operationalised definition and agreement about the form and content of formulations discussed previously may mean that the concept of measuring the validity of formulations is invalid in itself. Indeed, Garb (1998, cited in Garb, 2005) was unable to locate a single study in which the validity of formulations was good or excellent for individual clinicians and stated that the small amount of research that has been conducted into the validity of case formulations is often poor. The only form of validity which seems to be relatively high is the face validity of formulation. Face validity refers to how valid a test (or indeed a formulation) looks and whether it comes across as professional and feasible to those undertaking the test (or indeed, constructing formulations). The ability of our profession to construct formulation as a key part of its identity and practice may mean that to some, the concept of formulation has relatively high face validity, particularly when is espoused as one of the four key skills of the profession by the DCP. Indeed, before writing this essay, I was highly convinced of the 'face validity' of formulation to the extent that I had in some ways elevated formulation to a status that seemed so far out of reach it evoked substantial anxiety at the very thought if it. However, adopting a more critical stance to the use of formulation within clinical psychology practice has served to loosen the reigns on the criteria I employ to judge my formulations and thereby my competence as a trainee clinical psychologist. It is for this reason that I have found the concept of the 'usefulness' of formulations a more helpful approach than trying to evaluate the 'truth' of formulations.

**Evaluating the usefulness of formulations**

In view of the difficulties highlighted above with the lack of agreement about the form and content of formulations, it may be more feasible to evaluate the usefulness of formulations according to the individual case rather than evaluating the 'truth' of formulations per se. Butler (1998) encourages clinicians to take a step back from the debates about the reliability and validity of formulations and believes that formulations do not need to be 'true' but do need to be useful. Butler has proposed ten criteria for judging the
usefulness of formulations which include whether it makes theoretical sense, if the formulation fits with the evidence surrounding the presenting problem, whether it accounts for the predisposing, precipitating and perpetuating factors, the feasibility of the formulation from the perspective of other colleagues and supervisors, whether it can be used to make predictions, whether it directs the clinician as to how to test those predictions, whether the past history is well linked to the current formulation, whether the treatment identified by the formulation follows the expected trajectory that evidence would suggest, whether it can be used to identify future difficulties and whether the formulation leaves important factors unexplained. Rather than acting as a 'checklist' of what formulations should include, the above criteria can be postulated as questions to guide the clinician in ensuring that their formulations are as full, detailed and useful as possible.

Conclusion

In reading for and constructing this essay, I came across more questions and compromises than concrete answers about formulation. Despite formulation being constructed as a cornerstone of clinical psychology practice, there are still more questions and complex debates about formulation than 'truths', as highlighted by the dearth of research in a number of areas, including the influence of formulation on therapy outcome and clients views of the usefulness of formulation. However, a main part of clinical psychology practice is the ongoing evaluation and modification of our theories and methods in order to advance our knowledge and practice and the issue of formulation should be no different. Indeed, there are many advantages and disadvantages of the use of formulation to clinical psychology practice, however, personally, I have found it invaluable as a way of helping to synthesise clients presenting problems and psychological theory in order to inform interventions and believe that my skills in formulating will develop in parallel to the evidence base for formulations.


Problem Based Learning Reflective Account

The relationship to change

March 2006

Year 1
Introduction

This account provides a reflective overview of the process of formulating and conducting the problem-based learning (PBL) exercise in the light of subsequent clinical experience on my adult mental health placement. I have chosen to use the first person narrative throughout this account to provide opportunities for reflection and the integration of academic theory and subsequent clinical experience into the process of retrospectively evaluating the PBL process.

The Relationship to Change

The task was to construct a presentation around the concept of the relationship to change. The concept of the relationship to change was particularly salient as it touched on some of the anxieties that I and perhaps other members of the group were feeling about beginning clinical training and the personal and professional changes in roles and expectations that we were about to embark on. Since beginning my clinical placement I have noticed parallels between the problem we were presented with which was initially anxiety provoking and difficult to make sense of and the perspectives of many clients who may be finding it difficult to make sense of a problem and how to approach the perhaps daunting process of change. Furthermore, just as we had been given a number of possible directions to focus on, the client and therapist are presented with a number of possibilities at the beginning of a therapeutic contract about the type of therapy and what changes can be realistically expected which they must formulate and construct through a collaborative relationship.

Our group decided to explore the views and experiences of clinical psychologists and their relationships to change both within themselves and the wider system of clinical psychology as they move through the clinical career pathway. On reflection, I believe that I and other group members may have chosen to focus on change throughout the clinical psychology career pathway as this was particularly significant for us at that particular stage of training. At some level, researching this may have served to allay some of the anxieties I had about the embarking on a career in clinical psychology which was a substantial change from my previous experience as an undergraduate student.
We researched two models of change; the developmental model (Hawkins & Shohet, 1997) and the transition cycle (Nicholson, 1990, in Fisher and Cooper, 1990) and decided to test the fit of each model to different stages and experiences in the clinical psychology career pathway. We did this by interviewing a range of people at different stages in their career. The group acknowledged early on that it was important not to try to fit the individual’s experiences into these models but to see how the models helped to explain each person’s experiences. This is a valuable lesson that has been reinforced since being on placement as I had often found it difficult to fit a client’s experiences into a pre-existing model that explained their difficulties. For example, while attempting to formulate the difficulties of one of my client’s with Obsessive Compulsive Disorder (OCD), I had struggled to fit the client’s account of their experiences into the cognitive behavioural model of OCD that I had been directed to by my supervisor. It was only after taking my concerns to supervision that my supervisor helped me to realise that while theory-practice links are important, I should not attempt to force the clients’ experience into a model that does not adequately conceptualise their difficulties.

Models of change

The developmental model

The developmental approach to supervisee development is comprised of four levels of change and development experienced by trainee therapists working in mental health professions. I have found that at least the first stage of this model resonated particularly well with my experiences of clinical placement and supervision to date and found it reassuring to see my experiences so accurately represented and portrayed in a model of supervisee development. Interestingly, I have been able to empathise and identify more closely with at least one of my clients in the feeling of relief at my experiences and difficulties being shared by others and in seeing this formally explained in a model.

The first level is the “self-centred” level where supervisees are dependent upon their supervisors and may be anxious and insecure about their role as a therapist and their ability to fulfil it. I have been able to identify strongly with this stage of supervision, particularly with the difficulties of having an overview of both the technical and process aspects of the
therapeutic process. The second stage is the client-centred level within which the trainee fluctuates between submergence in being unable to objectify their own experience from that of the client and over-professionalism and avoiding any personal involvement with clients at an emotional or process level. The third level sees the trainee becoming more “process-centred” and is able to work within an integrative framework, adapting their approach to meet the needs of the individual client. The trainee is able to simultaneously hold in mind the total process of the therapeutic relationship, including the client’s personal history, external life circumstances, social and cultural factors whilst attending to the more complex elements of the collaborative relationship. Moreover, the trainee has developed a personal style by integrating their professional training and their personality to work in an individual way rather than using therapeutic techniques as a piece of learnt technology. The “process-in-context-centred” level is also known as the ‘master’ level which is characterised by personal autonomy and security and an insightful awareness of the need to integrate the personal and professional to offer a consistent approach to working with clients. At this stage, the emphasis is on integrating and deepening knowledge rather than acquiring new information or skills.

The transition cycle

The transition cycle was developed from the theory of work-role transitions which focuses on both personal change and role development over time. The transition cycle can be used to explain a number of different transitions throughout work and our personal lives and recognises that an individual and/or an organisation may be engaged in any number of transition cycles and at different stages at any given point in time. I have found this helpful to keep in mind in my clinical work that at any one time the client will be in a number of transitions both within therapy and in their personal lives. The model holds that each stage exerts a powerful influence over what happens in the proceeding stages. Figure 1, below, illustrates the transition cycle:
Figure 1: The Transition Cycle

Preparation

Expectations and Motives

Stabilisation

Relating and Performing

Encounter

Emotions and Perceptions

Adjustment

Assimilation and Accommodation

The authors noted that the transition cycle may be a useful building block for analysing career patterns and therefore this model seemed particularly suited to help explain some of the changes that clinical psychologists face at different stages in their career.

Group dynamics in addressing the task

For me, one of the most significant aspects of working on the PBL task within our group was that it was relatively free from disputes and arguments. The ambiguity surrounding the task coupled with the unfamiliarity of people in the group contributed to the initial anxiety about the task, however, it seemed that at this point all group members were still wanting to make a 'good impression' on other people which may have served to keep strong opinions at bay. There were a number of sessions when the nature of the task and materials seemed very intangible and these were the times when the group seemed to become strained. In particular, one group member became concerned quite early on about what the final presentation would look like and frequently reminded other group members
of their concern. I and other group members perhaps felt more comfortable in allowing the
task and presentation to take shape more slowly and naturally depending on the outcome of
the interview. In this sense, the group almost seemed to take a guided discovery approach to
formulating the concept of the relationship to change and initially did not have much
direction or structure. Interestingly, while I felt quite comfortable with the guided discovery
approach in the group setting, I have found with subsequent clinical practice that I am less
comfortable with the guided discovery approach in individual one-to-one therapy with a
client and have a tendency to be rather solution driven and concerned about the technical
‘doing’ side of therapy and feeling anxious at times in the process territory of just ‘being’ in
the therapeutic relationship with a client. I believe that this is in part a reflection of my
current stage of training. On some level the different approaches of each group member to
formulating the presentation may in part be reflective of the different preferred therapeutic
orientations used or of the personal style taken in client work.

A key point in the process of constructing an approach to the relationship to change
came when the group decided to convey the findings of our interviews through the
humorous medium of a ‘Family Fortunes’ game-show. Humour has been and remains an
important underlying theme throughout our group interactions. For example, as within the
therapeutic relationship, the use of humour within the group at times served to forge,
consolidate and repair ruptures in the group (Lemma, 2000) when the group at times
became divided in opinion or frustrated with the ambiguity of the task. Humour has
remained an important style of communication within our group and I have found it helpful
to reflect on the possible impact of this upon my own personal style in my clinical work as a
therapist1. In the context of reflective practice, I feel it is important to acknowledge or at least
consider the contribution of the personal style of the therapist to the therapeutic
relationship, alliance and outcome. This is an issue I am particularly interested in as in this
stage of training. I believe I am still in the process of developing my own personal style as a
clinical psychologist. I have at times found it difficult to integrate aspects of the type of
therapy, my own personality and professional boundaries into a personal style whilst also
having an awareness of the impact of my personal style on the therapeutic relationship.
However, in terms of the developmental model, the full integration of the personal and the

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1 I use the term ‘therapist’ to refer to my clinical work with clients which I view as just one of my roles as a
trainee clinical psychologist.
professional does not occur until the fourth level and as I stated earlier, I personally identify with level one of the model at this pointing my training within which the trainee is still in the process of developing personal and professional skills but may have some difficulty integrating them into a coherent approach as a therapist.

Conclusion

I have enjoyed writing this reflective piece as it has allowed me to draw parallels and make explicit links between the academic aspects of the course and the relevance to clinical practice. I have had the opportunity to reflect on the process elements of the group’s approach to the PBL task and also on the process elements of therapy which I have acknowledged as a learning need. By reflecting on the process elements of the group task I have been able to evaluate the strengths and weaknesses of the approach adopted by our group. I feel that the use of humour in the presentation and in our approach to the task helped to facilitate group cohesion and also to integrate ourselves within the wider course team and other trainees. I found it extremely helpful to look at other people’s experiences of change throughout the clinical career pathway and this may have served to allay some anxieties we may have had about the profound changes that we may face as we progress through our careers in clinical psychology. On reflection, it may have been useful to examine our own approaches to change as part of reflective practice to help us to understand how we personally deal with change. This may have helped me to relate to and empathise with my clients a little better in understanding both their and my own relationship to change.
References


Appendix 1

Questionnaire questions
1. Where are you in your career now?
2. What was the most significant change in your career in the last 12 months?
3. How did you approach / prepare for this change?
4. What was difficult about this change and why?
5. How do you think you managed this change? (Did you have any help?)
6. Is this how you normally handle change?
7. What changes have you noticed in yourself in your career?
8. Is there anything that stays constant during a change in your career?
9. What aspects do you feel are the most comfortable / challenging at the moment in your career?
10. What is your relationship to change? How do you visualise change? Can you draw change or your relationship to change?
Problem Based Learning Reflective Account

Child Protection, Domestic Violence, Parenting and Learning Disabilities

March 2007

Year 2
The Problem Based Learning (PBL) Task

The PBL task was centred around a case involving a number of complex issues. The task outlined the case of the Stride family, who had twin daughters aged three (see appendix 1). Concerns had been expressed about the ability of Mr and Mrs Stride to adequately care for their children and both Sally and Sarah had been placed on the child protection register under the categories of emotional abuse and neglect. In response to this, a full child protection case conference had been called following concerns about the parent's ability to care for the children. In the meantime, Sally and Sarah Stride had been placed in short-term foster care, which Mr and Mrs Stride resented and vehemently protested about having their children back in the family home. The case was further complicated by a number of additional factors including domestic violence within the family of which the twins had witnessed and Mrs Stride had previously had two children removed from her care due to her not protecting the children from the abuse of her last partner. Mrs Stride was considered to have a 'mild' learning disability and Mr Stride had attended a school for children with special educational needs. The task identified the role of the clinical psychologist as conducting a full and formal risk assessment and if needed, providing a rehabilitation plan for the children.

Our approach to the task

My initial response to the task was to feel overwhelmed by the complexities of the case and unsure of both my personal and professional opinions on what might be the best way forward. Our group spent the first session exploring the different issues and deciding which areas we felt were the most pertinent to focus on. We allocated research to each person according to the issues that we had decided to focus on which were the disability discrimination act, the children's act, child protection, the effects of witnessing domestic violence in children and parenting in people with learning disabilities. The first two sessions were spent sharing information within the group and prioritising what we saw as the most important issues. This was an important process and one that paralleled those in clinical practice in terms of sharing information and consulting colleagues about what feasibly can be done to come up with a plan of action. I had initially felt quite overwhelmed when beginning to conceptualise the complexities of the case, however, the process of sharing
information and jointly constructing a course of action served to allay some anxiety and help conceptualise the case.

In approaching the task and constructing the presentation, our group adopted a very task-focused approach and had decided on the main issues and mode of presentation within the first two sessions. This was quite a change from the first PBL task in the first year on 'The Relationship to Change' in which the majority of the group were more process-oriented and we did not decide on the mode of presentation until the final few sessions. In the relationship to change PBL, one member of the group expressed concerns about the lack of task-focus, though the majority of the group disagreed. Interestingly, in this task, we all quickly focused on constructing the presentation which we decided was to be a court room scenario to represent the two sides of the case; the protection of the children and the rights and abilities of people with learning disabilities. The difference in the approach we took to the task in this PBL may in some ways reflect important changes in ourselves as trainee clinical psychologists. The task-focused approach and the efficient way we constructed the presentation may reflect our increasing confidence in the decisions we make which are part of the maturational process of progressing through training. Whereas in the first PBL task, the group were quite anxious about the approach we took to the problem and the presentation, in this PBL exercise, we demonstrated more confidence in our decisions about the angle adopted and the form of presentation. In some ways, the group seemed more able to contain any anxieties or uncertainties about the task and were concerned with doing a "good enough" job with the limited time and resources available. This process mirrors some of the issues faced when working in a resource-constrained NHS with a focus on time-limited interventions. Realistically, this is something that as trainee clinical psychologists, we need to adjust to and become tolerant of, particularly with the current discussions in the 'Improving Access to Psychological Therapies' (IAPT) agenda (Wake, Foster & Evans, 2007) about the proposed reformation of the way that high volume / low intensity psychological interventions are offered. For example, it seems that one strand of the IAPT strategy is that the form of therapy offered should be restricted to CBT, with other forms of therapy needing to be vehemently defended if the clinician intends to use them. Therefore, clinical psychologists will be required to become increasingly confident in their decisions about the approach taken to their clinical work. Similarly, within this PBL task, we could have adopted a number of approaches to the task, but we felt confident in our decision to present
the complexities of the task in a court-setting with a 'battle' between the Children's Act (Crown Copyright, 2004) and the Disability Discrimination Act (Department for Work and Pensions, 2005). While clinical psychologists are of course required to have a clear evidence base underpinning their clinical work, there is still an element of flexibility in the ways that we work and the theories / models we draw on. Indeed, in clinical training, a knowledge and use of different therapeutic models is required, whether they are used in their pure form or integratively. The PBL exercise was facilitated by the fact that we drew on theory, research and policy from different areas within the child and learning disability literature to construct our presentation.

**The presentation**
*Setting the scene: The courtroom scenario*

The idea to represent our approach to the task in a court-room setting was suggested by one member of the group following discussions about the different perspectives of people supporting the parents and those supporting the local authority. Our group had made a dichotomous divide between the side of the parents (in terms of the rights and abilities of people with a learning disability) and the side of the local authority (protecting the best interests of the children). This divide in some way represented the divide in the group between those members on child and those members on learning disability placements. Once roles were assigned (see below), we worked individually and with those either on the same 'side' and with the group as a whole to bring the presentation together. As we adopted a very task-orientated approach, the group had to work collaboratively in the short time available to bring all the information together in a coherent form, but also to come to some sort of agreement about the outcome of the court hearing. On reflection, the court-hearing scenario may have provided an outlet for the underlying competitiveness within the group or throughout the cohort more generally. Though the group worked together to construct the presentation, the adoption of a court-room scenario in order to pitch the Children's Act and the Disability Discrimination Act against each other may have allowed us to express the competition between trainees which we perhaps feel unable to express outwardly.
Roles adopted within the presentation

The six roles available were a narrator, judge, two psychologists and two lawyers, one of each for each side of the argument. On reflection, the roles that each person adopted said something about their role within the group at a broader level. One member of the group opted to be the narrator as she felt that this would involve less acting than other roles as she did not feel confident in adopting a main role. One male member of the group was nominated to be the judge by the other male member of the group. The group member who became the judge played quite a specific role within the group in the first year in terms of being older and adopting a somewhat 'wise' role within the group. The other four roles of two psychologists and two lawyers were left for members of the group to adopt. I played the role of the psychologist for the local authority to support the argument that the children should be removed from the home. I had opted to represent this side of the case which on reflection was an interesting juxtaposition considering I was just starting my learning disability placement. I have discussed my position in relation to the outcome of the court hearing in the ‘Outcome of the court case’ section below. Interestingly, two members of the group who have an alliance both within the group and within and outside of the training course chose to be on opposite sides of the case. On reflection, I found this interesting considering the underlying competition that the two sides of the case perhaps represented.

Outcome of the ‘court case’

The group had decided that we wanted to have an outcome rather than just presenting two sides of the case. The evidence base stated that a very high proportion of adults with a learning disability had their children removed from their care. The group also chose to remove the children from the family home for a certain element of 'shock value'. It would have been very easy to come to a compromise decision in which the parents received more help with learning to become 'good enough' parents. However, though this would perhaps have been the preferred option in terms of believing in the abilities of parents with a learning disability, this outcome was incongruent with the research evidence which suggested that currently parents with a learning disability are underestimated in their ability to be good enough parents.
In terms of the court-case, the outcome rested in favour of the side I had provided 'evidence' for. Even though I was on and am still currently on my learning disabilities placement, I still feel that it was the best outcome for the children to be removed from the care of their parents. Although I have not done any specific clinical work on parenting and learning disabilities, my experience of people with mild learning disabilities and also the information available from scenario suggested to me that perhaps the parents would not have been able to provide adequate care for the children and also that the services surrounding the family may not have provided adequate support to help the parents care for the children.

Main lessons and learning curves

This PBL task allowed me to learn a lot of practical information about the children's act and the disability discrimination act. It can be difficult to make decisions about the best course of action in cases where there are supportive arguments for both sides of the case. Cases like this are also quite emotive and it may be difficult for individuals involved to separate their personal feelings about the case when trying to decide what the best outcome may be. Moreover, this task also helped me to realise the changes that both I and the group have made since the last PBL task. For example, as individuals and as a group we were more able to contain our anxieties about our approach to the task and be happy with doing a 'good enough' job instead of comparing ourselves to other groups and worrying about what we had not covered. I look forward to beginning my child placement to see how I respond to cases involving similar issues of child protection.
References


Appendix 1:

The PBL task and case scenario
Problem Based Learning Exercise

Child Protection, Domestic Violence, Parenting, and Learning Disabilities

The Stride Family

Live locally

Raised in the care system

No contact with mother and father

Domestic Violence
The Problem

The twins, Sally and Sarah Stride, were placed in short term foster care, following a recommendation of a full child protection case conference, and enacted at an initial Court hearing, that the children continued to be at risk in the care of their parents. The children were on the child protection register, under the categories of emotional abuse and neglect. The children's Guardian has approached you, and asked you to help the Court by conducting a full risk assessment, and if appropriate, to help the Court develop a rehabilitation plan for the children. This is a joint instruction by all parties to the proceedings. However the Local Authority wishes to place the children for adoption, before it is too late, in the belief that Mr and Mrs Stride will never be able to care adequately for their children. Mr and Mrs Stride are passionate in their commitment to have the children returned to their care. Whose problem is it? Why?

Background Information

Mr and Mrs Stride are white English. They live on State benefits. Mrs Stride is described as a woman with learning disabilities, in the mild range. Mr Stride attended a
school for children with special educational needs. Mr and Mrs Stride do not read and write English. It should be noted that many long reports have been written about them, their children, their care of their children and so on. Their solicitors read the reports out loud to them, usually once, and sometimes on the morning of a Court hearing.

Mrs Stride has two older children living with separate adoptive families. She is not able to have contact with them at the moment, as it was a closed adoption. This is because her first husband was extremely violent to her, and threatened violence to the previous social workers. Social Services staff feared for the safety of the adopters if their whereabouts were known. Mrs Stride promised herself it would be different with this marriage and for these children.

Mr Stride has physically assaulted Mrs Stride, during disagreements. She minimises his behaviour, saying it is nothing compared to what her previous husband used to do to her. The two children have witnessed these arguments and assaults.

Mr Stride’s parents are supportive. They buy clothes and toys for the children, and occasionally buy food shopping for the family. Apparently, they are unable to look after the children, because Mr Stride’s mother suffers from a painful rheumatic condition. Mrs Stride was raised in the Looked After Children system, and has no contact with her family of origin.

Mr and Mrs Stride live in conditions of deep poverty. They do not have many household appliances that work, and it seems that Mrs Stride struggles to understand the workings of the second-hand appliances donated to them by family. It would seem that Mr Stride understands their workings, but is not prepared to use them. Social Services staff are most concerned about physical neglect of the children’s needs. Family Centre staff say they have tried to engage both Mr and Mrs Stride in parenting classes, but the couple do not attend on a regular basis. The Family Centre appointed a family worker to visit the home, and show Mrs Stride ‘how to keep house’. The family support worker has not been trained
to work with parents with learning disabilities. The Social Worker says the Department has offered the family everything, and it makes no difference to the care of the children.

Mr and Mrs Stride are desperate about the loss of their children. They want them to come home. They fiercely resent the foster carers, and the supervisor of their contact with the children. The children’s Guardian believes the parents can learn to be ‘good enough’ to satisfy Social Services requirements. Mrs Stride was referred to the local AMH service for help with feelings of despair and depression. She is taking anti-depressant medication, and is seeing a CPN for counselling.

Prompt Questions

......something about paying attention to the professional network (liaison, communication, respective roles)

......something about safety, risk assessment and risk management

......something about parenting and LD

......something about child witnesses to domestic violence

......something about the effects of poverty and class discrimination

......something about literacy and verbal comprehension (effects of anxiety and stress on memory and comprehension, and willingness/ability to express concerns, and say, ‘I don’t understand these reports’)  

......something about resilience, adversity, depression and coping

......something about the role of grandparents in the care of children

......something about children of parents with learning disabilities

......something about gender issues and scripts

......something about psychologists, child protection and the legal system
....How would you address things differently if this family were black, or if the parents were both of the same sex, or if the family came from a middle class background or if they were of average intelligence?
Appendix 2:

The court-room scenario script
Gillian

When preparing our presentation we were very aware of the gravity of the topic and yet it was a challenge for some members of our group not to dress up – so, we have a presentation that we really hope strikes a good balance between this very serious topic but at the same time is memorable because it is interesting and entertaining.

Firstly I’d like to introduce you to the legal representatives and expert witnesses -

- Ms Matilda Biggleswade is the lawyer representing the local authority
- Their expert witness is clinical psychologist Dr Shochlan O'Rourke
- Ms Anastasia McBeal is the lawyer representing the family
- And Professor Sebastian Tennyson is their clinical psychologist and expert witness.

Now could I ask you to ALL RISE for Judge Jethro Darwin-Fitzpatrick-Huxley

Tony:

So what have we here? Hmmm. Two young children in short term care, some risk concerns significant enough for the Local Authority to want to place the girls up for adoption. Parents, Mr and Mrs Stride both on benefits, two other children already adopted away from the family. Domestic violence is a past and current issue. Limited support available from within the family. A plethora of service provision staff involved, but there seems to be a lot of resistance in taking up this care offered. What I don’t understand at this point though, is what are the reasons for wanting to take these children permanently away from Mr and Mrs Stride? I see this as a relatively straightforward case.

Amanda:

But Your Honour you do realise that the parents have a learning disability?
Tony:

(Shock horror and full of contemplation) Ah-ha, that changes things. Would Ms Biggleswade and Ms McBeal approach the bench?

Gillian

We'll leave them there to huddle for a moment. Obviously we have over simplified an extremely complex situation. We do not pretend to be legally accurate. In reality cases like this could take weeks and would be very upsetting and disempowering for the parents. In this case all the witnesses have been heard previously and expert witnesses have given their opinions. The summation of the case will now be presented from the points of view of both sides - this will include mention of the relevant policies and Acts particularly the Children Act and the Disability Discrimination Act.

Tony:

The state may not interfere in family life so as to separate children from their families...unless it has been demonstrated to be both necessary and proportionate...and that not other less radical form of order would achieve the essential aim of the welfare of the children. Before making my decision, I'd like to hear your concluding summaries. Ms Biggleswade, please present your arguments concisely.

Amanda:

I'm sure my learned colleague will talk at length (and at length they do!) about the discrimination that they say is rife within this case. However, I put it to you Your Honour that all their well meaning but somewhat flimsy claims can be contested simply by using the first principle of the Children Act- that the welfare of the child is paramount.

You will see from both my speech and that of my expert witness, that we are acting within the key principles of the Children Act. This denotes the powers and duties of the
local authority for children in need. In addition you will hear evidence of us using the Welfare Checklist by assessing the capabilities of the parents, the physical emotional needs of the children and the level of harm suffered or risk of future harm. We have also ensured that the orders we are proposing under the Children Act are better for the children in question.

We have two young children who are deemed so significantly at risk that they have been placed on the child protection register for neglect and emotional abuse and are in a situation which just does not seem to be changing. You will hear shortly from our expert witness, Dr O'Rourke who will provide information on the life-long consequences for young people suffering from abuse which cannot be ignored in the decision that is being made today.

We've heard during these proceedings from the numerous professionals who are involved in this case on behalf of the local authority and the level of support offered to this family. They have a support worker, been invited to attend family therapy and have contact with psychologists and a CPN. Yet, this help has not made a blind bit of difference to the care of these children. From what I understand they have not really engaged with services. The concerns about their risk of exposure from domestic violence, from abuse themselves and from social deprivation are still just as high, high enough to warrant the children being temporarily placed in foster care. A decision that Your Honour will understand has not been made lightly. However, this was a temporary measure and the time has come to make a more permanent solution. Unfortunately, I believe that we have no choice but to impose the power of the local authority to safeguard these children by permanently removing them from the home. Despite us only using this as a last resort measure, we feel that there is no alternative. We have met our duty in attempting to promote parental responsibility but to no avail and therefore we must act quickly as any delay is likely to prejudice the welfare of the children.

I'm sure that there is going to be considerable disagreement to this decision, no more so than from my learned colleague over there who will no doubt bring up again and again
Mrs Stride’s learning disability and while I can show sympathy for the position that their clients are in, I must emphasise that this is a child protection matter and these children are not being protected!! Looking at Mrs Stride’s relationship history she does not seem in a position.....

Emma

Objection, I hardly think Mrs Stride’s previous relationships are relevant

Tony

Why is this relevant?

Amanda

This is relevant to the case because it shows Mrs Stride has a history of abusive relationships and therefore raises concerns about whether she is capable of protecting herself and her children

Tony

Over ruled

Amanda

We do not even know if Mrs Stride has indeed been assessed as being capable of protecting herself from violence and abusive relationships so how can she possibly protect her children? Does she even understand the consequences of this for them? Her minimisation of Mr Stride’s violence is evidence that she does not appear to appreciate the level of harm and risk that both herself and her children can be placed under. The local authority must therefore take the lead and say that if Mr and Mrs Stride are not protecting these children from future emotional harm, then we must. I will now ask my expert witness
to elaborate more on the consequences for these children in staying in their home environment before I make my concluding comments.

Jo

There are three main concerns pertaining to the welfare and protection of the children that lead on from the arguments articulated by Ms Biggleswade. These relate specifically to the level of risk posed to the children, the issue of psychological attachment and that of the longer term development and consequences for the children if they remain in the care of their biological parents.

Amanda

Dr O'Rourke, could you tell us what are the effects of witnessing domestic violence on the children?

Jo

Firstly, as highlighted by Ms Biggleswade, these children have been placed on the Child Protection Register under the categories of emotional abuse and neglect. There are a number of issues that may indicate that the children are at risk of significant harm should they remain in the family home. Firstly, both Sarah and Sally have witnessed domestic violence within the family home on a number of occasions. There is a plethora of research and anecdotal evidence pertaining to the detrimental effects associated with witnessing such abuse on a number of aspects of child development including behavioural and emotional functioning, cognitive functioning and attitudes and longer-term developmental difficulties including a heightened risk of mental health difficulties and trauma.

Furthermore, I am concerned about Mrs Stride's ambivalence about the violence and her attempts to minimise both the level of violence experienced from her partner and the impact of this upon her children. Unfortunately, this does seem to be a repeating pattern of behaviour as Mrs Stride's two other children from a previous relationship were removed
from her care as it was deemed that she was not capable of protecting these children from significant harm. While I can empathise that this must have been a very difficult situation for Mrs Stride to deal with, the research evidence tells us that when considering future risk, past behaviour is a significant factor in determining such future risk. It is therefore my professional opinion that Mrs Stride is either unwilling or unable to protect her children from the harm posed by her husband.

Amanda

What implications are there for the children's attachment should we delay in a decision to place them?

Jo

Secondly, I would echo the concerns expressed by Miss Biggleswade regarding the prevention of undue delay in making a decision about the future care of the children. It is important to consider the effects of this situation on the children's attachment relationships as research tells us that these bonds form a significant part of the children's psychological and emotional well-being. The children will obviously have developed strong attachment bonds to their biological parents, however the children are currently in temporary foster care and the length of such separation must be minimised. I suggest that the emphasis be placed on finding a suitable adoptive placement as soon as possible to enable the children to settle and begin to develop new attachment relationships and to prevent any further and unnecessary disruption to their lives.

Amanda

Can you tell us more broadly about what you may expect are the long-term consequences for these children?
My third concern pertains to the longer-term development and opportunities for the children should they stay in the care of Mr and Mrs Stride. I do have some concerns relating specifically to Mrs Stride's intellectual and functional disabilities and her ability to provide an adequately stimulating environment within which the children can grow and thrive. In my opinion as an expert witness, these children may end up taking on certain parental responsibilities for their parents as they cognitively and intellectually 'overtake' their parents, which again may have detrimental consequences for the children's development and well-being.

It would not be fair to conclude my argument without acknowledging Mr and Mrs Stride's obvious love for and dedication to their children which has been vehemently expressed in their wishes to keep their children. However, unfortunately, as I have outlined, I believe that there are wider issues to be considered, all of which have far-reaching implications for the future welfare and well-being of Sally and Sarah.

Amanda

We have now heard the professional opinion of what the consequences are for these children if they remain in the care of Mr and Mrs Stride and I must say they do not make easy listening. I for one do not feel we have any choice but to uphold the Children Act but to make the local authority responsible for the care of these children and to find them an adoptive home. This is the correct legal and lawful decision taking all the facts that have been laid before you into place Your Honour.

Tony

Thank you Ms Biggleswade, I see. Ms McBeal, I'd now like to hear from you please.

Emma

Certainly your honour...
I have listened with interest to the information provided by my learned colleague and indeed we, on behalf of the family would not argue the importance of the Children Act – of course the welfare of the child is paramount.

However, I hope to put to you a rather more complete story regarding the issues of this case. Council for the Local Authority has painted a picture of negligent parents ignoring all Local Authority intervention. And yes, Mr and Mrs Stride have had some difficulties within their relationship, which nobody in this court would wish their children to have witnessed. Mr and Mrs Stride also have difficulties relating to poverty, lack of vocational skills, emotional difficulties and a lack of parenting models. But look at the research into this area; most parents in the general population share these difficulties. Do any of these issues warrant taking a child away from a normal family? I don’t think so.

Finally, Mr and Mrs Stride have what could be described as mild to moderate learning difficulties, which undoubtedly leaves it more difficult for them to raise a family. And I put to you, your honour that these children, Sally and Sarah Stride were taken from the family home because their parents had a learning disability – which goes directly against the Disability Discrimination Act, the Human Rights Act and the Disabled Persons Independent Living Bill 2006. Mr and Mrs Strides cognitive limitations add another dimension to this case that the Local Authority were not prepared to provide for.

This goes directly against the Human Rights Act which states that there should be no discrimination in access to services on the grounds of disability, the right to marry or have a family and differences should be taken into account in the provision and delivery of services. Similarly, the Disability Discrimination Act note that Local Authorities must ensure that any services offered to parents are equally available to parents with disabilities, promoting equality of opportunity for disabled parents. I could go on your honour...
You have heard my learned colleague and her expert witness talk about all that the Local Authority has offered the stride family. However, do we truly believe that parenting classes that do not cater for a learning disability and the provision of an untrained family worker is meeting the needs of this family? I put to you your honour that these types of provisions are similar to providing a deaf parent with a support worker who could not sign.

Mr and Mrs Strides needs are clear. They have learning disabilities, which impede, but do not prevent their ability to parent. The Local Authority has failed in their duty to cater for the needs of these parents.

What we have here are two parents desperately motivated to have their children returned to them. However, ignoring the parents wishes, ignoring the children's guardian and ignoring the Disability Discrimination Act, the Human Rights Act and the Disabled Persons Independent Living Bill, the Local Authority have not carried out a full and detailed assessment of Mr and Mrs Strides capabilities, strengths and needs. I put it to you that the Local Authority do not even know what Mr and Mrs Stride are capable of in relation to childcare.

Through appropriate support and training, Mr and Mrs Stride would likely be able to care adequately for their children - research and good practice clinical experience says it is perfectly possible for this to happen.

Before I end your honour, I would like to draw your attention to one further issue. My learned colleague has quoted the Children Act on several occasions today. The Local Authority hide behind the Children Act quoting the statement regarding “the welfare of the child being paramount” as one of the primary reasons for removing Sally and Sarah from their home. However, I would like to draw your attention to the next section of the Children Act - ignored by the Local Authority and my learned Colleague, and I quote, “it is the general duty of the Local Authority to safeguard and promote the welfare and upbringing of
such children by their families by providing a range and level of services appropriate to their needs.

It is our opinion your honour, that the rights of this family unit have been ignored in a case of defensive practice rather than best practice by the Local Authority. I would now like to call on my expert witness, Professor Sebastian Tennyson, clinical psychologist to provide his expert psychological opinion related to the case. Thank you for your time Professor Tennyson. I'd like to start by asking you whether it is feasible to expect services to support the Stride family in their efforts to care for the twins.

Gav

Your honour, it is my opinion that the services involved in the care of the twins so far have been ill-coordinated and that this has been a major causal factor in the situation the family has found itself. As you have seen, there are a number of agencies investing time and money into their efforts to assess and assist Mr. and Mrs. Stride and I believe that these agencies could be used more creatively and to better effect. We have found very little evidence to suggest that Mr. and Mrs. Stride are unable to provide attentive and responsive care for their twins, given the right support. I would suggest that Mr. and Mrs. Stride be allocated a small number of key professionals from PLD and children’s services who work closely together to ensure that they fully understand what is expected of them; and that these professionals develop a more detailed understanding of the capabilities and difficulties faced by these parents. I would direct you, your honour, to a recent report by the Norah Fry research centre at the University of Bristol which highlights the excessively high expectations held by services whose primary focus is not learning disability. I believe that this bias is significant in this case.

A potential task for the professional group is to assist Mr. and Mrs. Stride to engage with parenting services such as those provided at Sure Start. This will include education and consultancy to these services in order that they are better equipped to take Mrs. Stride’s learning disability into account.
I would also suggest that the Strides' social worker complete a review of the benefits they receive. It is clear to me that the family is struggling to cope with extreme financial hardship which places extra strain on the relationship of the parents and impacts, to no fault of their own, on their ability to care for the children. It seems that the Strides are not getting the service that the Valuing People document insists that they deserve from my social work colleagues.

Finally, I would suggest that the Strides are introduced to an independent advocate who can help them address a number of issues. An advocate could assist them in navigating complex legal proceedings and assist them in managing their contacts with their professional network.

A better organised service will not require further funding or professional time. It will simply enable the family to make better use of the support available and will help them to succeed rather than set them up to fail. Failure to carry out such measures would amount, your honour, to gross negligence.

Emma

In your professional opinion, do you feel the children at risk from harm from Mr and Mrs Stride?

Gav

Clearly we would not be here today if professionals involved in the case were not concerned for the safety of the twins. However, in my opinion your honour, the twins are not at risk of harm from their parents given the right support. We have evidence that Mr. Stride has physically assaulted his wife and we know that their relationship is sometimes tumultuous. Mr. Stride in particular must take responsibility for managing his behaviour at such times. However, neither parent has been aggressive in any way towards the twins. Furthermore, I would argue your honour, that putting into practise the recommendations I made earlier will ease the strain placed on Mr. and Mrs. Stride, thus directly reducing risk of the children witnessing further incidents of domestic violence. I would echo the belief of the
children's Guardian that Mr. and Mrs. Stride can learn to be 'good enough' parents. Despite the deep poverty in which the family are living, the twins are deeply loved and cared for by parents who are committed to do what it takes to keep them.

Emma

In the eventuality, Prof. Tennyson, that the children are removed permanently from their parents care, what potential risks are there?

Gav

Your honour, these children are aged 3. They have reached an important developmental milestone and it is quite likely that to remove them from their home at this age would have significant negative consequences. A secure attachment to caregivers is an important factor helping children as they develop. I believe, your honour, that the twins are securely attached to their parents and that to break this bond at this stage puts them at greater risk than they would be under if the Strides were properly supported. Indeed I would put it to Dr O'Rourke that the truth, and she may not be able to handle the truth, is that to form such a bond will be an impossible task within our local care services. A decision to remove them from their parents would be concerning for me as a mental health professional.
Problem Based Learning Reflective Account

*Older Adults, Families and Culture*

March 2008

Year 3
Introduction

The final Problem Based Learning (PBL) exercise pertained to thinking about the issues involved in the lives of many older adults who may experience changes in their ability to look after themselves. This PBL exercise also incorporated issues of culture, family and the community. Within this account, I have reported and reflected on the approach of our group to the task and the specific issues that this particular case exercise raised. However, I have taken the opportunity as the last PBL reflective account to think about the approach to the PBL task and presentation more generally in terms of the changes and developments at an individual and group level that engaging in this task allowed us to recognise.

The current PBL task

The current PBL task presented a case in which an elderly Asian gentleman was experiencing difficulties in looking after himself which had worsened since the death of his wife. He had subsequently disengaged from the local Muslim community. His daughter with whom he had little contact as she had followed a path in life which deviated from the one favoured within his culture, had approached social services with concerns about her father.

The process of approaching the PBL task

Our initial approach to the task was to identify the main key points in the case material and to disseminate reading accordingly. For example, we allocated reading on the philosophy of ageing and the difficulties associated with ageing, the assessment and treatment of dementia, the effects of grief and depression on functioning, issues associated with Muslim culture and a more general task of thinking systemically about the different points of view held by each individual and/or agency involved with the case. The group then came together and shared a summary of the main points arising from the reading and thinking that we had done. This case raised a number of dilemma's both in relation to the presenting problem, the approach that could be used and the more complex family and cultural issues. However, such a case example is representative of the kinds of referral that psychologists within any Older Adults service may receive. Clinical psychologists may be faced with many cases in which it is possible to formulate multiple hypotheses about the nature of the presenting problem and indeed, multiple intervention strategies depending on the context. I feel that a year ago or longer, I may have felt overwhelmed with such a
seemingly complex case, yet as a group, we acknowledged the dilemma's posed by the case and were able to formulate and hold in mind a number of possible hypotheses about the presenting difficulties without feeling anxious about needing to 'diagnose' or come to one concrete decision. I felt that this reflected a level of sophistication in our thinking that was indicative of significant development in our roles as Trainee Clinical Psychologists in being able to synthesise complex information and be flexible in our thinking and approach to a particular person's difficulties. I felt that one of the main factors in not feeling overwhelmed by the information pertaining to the case was that we all shared the task of trying to make sense of the information available. In this sense, the PBL group process paralleled the process of an effective multi-disciplinary team, that is, different people, with different expertise and knowledge, coming together to hold, think about and formulate a way forward to help someone who had been referred to the team.

The group became aware of changes in the approach to the task (e.g. being more flexible) quite early on and I can recall the group making comments about how we seemed to be able to hold in mind more than one possible hypothesis. This type of meta-communicative process (Watzalawick, Beavin & Jackson, 1967) served an important reflective function for the group in that we recognised the difference in our approach and it was this recognition of our approach to the task that helped us to define the way that we wanted to present the final PBL presentation, discussed below. It is important to note the value of being able to be reflective and reflexive about one's own role within a group and about both the overt and the more subtle and covert processes that groups go through. This is a skill that clinical psychologists can bring to multi-disciplinary teams within NHS settings that may facilitate the work of teams and a skill that may also be helpful in enabling clinical psychologists to provide consultancy to teams as a wider part of their roles. The group wanted to try and capture and convey the richness and complexity of our conversations through the presentation and decided to present a discussion in the form of a referral meeting.

The presentation

The presentation took the form of a discussion at a psychology referrals meeting. We presented the different hypotheses available about the presenting problem and the possible ideas for intervention as well as those areas in which the team felt that more information was required. There were two important points about our presentation which I felt reflected
significant development in ourselves both as a group and as individuals. Firstly, we were able to hold in mind and present a number of different hypotheses about the presenting problem as well as to identify where we required further information and the possible difficulties that may arise from the points of view of each of the individuals and agencies involved. For example, we identified the potential difficulty associated with Mr Khan's estranged daughter having raised concerns about her father; it was important to consider and not to lose sight of Mr Khan's point of view. Secondly, the presentation was unscripted and did not include any props or 'gimmicks' such as dressing up or humour which our group had somewhat relied upon in previous PBL presentations. The group had a practice run through prior to the actual presentation, but other than that, we 'did it on the day'. Rather than show a lack of preparation, the group wanted to demonstrate and capture the fluidity and flexibility in our thinking and approach to the task. Having no props, humour or scripts to hide behind was a potential risk for our group though I felt that this approach worked well.

Reflection on roles adopted within the presentation

Though as a group we adopted a flexible approach to the presentation, I felt that the roles played within the presentation reflected some of the individual characteristics that we each brought to the case discussion group (CDG) in general. For example, one individual in the group adopted the role of 'chair' of the meeting and summarised the main points of the presentation in a succinct and direct way. I felt that this reflected the role of this person in the wider year group – being quite open and direct about their point of view. My approach to the PBL task and during the presentation was to adopt a position of curiosity in relation to each of the hypotheses presented and to encourage the group to think more critically about the different points of view of each individual and agency involved in the case and to help the group identify assumptions, e.g. that Mr Khan would be uncooperative with services. In this sense, I felt that I brought more of a reflective, systemic perspective to the preparation and presentation. Some members of the group had commented that they perceived this to be within my interests and I became aware of feeling surprised that they had perceived this of me. This led me to reflect on what I thought and felt about the other group member's perceptions of me and my interests and strengths as a Trainee Clinical Psychologist. This process resonated with an article I had read on problem construction (in narrative terms) and the effects of the perception of self, the perception of others and the preferred view of self on self-esteem and identity. In particular, I was struck by the relevance of the idea that
"People have strong preferences with regard to how they would like to behave, how they would like to see themselves, and how they would like to be seen by others. We refer to this constellation of ideas about self as a person’s “preferred view”" (Eron & Lund, 1996). The issue of developing professional identity and the views of peers and colleagues about my strengths and interests as a Trainee Clinical Psychologist had been and remains a particularly salient issue for me, particularly with the prospect of becoming newly qualified soon. This is something that I had identified in supervision as being an important area to explore. I felt quite pleased that my peers were aware of my interest in systemic approaches but wondered about what aspects of my approach to the work had helped them to form that perception or opinion of me. This is something that I continue to explore both personally and in supervision on placements.

The bigger picture: Mapping the influence of the PBL task onto the wider processes within the cohort

One of the most important factors that have contributed to my PBL learning experience has been the stability of the group over the three years. We have been in the same group for the Case Discussion Groups and PBL tasks and this has given us a broad range of experiences of working and learning together. There had been some consistent differences of opinion throughout the three years in how to approach the PBL tasks (e.g. being task as opposed to socially oriented in the approach to the task, Bales, 1950). There had also been some difficulties within the wider cohort which had contributed to some members of the PBL group and of the wider cohort feeling as though their diversity and difference had not been respected. I believe that the processes underlying these feelings were very subtle and complex and therefore difficult to overtly identify. There is an important body of research which highlights the role of unconscious interactional processes within groups where actions are jointly constructed and we may become aware of a particular outcome but be uncertain about how such situations have come about (Shotter, 1987). I believe that this may have happened at both a micro (CDG/PBL group) level and a macro level (within the wider cohort). Thinking about such parallel processes had reminded me and reinforced the significance of the influence and strength of intergenerational patterns of relating within families (Vetere & Dallos, 2003). In my clinical experience, I have come to recognise the importance of identifying intergenerational patterns of relating which may be outside of conscious awareness. Once acknowledged, those patterns can then be worked through in order to help the individual to understand situations, experiences and patterns of relating in
their lives that have been difficult or unhelpful for them and begin the process of making helpful changes (Dallos, 2006). In relation to the difficult situations that had arisen within the group and the cohort, the process of acknowledging such difficult situations and trying to work through them may be helpful for us.

Conclusion

Within this account, I have found it useful to reflect on the learning and development that both this task and other PBL tasks have allowed me to recognise at an individual and a group level. It has been interesting and valuable to have the opportunity to think about how the group’s approach to the task represent significant developmental changes. Overall, I have found the PBL exercises useful in developing knowledge in different areas and generic skills that can be more broadly applied to my training and practice. Interestingly, it has been the PBL reflective accounts that have enabled me to synthesise and reflect on the changes that the PBL tasks have fostered in myself and in the group.
References


Summary of Case Discussion Group (CDG) Process Accounts

Summary of CDG process account (September 2006)

Summary of CDG process account (July 2007)
Summary of Case Discussion Group (CDG) Process Accounts (Years 1 and 2)

Summary of CDG process account (September 2006)

Within this account, the remit and function of the CDG was explored, particularly in relation to how the group had used the time together and the value of the activities conducted within the group such as formal case presentations and cultural genograms. The different roles of individuals within the group and the dynamics of the group as a whole and the role of our CDG within the wider cohort was reflected on. The experience of cohesion and conflict within the group and in the wider cohort was discussed, with particular emphasis on the parallels between group processes at the CDG and wider cohort levels. The process account concluded with an open curiosity about the ways in which I could use the ideas and insights developed through the process of writing the CDG process account.

Summary of CDG process account (July 2007)

The second CDG process account reflected on the issues discussed in the first account, with particular reference to the changes that had occurred in the group and in the wider cohort since the first account had been written. In particular, the account discussed instances of conflict and change within the CDG and how these mirrored some of the processes that had occurred in the wider cohort, using aspects of psychodynamic theory to reflect on this process. The account reflected on the changes that had occurred and what this meant for the forthcoming years of CDG’s in relation to the types of topics that would be discussed and activities that would be undertaken.
Summary of Case Reports

Adult Mental Health 1

Adult Mental Health 2

People with Learning Disabilities

Children, Adolescents and Families

Specialist Systemic and Narrative Therapies
Summary of Adult Mental Health Case Report

All details pertaining to the identity of the client have been changed and/or anonymised to preserve anonymity and confidentiality.

Title

Cognitive Behavioural Therapy (CBT) with a working-age adult female with Health Anxiety (Hypochondriasis).

Referral and presenting problem

Mrs Kate Williams was referred to the Primary Care Mental Health Team by her General Practitioner (GP) for help with Obsessive Compulsive Disorder (OCD) related to breast checking. Kate frequently checked her breasts and regularly consulted her GP for breast examinations due to fears surrounding breast cancer. This checking was having a significant detrimental impact on Kate’s quality of life and well-being.

Background information

Kate was an only child and described a happy childhood up until the time when her parents separated when she was 16 and her mother left the family home and subsequently had sparse contact with Kate. Kate was left to care for her father who suffered from a breakdown in the form of a depressive episode. Soon after this, Kate experienced the loss of a number of significant female figures in her life, including her paternal grandmother who died of lung cancer after who had also suffered with breast cancer and her paternal aunt who was imprisoned for murdering her husband after many years of emotional and physical abuse. The current episode of health anxiety appeared to be triggered during breast cancer awareness month when she checked her breasts and was shocked by the variation she felt. In the same year, Kate had received abnormal results from a cervical smear test and began to have frequent concerns about cancer and the impact that this would have on her and her family. The checking had increased around the time that her previous GP, with whom she had reported a good, trusting relationship had left the surgery.
Formulation

There were a number of experiences in Kate’s life which may have been significant in forming concerns around health. Firstly, Kate experienced a number of difficult significant losses at an important time in her development at aged 16. The loss of her paternal grandmother was particularly linked to cancer as her grandmother died of lung cancer and had previously received treatment for breast cancer. These experiences may have led to the development of a core schema surrounding a vulnerability to harm and illness within which Kate had developed an exaggerated fear that an imminent medical catastrophe may strike and she would be unable to prevent this, e.g. developing breast cancer. This episode of health anxiety appeared to be triggered by breast cancer awareness month and receiving abnormal results from a smear test. She then began to check her breasts regularly and consult her GP for regular examinations which may have served to reduce anxiety. The checking behaviours increased around the time that her previous GP left the surgery which may have signified the loss of an important female figure in her life and reactivated the core schema of a vulnerability to illness which may have developed from her early experiences of loss.

In a cognitive-behavioural formulation, Kate’s checking behaviours are triggered by intrusive thoughts about needing to check her breasts. Once Kate begins checking, she becomes distressed by the natural variation in her breasts and misinterprets this as a lump that could signify breast cancer. Kate’s breast checking may have served as a compensatory strategy to neutralise the negative images and connotations associated with breast cancer developed from her early experiences. Such checking paradoxically increased anxiety and maintained the problem by preventing disconfirmation of Kate’s fears about what natural variation in her breasts could mean.

Intervention

Kate and I saw each other for 12 sessions of CBT. The work comprised a number of components including cognitive techniques and socialisation to the CBT model of health anxiety, behavioural experiments and exploration of death anxiety contained within a trusting therapeutic alliance. Kate kept thought diaries which identified that the checking
and anxiety were often triggered by difficulties with her husband and her mother. Kate was encouraged not to avoid television, magazines and newspapers which reported information about cancer and was able to identify that the more she exposed herself to such material, the less it bothered her and was able to identify positive outcomes associated with cancer. We also reduced the number of times Kate was allowed to check her breasts and seek reassurance from her GP in a structured way. The main cognitive components of the work involved engaging Kate in the psychological model of health anxiety to develop an alternative explanation for her difficulties and restructuring her beliefs about cancer, death and her own coping efficacy. Part of the work also involved constructing an illness story to delineate and explore Kate’s worries about death and illness in a safe and contained environment.

Outcome

Kate completed a number of outcome measures for anxiety, depression and health anxiety. The results showed a reduction in anxiety from the moderate to the mild clinical range and a reduction in depression from the moderate to the minimal clinical range. The results of the health anxiety rating scale indicated a reduction in the distress associated with thoughts about illness and a significant reduction in the number of times Kate checked her breasts each day.
Summary of Adult Mental Health Case Report

All details pertaining to the identity of the client have been changed and/or anonymised to preserve anonymity and confidentiality.

Title

Cognitive-Behavioural Therapy (CBT) with a working-age adult female with Obsessive Compulsive Disorder (OCD) and bereavement and loss difficulties.

Referral and presenting problem

Mrs Rebecca Hunt was referred to the Primary Care Mental Health Team by her General Practitioner (GP) for help with Obsessive Compulsive Disorder related to driving. Rebecca's main difficulties with driving were that she would retrace the routes she had driven to check that she had not hurt someone or caused an accident. Rebecca also engaged in a number of compulsive checking behaviours at home, for example, checking appliances. Rebecca's father had also suffered from lung cancer and died while she was in therapy for the OCD.

Background information

Rebecca had experienced a number of difficulties in her childhood which she attributed to her sense of low self-esteem and self-confidence in adulthood. Rebecca was bullied in school and witnessed the physical and emotional abuse of her mother by her father throughout her childhood. Rebecca had many vivid memories of witnessing domestic abuse and feeling helpless and powerless to help her mother. The current episode of OCD was triggered by a near-miss car accident after which Rebecca began retracing the route and seeking reassurance from her husband and children.

Formulation

Rebecca's early experiences such as being bullied and witnessing domestic abuse may have served to deplete her self-confidence and also to develop a core belief around responsibility for the protection and prevention of harm towards others. There is some evidence to suggest a link between the negative cognitive effects of exposure to trauma and the excessive labelling of stimuli as threatening which may lead to heightened anxiety. In this sense, Rebecca's checking rituals may have served to symbolically reduce the feelings of guilt and helplessness she experienced as a child in being exposed to the domestic abuse of
her mother and being unable to protect her. Such experiences may have led to the development of a core belief surrounding responsibility for the protection of others and the prevention of harm. The critical incident may have activated assumptions about needing to take responsibility for the prevention of harm coming to others. Rebecca experienced persistent intrusive thoughts which she equated with actually having caused harm (thought-action fusion) which caused intense anxiety about having caused an accident. Rebecca employed strategies such as retracing her route in order to neutralise anxiety in the short-term. However, such checking behaviours served to reinforce the compulsion as it did not allow Rebecca to disconfirm the validity of the intrusive thoughts.

Intervention

Rebecca and I saw each other for eight sessions of CBT for OCD which included Exposure and Response Prevention (ERP) and Cognitive Therapy. The ERP components of the treatment included setting up an exposure hierarchy to expose Rebecca to feared stimuli and situations in a structured way, such as reducing avoidance of driving by incorporating trips out in the car and then preventing her from responding to intrusive thoughts about harm by retracing the route and encouraging her to continue driving despite feeling anxious about thinking she had caused an accident. The cognitive elements of the work included developing a psychological formulation to help Rebecca adopt an alternative understanding of the onset and maintenance of the difficulties and challenging beliefs about the validity of thoughts and belief in thought-action fusion and restructuring appraisals about responsibility for harm and the protection of others.

Part of the work also included some exploration of the loss of Rebecca's father, including the difficult ambivalent feelings she had towards him in view of the physical and emotional abuse that Rebecca witnessed from her father towards her mother. Reviewing the lost relationship, particularly the positive and negative aspects of her father and her relationship with him was a difficult but very important part of the work.

Outcome

Rebecca completed measures for depression, anxiety and obsessive and compulsive symptoms. Interestingly, pre and post therapy measures indicated that there had been an increase in anxiety, depression and OCD symptomatology. There were a number of possible explanations for the increase in self-reported symptoms, the first being that such changes
were indicative of a deterioration in Rebecca's functioning. It is also possible that these changes could have been reflective of Rebecca feeling more comfortable and able to express such difficult feelings openly and honestly in the therapeutic relationship. Alternatively, it is also possible that such increases in anxious, depressive and obsessive-compulsive symptomatology may be attributable to the re-processing of traumatic memories and feelings when discussing the loss of Rebecca's father and events from her childhood.
Summary of People with Learning Disabilities Case Report

All details pertaining to the identity of the client have been changed and/or anonymised to preserve anonymity and confidentiality.

Title


Referral and presenting problem

Mr Hughes had been referred to the Community Team for People with Learning Disabilities for an incident of head banging which was defined as a 'challenging behaviour'. Staff at the residential home had become concerned about the duration and severity of the head banging and had consulted the on-call Duty service at the Learning Disability team who had advised that Mr Hughes be taken to casualty and a referral to the psychology service was made.

Background information

Mr Hughes is a working-age adult male with profound impairments of intellectual and social functioning. He also had a diagnosis of rubella syndrome which meant that he was now blind and deaf. Mr Hughes had been a resident at a large long-stay hospital for people with learning disabilities up until 1997 when he was moved to a community residential home where he has been since. His father and step-mother visit him approximately once per month. Mr Hughes' learning disability and sensory impairments had a severe impact to communicate and understand the world around him. He is reported to be able to show others when he likes or dislikes something. Mr Hughes had a history of head banging throughout his life, though this had reduced in frequency since moving to the residential home. The keyworker estimated that Mr Hughes banged his head approximately once per month and that there were no identifiable triggers for the head banging. However, prior to the incident for which Mr Hughes had been referred, the keyworker reported that Mr Hughes had not banged his head for approximately one year. Staff usually responded to the head banging by touching Mr Hughes' arm to show him that they were there which usually resulted in cessation of the head banging. However, on the most recent occasion for
which he was referred, Mr Hughes continued to bang his head severely despite staff responded in the usual way.

Three observation sessions at the residential home using Momentary Time Sampling (MTS) showed that there was a very low level of staff interaction with Mr Hughes. He tended to sit in a chair in the living room with very minimal tactile interaction and stimulation from staff. Only once during the three observations did staff engage with Mr Hughes and this was to engage him in a functional mealtime activity. He also had a very limited set of toys to use but these were not used with Mr Hughes during any of the observation sessions.

Formulation

In thinking about the function served by challenging behaviours such as head banging, it is important to consider the personal and environmental contexts surrounding such incidents. From a personal perspective, Mr Hughes has a learning disability and sensory impairments which make it difficult for him to communicate and get his needs met. In considering the environmental context, Mr Hughes lives in a busy residential home where other residents may or may not be more able to communicate their needs effectively to staff. Mr Hughes may be unable to predict when he will receive social/tactile interaction. Mr Hughes has engaged in head banging throughout his life which may have served functions such as being able to exercise some control over aspects of his environment and personal state or communicate his needs to others. It is only possible to hypothesise about the triggers for incidents of head banging. Pain, illness, an immediate problem (e.g. a wheelchair going over his foot), boredom or frustration may be possible antecedents for the challenging behaviour. However, the usual response from staff did not appease Mr Hughes on this occasion and it is only possible to hypothesise that the tactile attention from staff did not meet Mr Hughes' needs on this occasion, for example, he may have been in pain.

Intervention

The main intervention was intensive interaction as it was hypothesised that the lack of tactile stimulation available to Mr Hughes' from staff in the residential home was not meeting his needs and that he may benefit from such interactive stimulation. Intensive
Interaction is a form of interaction that can be used to develop sociability and communication skills in people considered to be operating at a very low developmental level. Mr Hughes and I engaged in a tactile relationship using different objects, toys and materials. Over the course of the four intensive interaction sessions, Mr Hughes and I developed a game in which we passed toys and materials to each other and experimented with different textures and sensations such as hand massage. Part of the intervention also involved liaising with staff to share some suggestions for incorporating intensive interaction activities into his regular routine. Staff observed a session of intensive interaction and were given materials with suggestions for activities, materials and toys to use with Mr Hughes which he had enjoyed using in our sessions together. They were also asked to keep a record of intensive interaction sessions that staff conducted with him.

Outcome

No formal outcome measures were used to assess change in the frequency and severity of the challenging behaviour due to the low frequency and unpredictable nature of the head banging that had been observed. The Vineland Adaptive Behaviour Scales were completed as part of the assessment process to gauge the level of Mr Hughes' functional skills. It is possible that there may be a slight increase in some specific skills in the socialisation domain through using intensive interaction. The MTS observations were to be repeated three months after the end of the work to assess whether staff had been able to incorporate the activities into Mr Hughes' regular routine.

It is possible to make a qualitative evaluation of the outcome of the work. The proponents of intensive interaction state that it is the process rather than the content of intensive interaction that is important. Over the course of the sessions, a pattern or game emerged with Mr Hughes in which we exchanged objects. Mr Hughes showed several signs of enjoyment such as smiling and laughing and making spontaneous attempts to maintain the interaction, such as by leaning forwards in his chair to give me an object.
Summary of Children and Families Case Report

All details pertaining to the identity of the client have been changed and/or anonymised to preserve anonymity and confidentiality.

Title

Cognitive-Behavioural Therapy (CBT) and Systemic Family Therapy with a young female with a Specific Phobia of Vomiting.

Referral and presenting problem

Georgina had been referred to a Tier 3 Child and Adolescent Mental Health Service (CAMHS) following concerns that she was tired, refusing to eat lunch and feeling nauseous. Following some counselling at the Tier 3 service, Georgina’s condition deteriorated and she was hospitalised for tube feeding as she had refused to eat. Following this, Georgina was referred to Tier 4 CAMHS and was admitted for a period of inpatient care. Georgina was referred to the psychology and family therapy team within the Tier 4 service for individual and family work surrounding the difficulties with eating and the dynamics between Georgina and her mother.

Background information

There were no difficulties with Georgina’s development and she reached all her milestones at appropriate times. Georgina had enjoyed school up until year six when she began to become conscious of what her peers thought of her and she experienced some bullying about her shape. Georgina described a difficult relationship with her mother which was up and down at times. Georgina’s father left when she was eight years old and there is a sense that she feels very hurt and abandoned by her father as contact between them has been sparse and he had since moved to France. The maternal family of origin were quite involved in Georgina’s care but there is a sense that they do not understand the nature of her difficulties and feel that displays of emotion are inappropriate and they place importance on being strong and not showing emotion.
Formulation

An integrative formulation was constructed and adapted over the course of the work together as more information became available through individual sessions and family therapy. The vomiting phobia was formulated drawing on a cognitive-behavioural model, making links between Georgina’s previous experiences and her current phobia of vomiting. A theme of safety was identified as being important, as Georgina’s food restriction was understood as a way to form and impose boundaries around her that made her feel safe. Georgina’s observed difficulties with regulating her emotions and comforting herself were linked to the relationship with her mother. From an attachment perspective, the nature of Georgina’s interactions with her mother were consistent with an insecure (ambivalent) attachment style. Georgina’s mother may have found it difficult to impose and maintain firm boundaries throughout Georgina’s childhood which meant that Georgina may not have been able to internalise a secure base (i.e. a core sense of safety) from which she was subsequently able to explore the world and new situations.

Intervention

Georgina engaged in a combination of individual cognitive-behavioural therapy (CBT) and systemic family therapy with her mother. The three main components of the CBT approach to treatment comprised of psychoeducation about anxiety, teaching behavioural coping skills and training in cognitive coping strategies. The systemic family therapy involved exploring intergenerational beliefs and practices related to comfort and emotion to help Georgina and her mother understand their own patterns of relating, particularly in relation to seeking and providing comfort. From an attachment perspective, the family therapy aimed to provide a secure-base from which the family could begin to feel safe enough to explore difficult situations and feelings.

Outcome

It was not possible to formally evaluate post-therapy outcome measures as Georgina did not complete and return the evaluation forms. However, there were a number of behavioural and qualitative changes observed that provide information about outcome. Georgina was discharged from the inpatient unit as she had reached a target weight. She
had expanded the range of foods in her diet and continued to integrate new foods into her diet. Georgina’s mother commented on how she perceived the family sessions to be very supportive and both Georgina and her mother reported concordant positive changes in their relationship. Georgina was followed-up by the Tier 3 CAMHS.
Summary of specialist systemic and narrative therapies with children and families case report

All details pertaining to the identity of the client have been changed and/or anonymised to preserve anonymity and confidentiality.

Title

The contribution of psychometric assessment to a wider neurodevelopmental assessment: An eight year-old boy referred for an assessment of Aspergers Syndrome and/or Attention Deficit Hyperactivity Disorder (ADHD).

Referral and presenting problem

Jonathan was referred to the Child and Adolescent Mental Health Service (CAMHS) by his Health Visitor, after his mother, Mrs Lee, highlighted a number of concerns about Jonathan’s behaviour. The difficulties described by Jonathan’s parents had led professionals to question whether Jonathan’s difficulties were consistent with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and/or Aspergers Syndrome (AS). The reason for referral to Clinical Psychology was to use psychometric assessment to inform the overall assessment and diagnostic process. It was clear from the descriptions provided by Jonathan’s parents that they found his behaviour difficult to manage and that they perceived him to have a negative impact on the family.

Background information

Jonathan was the second of three children and had an older sister, aged 8 and a younger brother aged 5. There were no difficulties identified in Jonathan’s developmental or medical history. Reports from his school teachers stated that Jonathan sometimes had difficulties with peers and responded well to structure.
Hypotheses

The following hypotheses were posed:

• Jonathan's behaviour, difficulties and abilities can be explained by underlying cognitive difficulties;
• Jonathan's behaviour, difficulties and performance fit with the criteria that are consistent with considering AS and/or ADHD as a framework for understanding his needs.

Intervention

A comprehensive assessment was conducted which involved obtaining information from Jonathan’s parents and teacher and administering a number of psychometric assessments including the Wechsler Intelligence Scale for Children (Version Four, UK Edition) (WISC-IV), the Wechsler Individual Achievement Test, Second Edition, UK Version (WIAT-II), the Test of Everyday Attention for Children (TEA-Ch), Connors Rating Scales (CRS) for parents and teachers, the Australian Scale Questionnaire (ASQ) and Strange Stories.

Outcome

The results of the assessment highlighted that there was neurodiversity in Jonathan’s cognitive profile which could account for some of the behaviours reported by Jonathan’s parents and teacher. The findings suggested that a diagnosis of ADHD would not be useful in explaining the all the reported behaviours. Rather, there were some aspects of the cognitive profile in conjunction with other factors may account more fully for the reported difficulties. The combination of neurodiversity in the cognitive profile and the relatively negative and critical views of Jonathan’s behaviour expressed by his parents are a better explanation of the reported difficulties than a diagnosis of ADHD. The assessment identified a number of behaviours and abilities as rated by Jonathan’s mother that are consistent with some of the core features of AS. The results of this aspect of the assessment were incorporated into the wider diagnostic assessment being conducted within the multi-disciplinary team.
Summary of Clinical Placements

Adult Mental Health
People with learning Disabilities
Children, Adolescents and Families
Specialist Systemic and Narrative Therapies with Children and Families
Older Adults
Adult Mental Health Placement (November 2005 – September 2006)

On this placement I saw a number of male and female clients, and conducted a lot of assessments, did some individual client work which was primarily cognitive-behavioural in nature and set up, ran and evaluated a group with the newly qualified clinical psychologist. The range of presentations was mainly limited to anxiety disorders and I worked with one client with depression and one with low self-esteem and self confidence issues. I also did some bereavement work. The changes within the department made this placement difficult at times.

During my time at the PCMHT I arranged some psychodynamic supervision with a psychotherapist at Farnham Road Hospital which was helpful in helping me to consider the process issues and issues in the therapeutic relationship. Having this space to consider clinical work from a different perspective helped to justify from a different perspective the work I was doing with a number of my clients, though at times this opinion and what it meant for the direction of therapy differed from that of my CBT supervisor. The primary therapeutic modality used was CBT and I was able to work with a number of clients on an individual basis with a range of presenting difficulties. I was also able to set up, run and evaluate a CBT group for people with a diagnosis of Obsessive Compulsive Disorder (OCD).

Adult Mental Health Placement 2 (April – September 2006)

The Gershwin Unit is comprised of a multi-disciplinary team with staff members from various professions including clinical psychology, occupational therapy and technical instructors. The Gershwin Unit provides acute therapy services to two inpatient psychiatric wards. The clinical psychology service / part of the team typically receive referrals either for cognitive assessments, individual therapy (e.g. anxiety management) and psychological assessments of functioning. Team members run a number of groups from Monday to Friday which patients can either be referred to attend as part of their care plan on assessment or can attend freely depending on numbers, risk issues and availability of places.
I worked on the Gershwin Unit on Wednesday's and my role mainly pertained to running the relax your mind group which was based on mindfulness principles and also setting up the looking after yourselves group which was a forum underpinned by solution-focused principles for patients to bring any specific worries or difficulties they may currently be having with a view to discussing these difficulties within the group. Alternatively, patients were free to discuss their experiences of being in hospital, both positive and negative and to share experiences and ideas about maintaining well-being. I conducted one cognitive assessment while working on the unit which was to try and determine whether a patient's level of cognitive functioning could be considered within the learning disabled range. I also conducted a short piece of cognitive-behavioural work with a gentleman focusing on anxiety management. I found this placement particularly challenging for a number of reasons, firstly due to the acute nature of some of the patient's illnesses and therefore their inability / unwillingness to engage in groups and also because of the environment in which medication is used to control all behaviour. Also, my experiences of supervision were sparse and an ad-hoc question and answer session rather than having a focus on reflective issues, self development and learning needs.

Learning Disabilities Placement (October 2006 - March 2007)

This placement afforded a range of opportunities, in terms of individual client work, meetings, joint work with other professionals and work in a range of settings. I was able to work with clients with a range of levels of learning disability with a variety of presenting problems, including challenging behaviour, anxiety and dementia. I was also able to develop and run some training for care staff with a colleague about more effective ways of communicating with people with learning disabilities which was positively evaluated. The main therapeutic modality on the placement was behavioural, with some consideration of systemic issues and cognitive work with people with learning disabilities. I was also able to use several different cognitive and psychological assessment tools whilst on this placement.

Children and Families Placement (April - September 2007)

This placement was based in a Tier 4 Inpatient and Outreach service for children and young people presenting with a range of mental health difficulties. The main theoretical
models used on the placement were systemic, developmental and attachment. I was able to work individually with several children and adolescents with a range of complex presenting difficulties including OCD, anxiety and attachment difficulties as well as with young people with difficulties that had less of an impact on their day to day functioning such as nightmares. I was a member of the family therapy team and contributed both to the reflecting team and was able to co-lead some family sessions for two clients with my supervisor. This introduced me to and gave a good grounding in the theoretical and practical application of models of systemic theory to working with individuals and families. I attended a number of visits on this placement with related professionals in the local area including psychiatrists and special educational needs coordinators and was able to joint-work and liaise with a number of professionals both within and outside of the multi-disciplinary team. I was able to observe and take part in a psychoeducational support group for the family members of children and young people with eating disorders on the unit which was evaluated positively.

Specialist systemic and narrative placement with children and families (October 2007 – March 2008)

This placement was based in a Tier 3 Child and Adolescent Mental Health Service (CAMHS). The main theoretical models used on the placement were narrative and systemic, with some additional consideration of attachment, developmental and neurodevelopmental/neuropsychological models. I was able to work in a narrative framework with a number of children and adolescents with a range of presenting difficulties including encopresis, developmental disorders such as Aspergers syndrome, anger and depression. I also worked closely with the family members of the young people. I was involved in the family therapy team and contributed to both the reflecting team and was able to co-lead four sessions of family therapy with a colleague. I also significantly developed my knowledge, understanding and skill in psychometric assessment and report writing on this placement and was fortunate to receive individual psychometric/neuropsychological supervision as well as attending and contributing to the neuropsychological peer supervision sessions held by the psychology team.
Older Adults Placement (April – September 2008)

This placement was based in an acute psychiatric unit for older adults in a general hospital. The main theoretical model used on the placement was psychodynamic with additional consideration of attachment and developmental frameworks also informing the work. The nature of the work with clients was quite short term due to the throughput of clients on the ward and the majority of interventions were psychodynamically informed. I was able to do some psychometric assessment and contributed to ward rounds for those clients I was in contact with. I developed and ran some training for staff on a dementia ward about reflective practice and person-centred approaches to dementia care and also delivered a presentation to staff in the community mental health team for older adults on the relevance and importance of attachment theory to working with older adults.
Research Log Checklist
<table>
<thead>
<tr>
<th>Skills</th>
<th>Evidence / where demonstrated</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Formulating and testing hypotheses and research questions</td>
<td>SRRP, MRP</td>
</tr>
<tr>
<td>2 Carrying out a structured literature search using information technology and literature search tools</td>
<td>SRRP, qualitative research project, MRP, essays</td>
</tr>
<tr>
<td>3 Critically reviewing relevant literature and evaluating research methods</td>
<td>SRRP, qualitative research literature, MRP, essays</td>
</tr>
<tr>
<td>4 Formulating specific research questions</td>
<td>SRRP, qualitative research project, MRP</td>
</tr>
<tr>
<td>5 Writing brief research proposals</td>
<td>SRRP</td>
</tr>
<tr>
<td>6 Writing detailed research proposals/protocols</td>
<td>MRP</td>
</tr>
<tr>
<td>7 Considering issues related to ethical practice in research, including issues of diversity, and structuring plans accordingly</td>
<td>MRP</td>
</tr>
<tr>
<td>8 Obtaining approval from a research ethics committee</td>
<td>MRP</td>
</tr>
<tr>
<td>9 Obtaining appropriate supervision for research</td>
<td>SRRP, MRP</td>
</tr>
<tr>
<td>10 Obtaining appropriate collaboration for research</td>
<td>SRRP, MRP</td>
</tr>
<tr>
<td>11 Collecting data from research participants</td>
<td>SRRP, qualitative research project, MRP</td>
</tr>
<tr>
<td>12 Choosing appropriate design for research questions</td>
<td>SRRP, qualitative research project, MRP</td>
</tr>
<tr>
<td>13 Writing patient information and consent forms</td>
<td>Qualitative research project, MRP</td>
</tr>
<tr>
<td>14 Devising and administering questionnaires</td>
<td>SRRP (for evaluation of group)</td>
</tr>
<tr>
<td>15 Negotiating access to study participants in applied NHS settings</td>
<td>SRRP, MRP</td>
</tr>
<tr>
<td>16 Setting up a data file</td>
<td>SRRP</td>
</tr>
<tr>
<td>17 Conducting statistical data analysis using SPSS</td>
<td>SRRP</td>
</tr>
<tr>
<td>18 Choosing appropriate statistical analyses</td>
<td>SRRP</td>
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<tr>
<td>19 Preparing quantitative data for analysis</td>
<td>SRRP</td>
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<tr>
<td>20 Choosing appropriate quantitative data analysis</td>
<td>SRRP</td>
</tr>
<tr>
<td>21 Summarising results in figures and tables</td>
<td>SRRP</td>
</tr>
<tr>
<td>22 Conducting semi-structured interviews</td>
<td>Qualitative research project, Problem Based Learning exercise, MRP</td>
</tr>
<tr>
<td>23 Transcribing and analysing interview data using qualitative methods</td>
<td>Qualitative research project, Problem-</td>
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<tr>
<td>24</td>
<td>Choosing appropriate qualitative analyses</td>
</tr>
<tr>
<td>25</td>
<td>Interpreting results from quantitative and qualitative data analysis</td>
</tr>
<tr>
<td>26</td>
<td>Presenting research findings in a variety of contexts</td>
</tr>
<tr>
<td>27</td>
<td>Producing a written report on a research project</td>
</tr>
<tr>
<td>28</td>
<td>Defending own research decisions and analyses</td>
</tr>
<tr>
<td>29</td>
<td>Submitting research reports for publication in peer-reviewed journals or edited book</td>
</tr>
<tr>
<td>30</td>
<td>Applying research findings to clinical practice</td>
</tr>
</tbody>
</table>

**Key:**  
SRRP: Service Related Research Project  
MRP: Major Research Project
Service Related Research Project (SRRP)

Evaluation of a Cognitive-Behavioural Therapy (CBT) group for Obsessive Compulsive Disorder (OCD) in a Primary Care Mental Health Team (PCMHT)

July 2006

Year 1
Abstract

Background and purpose

A number of recent changes within the psychology department of a Primary Care Mental Health Team (PCMHT) had led to significant resource constraints and a high number of Obsessive Compulsive Disorder (OCD) referrals on the waiting list. In view of these issues, the service implemented a Cognitive-Behavioural Therapy (CBT) group for clients with OCD. The current service evaluation aimed to evaluate the efficacy of the intervention in terms of the amelioration of OCD symptomatology and client satisfaction with service provision with a view to making recommendations about improvements for future service delivery.

Design, participants and procedure

Participants were five clients referred to the PCMHT for CBT for OCD who were deemed suitable to attend an OCD group. The study adopted a longitudinal repeated measures design and participants completed a number of clinical outcome and satisfaction measures at three points over the course of the group. The data were analysed using a multiple case-study approach to explore participants' experience of attending the group.

Results

The OCD group was effective in meeting the aim of increasing participants knowledge and understanding of OCD and how it is maintained, yet was less effective in ameliorating symptoms of OCD. The majority of participants found the support derived from meeting others with similar difficulties the most helpful part of the group. Participants were generally satisfied with service provision, yet recommendations for future service delivery are made based upon the findings of the current evaluation.
Introduction

The service

The current service evaluation was conducted within the psychology department of a Primary Care Mental Health Team (PCMHT). There had been a number of recent changes within the department, including a number of psychologists leaving the team which led to significant resource constraints and a long waiting list. In view of these issues, the service chose to implement an OCD group. The group was jointly developed by the Clinical Psychologist and Trainee Clinical Psychologist in the service using a number of resources, including an existing protocol for group cognitive-behavioural therapy for OCD developed by other professionals within the Trust (Shibli, Gosling & Burns, 2005).

Policy guidelines and recommendations from the National Institute of Clinical Excellence (NICE)

The National Institute for Health and Clinical Excellence (NICE) recommend low intensity treatments of up to ten hours Cognitive Behavioural Therapy (CBT) with Exposure and Response Prevention (ERP) for the initial treatment of adults with Obsessive Compulsive Disorder (OCD) if the client's degree of functional impairment is mild (NICE, 2005). Within this, the NICE guidelines espouse the use of group CBT with ERP which should include up to ten hours of therapist contact time, though the guidelines acknowledge that group treatments may exceed this number of hours.

The efficacy of group CBT for OCD

There is a dearth of research pertaining to the effectiveness of group CBT for OCD and the small number of research studies that have been conducted (Enright, 1991; Whittal et al, 1997, cited in Morrison, 2001) provide inconsistent evidence regarding the effectiveness of group interventions for OCD. Morrison highlights the need for further evidence of the efficacy of and pros and cons associated with group CBT for OCD.
Current study and research questions

One of the most salient questions facing clinicians today is: *What techniques, offered by whom, under what conditions, are helpful to which kind of clients?* (Paul, 1967, cited in Schneider, 1999). In response to this question, the current study aimed to assess the effectiveness of the OCD group in terms of clinical outcome and client satisfaction with service provision. The following research questions were postulated:

- Is the group effective in ameliorating symptoms of OCD and how might such changes (if any) impact upon further client – therapist contact time?

- How satisfied are clients with service provision and what recommendations can be made to improve future service delivery?
Method

The OCD group programme

The OCD group was a 10.5 hour cognitive-behavioural programme run over 8 weeks. The OCD group was the first to be run in the service, therefore the Team Manager and facilitators were keen to evaluate the effectiveness of the group in terms of clinical outcome, client satisfaction and cost-effectiveness and to receive recommendations about future directions or improvements that could be made.

The course aimed to equip patients with the knowledge and skills required to tackle and reduce OCD symptoms by promoting an understanding of OCD and how it is maintained and to develop client’s cognitive and behavioural skills in tackling symptoms. A number of inclusion and exclusion criteria were devised and employed. The inclusion criteria consisted of:

- Metacognitive ability – ability to think about thinking
- Ability to label thoughts and feelings and to contemplate the link between each
- Adequate interpersonal skills to participate in the group
- Belief in the ability to change

The exclusion criteria were developed in accordance with the stepped care model outlined in the NICE guidelines by considering participants suitability for the group in terms of the severity and complexity of their functional impairment. The exclusion criteria were:

- Individuals with multiple / complex problems
- Individuals with very severe symptoms

Design

This study employed a longitudinal repeated measures design to evaluate the efficacy of the group intervention at reducing obsessive and compulsive symptoms and also to monitor client satisfaction with service delivery at various points in the programme.
Materials

Client satisfaction was measured by three short satisfaction surveys administered before, half-way through and at the end of the group (see appendices 1 - 3). The questionnaires were designed by the trainee clinical psychologist and approved by the clinical psychologist who co-facilitated the group. The surveys aimed to gauge client satisfaction in terms of the most and least helpful elements of the group, progress with goals and level of knowledge and understanding about OCD.

In addition, participants were asked to complete a number of outcome measures at the same three points over the course of the group to gauge clinical change over time. The Clark-Beck Obsessive-Compulsive Inventory (CBOCI; Clark, Antony, Beck, Swinson & Steer, 2005) was used to gauge change in obsessive and compulsive symptoms. In addition, changes in anxiety and depression were measured using the Beck Anxiety Inventory (BAI) (Beck & Steer, 1993) and the Beck Depression Inventory Version Two (BDI-II) (Beck, Steer & Brown, 1996), respectively.

Procedure

Ten clients assessed, of whom eight were deemed suitable for and invited to attend the group. All participants were invited to attend a planning meeting prior to commencing the group, and mid-way and post-group reviews to administer the outcome and satisfaction measures. Once all data had been collated, the outcome and satisfaction data were analysed and portrayed using a case-study analysis. The qualitative feedback to the open questions on the satisfaction survey were analysed using a rudimentary form of thematic content analysis (Krippendorff, 2003).
Results

Case study comparisons of clinical outcome and satisfaction

Due to the small number of participants involved in the study, it was inappropriate to conduct non-parametric tests on the data as this would neither be statistically meaningful or the best use of the available data. Instead, a multiple case-study approach to analysis was adopted (Yin, 1994) which allowed a deeper exploration of the experiences of group. Hayes (1999, cited in Barker, Pistrang & Elliott, 2002) suggests some criteria for improving the credibility of case-study design research which include:

- Systematic, quantitative (versus anecdotal) data
- Multiple assessments of change over time
- Multiple cases
- Change in previously chronic or stable problems
- Immediate or marked effects following intervention

The current study adheres to all the aforementioned criteria in addressing the research questions and as such increases the internal validity of the study in being able to make inferences about the link between any observed changes and the delivery of the group. Of those five people who consistently attended the group, we obtained a 100% response rate for both the outcome and satisfaction measures, although one lady (case three) completed the BDI incorrectly at baseline which meant we were unable to use this data. A description of each individual case in terms of demographic information and changes in outcome and satisfaction measures are presented below.

Case One

HP is a 58 year-old unemployed gentleman of White-British ethnicity. He resigned from his job two years ago and had subsequently become increasingly isolated and had been hoarding items for a number of years.
Table 1: Changes in outcome and satisfaction measures over time for HP

<table>
<thead>
<tr>
<th></th>
<th>Pre-group (baseline)</th>
<th>Mid-group</th>
<th>Post-group</th>
</tr>
</thead>
<tbody>
<tr>
<td>BAI</td>
<td>24</td>
<td>20</td>
<td>23</td>
</tr>
<tr>
<td>BDI-II</td>
<td>20</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Obsessions</td>
<td>27</td>
<td>20</td>
<td>24</td>
</tr>
<tr>
<td>Compulsions</td>
<td>29</td>
<td>25</td>
<td>29</td>
</tr>
<tr>
<td>Total</td>
<td>56</td>
<td>45</td>
<td>53</td>
</tr>
<tr>
<td>Knowledge of OCD</td>
<td>4</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Helpfulness of group</td>
<td>-</td>
<td>10</td>
<td>7</td>
</tr>
</tbody>
</table>

HP’s anxiety levels remained in the moderate range throughout the group (see appendix 4 for clinical scoring ranges of outcome measures). Depressive symptomatology reduced from the moderate to mild range by the middle of the group but had increased to the mild range post-programme, though this indicates a reduction in depressive symptoms overall. The changes in HP’s scores on the CBOCI reflect a shift from the severe clinical range at the beginning of treatment to the mild - moderate clinical range half way through the. However, the total score had increased by the end of treatment, placing him again in the severe clinical range which highlights no significant change in OCD symptomatology.

Case Two

CM is a 28 year-old unemployed gentleman of White-British ethnicity. He had a long history of OCD since age 12 though stated that it had become increasingly worse in the last five years.
Table 2: Changes in outcome and satisfaction measures over time for CM

<table>
<thead>
<tr>
<th></th>
<th>Pre-group (baseline)</th>
<th>Mid-group</th>
<th>Post-group</th>
</tr>
</thead>
<tbody>
<tr>
<td>BAI</td>
<td>6</td>
<td>17</td>
<td>9</td>
</tr>
<tr>
<td>BDI-II</td>
<td>8</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Observations</td>
<td>15</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>Compulsions</td>
<td>31</td>
<td>29</td>
<td>27</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>42</td>
<td>41</td>
</tr>
<tr>
<td>Knowledge of OCD</td>
<td>5</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Helpfulness of group</td>
<td>-</td>
<td>5</td>
<td>8</td>
</tr>
</tbody>
</table>

Changes in MC’s BAI scores reflects shifts from minimal to moderate to mild anxiety by the end of the group. Symptoms of clinical depression remained within the minimal range throughout the group. The changes observed on the CBOCI demonstrate that although there was a small reduction in scores on the compulsions scale and subsequently in the total score, CM remained in the mild - moderate clinical range throughout the course of the group.

Case Three

KT is a 44 year-old unemployed lady of White-British ethnicity. She has a 20 year history of OCD with comorbid recurrent depression.

Table 3: Changes in outcome and satisfaction measures over time for KT

<table>
<thead>
<tr>
<th></th>
<th>Pre-group (baseline)</th>
<th>Mid-group</th>
<th>Post-group</th>
</tr>
</thead>
<tbody>
<tr>
<td>BAI</td>
<td>16</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>BDI-II</td>
<td>?</td>
<td>2</td>
<td>48</td>
</tr>
</tbody>
</table>
KT’s anxiety reduced from the moderate to minimal clinical range by the mid-point evaluation but had substantially increased to the severe range by the end of the group. Symptoms of clinical depression had risen dramatically from the minimal to severe clinical range between the mid-point and post-group reviews. KT’s scores on the CBOCI reflect a number of clinical changes over the course of the group, with all scores reducing by mid-programme but increasing to the mild-moderate range by the end of the group.

Case four

HR is a 41-year old lady of White-British ethnicity and had been diagnosed with OCD approximately three years ago.

Table 4: Changes in outcome and satisfaction measures over time for HR

<table>
<thead>
<tr>
<th></th>
<th>Pre-group (baseline)</th>
<th>Mid-group</th>
<th>Post-group</th>
</tr>
</thead>
<tbody>
<tr>
<td>BAI</td>
<td>10</td>
<td>19</td>
<td>3</td>
</tr>
<tr>
<td>BDI-II</td>
<td>6</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Obsessions</td>
<td>21</td>
<td>21</td>
<td>13</td>
</tr>
<tr>
<td>Compulsions</td>
<td>12</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>33</td>
<td>35</td>
<td>20</td>
</tr>
</tbody>
</table>
RH's anxiety fluctuated from the mild to moderate ranges by the middle of the group but reduced to the minimal clinical range post-programme. Depressive symptomatology remained in the minimal range throughout. By the end of the group, both the obsessions and compulsions subscales had substantially reduced, meaning that HR's total scores on the CBOCI reflect a shift in OCD symptomatology from the mild - moderate to the minimal / nonclinical range.

Case five

LJ is a 51 year-old unemployed lady of White-British ethnicity. She had a long history of OCD and recurrent depression for approximately 15 years.

Table 5: Changes in outcome and satisfaction measures over time for LJ

<table>
<thead>
<tr>
<th></th>
<th>Pre-group (baseline)</th>
<th>Mid-group</th>
<th>Post-group</th>
</tr>
</thead>
<tbody>
<tr>
<td>BAI</td>
<td>34</td>
<td>25</td>
<td>19</td>
</tr>
<tr>
<td>BDI</td>
<td>44</td>
<td>33</td>
<td>33</td>
</tr>
<tr>
<td>Obsessions</td>
<td>24</td>
<td>26</td>
<td>22</td>
</tr>
<tr>
<td>Compulsions</td>
<td>21</td>
<td>17</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>45</td>
<td>43</td>
<td>35</td>
</tr>
<tr>
<td>Knowledge of OCD</td>
<td>3</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Helpfulness of group</td>
<td>-</td>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>
LJ's anxiety had reduced from the severe to moderate range which was maintained at the post-group review, however symptoms of clinical depression remained in the severe range throughout the group. Though the scores show slight fluctuations over the course of the group, both the obsessive and compulsive symptoms remained in the mild – moderate clinical range over the course of the group, reflecting no clinically significant changes in OCD symptomatology.

Client satisfaction with service delivery

The responses to the open questions were collated (see appendix 5) and analysed using a rudimentary form of thematic content analysis (Krippendorff, 2003). The themes were coded by the Trainee Clinical Psychologist who facilitated the group and by a colleague who was not involved in the running of the group to increase the reliability of the analysis and emerging themes. The full list of themes emerging from the analysis of the open questions is included in appendix 6. A full consideration of all the themes that emerged are beyond the scope of the current study, however, four main categories of experience of the group are outlined below.

Most helpful aspects of the group

All group members commented on either the anticipated or perceived helpfulness of the support derived from meeting other people with OCD and sharing experiences. Three group members identified specific cognitive and behavioural techniques such as the exposure hierarchy as useful. Group members also valued integrative techniques such as externalisation and imagery adapted from systemic therapy as helpful, for example, externalising the OCD as a “gremlin” to help group participants assert more control over obsessions and compulsions.
Least helpful aspects of the group

The majority of group members did not identify any aspects of the group which they either anticipated or perceived to be unhelpful. However, one group member identified the “jargon” as problematic at times in terms of being able to fully understand and integrate the ideas espoused in the programme (for example, “thought – action / event fusion”).

Changes experienced

Four of the five participants commented on additional changes in themselves such as more confidence, feeling happier and more positive. It is only possible to hypothesize about the contributory factors affecting such personal changes, however, the cohesiveness and support of the group may have facilitated such changes in attitude. One participant commented that seeking help to address the difficulties with OCD had been a significant step forward and increased feelings of autonomy and self-efficacy in being able to address the OCD.

Learning over the course of the group

Most of the participants commented on the specific pieces of information or techniques that they had found helpful in addressing their own individual difficulties, for example about anxiety management and the prevalence of OCD.
Discussion

Response to postulated research questions

The aim of this service evaluation was to assess the effectiveness of a cognitive-behavioural OCD group within a PCMHT. The efficacy of the group was evaluated in terms of clinical change in the amelioration of OCD symptomatology and client satisfaction with service provision. The two research questions posed at the beginning of the study are addressed below.

*Is the group effective in ameliorating symptoms of OCD and how might such changes (if any) impact upon further therapist–client contact time?*

Overall, the general lack of improvement of OCD symptoms on the CBOCI would suggest that the group was not overly effective in ameliorating symptoms of OCD in the participants. Moreover, all five participants required individual follow-up sessions after completing the group. This would suggest that in light of the resource constraints within the service, the OCD group was not a particularly cost-effective mode of treatment and subsequently that participants were receiving more than the recommended amount of therapist-client contact time delineated within the NICE guidelines. However, this may be due to the fact that the exclusion criteria developed from the NICE guidelines were not adhered to in that four of the five participants had either severe (e.g., long-standing) and/or complex (e.g., hoarding, comorbid depression) difficulties. The NICE guidelines recommend more intensive treatment approaches for such clients such as care coordinated individual CBT combined with pharmacological treatment with Clomipramine or Selective Serotonin Reuptake Inhibitors (SSRI’s).

*How satisfied are clients with service provision and what recommendations can be made to improve future service delivery?*

Despite the somewhat disappointing results in terms of clinical outcome, the client satisfaction survey results suggest that all participants were happy with the service provided as demonstrated by the high ratings of helpfulness of the group. The increases in perceived knowledge over the course of the programme demonstrated that the group met
the aim of promoting participant's knowledge and understanding of OCD and how it is maintained. All group members commented on the value of the group context in meeting others and deriving support which can be considered a useful outcome.

Recommendations for future service delivery

It is possible to make a number of tentative recommendations for future service delivery based on the findings of the current study. These recommendations are outlined below and were formally presented to the service on 6th July 2006 (see appendix 7).

Firstly, participants considered for future groups should meet the NICE guidelines in terms of the severity and complexity of their difficulties and level of functional impairment. The current study suggests that clients with more complex or enduring difficulties may not experience many benefits from group CBT other than the support derived from meeting others with similar difficulties. The existing inclusion and exclusion criteria should be maintained and adhered to when assessing clients for future groups in order to provide both the most helpful and cost-effective treatment for clients and for the service.

Secondly, a number of comments from participants pertain to improvements that could be made to future groups. The use of jargon such as “thought-action/event fusion” in the group and in the materials used may serve as a barrier to understanding OCD and as such the facilitators could adapt the materials and complexity of concepts according to the ability level of the group members. Furthermore, while a number of participants found the specific cognitive and behavioural techniques useful, they also commented on the helpfulness of integrative techniques such as externalisation and imagery adapted from systemic therapy.

Limitations of the study and further evaluation

There are a number of limitations related to the design of the study. Firstly, the small sample size means that the findings of the study are not generalisable to a wider population.
Therefore, further service evaluation of subsequent groups is required in order to decide whether the group format will be a cost-effective treatment in the longer-term. Despite the small sample size, the study has high ecological validity due to the case-study analysis adopted. Without a comparison group, it is not possible to deduce whether the small changes observed can be attributed specifically to the OCD group. Elliott (2002, cited in Barker, Pistrang & Elliott, 2002) delineated a number of non-therapy factors that may account for observed clinical changes. Such factors include non-improvement in that apparent changes are trivial or even negative, client expectations in which apparent changes reflect client expectations or wishful thinking and relational artifacts – where apparent changes reflect attempts to please the therapist or researcher. The latter point may account for the lack of feedback from participants about less helpful aspects of the group, particularly as one of the facilitators was also leading the service evaluation. Therefore future evaluations should either be run by someone not involved in the running of the group, or feedback should be made anonymous to encourage more open and honest and feedback.

Conclusions

In conclusion, the service evaluation found that the OCD group was successful in meeting its aim of increasing participants knowledge and understanding of OCD and how it is maintained, yet was relatively unsuccessful in terms of reducing obsessive-compulsive symptomatology. There were a number of unanticipated changes observed in some participants attitudes and confidence which may have been facilitated by the supportive nature of the group. Further evaluation is required with a broader range of clients to deduce whether the group is a cost-effective and efficacious treatment modality for the treatment of OCD.


Qualitative Research Project

Therapist's understandings of intense personal experiences and their implications for therapy

May 2006

Year 1
Introduction

Self actualisation

Abraham Maslow (1969) is perhaps best known for his significant contributions to the field of psychology in terms of his hierarchical theory of motivation and for the concept of self-actualisation. Maslow described the overarching characteristic of self-actualisation as "more efficient perception of reality and more comfortable relations with it". Within this, he described a number of qualities associated with the way self-actualised people view the world and their place within it, for example, clarity of percept and being less motivated by the need for social approval.

Maslow had originally maintained that self actualisation was a state that could only be achieved a very few people. However, in his later work, Maslow broadened his understanding of such experiences and stated that self-actualisation was a human height to which anyone could potentially ascend. Maslow described these moments as peak experiences – a kind of transient self actualisation within which the person ascends to a very high peak and from there can look out alternative horizons with a sense of wonder and awe. From this point, Maslow maintained that self-actualisation was no longer an all-or-nothing experience, but more a matter of degree or frequency. Maslow maintained that in theory, episodes of self-actualisation (peak experiences) may occur in the life histories of any person, but particularly those of artists, intellectuals or profoundly religious people and in people experiencing great insights in therapy or other important growth experiences.

Qualities of the peak experience

In further work, Maslow elaborated on the concept of the peak experience and delineated 17 qualities which characterise the peak experience. Though a detailed synopsis of each of these qualities is beyond the scope of this report, below are the core qualities of peak experiences espoused by Maslow as the defining characteristics of such experiences:

1. In B-Cognition, the experience of the object tends to be seen as a whole, a complete unit, detached from relations, from possible usefulness, from expediency and from purpose
2. When there is a B Cognition, the percept is exclusively and fully attended to

\(^2\) Maslow used the term B-Cognition ("Being" Cognition) to refer to the characteristic qualities of cognition in the peak experience.
3 In peak experiences, there is a differentiation in perception between external objects that are relevant to human experience and external objects that are irrelevant to human concerns

4 B-Cognition seems to make perception richer

5 Perception can be relatively ego-transcending, self-forgetful and egoless

6 The peak experience is felt as a self-validating, self-justifying moment which carries its own intrinsic value with it

7 In all the common peak experiences outlined by Maslow, there is a very characteristic disorientation in time and space

8 The peak experience is only good and desirable and is never experienced as evil or undesirable

9 Peak experiences are more absolute and less relative

10 While ordinary cognition is a very active process, B cognition is much more passive and receptive than active (choiceless awareness)

11 The emotional reaction in the peak experience has a special flavour of wonder, of awe, of reverence, of humility and surrender before the experience as before something great

12 In some reports, particularly of the mystic experience or the religious or philosophical experience, the whole of the world is seen as unity, as a single rich live entity. In other of the peak experiences, most particularly, the love experience and the aesthetic experience, one small part of the world is perceived as if it were for the moment all of the world

13 At the higher levels of human maturation, many dichotomies, polarities and conflicts are fused, transcended or resolved

14 The person at the peak is godlike, not only in senses that have previously been touched upon, but in certain other ways as well, particularly in the complete, loving, uncondemning, compassionate and perhaps amused acceptance of the world and of the person

15 Perception in the peak moment tends strongly to be idiographic and non-classificatory

16 One aspect of the peak experience is a complete, though momentary, loss of fear, anxiety, inhibition, defences and control, a giving up of renunciation, delay and restraint

17 There is a kind of dynamic parallelism or isomorphism here between the inner and the outer. This is to say that as the essential Being of the world is perceived by the person, so also does he concurrently come closer to his own Being (to his own perfection, of being more perfectly himself)

The literature reports that peak experiences come in a variety of shapes and sizes, some of which are concordant with Maslow's idea of the peak experience, and others that
fall well outside the peak experience parameters described by Maslow (Wilson & Spencer, 1990).

**Peak experiences in the therapeutic situation**

There is a relative paucity of research into the prevalence and characteristics of peak experiences in the therapeutic situation. In describing certain qualities of the peak experience, Maslow identified the moment of insight in the therapeutic situation as a self-validating experience which carries the intrinsic value characteristic of the peak experience. Though the insight may be defended against and therefore painful to accept, such insights are universally reported to be desirable and worth-while in the long-run. Moreover, though the peak experience itself is transitory, the effects or after effects may be beneficial to the individual in terms of feeling remotivated and enhancing holistic understandings of the self (Chambers-Christopher, Manaster, Campbell & Weinfield, 2002). Research by Lanier, Privette, Vodanovich and Bundrick (1996) supported Maslow's assertion that the peak experience has significant meaning for the individual and are often seen as significant turning points in people's lives. Moreover, the authors concluded that peak experiences with the potential for lasting consequences can influence quality of life and in psychotherapy, may hold personal meaning and give guidance for direction of change in people's lives.

**The current research project**

In view of the possible benefits associated with peak experiences and given the dearth of research into the prevalence and effects of peak experiences in the therapeutic situation, the current research study aimed to gain an insight into intense personal experiences in therapy with a view to assessing whether such moments met Maslow's criteria of a peak experience. Furthermore, by exploring the nature of intense personal experiences, the meanings attributed to them and the possible after-effects, it may be possible to determine the occurrence and value of such intense moments in therapy and to deduce whether there are any common factors that may facilitate such experiences.
Methodology

Interpretative Phenomenological Analysis (IPA) is a qualitative research paradigm that was first used in health psychology (e.g., Smith, 1996; Flowers et al., 1997), but has since been employed in social and counselling psychology (e.g., Macaran et al., 1999; Coyle & Rafalin, 2000). It aims to define human experience within the person’s social, cultural, and historical contexts by searching for meaning in the phenomenon that is being studied. As such, it is interested in an individual’s personal, subjective account of the event, and allows an attempt by the researcher to understand the diversity within human experiences (Willig, 2001).

IPA attempts to define experience from people’s narratives. Unlike discourse analysis, IPA considers that, while narratives do not accurately reflect a person’s thinking, conclusions can be drawn regarding how people make sense of their world (Smith et al., 1999; Yardley, 2000). This requires the phenomenon under investigation to be interpreted meaningfully by the researcher. The researcher using IPA recognises his/her own influence upon the interpretation (Elliott et al., 1999), and that their own beliefs and experiences (social, cultural, historical) will be drawn upon in the interpretation (Smith et al., 1999). The analysis, therefore, is the “product of the interactions between the participants and the researcher” (Grigoriou, 2004, p. 8).

Participants

Participants were drawn from an opportunity sample. Each researcher approached a qualified counselling or clinical psychologist for interview with whom they were working. Our inclusion criteria for the study were that all interviewees had a minimum of two years post-qualification experience and were accredited by the BPS or UKCP.

A total of six qualified psychologists were interviewed, five female and one male. Their ages ranged from 30 to 60, with a mean of 46.4. Their mean years of experience was 16.83 (range 3 to 34), and they consisted of one counselling psychologist, three clinical psychologists, and one psychotherapist. Three considered their therapeutic orientation to be integrative, one considered it to be cognitive behavioural, and one psychodynamic and
integrative. One interviewee was Catholic; the remaining five did not identify a followed religion.

Table 1: Demographic information of participants

<table>
<thead>
<tr>
<th></th>
<th>T1</th>
<th>T2</th>
<th>T3</th>
<th>T4</th>
<th>T5</th>
<th>T6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>60</td>
<td>42</td>
<td>30</td>
<td>43</td>
<td>57</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>M</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>British</td>
<td>British</td>
<td>British</td>
<td>Irish</td>
<td>British</td>
<td>Italian</td>
</tr>
<tr>
<td>Orientation</td>
<td>Int</td>
<td>Int</td>
<td>CBT</td>
<td>PsD/Int</td>
<td>Int</td>
<td></td>
</tr>
<tr>
<td>Experience</td>
<td>34</td>
<td>8</td>
<td>3</td>
<td>16</td>
<td>25</td>
<td>15</td>
</tr>
<tr>
<td>Religion</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>Catholic</td>
<td>None</td>
<td>None</td>
</tr>
</tbody>
</table>

Int: Integrative
PsD: Psychodynamic
CBT: Cognitive Behavioural Therapy

Measures
A semi-structured, self designed interview was used to elicit information about the therapist's personal experience of intense emotions in therapy (see appendix 1). Smith et al. (1999) consider this type of interview to be the most appropriate method of data collection for IPA.

The main content of the interview schedule was based upon Maslow's (1962, 1986) description of peak experiences, with the prompts being informed by Wilson and Spencer (1990). The interview was divided into three main areas of interest: the subjective effects of intense emotions in therapy, the interpretation and meaning of these experiences, and the after effects of these experiences.
Procedure

A pilot study was conducted to evaluate the interview schedule. As qualitative research can be time consuming (Elliott et al., 1999), we used this to inform us of the time scale required to complete the interview. The pilot interview was completed in 40 minutes, which the research team considered acceptable given time restraints, and thus there was no need to abridge the schedule. It also allowed us to recognise that the questions were understood by the participants, and that no questions offended or upset the interviewee.

Each researcher arranged to interview the participant in a private room. A standardised paragraph was first read to the interviewee (see appendix 1) to introduce the study, to explain what would happen to the collected data, and to gain consent for the interview to be recorded and analysed. After consent was gained, the interview was commenced and recorded.

Analysis

IPA was used to analyse the data as we were attempting to find meaning within the narratives of interviewees. Following the completion of the interviews, each member of the research team transcribed verbatim their audio recording of their interview. Each member then read the transcripts a number of times in order to familiarise themselves with the contents.

An interpretative team was then convened to identify initial interpretations, connections, contradictions, and themes in the narrative. One transcript was reviewed and discussed, and any striking or significant statements made by the respondent were noted in the left hand margin. This data was then discussed within the group, and emerging themes were identified and noted in the right hand margin of the transcript, and then drawn out on a separate sheet. The remaining transcripts were then subject to the same process, where evidence for the identified themes was sought, as well as evidence of new emergent themes, and connections between the narratives. The list of master themes was then revised in light of each analysed transcript; redundant themes removed and new emergent themes added (according to Smith et al. allowing new themes to emerge is characteristic of IPA). Smith et al.
(1999) recommend this approach for smaller sample sizes as it allows the researcher to keep other transcripts in mind, which aids further analysis. Analysis was complete when no new themes emerged (Crist & Tanner, 2003).

Various themes clustered together, and again the master list of themes was revised to include superordinate themes that contained sub-themes. Other themes were dropped because they were not well represented in all the transcripts or did not add any further depth to the analysis. The final list of superordinate and sub-themes was then checked with the narratives to ensure that they were actual representations of the participants said (Smith et al., 1999).
Results

Table 2: Quotations to support themes and subthemes

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Sub-themes</th>
<th>Description</th>
<th>Examples from raw data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connection</td>
<td>Connection with self and others</td>
<td>A feeling of connectedness and intimacy with parts of the self or with others, including reciprocity</td>
<td>&quot;I understand it as something about a very deep connection, the effect of one persons unconscious on another. They are all examples of how powerfully we effect each other as therapists and as patients.&quot; (2:1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&quot;I think in a sense relating at a deeper level with myself and finding a sense of calmness led me to deepen my connection with the other people in my life&quot; (3:1)</td>
</tr>
<tr>
<td>Transcendent</td>
<td>Connection</td>
<td>In which the connection with another is experienced as an altered state of awareness</td>
<td>&quot;I wasn't even bothered about time I think. It was just peaceful being in the present...&quot; (3:2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&quot;I had this strong sense of disconnection from worldly things, myself and losing sense of space and time.&quot; (4:1)</td>
</tr>
</tbody>
</table>
**Distancing Self as different from or distant from clients.**

"I'm a Catholic, a practising Catholic, but I actually don't discuss my religion with any of my clients." (1:1)

"I don't feel a deep seated connectedness to this man and I don't feel any great positive feelings other than pleased for him" (5:1)

"A slight distancing from the emotion and bringing in kind of more cognitive processes reflecting on, you know, where that's coming from" (6:1)

**Factors influencing deeper connection**

"It wasn't about thinking. When I stopped thinking it was better. Hmmm...it was letting myself not to think. Allow myself just to be there" (3:3)

"I think it is more about the kind of person, the kind of hunger with which they come, how they respond to you as a person in the room, how they relate to you, and whether you feel that they really are motivated and connecting with the work" (5:2)
| Creation References to creation in the context of the therapeutic relationship. | "Like the relationship between a baby and its mother, that sense of safety and security" (3:4) |
| "A union is being made here, you are fertilising, all that learning, all that coming togetherness, a seed is taking place." (5:3) |

| Intense emotion | Positive emotion | Love and joy | "In a sense I smile when I think of it so there is a sense of joy attached to it" (3:5) |
| "I think at the end of the day, maybe it is all about love ... human connection, warmth and recognition." (5:4) |

| Negative emotion | Suffering, often experienced by the therapist as a shared suffering with the client. | "And it was horrific ... that was actually a really intense experience in the therapy when he was describing that story because it was like we were kind of watching it nearly happening." (1:2) |
| "Some people are so defended that when you begin to make contact" |
they run, and you feel spurned and terrible and ashamed almost sometimes, that you have damaged them or that you are crap.” (5:5)

“The feeling was of sadness really, of kind of intense sadness” (6:2)

<table>
<thead>
<tr>
<th>Change</th>
<th>Change in the moment for the therapist</th>
<th>Including the subjective experience (e.g. cognitive, physiological and emotional) or an expanded quality of experience (e.g. greater self understanding).</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“It was like the thinking part of me linking with some physical, emotional experiences...” (3:7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“I would call that a moment of strong shift, and raised awareness of myself and my emotions.” (4:2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“It’s more likely to happen I think, erm, in supervision, or in reflection outside of therapy.” (6:3)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Controlling change</th>
<th>References to the possibility of facilitating change.</th>
<th>“I would just present it as something that happens within them and that we have just worked out the right combination for them at the time ... sometimes I can, I know when it will happen.” (1:6)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>“I think if you try to control and...”</td>
</tr>
</tbody>
</table>

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contrive those moments then I don't think you would have the same response." (2:2)

<table>
<thead>
<tr>
<th>Long term change</th>
<th>Therapist learning from the client.</th>
<th>“I've had to change my view of life and spiritual life and values and the meaning of life, all those kind of things. But it hasn’t been a sudden change.” (1:7)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>“Your understanding of the profession, of the work and of the mind just grows with your clients, you learn from them, huge amounts.” (5:8)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“No, it wasn’t restricted to that client, I think it adds, every experience like that adds to a skill that you are already using” (6:4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Faith</th>
<th>Trust in persons (therapist for client)</th>
<th>Refers to the faith the therapist has in people’s potential.</th>
<th>“I’m not such a great believer in god, but I am a believer in man … and you have to have faith in your clients and you have to have faith in man, and I think that is very spiritual, definitely.” (5:6)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>“You never judge people just by .......” (5:6)</td>
</tr>
</tbody>
</table>

```
<table>
<thead>
<tr>
<th>Trust in process / change</th>
<th>The faith the therapist has in the therapeutic process.</th>
<th>“I suppose it gives me a real confidence about the power of the individual’s mind. So I can relax often in therapy because of that. Because I know that will come into action” (1:4)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>“I think I am more aware where it can go. It is important for me in terms of reaching a state of peace, calmness and security.” (3:6)</td>
</tr>
<tr>
<td>Spirituality</td>
<td>References to spiritual faith.</td>
<td>“I think I’m very aware that people believe lots of different things.” (1:5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Because you have to have faith in human beings ... you use that spirituality all the time.” (5:7)</td>
</tr>
</tbody>
</table>
All our participants described moments of intensity that arose from having formed a connection with a client. The experiences relayed were of especially deep and intimate connections. For some this was at an unconscious level (2:1). For another participant the connection was more practical, she described her work with asylum seekers; “they were fighting in their situation and I felt a degree of responsibility to do what I could in this environment for them” (Participant 1). For participant 3 his relationship with self facilitated his relating with others (3:1).

The theme of connection is closely linked to the next two themes of ‘transcendent connection’ and ‘distancing’. These two themes could be placed at either end of a spectrum with the connection already described in between. Two of the participants described experiences which could be categorised as an altered state of awareness as a result of a deep connection in therapy which we labelled transcendent connection. Both experiences were characterised by a sense of transcending the usual sense of space and time (3:2 and 4:1). These accounts probably come closest to a peak experience (PE) in the sense Maslow describes it in that they appear to be egoless (point 5 of Maslow’s characteristics presented in introduction) and there is disorientation in time and space (important in all the peak experiences described by Maslow - point 7).

At the other end of the connection spectrum three participants made statements that revealed feelings of distance and difference from their clients. Sometimes this was an observation of difference which therapy worked despite of (5:1). For others this was a more conscious decision to keep a distance (1:1) and for one participant it served a function in therapy (6:1).

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3 Participants were given the opportunity to share their intense personal experiences both from the perspective of therapist and client. Just 2 of the 6 participants chose to share their experiences of being the client in the therapeutic relationship. In order to keep to the word limit we will focus on just the main themes involving the participant as therapist.
Intense emotion

For all our participants the poignant moments they chose to share involved intense emotion. The positive emotions of love (5:3) and joy (3:5) seemed to be dependent on the connection the participants had formed with clients. Likewise most of the comments about negative emotion described the sharing of pain or suffering with a client (1:2 and 6:2). However participant 5 revealed a different source of negative emotion for the therapist; feeling rejected by the client or concerned that ‘you have damaged them’ (5:5). These intense moments contrast greatly with Maslow’s PE’s which are only good and desirable (point 8) and are self-validating (point 6).

Change

Another significant experience common in our sample was change. Participants described both specific moments of change or more gradual, long term change. Two participants (the same two who described transcendent connections) identified distinct moments in therapy when they had felt themselves change. This seemed to be related to different parts of the self coming together (3:7) or a sharp increase in self awareness (4:2). Where Maslow talks of peak experiences in therapy he seems to suggest that these are more likely to occur as moments of insight by the client. Our data suggest that these moments of insight might occur for the therapist also. Other participant described the powerful experience of observing a moment of change in a client. Participant 1 described powerful physical sensations of ‘feeling very warm and start[ing] to get goose pimples’ when she observed a client ‘totally change [a] disturbing visual image ... into something really positive’. For some these moments of change were described in terms of their immediate subjective effects (participant 1 above and 3:7). For participant 4 (above) although describing a specific moment, there is an implication of a longer lasting effect.

Faith

Three of the 6 participants shared the ways in which their beliefs influenced their therapeutic work and the way their work influenced their beliefs. Participant 1 talks about her faith / belief in the ‘boundless possibilities’ of people (1:3). Participant 5 says this faith in people’s potential has a spiritual quality (5:6). Only within the ‘faith’ theme do we see evidence of the wonder, awe and humility described by Maslow (point 11). This theme relates to Maslow’s description of a PE as a sudden awareness of limitless horizons,
although an important difference is that our participants had developed this belief over years of experience whereas Maslow is describing a rare glimpse of understanding. On a similar vein Participants 1 and 3 express faith in the therapeutic process and the possibility of change. This faith helps them to relax in their work (1:4 and 3:6) invoking Maslow’s description of self actualised persons having ‘more comfortable relations with [reality]’.
Discussion

In conclusion certain of Maslow’s 17 characteristics of a PE are evident in the data from our six therapists, but many are not. All the experiences conveyed in this study suggested that the client was ‘fully attended to’ as the percept is in Maslow’s point 2. The experiences by their interpersonal nature were concerned with ‘objects that are relevant to human experience’ (point 3). For some therapists the intense experiences appeared to be ego-transcending and disorientating in time and space (points 5 and 7) and for many were self-validating (point 6). For about half our participants the experiences led to a gradual faith reflecting awe and wonder at human potential, but this did not come as a sudden awareness (point 11). Both the long-term learning and the momentary change implied an increase in richness of perception (point 4).

However for most of our participants their experiences were not; always good (point 8), absolute (point 9), passive (point 10), free of dichotomies and conflicts (point 13), free of anxiety and fear (point 16) and did not suggest dynamic parallelism (point 17). During these experiences they did not appear to view the client as a unit detached from relations (point 1) or see the world as a single entity (point 12).

Point 15 of Maslow’s PE characteristics (perception in the peak moment tends to be idiographic and non-classificatory) is difficult to utilize. It seems to imply that an individual’s experience would not need to meet his criteria to be considered a PE because their perceptions will be unique and not easily categorised. This leads us on to the limitations of the current study. In addition to point 15 above, Maslow did not actually identify a single person whose experience met all his characteristics. How likely is it that with a sample of six we were likely to identify experiences that seemed to reflect Maslow’s description which is an amalgamation of 190 people’s experiences? Perhaps to replicate his study within a therapist population we would need to use a larger sample size and a similar method of data collection.4

---

4 Maslow asked his participants to write a short description.
Another way to identify evidence of Maslow style PE’s, if they had occurred for our sample, might have been to give a definition of a PE at the beginning of the interview. This was something we considered, but in the end selected instead to use neutral language (we did not even use the term PE in our schedule). Ultimately we think this was a strength of the study. As a group we were interested not only in Maslow’s very specifically defined PE, but also in psychologists experiences of being deeply moved and changed by their work, including feeling joy and love in therapy. The latter, more loosely defined concepts, were very evident in the results of the study. Given the openness of our approach in the interviews, the shared experiences and meanings expressed by our participants is noteworthy.

To review the theoretical implications of the study it is necessary to turn again to Maslow. Ours was a very different context to that of Maslow’s study with students. The therapeutic relationship represents a unique forum in which emotions are primary and in which issues of life, death and meaning (spirituality) are explored. This justifies an exploration of intense personal experiences in this context. Possibly the reason we did not find stronger evidence for a Maslow style PE is because psychologists frame their intense experiences using a language different from the transpersonal language of Maslow and others. Participants 3 and 4 were perhaps drawing on a broader range of languages in discussing their experiences creating a bridge between the two worlds.

Finally, we consider the implications for practice. The experiences revealed as most significant to our therapists were intense emotion, connection, change and faith. These themes struck us as being linked and could almost be presented as a model of therapy. Much of the intense emotion felt by therapists is due to the deep connection that they form with their clients, a deep empathy means that our therapists often shared in the suffering and pain expressed by their clients. It can be argued (for example from a Rogerian [1961] perspective) that this connection and shared emotion contribute to the ingredients required for change - the next theme identified. Finally the faith that our therapists expressed in the potential of their clients and in the possibility of change arises it appears from their experiences of observing change in their clients. This becomes a kind of spiritual faith or
belief system for some of them. Furthermore this then feeds into their capacity and ease in developing connections with clients.
References


Appendix 1:

Interview schedule
Therapists' Understanding of Intense Personal Experiences and Implications for Therapy:

Interview Schedule

Firstly, thank you for agreeing to take part in the study. As part of our PsychD Clinical / Counselling (delete as appropriate) psychology course we are conducting a small piece of research into therapists understandings of intense personal experiences and their implications for therapy. We have a number of exploratory questions we would like to ask you around this topic. Please answer as fully, openly and honestly as you can, however you do not have to answer any questions you feel uncomfortable with and we can stop the interview at any time. If it's ok, I will be tape-recording the interview (ask if ok / for consent). The interview will then be transcribed verbatim and analysed, along with a number of other interviews in an attempt to look for themes that may help us understand the research topic a bit better. The transcripts will be kept for three years after the date of our graduation and then automatically destroyed. However, all personal or identifying details will be anonymised when the transcript is being analysed. Do you have any questions that you would like to ask or is there anything you would like me to clarify?

Note: Remind interviewee that they may answer questions from the perspective of a therapist or a client.

Subjective effects:

1. Can you describe a moment of intense emotion (positive and/or negative) experienced by you in therapy?
   
   o Some people talked about experiences of joy, euphoria, excitement, love, sadness, hate, anger, loss
   o Are these experiences more cognitive, physiological or emotional?
   o How did it make you feel?

2. If you had such an experience were you aware at the moment of what was happening? How long did it last?

3. Can you identify a distinct moment in therapy in which you feel your perspective on life changed?
   
   o Including the experience already described
4. Can you describe having an experience of losing the awareness of yourself or becoming more aware of yourself?
   - Including the experience already described

<table>
<thead>
<tr>
<th>Questions below are optional. Can be used as prompts or to encourage discussion if the above questions above have not elicited much detail:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you experienced moments in therapy or outside of therapy, in which you have felt a sudden awareness of yourself, as if your view of yourself changed and became clearer?</td>
</tr>
<tr>
<td>Have you experienced a sense of losing the sense of time and space?</td>
</tr>
<tr>
<td>Have you ever had an intense experience in therapy that at the time you might had difficulty to express in words? Can you tell me about it?</td>
</tr>
<tr>
<td>Do you feel that spirituality plays a part in your therapeutic work?</td>
</tr>
<tr>
<td>Your spirituality?</td>
</tr>
<tr>
<td>Client’s spirituality?</td>
</tr>
<tr>
<td>Something between you?</td>
</tr>
<tr>
<td>The feeling that you were in close contact with something holy or sacred?</td>
</tr>
<tr>
<td>Have you ever experienced an altered state of consciousness during therapy?</td>
</tr>
<tr>
<td>Or something like it?</td>
</tr>
<tr>
<td>Can you describe a deeply moving experience in therapy?</td>
</tr>
<tr>
<td>Do you experience times of being at one with your client or at one with humanity during therapy?</td>
</tr>
</tbody>
</table>
I am interested in looking at moments of separation from the ego. have you had experiences as a therapist which might relate to this?

Can you remember how you were feeling and perhaps what you were thinking just before this experience?

Did you ever have:
- Experiencing the beauty of nature in a deeply moving way?
- Feeling that you were in harmony with everything around you (the universe!)

Interpretation and meaning

5. How do you make sense of such moments?

6. What in your opinion happened to yourself at the time?

7. What do you think it was about the moment that brought it about?
   - E.g. environment, therapeutic relationship, stage of therapy etc
   - Are these moments predictable?
   - Can you control them?
   - How do you explain their occurrence?

After effects

8. So what changed after this experience?
   - Momentarily, short term, long term, not at all?
   - For the client?
   - For your relationship with the client?
   - For the therapy?

9. I wonder if the intense experience you’ve talked about was restricted to that particular client or did it alter your practice in a more generalised way?
   - i.e. self esteem, job motivation, effectiveness etc.
10. I wonder if the experience you’ve described was restricted to therapeutic work or has it affected your life beyond therapy?
Appendix 2:

Sample interview transcript
Interview transcript

Interviewer - Can you describe a moment of intense emotion (positive and/or negative) experienced by you in therapy? Some people talked about experiences of joy, euphoria, excitement, love, sadness, hate, anger, loss.

Participant - I think it's really difficult actually to think about that. I think I've had a few experiences where people have experienced the therapy in such a positive way actually - that's what I'd be looking at - and I'm thinking about one client in particular who I've been seeing for about 3 years with complex post traumatic stress disorder and she was plagued by very bad nightmares. And through the use of... One time when we were doing EMDR she totally changed the disturbing visual image and that effected me. For the first time ever in the sessions she began to... She was sort of smiling at me and there was a feeling of, really there was a kind of glow about her, which was interesting because of the way she was describing the images she was having during that part of the therapy. And it was as if something had lifted and she described it as that, she described the image fading away and actually the image changed into something really positive and it was kind of in the room with us, which was really nice. It was a really lovely experience. And considering that she had complex PTSD and she was borderline personality disorder, it was actually really meaningful and that was a lovely experience. That was a good experience.

Interviewer - And how did that affect you in that moment? How do you remember feeling?

Participant - I remember feeling very warm and I started getting like kind of goose pimples a little bit. And just very... yes, it was just a lovely feeling. There was a sense of at last there was some degree of relief for her. And she knew I wanted that for her. And she was really pleased and the change in her spontaneously and the faith, it was really lovely to see. She looked really beautiful, because often she looked very troubled you know so that was really nice so that was what I felt.
Interviewer - Can you identify a moment in therapy in which you feel your perspective on life changed? A distinct moment in therapy in which you feel *you* almost changed somehow?

Participant - Oh, it's very difficult. Um I think over a lot of the people I have seen I have changed. I think because of a lot of the work that is done with people who have been asylum seekers, especially when they've been in detention, I've had to change my view of life and spiritual life and values and the meaning of life, all those kind of things. But it hasn't been a sudden change; it's been a very gradual experience. I had a very... I suppose what it is it just confirms things that I already might have thought and making them more intense. I had a lovely experience with a man who... well it was very sad actually but there was a kind of period of lovely experiences in it. He was from [...] and one of the things he had done, in his attempt to escape which was very sad, he had described running away and leaving his wife behind and seeing his wife being captured. And it was horrific and - thankfully his wife did survive- and that was actually a really intense experience in the therapy when he was describing that story because it was like we were kind of watching it nearly happening. Yes, it was very intense and subsequently that relationship was... they were reunited and he was in detention and she was actually in London. Now there was a very sad end to the story which was dreadful, but at one stage as a result of the work we were doing he was going to be released from detention because of the adverse effects it was having and I'd written lots of reports. He had a book on [...] or something, something very... and it was the only, one of the few possessions he had and it was from a time when he was studying as an [...] and he gave me the book. And I didn't want to take it but I realised that I had to take it. It was his way of thanking me because it was an experience for him of something very... You know it was like, I think it was his first experience of being treated equally if you like and he wanted to give me something that was very important to him. So he gave me this book and then subsequently when he was released from detention he sent me a photograph of himself and his wife and his children all together and saying you know, you are responsible for this, which wasn't true, but it was a lovely experience. It had a very sad end as it happened. But that in itself... It kind of changed my attitude about... I feel, I suppose it's one of my political views that I feel very strongly that people need to take action about things. People need to
understand. Also it made me very aware that as a psychologist you’re not just dealing with the internal processes of an individual, sometimes there is a kind of ripple effect on... you know we’re aware of the effect on the family or the immediate contacts, but actually often there’s a stronger ripple effect and we have to realise that we’re working with clients and that it has implications for things not just in their immediate environment, but sometimes beyond and I suppose it also made me more aware what we would learn from people and maybe question more about imposing our views about meaning of... the westernised ideas about symptoms on people, those kinds of things. I suppose I learned a lot from those people which was really useful.

Interviewer - And that ripple effect was that almost a feeling of a greater effect on humanity almost? Was it at that level or...?

Participant - Well I felt that... I felt very strongly that these people were languishing away and that nobody knew about them, so one of the things I wanted to do was to make it be known what they were experiencing and so I talked a lot about it whenever I had opportunities in public environments. But I actually used the language of psychology to make more acceptable if you like to the powers that be so... I mean I remember at one stage somebody said to me that the Home Office asked ‘who was this [interviewee’s name], who was a psychologist?’ because there was such... you know I was causing hassle for them clearly. And what I was doing was what would happen hopefully on any mental health unit where somebody was on a ward that was having an adverse effect on them, saying it’s interfering with their human rights. So in some ways I suppose a lot of these people that I had seen who were in detention would often have been in conflict in their home situations and it had a major impact on me because in some ways they were fighting in their situation and I felt a degree of responsibility to do what I could in this environment for them. So a bit like sometimes they would have been victimised because they had said ‘no’ to certain things in their country - I wasn’t going to be victimised in the same way by any means - but I felt it was also important for me to say no in some ways so that’s where I learned things from them and that was then about us you know using the therapy as a way of enabling them to discuss their experiences in a way that other people could understand actually.
Interviewer - Yes and you almost took a kind of bravery from that it sounds like?

Participant - Well there was no bravery attached to what I did. No there wasn’t. I mean all I was doing was saying ‘look, look what these people have been through, look at what we’re putting them through now and we can’t justify this actually.

Interviewer - Do you think that... Would you ever frame any of this in a kind of spiritual way or is that not the sort of...?

Participant - I’m a Catholic, a practising Catholic, but I actually don’t discuss my religion with any of my clients. But one of the things I’ve learned in my practice dealing with clients from lots of different cultures and countries is that their religion, their spiritual beliefs are very important. So, I will use that whenever possible in the service of the client. But not in a prescriptive way. So if they’ve come up with something, I’ll use it. Or for example... I had an example of a woman who believed black magic was done to her in her country of origin and she believed that her new baby in this country would be damaged by her father who she believed could come into the room and damage her. So we called him up in the room and we got all these other female figures from the past for her, some of them alive, most of them dead, but she also wanted to include me in it, where they stood with us and they were behind her and so when she was aware that he was in the room we told him that he needed to go away, that he needed to leave her alone and that he no longer had any power over her and that it wasn’t only her and her baby, but that there was all of these other people behind her and that it was time for him to stop. It wasn’t going to work anymore. And it only took a few seconds and she was going ‘yeah it’s different, it’s completely different, he’s gone’ and he never appeared again.

Interviewer - Have any of these experiences affected your religion or spirituality do you think?
Participant - I don’t know that it affected that. I think... I think I’m very aware that people believe lots of different things and I’m very aware that sometimes that can be used really positively, so that’s kind of... that’s as far as it goes for me.

Interviewer - And you were able to bring that understanding partly because of your own understanding of your religion?

Participant - Yes, because of good yes. I’m also aware of bad and I have I suppose had... specially when I’ve dealt with a couple of cases where there’s been satanic abuse, I’m very aware of a presence of something malevolent – I don’t mean a spirit or anything – but, something that the client experiences, something that they’re holding in their minds and I’m very aware of that coming into the room at times. Scary, very scary, yeah. I suppose I’m – I’m not saying I’m used to it, but I’ve leaned more about it, in so far as how I deal with it.

Interviewer - Can you remember moments of almost losing an awareness of yourself in a therapeutic situation?

Participant - There was one period with this complex PTSD client where I think I lost time for I don’t know how long, a couple of seconds in the middle of the session. I became aware that I hadn’t heard what she’d said. I don’t know whether it was that I dozed off or what. It was very odd. I don’t think she noticed. I probably could have asked her of she had noticed, but that was the only time I’ve ever had a sense of being a bit surprised and finding myself...for a second,. But I don’t know how much time I lost, probably not very long.

Interviewer - Taking the first example that you told me about in which you saw that intense change in the client, how do you make sense of moments like that, how do you explain, if there are words to explain...?
Participant - Often I say to people - and a technique like EMDR helps, but actually I find dynamic principles really help as well - you know I talk about their internal wisdom, I talk about their brain wanting things to be better for them and that natural inclination towards help. So I work on the premise yeah well I can see why that would happen, that makes sense that that would happen, 'this is you sorting things out, this is you changing things, all we have to do is create the right condition and the right condition has been created and now you can do it and that's really great and yes I would have expected it.' So I would just present it as something that happens within them and that we have just worked out the right combination for them at the time.

Interviewer - Can you predict when that will come?

Participant - Sometimes I can yeah, sometimes I can, I know when it will happen. The right ingredients. And I get it, a feeling before the person verbalises it I anticipate it, I can feel something's about to emerge.

Interviewer - So would you partly attribute it to your relationship?

Participant - I think it's due to the therapeutic relationship, I think it's due to being sensitive. It's very hard to describe without sounding weird. I... you nearly get a sixth sense about something's about to happen before the client says it. You kind of have a sense of knowing what it might be, you can nearly feel it prior to them saying so it doesn't come as a surprise.

Interviewer - So taking the same example did you... what changed then between you and the client or for the client in the long or the short term? Did things change after that?
Participant - She was very positive about what had happened. I was very pleased for her, because I was very worried because she used to dissociate so it was a real risk. But once I started watching how she was I knew it was the right way, I knew it was going to be ok. I knew it was going to be fine. So there was a sense where we dealt with loads of things and she felt very confident. She felt very positive towards me most of the time anyway, so she felt very confident about things being dealt with. I mean I’ve since tried to discharge her and she finds that quite difficult actually because of the length of the relationship and the intensity of it.

Interviewer - How long ago was the moment?

Participant - It was in the past year.

Interviewer - So have things felt different since then?

Participant - Yes, we had a real sense of... I mean on a very practical level we didn’t have to deal with that stuff anymore. It just wasn’t there anymore. It had gone. So we were actually just starting to deal with more of the day to day, here and now stuff. Which was again stuff related to experiences that she’d had in the past, but it was no longer these horrific intrusions, this constant fear.

Interviewer - And did your relationship with her change or was it more the content of the sessions?

Participant - No I think my relationship had been so long established. She trusted me I suppose a lot. I was very clear to her about the risks we were taking doing this and I suppose maybe I was kind of pleased that it had happened and that it was ok. I don’t think she trusted me more as a result of it. I don’t think... I was just pleased for her. And there
was a part of me where I felt it would work, I suppose I felt it would work, but there was a part of me that was credit to her if you like. In some ways she surprised me a little bit in what she was able to do in that moment. I was kid of 'good for you, this is really good' yeah.

Interviewer - So taking both that moment and the intense moment with the Rwandan client, would you say that with those kind of moments you take something from that which you can generalise to other therapeutic work or is it restricted to that particular client?

Participant - No I think you do generalise it. I think it's about an extensive range of possibilities with people which you nearly begin to superimpose on other people you see. So, I'm always of the view that there's potentially more there for the individual that they could utilise. So even with people who are very limited or with long term problems with mental health services, that kind of thing, I kind of think well actually there's loads going on at the back that neither you or I can access at the moment, but it'll come out when it's the right time. And I suppose it gives me a real confidence about the power of the individual's mind. So I can relax often in therapy because of that. Because I know that will come into action and you know it is something that will catch both of us unawares at times.

Interviewer - And would you say those moments generalise to effect your life even beyond your work?

Participant - Yeah I suppose they do. I do... I notice people a lot. I notice people who maybe aren't noticed by others. I do find myself sometimes - this is more my imagination - constructing things about people that I see based on things that I might have heard or experienced. And I suppose I do feel you never know with people actually, you never judge people just by how they are, how they appear, there's kind of boundless possibilities with everybody that I meet actually and that can be quite exhausting at times, knowing that, so sometimes I switch that off, but other times... a lot of the time it's actually really nice because you do see things in people that... and it's really nice. An appreciation of people really, valuing of people. I suppose I'm less inclined to take just the face value of people and just
you know it’s good to know that there’s that level going on in people’s minds, with all these things that people have experienced and they’ve coped with. It’s a kind of resource generally I think, so it’s quite a positive feeling really.
Major Research Project

The experience of dual diagnosis in learning disability:
An exploratory IPA study of people with a learning disability and their core family members

July 2008

Year 3
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Abstract

The current study aimed to elicit and explore the experiences of four people with a dual diagnosis of a significant learning disability and a psychotic illness and the experiences of two of their core family members. The accounts were elicited through the use of semi-structured interviews and analysed using a qualitative methodology named Interpretative Phenomenological Analysis (IPA). The accounts of experience were analysed in family cases. A number of themes arose for each family which broadly touched on the experience, understanding and interplay of learning disability and psychosis, the onset and course of the psychotic illness, coping and adaptation, the effect on individuals and relationships within the family and experiences of and relationships with services. A discussion of the similarities and differences across the accounts of the four families is also given in relation to three common themes of understanding of and relationship to learning disability and psychosis, involvement of and impact on family members and service related issues. These themes were discussed in relation to psychological theory and research. A number of clinical, research and service implications are identified. The clinical implications include suggestions for the use of a conceptual framework for integrating the myriad of factors that impact on the experience of dual diagnosis of learning disability and psychosis and the incorporation of more holistic models of understanding and working with psychotic experiences, as have been espoused in work with the general adult mental health population. A number of service implications are identified which pertain to the importance of transparency and information sharing between services, service users and family members and the importance of identifying, eliciting and responding to the needs of families who are affected by dual diagnosis. The limitations of the current research study and a number of dilemmas faced by the researcher in conducting this research are discussed and subsequent recommendations for further qualitative research in this area are made in order to further enhance our understanding of the experiences of families affected by a dual diagnosis of a significant learning disability and psychosis.
The experience of dual diagnosis in learning disability: An exploratory IPA study of people with a learning disability and their core family members

1.0 Introduction

This section aims to outline the salient research literature linked to the current research project, including learning disability and mental health and the needs and experiences of family members. The need for an exploratory qualitative research project is highlighted, followed by the aims of the current study.

1.1 Learning disability and mental health

1.1.1 The incidence and prevalence of mental health difficulties in people with a learning disability

Until relatively recently, the area of mental health problems in people with a learning disability had been largely neglected by professionals and researchers (Hatton, Hastings & Vetere, 1999). The overall prevalence\textsuperscript{5} of mental health problems in people with learning disabilities appears to be greater than in the general population, though there are inconsistencies in the prevalence rates reported. Quantitative studies of people with learning disabilities using psychiatric assessments to identify cases tend to report prevalence estimates between 25 - 40\% (for example, Iverson & Fox, 1989). Similarly, there are varying prevalence estimates for the presence of specific disorders, such as psychosis in people with learning disabilities. Haddock, Lobban, Halton and Carson (2004) note that a number of studies have highlighted an increased prevalence of psychosis in learning disabled populations (see Turner, 1989 for a review) and some studies have reported that schizophrenia is twice as common in people with a learning disability than in general populations (Lund et al, 1985; Reiss, 1994). Caine and Hatton (in Emerson, Hatton, Bromley

\textsuperscript{5} Prevalence is defined as the number of cases, old and new, existing in a population at a given point in time or over a specified period (Richardson & Koller, 1985, cited in Emerson, Hatton, Bromley & Caine, 1998).
& Caine, 1998) state that there are differences in the distribution of disorders in populations of people with learning disabilities, with increased rates of conditions such as autism and psychosis rather than mood or anxiety disorders and substance misuse. Higher rates of mental health difficulties have been observed in people with significant rather than severe learning disabilities (Borthwick-Duffy & Eymon, 1990; Bouras & Drummond, 1992; Jacobson, 1990).

There are a number of obstacles to the valid and reliable identification of mental health problems in people with learning disabilities (Moss, 1995). Firstly, the applicability of standardised diagnoses as delineated within the main diagnostic classification systems such as the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV, American Psychiatric Association (APA), 1994) and the International Classification of Diseases Version Ten (ICD-10), World Health Organisation (WHO), 1993) to people with learning disabilities is questionable and as yet untested (Hatton, 2002).

In view of such difficulties, diagnostic criteria for psychiatric disorders as they present in adults with learning disabilities was developed (the DC-LD, Royal College of Psychiatrists, 2001) which was based on the consensus of diagnostic practices of learning disability psychiatrists in the United Kingdom (UK). However, even with this manual, difficulties in the diagnostic classification of mental health problems may still exist. People with learning disabilities may display clear psychotic symptoms but not a range of symptoms that would warrant a diagnosis of schizophrenia (Moss, Prosser & Goldberg, 1996). Moreover, the classification and diagnosis of mental health problems is largely dependent upon a description of mental state. This may be particularly difficult for people with perhaps more severe learning disabilities who may find it difficult or be unable to verbalise their internal experience. There is also widespread difficulty with diagnostic overshadowing (Reiss, 1994, 2000) in which the symptoms of mental illness may be attributed by carers or those around the person to their learning disability. For example, poor self-care which is often associated with psychosis may be attributed to a person being unable to care for themselves because of their learning disability (Caine & Hatton, 1998). However, there is research evidence to suggest that people with a significant learning disability (British Psychological Society, 2000a) can give descriptions of their mental state.
and experiences as long as interview schedules are sensitively adapted to their needs (Moss, Prosser, Ibbotson & Goldberg, 1996) which can contribute to the accurate understanding of the mental health needs of people with learning disabilities.

1.1.2 The experience of psychosis in people with learning disabilities and the wider population

There is a small body of literature emerging exploring the use of therapeutic interventions for people with a dual diagnosis of a learning disability and psychosis (Haddock, Lobban, Halton & Carson, 2004), but a relative paucity of literature and research pertaining to the qualitative experiences of such people. Within the adult mental health literature, there is a growing body of research exploring individual's experiences of psychosis and recovery from psychosis (e.g. Davidson, 2003). Furthermore, the British Psychological Society (BPS, 2000b) recently published guidance on new ways of approaching and understanding mental illness and psychotic experiences which acknowledges these experiences as relatively commonplace and espouses the view of a continuum between mental health and mental illness. Clinical psychologists are encouraged to adopt a more holistic approach to treatment in which the service user and clinician develop a collaborative relationship that respects the individual's own understanding of their experiences. The report represents a shift away from the traditional psychiatric model of such experiences to encompass issues of diversity pertaining to the experience of psychosis, however, the same ethos and enthusiasm has not yet penetrated the literature or services for people with learning disabilities.

In summary, there is evidence to suggest that the incidence and prevalence of mental health problems such as psychosis may be greater in populations of people with learning disabilities than in the general population. The majority of studies in the area of learning disability and mental health have employed quantitative methodologies to estimate the prevalence of mental health problems in this area rather than qualitative studies looking at the experience of mental health problems. There are a number of qualitative research studies with people with learning disabilities emerging which look at difficult experiences such as trauma (Mitchell, Clegg & Furniss, 2006) which demonstrate that this may be a fruitful form of research exploration with people with learning disabilities. Furthermore, there is an established research interest in the qualitative experience of psychosis in populations of
people who do not have a learning disability though this interest has not yet permeated the learning disability field. Therefore, qualitative research looking at the experiences of people with a learning disability with a diagnosis of a psychotic illness may be both warranted and useful.

1.2 The extent of family research within the learning disability literature

1.2.1 Setting the scene: The rationale for researching the family context and experiences of family members of people with a learning disability

The needs and experiences of the family members of people with a learning disability are becoming ever more visible and a primary focus for health and social care professionals and policy makers (Twigg & Atkin, 1994). The 1971 government white paper ‘Better Services for the Mentally Handicapped’ (1971, Department of Health) first acknowledged the needs of carers by emphasising the importance of respite care. This was built upon in the Carers (Recognition and Services) Act (Department of Health, 1995) in which the needs of carers became an exclusive focus for policy which reflected the growing recognition that carers had needs independent of the people they cared for (Department of Health, 1995; Nolan, Grant & Keady 1996; Todd & Jones, 2003). More specifically, Valuing People (Department of Health, 2001) and Valuing People Now (Department of Health, 2007) recognises the input and commitment of family members to supporting their relative(s) with a learning disability. Grant and Ramcharan (2001) recommend listening to the first-hand accounts of people with learning disabilities and their families members about their needs. The current study aims to contribute to an understanding of the needs and experiences of people with a learning disability and their family members by elucidating their accounts of what it is like to support a relative with a learning disability and a psychotic illness.

1.2.2 The importance of a systemic approach to understanding the needs and experiences of people with a learning disability and their family members

Given the influence and involvement of family members and wider support networks in the lives of people with learning disabilities, a systemic approach to
understanding and researching the lives of people with learning disabilities and their family members may be potentially useful. There are a number of definitions of what is encompassed within a systemic approach, though the Kensington Consultation Centre (KCC, 2004) states that "the systemic approach explores the networks of significant relationships of which each individual is part, considering the beliefs that give meaning to people's actions and the communication patterns between people as they interact with each other and each other's ideas" (p.4). Grant and Ramcharan (2001) espouse the need for further research which elucidates the views of service users and carers in relation to experiences of family life. They also suggest that a family systems framework may provide a useful structure for the integration and connection of individual, dyadic and family-wide perspectives. The combination of a social constructionist and systemic lens may be potentially useful in beginning to elicit and explore the accounts of experience in relation to learning disability, psychosis and families.

1.2.3 The extent of family research within the learning disability literature

There is a paucity of specifically systemic family research in the field of learning disabilities. Baum (2006) notes that until relatively recently, scant attention has been paid to the families of people with learning disabilities. The majority of the family research to date within the field of learning disabilities has tended to focus on young children and their parents rather than adults with a learning disability and their families. It is difficult to extrapolate and generalise the findings of research with children to adults with learning disabilities and their families. The research has also prioritised the voice of the mother to the exclusion of other gender and kinship ties and the views of the individual with a learning disability has tended to remain on the periphery (Grant & Ramcharan, 2001). Grant and Ramcharan draw on family and social systems theories to highlight a need for research which focuses on family interaction and adaptation that also takes account of wider social, cultural, economic and support systems. Overall, there has been a relatively narrow focus in the family research literature in the field of learning disabilities which means that there is a lack of a unified family research model in the field of learning disabilities (Vetere, 1993). This is particularly problematic in view of the fact that when asked about service provision, families often say that they would value a coordinated approach that took into consideration the needs of the whole family (Mitchell & Sloper, 2000).
The value of systemic family research with other populations suggests that this approach could be useful for people with learning disabilities and their families (Baum, 2006). Family research in learning disabilities to date has focused on three main areas: stress, coping and siblings (Baum, 2006). Baum highlights a number of areas within the learning disability field that would lend themselves to a systemic framework and be worthy of exploration in this way. These include transitions in the family lifecycle and relationships with the wider systems (e.g. professional and healthcare networks). Issues of transition have been extensively explored in the learning disability literature but rarely within a systemic framework. A new diagnosis of a mental health problem such as psychosis is an example of one of the changes and issues that people with learning disabilities and their families may have to face. Interestingly, to date, there is no published literature exploring the experiences of a person with a learning disability and/or their family members who have received a diagnosis of a psychotic illness. Therefore, the current research project aims to explore the experiences of people with a learning disability and their families who have received an additional diagnosis of a psychotic illness within a systemic framework.

1.2.4 The experience of family members

There is a substantial body of research exploring the value and use of family interventions in helping people in the general population who experience psychosis (Gorrell Barnes, 1998; Leff, 1998; Carr, 2006). Unfortunately, it seems that the emphasis on the role and importance of families and family work may not be mirrored in learning disability services or literature. Dallos, Neale and Strouthos (1997) highlight that until recently, there have been few attempts to explore the perspective of the family from the 'inside' on what it is like to live with a mental health problem. There is a small body of research using qualitative methods detailing the variety of experiences for family members living with a relative or partner with a mental health problem such as schizophrenia who do not have a learning disability (Saunders & Byrne, 2002; Jungbauer, Wittmund, Dietrich & Angermeyer, 2004). However, it may not be possible to extrapolate understandings from this population of people to try and understand the experiences of relatives of people with a dual diagnosis of learning disability and a psychotic illness. This means that there is an opening within the
literature for research which explores the experiences of the relatives of people with a dual diagnosis of a learning disability and a mental health problem.

1.2.5 Stress, coping, adaptation and resilience

Early research had tended to assume that the families of people with learning disabilities were subject to high levels of stress (Kew, 1975) though such studies were open to methodological criticism related to the assumptions of homogeneity among families (Baum, 2006). Later approaches to the study of stress in families acknowledged that stress would change over the course of the lifecycle and was related to a number of factors such as structure of the family, family stressors and the material, social and psychological resources available to the family (Baum, 2006). Research has attempted to specify the factors that may facilitate coping including: problem-solving skills, high income, emotional and physical well-being, social support networks, marital satisfaction and good working relationships with services (Baum, 2006). There is an emerging body of research on the factors that facilitate coping and adaptation in various kinship groups (Cuskelley & Gunn, 2003; Giallo & Gavida-Payne, 2006). Linked to models of coping and adaptation, there is a growing interest in resilience and non-deficit models of family functioning (Hawley & DeHaan, 1996). This research has suggested that families can 'bounce back' from challenging situations and that they may have a variety of resources and skills to equip them for coping with difficult situations (Quine & Pahl, 1991; Snowdon, Cameron & Dunham, 1994). Grant and Ramcharan (2001) underline the need for a shift from research which emphasises stress to a focus on the nature of resilience, expertise and factors that facilitate coping among family carers (Hawley & DeHaan, 1996). Such research should take account of the contextual factors surrounding such accounts, such as gender, kinship, ethnicity, life stage and service context (Grant & Ramcharan, 2001). Therefore, it is important to examine the strengths, resources and factors that facilitate coping in people with learning disabilities and their family members who face challenging situations such as those brought by psychotic experiences.

1.3 The service context

1.3.1 The mental health service context in relation to people with learning disabilities
Access to health services may be difficult for some people with a learning disability. People with learning disabilities may face a number of challenges when accessing healthcare. They often have greater health needs than the general population, yet use health services disproportionately less than other people (Marsham & Poyner, 2007). There are a number of other barriers which may make it difficult for people with learning disabilities to access healthcare, such as the way services are organised and designed, the discriminatory attitudes of healthcare workers and the lack of information in easy-to-understand formats (Marsham & Poyner, 2007). These difficulties have been recognised in Valuing People which espouses a commitment to enabling people with learning disabilities to access and benefit from high quality, consistent healthcare (Department of Health, 2001) and remain a priority in Valuing People Now (Department of Health, 2007).

The historical neglect of the mental health needs of people with learning disabilities has resulted in somewhat inconsistent and often inadequate mental health service provision for people with learning disabilities (Day, 1994; Patel, Goldberg & Moss, 1993). The separation of mental health and learning disability services may have hindered the integrated training of health professionals in the assessment and treatment of mental health problems in people with learning disabilities in some services (Day, 1994). A number of policy frameworks and reports have been developed which outline good practice (Foundation for People with Learning Disabilities, 2007) and delineate a service structure for health and mental health services for people with learning disabilities (Mansell, 1992; Department of Health, 2007).

1.3.2 The involvement of services to support family members and carers

Family members who may act as carers for their relative with a learning disability are seen as both consumers and providers in the delivery of care. People with learning disabilities and their families are often drawn into a complex professional network of care (MacLachlan, Dennis, Lang, Charnock & Osman, 1987; Todd & Jones, 2003). Services have generally been slow to respond to the emotional needs of people with a learning disability and their families (Baum, 2006). The literature on stress in families with a member with a learning disability suggests that unmet local service needs are a source of stress for many
parents (Byrne & Cunningham, 1985). Furthermore, uncoordinated services that do not consider the needs of the whole family have also been identified as a source of stress (Mitchell & Sloper, 2000). As with research in the stress and coping literature, professionals have been criticised for adopting a deficit model of family functioning and failing to recognise the strengths of individual family members and of the family unit more generally (Knox, Parmenter, Atkinson & Yazbeck, 2000; Grant & Whittell, 2000; Blacher & Hatton, 2001).

Service provision may be further complicated as there is currently no standardised service model in the UK for people with learning disabilities and mental health problems. Liaison between learning disability and mental health services is recommended (Mansell, 1992, 2007) in order to facilitate a collaborative system of care for people with learning disabilities. However, the literature conveys that there is a sense of confusion about the overlap between learning disability and mental health from both family members (Faust, 2003) and service providers (Scior & Grierson, 2004). Grant and Ramcharan (2001) highlight the relative paucity of UK studies examining the experience and effectiveness of service models and service interventions from a family perspective. It is feasible to suggest that eliciting the accounts of individuals with a learning disability and their family members about their experiences of and relationships to services in a local context may begin to highlight key areas of further exploration.

1.4 Conclusions and summary of research aims

In summary, there are a number of reasons why the current research study may be important and able to contribute to knowledge and understanding in the fields of learning disability, mental health and families. Firstly, people with learning disabilities may be at an increased risk of developing a mental health problem. Though there is a substantial body of literature on dual diagnosis in learning disability (O'Brien, 2002), the majority of this is quantitative in nature and there is a relative paucity of qualitative research exploring the experiences of people with a learning disability facing an additional diagnosis of a mental health problem. Secondly, the needs and experiences of the family members of people with a learning disability have been highlighted as a priority in government policy initiatives and frameworks. Despite this, Baum (2006) has noted that scant attention has been paid to the
needs, views and experiences of people with a learning disability and their families at both service and research levels. Moreover, Grant and Whittell (2000) highlight that there have been repeated calls for research that explores how families manage as they go through life-cycle transitions and adapt to changes that present over the course of caring for a person with a learning disability. The onset and development of a psychotic illness may be considered to represent a transition in the lifecycle of both the individual with a learning disability and of family members that is worthy of study in its own right. Therefore, there is an opening in the literature for research into the experiences of individuals with a learning disability and their families in how they understand and attach meaning to an additional diagnosis of a mental health problem such as psychosis. The current exploratory study aims to explore the experiences of people with a learning disability who have an additional diagnosis of a psychotic illness and to explore the experiences of core family members whose relative with a learning disability has received an additional diagnosis of a psychotic illness.
2.0 Method

This section aims to delineate the epistemological assumptions underpinning this piece of qualitative research and the steps involved in the analytic process of Interpretative Phenomenological Analysis (IPA). This section also outlines the procedure adopted at each stage of the research process and describes the sample of participants.

2.1 Rationale for the research methodology

2.1.1 The epistemological assumptions underpinning qualitative research

In any research endeavour, it is important to have a clear understanding of the epistemological position from which the research is approached. The main epistemological position underpinning the methodology was based on a social constructionist approach. This approach lends itself particularly well to qualitative research methodologies which tend to be concerned with an in-depth understanding of people’s experiences. Qualitative methodologies are concerned with the relationship that people have with their experiences and the way that they attribute meaning to such experiences. The emphasis on depth rather than breadth means that qualitative methodologies are particularly useful for the exploration of topics which have not previously been extensively researched as they allow for the generation of new theoretical understandings (Turpin et al, 1997). Research from a social constructionist position acknowledges the interaction between a ‘researcher’ and a ‘participant’ and therefore considered the process and product of research to be co-constructed (Burr, 1995; Willig, 2001).

In view of the epistemological position adopted and the nature of the research question, a qualitative method called Interpretative Phenomenological Analysis (IPA) was adopted for the analysis of the data. IPA was developed by Jonathan Smith (1996) and is concerned with trying to understand the lived experience of people and how they attribute meaning to and make sense of those specific experiences. There are three theoretical tenets underpinning IPA. Firstly, IPA is phenomenological in that the emphasis is on the exploration of individual’s personal perceptions and accounts of certain experiences as
opposed to trying to objectively measure or capture a record of an event or experience. Secondly, the interpretative element of IPA is informed by theories of hermeneutics (Heidegger, cited in Smith, 2008) and symbolic interactionism (Smith, 1996). IPA employs a double hermeneutic in that the researcher attempts to make sense of the participants sense-making processes. The interpretative element of IPA recognizes that the conceptions and ideas of the researcher will also form a part of the account of the person’s experiences which occurs naturally as part of the interpretative process. This was particularly important given my strong interest in this area. Symbolic interactionism places emphasis on the meanings that people ascribe to their experiences but acknowledges that those meanings are obtained through a recursive interactional process that occurs within a social context.

2.1.2 Outlining the position of the researcher

The delineation of the position and perspective of the researcher is a key factor in ensuring the quality of qualitative research (Elliott, Fischer & Rennie, 1999; Yardley, 2000). Fielding (1996) states that a qualitative research study is only useful if the researcher is reflexive regarding his/her influence. The researcher’s motivation for conducting the current study arose from personal observations, reflections and reactions to working with people with a learning disability and a psychotic illness. This interest developed whilst conducting some psychoeducational work to help people with learning disabilities understand the nature of mental health problems and the diagnosis that had been assigned to them. An interest developed about the ways that this was explained to them and how this impacted on their understanding of their experiences.

Part of the psychoeducational work also involved liaising with and gaining feedback from the family members of people with learning disabilities and a mental health problem to elicit their ideas, views and perspectives on the factors that may both facilitate and deplete the health and well-being of their family member. The work highlighted the importance of taking a systemic perspective and listening to the accounts of family members. Both the systemic tradition and social constructionist theory are key tenets underpinning the current research study.
2.2 Procedure

2.2.1 Ethical approval

A favourable ethical opinion was granted by the Kings College Hospitals (KCH) Research Ethics Committee and the Faculty of Arts and Human Sciences Ethics Committee (FAHS EC) at the University of Surrey. The Research and Development panel of the NHS Trust within which the research was conducted also gave approval for the study. See appendix 1 for ethics documentation.

2.2.2 Inclusion and exclusion criteria

There were a number of inclusion and exclusion criteria for participants which are delineated in the table below. The reasons underpinning the inclusion and exclusion criteria are explained in brackets.

Table 1: Inclusion and exclusion criteria for participants

<table>
<thead>
<tr>
<th>Participants with a learning disability</th>
<th>Inclusion Criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Significant learning disability</td>
<td>• Comorbid diagnoses of developmental disorder (e.g. autism) or other mental health problem (to be able to fully investigate the dual diagnosis of learning disability and psychosis)</td>
<td></td>
</tr>
<tr>
<td>• Received a diagnosis of a psychotic illness within the past five years (five-year time frame intended to open up the pool of participants and consider changes over time)</td>
<td>• Currently under Section of the Mental Health Act (so that there were no factors complicating consent conditions)</td>
<td></td>
</tr>
<tr>
<td>• Aged between 18-50 (to ensure still under the care of the learning disability service and still had living family members)</td>
<td>• Interview not to be conducted in participants home if there was a history of violent or sexually inappropriate behaviour (to protect the researcher)</td>
<td></td>
</tr>
<tr>
<td>• Contact with family members (to enable participants to reflect on experiences, involvement and perceptions of family members)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
It should be noted that two participants were included that met the criteria for exclusion from the study as they had additional diagnoses other than a learning disability and psychosis. Further consideration of the implications of this decision are included in the discussion.

2.2.3 Piloting the interview schedules

A pilot case was used prior to beginning the main process of data collection to try out the research process that had been formulated and to test the effectiveness of the materials conveying information to potential participants. A number of small changes were made to the materials following the pilot, for example, the word ‘research’ was used consistently rather than using the terms ‘research and ‘study’ interchangeably as in the previous versions. A rich volume of data was generated which could be usefully incorporated into the study, therefore, the pilot case was included as one of the main case studies.
2.2.4 Consultation with service-user groups

A process of consultation with a service user group and the Communications and Access Officer of the learning disability service was used in developing the materials in order to improve the accessibility of the materials. Small changes were made to the materials following the consultation process.

2.2.5 Materials

Two versions of the information sheet (appendices 3 & 4) and consent form (appendices 5 & 6) were developed, one for participants with a learning disability and one for family members. The information sheets and consent forms were developed in accordance with guidance from the KCH ethics committee about essential information to include in such materials. All materials such as information sheets and interview schedules were adapted to reflect the communication and comprehension capabilities and difficulties of the individual participants. The information sheet and consent form for the participants with a learning disability were adapted to include larger text, simpler language and include photographs (e.g. of myself as the researcher who conducted the interview) and pictures to facilitate understanding. All materials were checked and approved by the field supervisor who is a Chartered Clinical Psychologist who has worked within the field of learning disabilities for approximately four years.

2.2.6 Interview schedules

Semi-structured interviews were used as this is a common data collection tool in IPA (Smith, 2008). The interview schedules (appendices 7 and 8) were developed from a review of the literature pertaining to salient issues within the fields of learning disability, mental health and family systems. From this, the main sections of the interview schedule were organised around: coping and adaptation, the individual's understanding of what had happened to them, systemic perspective taking to elicit the views of the interviewee about the perspectives of other family members, the impact on relationships within the family and relationships with healthcare professionals and wider systems. The main areas of exploration were mapped on to each interview schedule to ensure consistency across interview schedules. There were some differences in the ordering and wording of questions.
between the two versions of the interview schedule. This is considered further in the
discussion. In addition, the researcher met with the consultant psychiatrist of the learning
disability service in which the research was being conducted to gather some background
information about the service context and to discuss mental health issues in people with
learning disabilities (see appendix 9 for summary).

2.2.7 Identifying participants

The research was conducted within a large area covered by one NHS community
learning disability team for people with learning disabilities. All participants were patients
of the Consultant Psychiatrist within the CTPLD. The Consultant was informed of the
inclusion and exclusion criteria to enable the identification of potential participants and once
identified, potential participants were selected by looking through files and checking
inclusion and exclusion criteria again. Of the 24 people identified by the Consultant
Psychiatrist and Clinical Psychologist, six were unsuitable in terms of the exclusion criteria,
it was not possible to contact four, five were not contacted either due to insufficient contact
information or the number of participants required had been reached and three declined to
take part, six agreed to take part, of which four were interviewed and another two were not
included as the number of participants had been reached.

Further on in the research process, it became difficult to maintain regular contact
with the Consultant Psychiatrist due to his work demands. This added significant pressure
to the recruitment process. Therefore, in consultation with the supervisors of the study, it
was agreed that access to information about potential participants would be provided
through the psychology service in the CTPLD. A letter of amendment was sent to the Chair
of the KCH REC (appendix 2).

2.2.8 Contacting participants

Once the participants had been identified, they were contacted either directly or
through their main carer and told some information about the study and asked whether they
would like to receive further information about the study. If the participant agreed, the
information sheet was sent and the researcher arranged a time to contact them once they had read the information. Each participant with a learning disability was visited and able to ask questions to clarify the process of the study and invited to take part. Once the person had agreed to take part in the study, consent was assessed using the framework outlined in section 2.2.9. A consent form was signed by both the participant and researcher.

Following this, the person was asked to identify two family members who they viewed as particularly important to them and consent to contact them was obtained. Family members were contacted and informed that their relative had agreed to take part in a research study. The study was explained to the family members and the participant information sheet sent out if the family members agreed. A time to contact the family members was arranged and they were offered the opportunity to ask any questions and invited to take part in the study. If the family members were willing to take part, they were sent consent forms and asked to return them. If family members consented to take part, the interview process then began. Therefore, the individual with a learning disability was not interviewed unless their family members had consented.

2.2.9 Gaining consent

Though consent was assessed at a number of points throughout the research process, consent was formally assessed using the framework outlined by Arscott, Dagnan and Kroese (1998). The authors outlined questions that can be used to assess the extent to which an individual is able to give informed consent to take part in research. The questions were adapted for use in this study, but adhere to the criteria espoused by the authors. The following questions were asked to each participant with a learning disability: what will we be doing together?; how long will it take?; what are the good things about taking part?; what can you do if you decide you don't want to take part anymore?

The questions were asked after the information on the information sheet had been explained to the individual. If the individual was unable to answer all four questions correctly first time, the relevant information was explained to them again. The questions were then repeated, up to five times if necessary. People were excluded if they were unable
to provide the correct answers to after this procedure. No participants were excluded on this basis as all were able to remember the purpose of the meeting and answer the consent questions, though three participants required the process to be explained to them on the day of the interview after which they were able to answer the consent questions. One participant answered all questions correctly without requiring further explanation.

2.2.10 Procedure for further support

Due to the sensitive nature of the topics being discussed, it was necessary to have comprehensive procedures in place for participants that may have required further help or support. Indeed, it is acknowledged that the discussion of sensitive issues may lead to distress for participants (McCarthy, 1998). All participants (identified service user and family members) were informed via the information sheet that they could be signposted to suitable organisations for further help and support if required. One family member (a participant) became upset during the interview and was offered the opportunity to move on to another area or to terminate the interview. The family member declined and opted to continue with the interview and declined information about further sources of support.

2.2.11 Procedure for disclosure of potential risk issues

Procedures for dealing with risk disclosures (e.g. abuse or other risk situation) were planned prior to any interviews being conducted. In setting out the confidentiality conditions at the beginning of each interview, all participants were told that should they disclose information pertaining to risk of harm to themselves or to others, the interview would be terminated and relevant information would be disclosed to the field supervisor. Procedures would then be put in place for their protection or the protection of others which would be dependent upon the nature of the disclosure. No disclosures from any of the participants were made which raised a significant risk issue.

2.2.12 Interview administration

Ten interviews were conducted in participant’s homes where they felt most comfortable as no risk issues were identified. Two interviews with family member
participants were conducted over the telephone. The reasons for and implications of this are considered further in the discussion. All interviews were conducted on a one to one basis with no other person(s) present. All interviews were recorded.

2.2.13 Analysis of the data

The interviews with participants were recorded and transcribed verbatim. The transcripts were analysed using the IPA procedure outlined in Smith, Jarman and Osborn (1999) and Smith and Osborn (2008). Initially, the transcripts were read and re-read in order to gain an in-depth holistic understanding of the participant’s account. Unfocused notes, including ideas, thoughts and associations were noted in the left-hand margin. Following this, conceptual themes were developed which pooled the unfocused notes together. The themes were labeled which aimed to “capture something about the essential quality of what is represented in the text” (Willig, 2001, p.55). The themes which had previously been ordered chronologically in relation to their emergence in the transcript were then listed and clustered depending on the connections between them at a more theoretical level. At this stage, it was important to refer back to the original transcript to ensure that the clustering themes fit with the actual words of the participant. This was an iterative analytic process which required a strong connection between the accounts of experience provided in the transcripts and my own interpretative resources. As part of the clustering process, a directory of extracts from the transcript to support each cluster of themes was compiled. A table of clustered themes was then produced with a view to assigning an overarching label to the clusters to develop superordinate themes with related subordinate themes. The location of extracts from the transcripts was mapped onto the table of themes to support the superordinate and subordinate themes that had emerged (see appendices 10-13).

The transcript of the person with a learning disability in each family was analysed first followed by the transcripts of each family member in the family case. Smith and Osborn (2008) identify two ways of continuing the analysis with other cases. The approach selected for the analysis of subsequent transcripts was to use the table of themes identified from the first transcript to guide the analysis of other transcripts within each family case. It was important to both remain aware of the themes that had already emerged and be open to new
information and emerging themes in subsequent transcripts. New themes were added to the table of themes and the previous transcripts were also analysed in the light of the new themes that emerged to search for evidence of the new themes in the previously analysed transcripts. This process was completed for each family case.

Though it would have been possible to analyse the data across the whole sample of participants, the decision was made to analyse the data in family cases; that is, to conduct one IPA for each family case. There were a number of reasons underpinning this decision. Firstly, the analysis of the data in family cases was concordant with the systemic theoretical lens that underpinned the research and which had been clearly mapped out throughout the report. The unique experience of the family unit was identified as an important area of exploration and the analysis of data in family cases enabled the research to maintain a focus on the in-depth experience of families and to pay attention to issues of pattern, process, relationship and connection which are important themes in systemically-orientated research (Gehart, Ratliff & Randall, 2001). The context surrounding the dual diagnosis of learning disability and psychosis was clearly delineated for each family to enable the reader to interpret and evaluate the analysis of each family case in view of the individual contexts surrounding the families. The transparency in delineating the context around each of the families was intended to enable the reader to position themselves in relation to the research and such transparency is also a way of ensuring the quality and ‘trustworthiness’ of qualitative research (Fielding, 1996). As systemic theory postulates, no family is the same and analysing the data in family cases rather than across the whole group was intended to protect against making assumptions about the structure, nature and experiences of families. Analysis of the data in family cases was deemed to be the most appropriate, particularly in view of the fact that the participants were not a homogeneous group and participants were of varying kinship connections.

Due to restrictions on word length and the need to convey the most salient themes that represented the experiences of each family, not all themes were selected for inclusion in the main analysis section. The other themes are included in appendices 14-17.
2.2.14 Feedback to participants

Although a feedback session to all participants was planned to share the findings of the analysis and elicit feedback, this was not possible due to time constraints. At the time of submission of the study, credibility checks were still in progress and a presentation to the service in which the research was conducted was planned.

2.3 Description of the sample

The participants as part of each family case are described below. All details pertaining to the identity of the client and services have been changed to preserve anonymity and confidentiality. A genogram has been used to delineate the structure of the family unit and the relationships between each family member. Family members who were not interviewed are included in the genogram, though no identifying information is given.

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Genogram key: circle: indicates a female; square: indicates a male; horizontal line: delineates horizontal connection between people of the same generation, e.g. by marriage; vertical line: delineates vertical connection between people of different generations, e.g. to denote connection between parents and children; cross: indicates death of a male or female.
2.3.1 The Foley Family

Figure 1: Genogram of the Foley family

Simon lived with his family at the time of the initial onset of the psychotic symptoms and spent a period of time as an inpatient in an Assessment and Treatment Unit (ATU). Simon lived in supported living accommodation at the time of participation in the research and had regular contact with his family. The schizophrenia was managed primarily with medication.
2.3.2  *The Williams Family*

Figure 2: Genogram of the Williams family

---

Rebecca was living at home with her mother and father at the time of the initial onset of psychotic symptoms and had a period of inpatient care at an ATU (though was no longer under Section) which she resided at during her involvement in the research. Rebecca was on medication at the time of taking part in the study.
2.3.3 The Harrison Family

Figure 3: Genogram of the Harrison family

Matthew lived with a family as part of an adult placement scheme at the time of initial onset of the psychotic symptoms. Matthew lived in a residential home for people with learning disabilities at the time of his participation in the research study. The psychotic illness was managed primarily with medication.
2.3.4 The Jayawardene Family

Figure 4: Genogram of the Jayawardene family

Tamara Jayawardene
(51)
Asian British Female
(Sri Lankan origin)
Diagnosis of mild learning disability and paranoid schizophrenia (for a number of years)

Geoffrey Jayawardene
(49)
Asian British Male (Sri Lankan origin)
Brother of Tamara Jayawardene

Victoria Jayawardene
Asian British Female
(Sri Lankan origin)
Sister of Tamara Jayawardene

Tamara lived in a residential care home though had previously lived in a large long-stay hospital for people with learning disabilities until it closed. The schizophrenia was managed with medication.
3.0 Analysis

This section conveys the salient themes arising from the IPA of the interview transcripts in each family case.

3.1 Findings arising from the analysis of each family case

Further background information about the participants from each family is given in the method section. The superordinate and subordinate themes from the analysis of each family case are presented. It has only been possible to present a selection of the themes that emerged for each family case. This was partly due to the restrictions on word length but mainly to convey the most salient themes for each family. The presented themes were judged to best encapsulate the experiences of each family. The process of prioritising and selecting themes was strongly informed by the interpretative lens of the researcher which was influenced by liaising with each participant and family and engaging at an in-depth level with the interview transcripts. An explanation of the reasons for presenting each theme is given below the table of themes for each family. The analysis is also punctuated by reflection boxes which form part of the interpretative aspect of the IPA in delineating the processes that underpinned some of the decisions made throughout the analysis, e.g. in relation to some of the interpretations of the text that have been made.

3.1.1 The Foley Family

The superordinate and subordinate themes that emerged from the analysis of the transcripts of each member of the Foley family are delineated below:
Table 2: Table of superordinate and subordinate themes emerging from the IPA of interview transcripts from three members of the Foley family

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subordinate themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Course of illness</td>
<td>• Insidious onset and nature</td>
</tr>
<tr>
<td></td>
<td>• Gradual development</td>
</tr>
<tr>
<td>Searching for an explanation</td>
<td>• Diagnostic overshadowing</td>
</tr>
<tr>
<td></td>
<td>• Looking for reasons/ways to explain</td>
</tr>
<tr>
<td>Experience of negative emotion</td>
<td></td>
</tr>
<tr>
<td>Coping and adaptation</td>
<td>• Strategies</td>
</tr>
<tr>
<td></td>
<td>• Changes</td>
</tr>
<tr>
<td>Relationship with services</td>
<td>• Information sharing</td>
</tr>
<tr>
<td></td>
<td>• Relationship with services</td>
</tr>
</tbody>
</table>

A full list of themes and supporting extracts can be found in appendix 10. The 'searching for an explanation' and 'experience of negative emotion' themes are discussed below as they encapsulate the salient experiences of the Foley family. The 'searching for an explanation' theme shows how each member of the Foley family engaged in a process of meaning-making to make sense of their experiences. This process was judged to strongly dominate the reflections of each member of the Foley family. The 'experience of negative emotion' theme is presented as this seemed to strongly characterise the accounts of experience of each member of the Foley family. The analysis of other themes are included in appendix 14.

3.1.1.a Searching for an explanation

3.1.1.a.i Diagnostic overshadowing

A number of the changes in Simon’s behaviour were initially attributed to his learning disability by both his family and by healthcare professionals. The process of diagnostic overshadowing (Reiss, 1994, 2000; Yalug & Tufan, 2005) formed one of the main explanatory frameworks in the process of searching for an explanation of Simon’s difficulties. This is the process by which symptoms of a mental health problem may be attributed to the person’s learning disability rather than to a different underlying disorder.
In this sense, mental health problems can often be overlooked in people with learning disabilities. Both Sally (below) and Gillian (lines 32-36 & 39-40) expressed a belief that some of the changes in Simon’s behaviour could have been accounted for by his learning disability:

Sally: *Because we didn’t really know it was a mental illness, we just used to think he’s got a learning disability.* (Line 272-273)

In the gradual unfolding and discovery of the schizophrenia, there is a sense of a mental health difficulty being much more difficult to deal with than a learning disability:

Gillian: *We even forgot about the disability because I know that with the disability we know how to help him but this type of problem, mental problem, you don’t know how to handle him anymore.* (Lines 185-188)

The development of schizophrenia seemed to present the family with a new challenge, perhaps which seemed larger than that of dealing with a learning disability. There is a sense of the family feeling somewhat disarmed of the coping strategies that they had previously developed in dealing with Simon’s learning disability or that these were not applicable to dealing with the challenge presented by the onset of a mental health problem.

3.1.1.a.ii Looking for reasons/ways to explain

Gillian (lines 425-432) and Sally (lines 118-123) both engaged in a process of searching for triggers for certain behaviours, rationalising Simon’s behaviours which often led to self-doubt about their own suspicions and of attributing blame or causality. Gillian (lines 540-541) and Sally (lines 920-927) remembered things that they had forgotten and recalled memories from previous years in the interview which they applied to explain recent events or behaviours which had occurred in the context of the schizophrenia. In this sense, the interview process itself seemed to form part of the process of searching for meaning.

In being asked to explain in any way he could what the experience of schizophrenia was like for him, Simon used several eloquent metaphors to explain his experience of schizophrenia and the impact on him. For example, he spoke of the restriction in diet that people with diabetes are required to live with and about being disabled and unable to walk
Though there may be multiple interpretations of Simon's use of metaphor, including that Simon became confused and began talking about physical health problems rather than about schizophrenia, one particular interpretation could be made about Simon's use of metaphor. The fact that this conversation arose from a question asking Simon to explain what schizophrenia is like for him suggests that his use of metaphors helped communicate his understanding and experience of schizophrenia. The reference to diabetics being unable to eat sweet things may be interpreted as Simon's experience that people with a learning disability and/or schizophrenia may be unable to do things they enjoy or there may be limited opportunities to enjoy themselves (if viewing sweets as being treats or things that people enjoy). This metaphor implies a sense of being restricted. The reference to falling over and being unable to get up may imply a sense of being unable to help or pick up oneself in the face of difficulties which may link to the sense of weakness felt by Simon. This may also allude to the need for help from those around Simon if he feels unable to help himself or pick himself up out of the difficult experience of schizophrenia. Interestingly, this metaphor is built upon further in the extract when Simon makes reference to being unable to walk which links to being disabled. This may draw parallels between being unable to walk and therefore disabled and the influence of schizophrenia in that it can stop you from moving forward more generally with life and ultimately leaves him with a sense of being disabled. The idea of being disabled by schizophrenia may also link to the myriad of negative emotions experienced by Simon, particularly of being weak.

The particular interpretations made may have been informed partly by a sense of the historical prejudice and discrimination that many people with learning disabilities and indeed, people with mental health difficulties may have experienced over time which may have subsequently led to experiences of denigration and restriction (e.g. of choice) for some people.

3.1.1.b Experience of negative emotion

The accounts of each person in the Foley family were characterised by the experience of a myriad of negative emotions. Gillian and Sally both expressed a mixture of shock, distress and sympathy in response to the self-harming behaviours Simon engaged in as the schizophrenia progressed:
Gillian: The worst thing he did was knocking himself and all that (Line 716).

Sally also commented:

Sally: So that time was distressing, he was suffering so much, he doesn't want to hear it and he'd end up crying... because a few times he'd been lying in the road and I was like “what?”. Just shock, because at that time he was getting much worse. (Lines 318-326).

Their accounts express a complex combination of emotions which give rise to a sense of underlying helplessness and powerlessness which seemed to disable them from knowing how to help Simon in those situations.

Simon’s account of the experience of schizophrenia is saturated with a number of negative emotions including sadness (line 85), anger (line 94) and weakness (line 479). The sense of weakness expressed by Simon may be reminiscent of the historical experience of people with learning disabilities who at times may have been viewed and treated as weak and defective. The dual experience of two heavily stigmatised conditions; learning disability and schizophrenia may have contributed to an overall feeling of weakness within Simon in comparison to those around him, including his family members. This was commented on by Sally, who in describing an incident in which Simon had pushed her over, she had been surprised to learn of Simon’s perception of himself as weak:

Sally: So then he pushed me on the floor and I think he tried to kick me too you know, so I was on the floor going “Simon, Simon, are you alright?”... Then it was almost as if a light switched on and he went “Oh, I’m not supposed to be strong, I’m supposed to be the weak one”... I was like, what?. (Lines 591-600).

There is a sense of Simon perceiving his position within the family to be somewhat lower compared to other members of the family and perhaps particularly his twin who does not have a learning disability. The metaphor of a light being switched on suggests a brief moment of clarity in which Simon was able to eloquently give an insight into his internal sense of self. There are other instances and examples of such clarity of expression and description throughout his account, as outlined in the 'looking for reasons/ways to explain' theme.
During the analytic process, I became aware of my own reaction of surprise to the eloquence and sophistication of thinking, particularly in the use of metaphor that Simon employed. On reflection, this sense of surprise may serve to highlight my own assumptions about Simon’s ability as a man with a learning disability to give an insightful account of his internal world.

3.1.2 The Williams Family

Three superordinate themes arose from the analysis of the interview transcripts of each member of the Williams family, two of which also had two subordinate themes. The table of themes is displayed below:

Table 3: Superordinate and subordinate themes emerging from the IPA of interview transcripts from three members of the Williams family

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subordinate themes</th>
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<tbody>
<tr>
<td>Experience and understanding of psychosis</td>
<td>• Experience of psychosis</td>
</tr>
<tr>
<td></td>
<td>• Understanding of experiences related to psychosis</td>
</tr>
<tr>
<td>Impact on the family</td>
<td>• Unhelpful aspects of services</td>
</tr>
<tr>
<td>Services</td>
<td>• Helpful aspects of services</td>
</tr>
</tbody>
</table>

The ‘impact on family’ and ‘services’ themes have been discussed in this section. The judgement about which themes to convey resulted from a combination of the important issues as discussed in the accounts of each member of the Williams family and also the interpretations made about the salient issues for this family made by the researcher. Each member of the Williams family conveyed how the observed changes in Rebecca’s behaviour and character strongly impacted on each member of the family and the family as a unit. The experiences of services strongly featured in the accounts of each member of the Williams family and were described as having a profound influence on their experiences. A full list of
themes and supporting extracts can be found in appendix 11. The analysis of other themes are included in appendix 15.

3.1.2.a Impact on the family

There was concordance between the accounts of each member of the Williams family that the psychotic experiences had a profound negative impact on each member of the family and on the family as a unit. Caroline reflected on the impact of the experiences as they struggled to manage Rebecca’s behaviour and safety and attempted to obtain help from services:

Caroline: Both my husband and I were on anti-depressants through it. Barely coping and still nothing was happening... So you’re getting torn in all directions and you just feel, well, I just felt a total failure as a parent because you couldn’t, you were struggling to help yourself let along try and get help for. (Lines 173-174 & 262-263).

Thomas also explained:

Thomas: This is when I said ‘no, it’s driving me mad’ and then after that I went onto depression tablets... I reckon that if it wasn’t for me wife being supported as she was, I reckon I would have committed suicide. (Lines 25-29).

Their distress was picked up on by Rebecca who commented “mum and dad found it quite hard actually, coping with it because you can tell, they had all red marks under their eyes and everything”. (Lines 374-376).

In addition to the personal impact on each family member, Rebecca (lines 759-763 & 789& 792), Thomas (lines 194-199) and Caroline (lines 899-902) all described how the experiences also had a detrimental effect on the family as a unit. All of the extracts highlight the significant change perceived from the family as a happy, cohesive unit to one where the relationships within the family became torn apart and the family atmosphere was characterised by a myriad of negative emotions.

Rebecca (lines 789-790), Caroline and Thomas also reflected on longer lasting
changes in themselves that they perceived had occurred as a result of their experiences. Both Caroline (line 370) and Thomas (lines 265-267) commented on how they have a lower capacity to tolerate stress and that they now wanted a quiet life. This suggests that the onset of a mental health problem such as a psychotic illness may have had a profound and long-lasting impact on the lives of Rebecca and her parents. This raises important questions about how the meaning of such experiences is developed and processed and the subsequent impact of this on sense of self and family relationships and functioning.

3.1.2.b Services

3.1.2.b.i Unhelpful aspects of services

The split between learning disability and mental health services was identified as being problematic in terms of access to services and ultimate responsibility for care and funding (Caroline: lines 23-24). Caroline described a struggle to obtain help from a learning disability service and difficulties with the service they did receive (lines 751-755 and 836-840). The sense of not being listened to may suggest that the family felt that their perspective was not as valued as the views of medical professionals which may highlight a power imbalance between the family and healthcare systems. Rebecca also picked up on the way that her family felt blamed and unheard:

Rebecca: Sometimes I didn’t like the questions they asked mum and dad... They’d want mum and dad out of the room you see and I’d say ‘why can’t you talk to them without them being here?’ cos I didn’t mind mum and dad being there. I normally let my mum and dad listen to me sometimes when like I say. Don’t think they like it, think they was a bit offensive by it. (Lines 274-283).

For Rebecca, the involvement of her family was important to her and this may not have been acknowledged by services. This highlights the importance of eliciting and valuing the perspective of family members for the Williams family.

3.1.2.b.ii Helpful aspects of services

Access to specialist learning disability and mental health services was viewed as being exceptionally helpful. There were a number of aspects of the approach to care that
were seen as helpful, including a sense of collaboration between the team and the involvement and information sharing both between the team members and with the family (Caroline: lines 223-230; Thomas: lines 60-64). The team’s interest in the family’s perspective was highly valued. Thomas expressed a sense of relief and shock (lines 307-308) when the specialist learning disability and mental health service were able to provide a diagnosis and treatment plan that provided a framework to enhance his understanding:

Thomas: Knowing what the doctors have said to me, I could understand, I could correspond with them a bit more now. At first I was more or less like a lemon, you know, didn’t know what was going on sort of thing. Now they’ve explained everything, you can correspond with them more... and it’s come more closer to us and I think we’ve got more closer now as a family than we ever were... I think we can understand the traumas of it, of the voices. (Lines 407-413).

The sharing of information with the family enabled the family to liaise more effectively with healthcare services. The above extract portrays how information and explanation about psychosis helped Thomas to build a relationship with the healthcare professionals which perhaps helped to redress the initial perceived imbalance of power between the family and the healthcare system. In this sense, knowledge became a powerful tool to help the family liaise with services, develop their own understanding and to bring the psychotic experiences closer to them, enabling them to have a relationship with their experiences that was facilitated through increased understanding. Subsequently, this increased understanding allowed the family to become closer, perhaps through being able to empathise with Rebecca’s experiences and attach meaning to psychotic experiences such as hearing voices. The positive experiences with specialist services had helped to foster trust and faith in the ability of services to address Rebecca’s needs if she required further help in the future (lines 1118-1119).

3.1.3 The Harrison Family

Three superordinate themes arose from the analysis of the transcripts from each member of the Harrison family. The third theme ‘aspects of the service context’ also had two subordinate themes. The themes are displayed in Table 4, below:
Table 4: Superordinate and subordinate themes emerging from the IPA of interview transcripts from three members of the Harrison family

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subordinate themes</th>
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<tbody>
<tr>
<td>Understanding of learning disability and psychosis</td>
<td></td>
</tr>
<tr>
<td>Family involvement</td>
<td></td>
</tr>
<tr>
<td>Aspects of the service context</td>
<td>• Communication and consistency</td>
</tr>
<tr>
<td></td>
<td>• Resources</td>
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</table>

A full list of themes and supporting extracts can be found in appendix 12. The 'understanding of and relationship to learning disability and psychosis' and 'aspects of the service context' themes are discussed below. It was important to include the first theme as it encapsulated the ways that each member of the Harrison family understood and related to learning disability and psychosis and the links between these two concepts. This theme also illustrated the links between the views and experiences of each family member which was an important process that emerged at different stages of the analysis. The second theme was selected as service issues were strongly represented in George and Jane’s accounts and seemed to exert a strong impact on the way they perceived and reflected on different experiences. Though Matthew spoke of his experiences with services, his voice was less well represented in this theme and this is considered further in the discussion. The analysis of the themes not discussed in this section are included in appendix 16.

3.1.3.a Understanding of learning disability and psychosis

George and Jane both expressed ideas about their understanding of learning disability and the impact of this on Matthew’s life and on the experience of psychosis. George expressed a range of ideas about the abilities, difficulties and experiences that characterised the lives of people with learning disabilities (lines 229-233; 361-363; 372-373; 439-447) and this was built upon by Jane:

Jane: Umm, I think sometimes, not just with Matthew, I’ve seen how some of the carers have spoken to some of the other children. I find it a bit sort of, they’re not
being spoken to as a normal person, they're being spoken down to because they've got a learning disability, those sorts of things. (lines 349-353).

Interestingly, Jane's almost unconscious use of the word "children" to describe people with learning disabilities may serve to convey an understanding of people with learning disabilities as 'eternal children'. This use of language subtly demonstrates the very point that she has tried to make, that people with learning disabilities may inherently be regarded and treated differently.

George and Jane believed that Matthew's learning disability may have had an impact on his ability to recognise that the psychotic symptoms he experienced were firstly "unusual" (lines 15-22; 36-37) and secondly that they formed part of a mental health problem (lines 439-447). Indeed, initially Matthew was unaware of what a mental health problem was but later, as the interview progressed was able to begin to convey his experience of psychotic symptoms, though he was unaware that these formed a specific illness:

Interviewer: Ok, good, good. Matthew, do you know what mental health means?

Matthew: No I don't (lines 370-384).

There was a sense that the onset of a mental health problem was seen as an extension of a learning disability and therefore did not present the family with any additional difficulties (George, lines 343-346 and 338-346; Jane, lines 238-241). There is a somewhat sense of resolute acceptance in George and Jane's accounts of their view and approach to the onset of a mental health problem which may have underpinned their approach to understanding and coping with the illness. This was also reflected in Matthew's understanding of and relationship to the psychotic experiences:

Interviewer: What do you talk about with the doctor?

Matthew: I, I don't believe it

Interviewer: You don't believe it?

Matthew: I don't. Load of mumbo jumbo
Interviewer: What's mumbo jumbo?

Matthew: I can see things (Lines 698-808).

The use of the term “mumbo jumbo” seems to fit with the resolute acceptance that characterised the views of the family and could be interpreted as being almost dismissive of the psychotic symptoms and their possible impact. This is also reflected in George’s response to being asked about the personal impact of the psychosis:

Interviewer: Ok, can you tell me about how any of the experiences that may have happened along the years with Matthew in terms of the learning disability and the psychotic symptoms may have affected you personally?

George: [laughs] Affected me personally?

Interviewer: Yes (Lines 330-337).

The use of laughter before querying the question about the effect on him personally may suggest that George was somewhat surprised at being asked about the personal impact of Matthew’s mental health difficulties. This seems to fit with the resolute acceptance of the mental health problem and the approach to coping adopted by both George and Jane. The apparent surprise at being asked a personal question may be interpreted in a number of ways. One interpretation may be that it had not been made clear from the outset that questions about the impact on family members would be asked. Alternatively, it may reflect the style and approach to coping with difficulties adopted by individuals within the family or it may be that George was not used to being asked about the personal impact on himself and his life as this had perhaps been previously neglected by services.

3.1.3.b Aspects of the service context

3.1.3.b.1 Communication and consistency

George and Jane both described difficulties with services related to lack of communication and inconsistency between professionals and services and between services and people with learning disabilities and their families. This was encapsulated succinctly by George who stated “so there’s an awful lot of things in the life of a person with a learning disability that is not joined up” (lines 682-683). This sense of disconnection was perceived and
experienced at multiple levels, including the quality and consistency of care provided in Matthew's residential home (Jane, lines 631-632), in the rotation of professionals involved in delivering care (George, lines 889-890, Jane, lines 327-331), between professionals from different services and agencies such as psychiatrists, care managers and GP's (George, lines 975-989) and in the way that government policy and initiatives were developed, interpreted and applied to services on the ground (George, lines 509-514). There was a sense that such difficulties with communication and consistency at multiple levels had a profound effect on the lives of people with a learning disability as many aspects of their lives were linked to and in some ways controlled by access to services:

George: For people with a learning disability, their life revolves around the fact that they have to have assessments, they have to have care plans... which basically regulates the life potential of someone with a learning disability. (Lines 657-659).

3.1.3.b.ii Resources

The issue of resources was raised as a significant difficulty and in some areas a barrier to access to services more generally:

George: Again it rather comes back to the fact that changing his day services has involved a change in finance and extra financing... But if there's money involved, even if it's part of an assessment or care plan, just because it's there does not mean to say it's going to happen. (Lines 917-922).

This concern was echoed by Jane who believed that there was a lack of opportunities available for people with learning disabilities due to resource constraints which was fundamentally unhelpful:

Jane: I suppose in an ideal world, more opportunities to be available for them and with all the cutbacks they just seem to be leaving them to fend for themselves... I think they need stimulation, it makes their lives better... they're not being stimulated so in that sense I think more needs to be done but it's all down to money. (Lines 539-546).
3.1.4 The Jayawardene Family

Two superordinate themes emerged from the IPA of the interview transcripts of three members of the Jayawardene family. Each superordinate theme also had a number of subordinate themes as delineated in Table 5, below:

Table 5: Superordinate and subordinate themes emerging from the IPA of interview transcripts from three members of the Jayawardene family.

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subordinate themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes over time</td>
<td>• Progression of illness</td>
</tr>
<tr>
<td></td>
<td>• Service changes</td>
</tr>
<tr>
<td></td>
<td>• Wider societal changes</td>
</tr>
<tr>
<td>Impact of learning disability and schizophrenia at multiple levels</td>
<td>• On Tamara</td>
</tr>
<tr>
<td></td>
<td>• On family member’s perceptions of Tamara</td>
</tr>
<tr>
<td></td>
<td>• On family members and the family unit</td>
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</tbody>
</table>

The themes have been primarily developed from Geoffrey and Victoria’s accounts due to communication difficulties which made it difficult to transcribe and understand some of Tamara’s account. The theme of ‘impact of learning disability and schizophrenia at multiple levels’ is discussed below to convey a sense of the unique and salient experiences of each member of the Jayawardene family. This theme was selected to enable Tamara’s experiences to be represented and the issues raised in this theme also brought out and demonstrated the interpretative aspects of the IPA and therefore helped to demonstrate the usefulness and applicability of this methodology to the study of people with learning disabilities, psychosis and families. A full list of themes and supporting extracts can be found in appendix 13. The ‘changes over time’ theme that emerged from the analysis is included in appendix 17.

3.1.4.a Impact of learning disability and schizophrenia at multiple levels

3.1.4.a.i Impact on Tamara

The move from institutionalised to community care was perceived to have had a
beneficial impact on Tamara (Tamara, lines 455-461 and 431-437, Victoria, lines 405-412 and 433-438, Geoffrey, lines 493-508). Victoria explained how she believed that her sister’s learning disability impacted on her life which meant she was missing out:

Victoria: I know that she knows that she’s missing out on certain things... like getting married or starting a family. She knows she can’t do those things, she knows she can’t do it. Whether she knows but I don’t know if she accepts that she can’t do those things. I know that she really wanted children and she can’t do that so emotionally, it’s hard. (Lines 127-130).

Victoria continued to describe how she believed that it may have been difficult for Tamara to compare her life to that of her sister who did not have a learning disability or schizophrenia and subsequently directed some of her physical aggression towards Victoria (lines 229-234 and 238-243). In reflecting on the nature of Tamara’s experiences, Victoria acknowledged that more contact with her family may have been beneficial for Tamara (lines 456-459).

3.1.4.a.ii Impact on family member’s perceptions of Tamara

The external behaviours which Tamara displayed such as physical aggression which arose from a complex interplay of her learning disability and schizophrenia were perceived negatively by some members of the family, for example, some behaviours were experienced as controlling. Subsequently, it seemed that the difficulties were located as being within Tamara:

Victoria: Yeah, I think she would like throw tantrums if she didn’t get what she wanted but obviously I know with bringing up a child, you don’t give into those because otherwise they’re controlling you the whole time. It felt like the whole time she was in control of everything because if she didn’t get what she wanted she would create a big fuss. (Lines 275-279).

There is a sense of intent implied behind Tamara’s actions as described in the above extract and also perhaps a sense of negative feeling towards Tamara due to her behaviour. In this sense, Tamara appears to be constructed as being inherently difficult and controlling. The reference to the role of “tantrums” in controlling behaviour and the parallels drawn between the behaviour displayed by Tamara and a child is particularly interesting. This use of language may serve to construct a power differential between Tamara and her siblings.
There are other examples in which language is used to describe aspects of Tamara's disposition or behaviour to convey a sense of the somewhat negative perception of Tamara and perhaps of learning disability (Geoffrey, lines 240-242). This interpretation of Victoria and Geoffrey’s accounts may suggest that the complex interplay of learning disability and schizophrenia which impacted on Tamara’s behaviour may serve to negatively impact on the way she is perceived by those people around her.

The interpretation of Geoffrey and Victoria’s accounts as delineating a negative attitude towards Tamara was based upon the use of language and the sense invoked during the research interviews. The sensed negativity had raised discomfort which may have been partly due to the way in which this view differed from the view and position of the researcher (e.g. in terms of views and approaches to people with learning disabilities, a critical awareness of the use of language informed by systemic and social constructionist ideas). Despite this, the interpretation of certain extracts in this manner was required and important as it highlights the experience of some family members which is an important finding for clinicians. It was important to bear in mind the need to listen to and respect the views, experiences and ideas of both the individual with a learning disability and their family members.

3.1.4.a.iii Impact on family members and on the family unit

Both Geoffrey and Victoria initially stated that they did not feel the experiences brought by Tamara’s learning disability and schizophrenia had affected them significantly. However, Victoria (lines 275-279) and Geoffrey (lines 65-77) went on to describe poignant memories of difficult experiences which had exerted an impact on them individually and on the family as a unit:

Geoffrey: Now, the most difficult thing for me to do was physical, it was to stand between my father and [at this point, it seemed to become difficult for Geoffrey to recall those memories]... that I would have to stand between my father and Tamara to stop him punching her so I was taking the punches. I’d forgotten all about that until now. I don’t think anyone has ever asked me about that and you’re the first person to know about that (Lines 134-160).

It seemed difficult for Geoffrey to recall difficult and painful memories and there is a sense
that other people around him may not have known about the impact of this on Geoffrey. This extract may also serve to convey some of the distress experienced within families who try and manage difficult experiences associated with mental health difficulties. Similarly, Victoria made reference to distancing between family members which she attributed to an atmosphere in the house linked to some of the difficult experiences described (lines 295-301). The distance between members of the family was also conveyed by Tamara (lines 48 and 70-73).

In thinking about their coping with the experiences that they recalled and reflected on in the interview process, both Geoffrey and Victoria queried the use of the term ‘coping’ to portray their adaptation to the difficult experiences they described:

Geoffrey: I don’t know because it wasn’t that cut and dry. I don’t know because it’s something you sort of fall into, it’s like water flowing out of a fountain. (Lines 395-399).

Victoria also queried whether this term reflected the nature of the adaptations she had made:

Victoria: To be honest, I haven’t really had to cope... I mean, managing is probably the right word in the sense that only having her come up for short visits, you know. (Lines 223-225).

Geoffrey’s account suggests that he may not have been consciously aware of using any type of coping strategy at the time and that looking back from his current position, as with the experience of some other families, he dealt with the experiences gradually as they arose, on a day by day basis. Victoria’s account suggests that she felt that she had to make practical adaptations and changes to accommodate and manage Tamara’s visits rather than have an awareness of an overarching model of coping.
4.0 Discussion

This study aimed to elicit and explore the experiences of people with a significant learning disability with an additional diagnosis of a psychotic illness and the experiences of two of their core family members. The following discussion aims to link the experiences of each of the four families to psychological theory and research. The similarities and differences between each of the four families are also considered in relation to three common themes that can be drawn from the analysis of the four family case studies. The capacity of the study to address the research aims and a number of clinical and research implications will be discussed.

4.1 Summary and discussion of the salient themes for each family case

This section considers the themes for each family that were discussed in the analysis section in relation to psychological theory and research.

4.1.1 The Foley family

The salient themes discussed in the analysis section for the Foley family were 'searching for an explanation' including 'diagnostic overshadowing' and 'looking for reasons/ways to explain' and 'experience of negative emotion'.

Gillian and Sally engaged in a process of searching for triggers and explanations to account for the changes in Simon's behaviour. This seemed to begin with looking for triggers in the external environment but then shifted to looking to themselves and to each other to assign causality and blame in the process of trying to make sense of the behaviour and changes that had occurred. Once it became clear that the perceived changes could not be accounted for by Simon's learning disability, but were attributed to the onset of schizophrenia, this seemed to present the family with a new challenge which they seemed to feel somewhat unequipped to deal with. Evidence from a cross-sectional study (Grant & Whittell, 2000) suggests that everyday family coping strategies undergo transformations across the lifecycle in response to different events. In this sense, it seems that the onset of a
mental health problem such as schizophrenia may have presented a challenge for the Foley family which required the development of new skills and coping strategies.

Simon, Gillian and Sally’s accounts were all characterised by the experience of negative emotion in relation to the experiences that accompanied the onset and development of schizophrenia. Gillian and Sally expressed a mixture of shock, distress, sadness and sympathy in relation to the self-harming behaviours that Simon engaged in as the schizophrenia developed. This appeared to be partly linked to levels of involvement as Simon, Gillian and Sally all lived together during this time. This is consistent with other research which found a higher rate of carer stress associated with higher levels of contact (Winefield & Harvey, 1994). Simon too expressed a myriad of negative emotions such as sadness, anger and weakness to describe the feelings that schizophrenia brought. This may also raise questions about the support available for people with learning disabilities to understand their experiences. The personal impact of these experiences on all members of the Foley family raises questions about how services may respond to meet the needs of all family members. Neither Gillian or Sally were offered any form of assessment or support of their needs. Some form of psychotherapeutic intervention may have been helpful to enable Simon to develop personalised understandings of his experiences and feelings. Indeed, there is some evidence pertaining to the use and value of cognitive-behavioural therapy with people with learning disabilities and psychosis (Haddock, Lobban, Halton & Carson, 2004).

4.1.2 The Williams family

The main themes discussed in the analysis section for the Williams family were ‘impact on the family’ and ‘services’, including ‘unhelpful aspects of services’ and ‘helpful aspects of services’.

The experiences that accompanied the onset and development of psychotic episodes seemed to have a profound negative impact on each member of the family and on the family as a unit. The impact on the family appeared to be partly mediated by the level of
involvement and contact. This is consistent with the findings of Winefield and Harvey (1994) who found that increased carer stress was associated with increased levels of contact. Rebecca, Caroline and Thomas all described how the onset and development of a mental health problem affected the family as a unit in a number of ways. Between them, they described a change in the family functioning from being happy and cohesive to being unhappy and torn apart. As discussed below, the family were not specifically offered any form of family work or support. The involvement of family members is well established in the support services of people who have a diagnosis of a psychotic illness but do not have a learning disability (Burbach, 1996; Fadden, 1998; Gorrell-Barnes, 1998; Leff, 1998). Ideally, multimodal treatment incorporating anti-psychotic medication coupled with psychosocial interventions such as family therapy which aim to reduce family stress and enhance coping (Carr, 2006) are available for some families. The adoption of psychosocial interventions that involve family members therefore may be helpful in mediating the impact on people with a learning disability such as Rebecca and her family members.

Dealings with services were a key factor that coloured Rebecca’s, Thomas’ and Caroline’s perceptions and portrayal of their experiences. The accounts of Rebecca and her parents portrayed stories of both difficult dealings with services and of helpful support and care. Rebecca, Caroline and Thomas all expressed feelings that could be interpreted as frustration and disappointment in relation to feeling blamed and unheard by services which further compounded the negative impact on each individual and the family as a unit. Indeed, research has shown that where family members do not feel listened to or their strengths acknowledged, this may lead to service users and family members feeling unheard, devalued and disempowered (Williams & Robinson, 2001) which could hinder the development of a trusting collaborative relationship with professionals. This seems to encapsulate some of the unhelpful aspects of the encounters with services for the Williams family.

Access to specialist learning disability and mental health services was seen by Rebecca, Caroline and Thomas as a helpful turning point. Aspects associated with positive perceptions of services included a collaborative approach and communication at multiple levels: between staff, different services and agencies and between staff/services and services
users and carers. Thomas and Caroline expressed how feeling valued and listened to was helpful. Improved relationships have been attributed to improved listening, providing information tailored to the individual’s situation and acknowledging both the family’s concerns and strengths (Case, 2001; Maxwell & Barr, 2003). This may draw attention to the importance of eliciting and listening to the views, ideas and experiences of people with a learning disability and their family members.

4.1.3 The Harrison family

The main themes that were thought to encapsulate the experiences of the Harrison family were ‘understanding of and relationship to learning disability and psychosis’ and ‘aspects of the service context’, including ‘communication and consistency’ and ‘resources’.

The understanding of and approach to coping with the onset of a mental health problem seemed to be linked to the ways in which George and Jane perceived that they viewed and responded to the diagnosis of a learning disability. The onset of a psychotic illness was viewed as being an extension of Matthew’s learning disability and in this sense was not perceived to present George and Jane with any additional difficulties. This links to research about differences in the caregiving trajectories of different families. As carers develop expertise and competence through everyday caregiving, they move from being ‘novice’ to ‘expert’ carers (Grant & Ramcharan, 2001). For George and Jane, it seemed that their previous experiences of caring for Matthew in view of his learning disability equipped them to continue caring for and helping him with the onset of a psychotic illness. The view of the psychotic illness as an extension of a learning disability seemed to mediate the impact of the diagnosis on them personally.

Difficulties in dealings with services also seemed to characterise George and Jane’s accounts. They identified a lack of communication and consistency at multiple levels in the systems around themselves and Matthew, including with staff, within and between services and between services and users and carers and at the level of policy. Resource constraints were also perceived as being a significant barrier to adequate facilities, care and treatment. Though service issues were selected as a salient theme for the Harrison family, the same
issues did not significantly feature in Matthew’s account of his experience. Matthew spoke about his regular contact with services and his various experiences of treatment, though not about lack of communication and consistency or resource constraints. The implications of this are discussed further below.

4.1.4 The Jayawardene family

The subthemes of ‘family members perceptions of Tamara’ and ‘impact on family members and the family unit’ highlighted the ways in which the behaviours that arose from a complex combination of learning disability and schizophrenia seemed to have a strong impact on family member’s perceptions of Tamara and on relationships in the family unit. Interestingly, both Geoffrey and Victoria initially stated that they did not think that Tamara’s learning disability and diagnosis of schizophrenia had had a significant impact on either themselves as individuals or the family. However, the memories and examples they went on to recall suggested that these experiences indeed have had an impact on themselves and on the family. This process may be understood in relation to the concept of coherence in developing narratives (Dallos, 2006). The concept of coherence relates to the way in which a story about a particular event is told and developed. The perceived discrepancies between the initial statements and further examples about the impact of learning disability and schizophrenia may highlight how neither Tamara, Victoria or Geoffrey had had the opportunity to story their experiences before. Indeed, the research interview seemed to form part of the process of developing an account or narrative of their experiences in relation to dual diagnosis. This may serve to highlight the value of carers assessments to take into account the needs of family members of varying kinship connections. This links to research by Grant & Ramcharan (2001) highlighting that nationally, there seem to have been difficulties in offering assessments to all family carers who need them.

In keeping with the narrative therapy model, the sense of negativity that was interpreted as characterising the accounts of family member’s perceptions of Tamara may have been described as ‘problem-saturated’. Some of the use of language in Geoffrey and Victoria’s accounts may have served to construct Tamara as being ‘the problem’ rather than thinking of the symptoms of schizophrenia as being a problem which impacted on Tamara. White and Epston (1990) postulate that the stories told by individuals and families often
tend to have a profound influence on the way people live their lives. Such problem-saturated stories can have remarkable longevity in the context of the lives of people with learning disabilities and their families (Scior & Lynggaard, 2006) where resources and strengths may be overlooked in the face of perceived difficulties and problems. For the Jayawardene family, there was a sense that problem-saturated stories of learning disability and schizophrenia in relation to Tamara tended to dominate their accounts.

4.2 Drawing out common themes: similarities and differences between the experiences of the four families

Though the decision was made to analyse the data in family cases, it may also have been possible to analyse all the families together to pull out common themes that encapsulated the experiences across the four families. It was possible to identify three common themes that were represented in the experiences of all four families. The similarities and differences between each of the families in relation to the three common themes are discussed below.

4.2.1 Experience and understanding of learning disability and psychosis

All families described different trajectories of the onset, course, outcome and ongoing management of the psychotic illness. The ways in which family members explained and understood the onset, course and impact of the illness on their relative with a learning disability and on the wider family unit seemed to be affected by processes at intrapersonal (individual ideas and beliefs), interpersonal (through interactions within the family and with services) and societal (socio-political constructions of and culturally shared beliefs about learning disability and mental health) levels. Participants with a learning disability and their family members appeared to be engaged in a recursive interactional process (Dallos, Neale & Strouthos, 1997) where their explanations and actions were continuously shaped in reference to their individual beliefs, memories and ideas which were in turn influenced by their interactions with other family members, people in extended support networks, staff and services. Indeed, for some family members, the interview process itself seemed to form part of the process of constructing their understandings. For family members, beliefs and ideas about learning disability and mental health difficulties such as psychosis also seemed
to be shaped by their understanding and perception of prevalent discourses surrounding these issues. This is consistent with the findings of Dallos and Hamilton-Brown (2000) who found that the initial reactions of families to problems were shaped by their individual beliefs, the beliefs of and interactions with other family members, friends and professionals which in turn were shaped by culturally shared discourses about the problem under consideration.

4.2.2 Involvement of and impact on the family

In all family cases, the involvement of family members and the impact of the development of a psychotic illness in their relative with a learning disability was identified as a salient theme. This was evident in the accounts of both people with a learning disability and their family members, which indicates reciprocity in their acknowledgement of the involvement of and impact on each other. The strong presence of this theme suggests that further exploration of the role and impact of family involvement in the onset of a mental health difficulty is a worthwhile topic of exploration.

Interestingly, there were a range of responses in terms of levels of involvement and the ways in which members of each family were personally affected which further serves to highlight the importance of the differences as well as the commonalities across experiences. For some family members, the experiences in relation to the psychotic illness had a profound negative impact on them personally. This appeared to be linked to more involvement, for example, where their relative with a learning disability was living with them which is consistent with other research which found a higher rate of stress associated with higher levels of contact (Winefield & Harvey, 1994). Yet for others, they believed that the illness experiences had not exerted a particularly positive or negative influence on either them personally, their relative with a learning disability or on the family unit. The nature of responses about the personal impact of the illness seemed to be linked to differences in individual and family dynamics and beliefs and their interactions within the family and with services. This further supports an individualised approach to the needs and experiences of each service user and consideration and involvement of family and systemic issues in understanding and addressing their experiences.
4.2.3 Service issues

Dealings with services were often a key factor that coloured family member’s perceptions and portrayal of their experiences. Indeed, Redmond (2003) highlighted the salience of services in the lives of family members of people with learning disabilities and has argued that involvement with a network of services and professionals provides a distinctive and defining dimension to their lives. The accounts of people with learning disabilities and their family members portrayed stories of both difficult dealings with services and of helpful support and care. Aspects associated with positive perceptions of services included a collaborative approach and communication at multiple levels: including within and between the professional network and with services users and carers. Listening to and valuing the voices of people with learning disabilities and their families was also thought to be helpful. This is linked to research highlighting that satisfaction with services has been linked to subjective experiences of feeling supported and listened to (Case, 2001). Improved relationships have been attributed to improved listening, providing information tailored to the individual’s situation and acknowledging both the family’s concerns and strengths (Case, 2001; Maxwell & Barr, 2003).

Accounts of difficult encounters with services were characterised by a perceived lack of resources, lack of information sharing and transparency, inconsistencies in the approach to care and information available and the concerns and views of people with a learning disability and their family members not being heard. This links with research which has highlighted that service users and carers may experience a number of difficulties including inconsistency in points of contact (MacLachlan, Dennis, Lang, Charnock & Osman 1987), power differentials (Knox, Parmenter, Atkinson & Yazbeck, 2000) and conflict with workers (Williams & Robinson, 2001; Todd & Jones, 2003). Family members adopted different approaches to these perceived difficulties, which ranged from putting faith and trust in services to manage the situation to adopting a firm and assertive approach with staff and services. A number of clinical and research implications arising from these findings are discussed below.
4.3 The capacity of the study to address the research aims

This section aims to discuss a number of issues that occurred throughout the research process that may have impacted on the capacity of the study to address the research aims. The study aimed to elicit and convey the multiple perspectives of four families affected by the experience of dual diagnosis. The concept of multiple perspectives may also include that of the researcher. Although not explicitly stated in the research aims, the choice to use a qualitative methodology, particularly IPA, with its emphasis on the interpretative element of the analytic process implicates the researcher as a key part of the process of constructing the accounts of the experience of dual diagnosis in learning disability. A number of aspects of the research design and process meant that the way in which the accounts were elicited and conveyed may have been heavily influenced by the researcher. For example, the nature of surveying the salient research literature to develop the semi-structured interview schedule meant that in some ways the nature of the experiences discussed were pre-defined. However, Ezzy (2002) suggests that though qualitative research may be biased to a certain degree, so all research endeavours are inherently political and therefore biased.

Similarly, the extraction and prioritisation of some themes over others was determined primarily by the researcher. The strength in focusing on one or two salient themes was that this facilitated an insight into the unique experience of each family, without becoming lost in relation to the other themes. However, this process was difficult as it is neither easy or perhaps meaningful and representative of the experiences of participants to separate out and compartmentalise such rich accounts of experience, as each ‘theme’ is essentially interconnected with a number of others. In this sense, the experiences conveyed in the main analysis section represent the accounts of the research participants as viewed through the interpretative lens of the researcher. The above critique of the research processes are intended to ensure the quality of the current study. Fielding (1996) and Clear (1999) espouse transparency in delineating the position of the researcher and the contexts in which the research was constructed and conducted. The contexts in which the current research project was constructed and conducted have been delineated throughout the research paper which may go some way to ameliorating the potential limitations identified above.
As mentioned in the method, two family member interviews were conducted on the telephone. The Jayawardene family were the last to take part in the study. Difficulties with recruitment had significantly delayed the data collection and analysis stages adding significant pressure to ensure completion of the project. Two family members lived between 300 and 400 miles away from the study base and travel to these destinations was not feasible within the time and budget constraints, and the only possibility of interviewing them was by telephone. Sturges and Hanrahan (2004) have argued strongly for the use and validity of telephone interviews. They argue that participants who agree to be interviewed about sensitive topics may prefer the increased anonymity offered by telephone interviews compared to face-to-face interviewing.

Therefore, following the position taken by Sturges & Hanrahan (2004) a decision was made to conduct two telephone interviews. The same procedures were adopted for the telephone interviews as the other face-to-face interviews in terms of the interview schedule, length of interview, information given and mode of recording. The inclusion and exclusion criteria stipulated that family member participants should have sufficient levels of contact with their relative with a learning disability but did not make any specifications about location or distance from their relative.

This situation was not anticipated in the original design of the study and it is an important issue to consider. In particular it is important to reflect on the potential impact of the telephone interviews on the participants and the implications of conducting telephone interviews on the depth and quality of the data yielded from this mode of interviewing. The absence of face-to-face contact and visual cues could impact on the development of rapport between the researcher and participant and result in the loss of contextual and non-verbal signals (Miller, 1995) which may have otherwise informed the interpretative process. However, Sturges and Hanrahan (2004) suggest that respondents also provide other verbal cues such as sighs, silences, pauses and hesitation which may provide the researcher with information that can be picked up on in the telephone interview and enable the researcher to read the situation, for example, whether a follow-up question or prompt is required.
The fact that the two family member participants of the Jayawardene family were not within the local area may have presented an ethical dilemma in that they were not within the catchment area of the learning disability service in which the research was being conducted and therefore would not have been eligible to receive support from them if it was required. However, the researcher would have been able to make recommendations on how additional support could be acquired.

Another consideration is the effect the telephone interviewing had on the depth and quality of the data obtained and how comparable this data was with the face to face interviews. Novick (2008) notes how telephone interviews have been largely neglected in the qualitative literature until relatively recently due to an implicit assumption that telephone interviews yielded lower quality data compared to face-to-face interviews. However, both Sturges and Hanrahan (2004) and Novick (2008) contend that there is a paucity of evidence to suggest that telephone interviews produce lower quality data and suggest that with a consideration of the potential impact and implications of this method of interviewing, telephone interviews can be used productively in qualitative research. Both Sturges and Hanrahan (2004) and Tausig and Freeman (1988) found that telephone interviews can yield good quality data. This may suggest that the data yielded through telephone interviews is comparable to that collected in face-to-face interviews and thus is an effective means of data collection (Harvey, 1988). Despite the potential limitations of conducting two telephone interviews, the researcher was still able to engage with the interview transcripts at an in-depth level to analyse and interpret the data in a meaningful way. The participants had the opportunity to convey the essence of their experiences and these accounts should be valued and respected in their own right (Sturges & Hanrahan, 2004; Novick, 2008).

It should be acknowledged that the interview schedules for people with a learning disability and their family members differed slightly in the way the main sections were divided and ordered and in the nature of the questions asked. Though there were differences in the organisation of the main topics covered by the two interviews, the core themes were the same across both interview schedules. The flexibility afforded by semi-structured interviews meant that the wording and ordering of questions for each participant may have deviated slightly from the original interview schedules. Indeed, Rice and Ezzy
(1999) and Minichiello (1995) highlighted the importance of maintaining a flexible approach in qualitative interviewing and adapting as seems appropriate to each participant in the interviews. Broom (2005) also emphasised that being impromptu and flexible is part of being a good interviewer and that interview schedules should provide possible lines of enquiry but should not be rigidly imposed on the participant’s experience. Instead, it is perhaps more useful in developing rapport and enabling participants to feel heard to move through their experiences at the participants pace, reflecting on how the themes in the interview schedule and other issues that come to light are related to their experience. This means that the slight differences in the organisation and ordering of themes and questions across the two interview schedules may not have had a detrimental impact on the quality and comparability of the data collected.

All of the core themes of knowledge and experience of the psychotic illness, experiences with services, systemic perspective taking in eliciting the participants’ views of their other family members and coping and adaptation are represented within both interview schedules. The ‘knowledge’ and ‘experiences’ sections were separated out in the interview for participants with learning disability to introduce the topic and find out information about their knowledge of the psychotic illness. This then guided further prompt questions. Questions about family members’ knowledge of the diagnosis were embedded within the section on their ‘experience in general’ in relation to learning disability and psychosis. The interview schedule for family members had a specific section on coping and adaptation whereas questions about coping were embedded within the section on ‘experience in general’ for participants with learning disabilities. This was intended to reduce the number of conceptual shifts in the interview schedule for participants with learning disabilities and make it easier for them to follow as the prompt questions developed on from each other in a gradual way. The interview schedule for family members had a separate section on relationships within the family whereas questions about relationships and functioning within the family were embedded within the section about the views and experiences of their family members for participants with a learning disability.

As mentioned in the method, two participants with a learning disability were included that would have met the criteria for exclusion from the study. One participant had
an additional diagnosis of autistic spectrum disorder which may have affected his ability to convey his experiences because of social and communication difficulties. Another participant had an additional diagnosis of bipolar affective disorder. Though this participant and her family members were clearly informed that the research interview and study were about the experience of learning disability and psychosis, it may have been difficult to disentangle the diagnoses and the impact of these on their experiences. The inclusion of these participants was discussed with the field supervisor and although it was acknowledged as deviating from the original inclusion and exclusion criteria, they were deemed acceptable in view of the potential impact of lack of participants on the timely delivery of the research project. Two other potential participants responded very late in the research process, once all data had been collected and was in the process of being analysed, and their core family members had not been identified or approached. Thus, their inclusion would have significantly affected the timely delivery of the research project.

Nevertheless, the inclusion of two participants with multiple diagnoses could be considered as a 'limitation' in the current study because of a lack of homogeneity between the families resulting from the differing complexity of needs for the person with the learning disability. This highlights the challenge of interviewing participants with learning disabilities who have multiple problems. Their experience becomes embedded within their perceived deficits rather than understood within the limitations of the methods currently available to research those experiences and needs. Booth and Booth (1996) suggest that the emphasis should be on overcoming barriers that impede the inclusion of people with multiple and complex needs in research instead of attributing such difficulties to the individual participants, particularly in a group of people who may face discrimination and exclusion in a number of other areas of their lives. In relation to the current study, although the study did not aim to investigate the experiences of people with multiple diagnoses, the inclusion of such groups of people may serve firstly, to highlight the fact that many people with learning disabilities often have multiple diagnoses attached to them (Caine & Hatton, 1998) and secondly, that the standards of conventional research methods may not be set up to adequately research the experiences of people with learning disabilities with additional complex needs.
Linked to the above point, further consideration should be given to the ways in which the voices of participants with a learning disability were represented in the current study. Some participants with a learning disability appeared to have a difficulty with participating in the interview process because they had a difficulty with verbal communication, comprehension and engagement. The verbal communication difficulties experienced by some participants with a learning disability may have limited the extent to which their voices could be heard and is a limitation of the current study. This suggests that the possibility and impact of communication difficulties was not adequately considered in the design of the study.

These difficulties meant that at times, their voices could not adequately be heard in the analysis or in the discussion since their experiences were overshadowed by the voices of family members and the subsequent prioritisation and selection of some themes in the analysis and discussion did not always include their views. Booth and Booth (1996) suggest that researchers should place more emphasis on overcoming the barriers that impede the involvement of people with learning disabilities (e.g. with verbal communication difficulties) instead of dwelling on their limitations as participants. They argue that often, idiosyncrasies and styles of communication can only be picked up by getting to know the participant. In order to improve the ability of participants with a learning disability to participate in the research interview, it might have been helpful to have had a few meetings in close succession with each participant prior to the main research interview to enable participants to familiarise themselves with the researcher, aid the development of rapport and repeat information about the nature of the study and the interview to help them remember and begin thinking about this. However, this may have affected the interpretative process since it would have been difficult to interview all participants over multiple sessions. On reflection, it may have been more useful to have set exclusion criteria for levels of verbal communication where participants with a learning disability who did not have a certain level of verbal communication were excluded from the study. The purpose and design of the current study with the emphasis on eliciting and exploring verbal accounts of experience and the use of IPA to analyse their accounts meant that the ability to verbally communicate was very important. In relation to the current and future qualitative studies with people with learning disabilities, it may be useful to have conducted an assessment of verbal communication prior to engaging participants with a learning disability in the
research interview or to have liaised with speech and language therapy colleagues within the service to see whether they could assist with such assessments or if any information about their levels of verbal communication was readily available.

Rephrasing questions, using simpler language and prompts to illustrate a form of response could have been used to help participants with learning disabilities understand the questions and voice their experiences (Booth & Booth, 1996; Rodgers, 1999). This process is referred to as 'self-developing' (Booth & Booth, 1996) in that the researcher refines the interview method over the course of the session(s) as the participants' knowledge and ability is gradually revealed. This process of adapting questions and language was conducted during interview process, however, it was difficult to understand one participant with a learning disability with verbal communication difficulties. The researcher considered the possible detrimental impact of these repeated requests for clarification on the participant in terms of not feeling listened to and heard.

It is also important to consider how the voices of participants with a learning disability could have been better represented in the analysis and discussion sections of the report. Though the reasons behind the selection of themes was outlined in the analysis, the selection and discussion of themes which represented the voices of all family members in each family case, including those of participants with a learning disability would have ensured that their views were more identifiable. Consequently, this may have led to a fuller discussion of the outcomes for and needs of participants with a learning disability. It may have been helpful to have discussed the outcomes and implications for participants with a learning disability and their family members separately to ensure that their needs were attended to in the report. However, the outcomes and implications were discussed in family cases as this was congruent with the way the analysis was conducted.

The current study explored the experiences of family members representing a number of different kinship ties, rather than prioritising the voice of the mother or parents as had been a criticism levelled at some previous research (Grant & Ramcharan, 2001). People with a learning disability were asked to select two family members of their choice to
be approached for inclusion in the study. This may be viewed as a strength in enabling participants with a learning disability to exercise some control over this aspect of the study. There were a number of differences between the participants in each family in relation to the details surrounding gender and kinship connections, onset, development, and length of time since the diagnosis of the psychotic illness and residential status at the time of onset. As acknowledged in the introduction and method, in keeping with the systemic tradition, the study did not make any assumptions about family structure and the relative importance of some family members over others. It was acknowledged that no two families are the same and therefore, the differences between the participants in each family may serve to highlight the external validity of the research in that it conveys the differences, nuances and complexities of real life families. Indeed, Broom (2005) argues that qualitative research is more concerned with external validity in terms of how the analysis represents the lived experience of participants than with generalisability. Furthermore, the analysis of family cases also ameliorated the lack of homogeneity among participants as each family case was analysed separately rather than amalgamating the sample and conducting one IPA across the whole group which may have been more problematic in terms of the impact of lack of homogeneity on the analytic process. Moreover, the context surrounding each family was clearly delineated, including information about the onset, development and length of time since diagnosis and the residential status at the time of diagnosis. Such details were given to enable the reader to locate the analysis, interpretations and their evaluation of the findings in relation to the context surrounding each family. The transparency in outlining the differences between the participants in each family case may in fact aid comparison between cases.

Rodgers (1999) highlights that research about the lives and experiences of people with a learning disability and their families should recognise the heterogeneity of this group. Rodgers reflects on how the inclusion of participants with a range of ages, backgrounds and circumstances can be a strength of research which highlights the heterogeneity of a group of people such as the participants in the current study. Indeed, Baum (2006) reflects on how early research studies looking at the experience of stress in families were criticised for the assumptions of homogeneity among families that underpinned the research. Therefore, homogeneity is not necessarily a key factor ensuring the quality and comparability of research in the field of learning disabilities and families. The current study has always been
acknowledged as exploratory and broad generalisations about the applicability of the findings to populations outside of the research sample have not been made which again may serve to lessen the potential detrimental impact of the lack of homogeneity of participants on the quality of the research study.

It is important to consider the impact of the analysis in family cases on the capacity of the study to meet the research aims. Close attention to the personal accounts of families is perhaps more important at this early stage in our understanding about the experiences of people with a dual diagnosis of learning disability and psychosis and their family members. Broom (2005) warns against being too quick to generalise the findings of qualitative research to populations outside of the research sample and highlights the value and importance of taking time to stand in and stay with the nuanced, detailed experiences that are conveyed through qualitative research. Broom suggests that this can help protect against blurring and moulding the findings of qualitative research into pre-existing models or theories and denying those processes which do not fit our image of a particular experience or phenomenon (Broom, 2005).

Furthermore, there are many examples of the use of IPA in both individual (e.g. Bramley & Eatough, 2005) and series case studies (e.g. Osborne & Coyle, 2002; Dallos & Denford, 2008). Smith and Osborn (2008) state that there is no definitive way to do IPA and that IPA can be flexibly adapted to suit the particular topic of investigation and the purpose and aims of the research study. There are other examples of the use of IPA to explore the experiences of families in family cases. Dallos and Denford (2008) have recently used a combination of qualitative methods, including IPA and discourse analysis to look at the experiences of families in relation to eating disorders and attachment. Dallos and Denford analysed the experiences of four families and drew out salient findings that encapsulated both the individual and shared experiences of each family. Haddad (2007) used IPA in a series of four family case studies to look at the way family therapists understood the impact of therapy on each family. There is no single recommended or established qualitative method to analyse whole families, but IPA appeared to be able to meet the purpose and aims of the current exploratory study, namely that it could lead to an understanding of the
unique experience of each individual family affected by a dual diagnosis of learning disability and psychosis.

4.3.1 Personal dilemmas faced by the researcher

During the research process, a number of dilemmas arose at each stage for me as a researcher. While these are not necessarily classed as limitations of the study, they posed some interesting questions and challenges which are important to reflect on in relation to the current and future research studies using a similar population of people or employing similar methods or methodology.

During the interview and analysis process, the accounts of the family members in one family case were interpreted to be particularly negative about their relative with a learning disability. These examples posed several dilemmas in knowing what to include and how to respectfully convey their accounts and the interpretations of those accounts. This situation was experienced as being quite difficult for the researcher as the views conveyed of their relative with a learning disability were incongruent with the views and beliefs of the researcher in relation to people with learning disabilities. In particular, the use of language to describe certain aspects of their relative and to attribute and locate difficulties as being inherently within the person also aroused strong feelings in the researcher. Though these reactions and impressions may have formed part of the interpretative process, personal reactions also needed to be suppressed during the research interviews. However, it is also important that such negative or difficult experiences are acknowledged, interpreted and discussed as they represent the lived experience of people dealing with learning disability and psychosis. Clear (1999) discusses how potentially difficult or ‘politically incorrect’ views and experiences should not be dismissed or disguised if they do not fit comfortably with the dominant or preferred discourses surrounding the issues under study. Though this is a potential difficulty for many qualitative researchers, the design of the current study in that accounts were analysed in family cases may have heightened this dilemma.
4.4 Implications for clinical practice and further research

The exploratory nature of the study and the fact that there is a dearth of research in this area gives licence for a number of creative ideas and implications to be drawn from the current findings in relation to clinical practice, service and research contexts.

The current study has highlighted the potential value of looking simultaneously at the experiences of people with a dual diagnosis of a learning disability and a psychotic illness and their family members. The use of Rolland's (1987, 1994) conceptual framework of chronic illness and the lifecycle may provide a useful model to integrate these concepts to enable clinicians, service users and families to understand the complex interactions between these dimensions. Rolland's model considers the system created at the interface of a chronic illness with a focus on individual, illness and family developmental lifecycles. Locating Rolland's model within the social, historical, political and cultural context that surrounds and connects with these three threads may provide a model for beginning to understand the experiences of each family faced with dual diagnosis. The use of this model may also link in with the move towards non-deficit models of functioning to conceptualise individual difficulties and family functioning (Hawley & DeHaan, 1996; Grant & Whittell, 2000; Grant & Ramcharan, 2001). To date, Rolland's model has been applied mainly to chronic illnesses affecting physical health, though there is some research citing the use of this framework in bridging biopsychosocial models of schizophrenia and family dynamics (Tienarri, Wynne & Wahlberg, 2006) though as yet, this model has not been applied to families with a relative with a learning disability and a psychotic illness.

The sharing of experiences may enable people with learning disabilities and their family members to develop a personalised understanding of the ways in which their lives have been touched by the experiences linked to learning disability and psychosis. Such approaches have been outlined and espoused in relation to the psychotic experiences of people in the general population who do not have a learning disability (BPS, 2000b), though this philosophy and approach has not yet penetrated learning disability services. Such approaches may be helpful to enable people with learning disabilities and their family members integrate and attach meaning to their experiences in a way that prioritises their
own views and understandings rather than those of the dominant professional network. The findings from this study suggest that a further consideration of such approaches may be useful.

The use of systemically-orientated therapies such as narrative therapy (Scior & Lynggaard, 2006) and family therapy may also be valuable endeavours in view of some of the themes, issues and processes identified that may have affected the lives of people with a learning disability and their families in this study.

Further qualitative research in this area would be useful to develop understandings of the experience of learning disability and psychosis from multiple perspectives. This may take the form of replications of the current study, particularly using IPA and other qualitative methods. Longitudinal studies which look at the needs and coping approaches of families over the lifecycle as they face transitions may also be helpful to further develop research and knowledge in this area.

A number of important service implications may be drawn from the findings of the current study. These include the importance of information sharing and transparency at multiple levels about the way the service works and makes decisions. Ultimately, inviting and listening to the views and ideas of the person with a learning disability and their family members is imperative to ensure that they feel heard and a collaborative working relationship can be forged where their perspectives are synthesised with other forms of information, e.g. assessments by health professionals. The current study has identified that the family members of people with learning disabilities and a diagnosis of a psychotic illness may have needs which are not currently being assessed or met by some services. An awareness of the needs of family members may prompt audits of local need in services to establish whether and what the needs of families are and how services could respond to meet those needs.
4.5 Conclusions

The current study aimed to offer an in-depth insight through the use of IPA into the experiences of people with a dual diagnosis of a significant learning disability and a psychotic illness and the experiences of two of their family members. The combination of a social constructionist and systemic lens has been useful in eliciting and analysing the accounts of experience that emerged. The clinical, research and service implications and suggestions arising from the findings of the study present very real opportunities for clinicians and researchers to contribute to the development of knowledge, understanding and theory in this area.
5.0 References


O’Brien, G. (2002). Dual diagnosis in offenders with intellectual disability: setting research priorities: a review of research findings concerning psychiatric disorder (excluding


Appendix 1:

*Ethical approval documentation*
20 September 2007

Ms Joanne Coombs
Trainee Clinical Psychology

Dear Ms Coombs

Full title of study: The experience of dual diagnosis in learning disability: An exploratory IPA study of people with a learning disability and their core family members

REC reference number: 07/H0808/119

Thank you for your letter of 6th September 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

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<tr>
<th>Document</th>
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<tbody>
<tr>
<td>Application</td>
<td>5.4 dated 30/07/2007</td>
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<tr>
<td>Investigator CV</td>
<td>Ms Jo Coombs</td>
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<tr>
<td>Protocol</td>
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<td>Covering Letter</td>
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<td>Interview Schedule</td>
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This letter is an advisory committee to London and represents the views of the National Patient Safety Agency and Research Ethics Committees in England.
R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.


Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at: https://www.nresform.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx

We value your views and comments and will use them to inform the operational process and further improve our service.

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With the Committee’s best wishes for the success of this project

Yours sincerely

[Signature]

Dr
Chair

Email:

Enclosures: Standard approval conditions
Site approval form

Copy to:

An advisory committee to the Strategic Health Authority
The notes column may be used by the main REC to record any early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension or termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.

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**Date of Issue:** 20/09/2007

**Full Title of Study:**

**Research Leader:** Ms Joanne Coombs

**Date of Review:** 20/09/2007

**REc Reference Number:** 07/H0808/119

The study was given a favourable ethical opinion by the Research Ethics Committee.

**List of Sites with a Favourable Ethical Opinion**

Research Ethics Committee
22 October 2007

Dear Ms Coombs,

Lead researcher: Joanne Coombs
Project title: The experience of dual diagnosis in learning disability: an exploratory IPA study of people with learning disability and their core family members
R&D Reference: ReDA 250/C
REC reference: 07/H0808/119

Thank you for providing us with the documentation listed below relating to your research project.

I am satisfied that your proposal and documentation meet with the requirements of the Research Governance Framework (DH 2005) and approve your project on behalf of subject to the conditions listed overleaf.

<table>
<thead>
<tr>
<th>Documents Received &amp; Approved</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Ethics application form</td>
<td>✓</td>
<td></td>
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<tr>
<td>SSI form</td>
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<tr>
<td>Ethics approval letter</td>
<td>✓</td>
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<tr>
<td>Final version of Participants’ Information Sheet (PIS) on headed paper</td>
<td>✓</td>
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<tr>
<td>Letter from sponsor and/or signed page on ethics form</td>
<td>✓</td>
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<tr>
<td>Protocol</td>
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<td>MHRA letter</td>
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If you require any further information, do not hesitate to contact me at the above address

Yours sincerely,

Consultant in Public Health Intelligence
The above study is approved subject to the following conditions:

1. The study must adhere to the requirements of the Department of Health's Research Governance Framework for Health and Social Care (2005).

2. The protocol approved by the Research Ethics Committee (REC) must be followed and any changes only adopted according to your REC approval. Changes must be reported to us. Please also inform us if the project is discontinued or suspended for more than 6 months.

3. There will be no call upon PCT resources other than any mentioned in the application.

4. The PCT must be notified promptly of any adverse incidents involving PCT patients, staff or anyone else, that occur during or as a result of this research. The contact is given in the enclosed letter.

5. Your organisation must have in place procedures for detecting and dealing with misconduct and fraud. All researchers must be aware of these procedures and any instances must be reported to us. Alternatively suspected incidents may be reported, in confidence, directly to us.

6. Unless you request otherwise, we will include details of this project on the National Research Register (NRR), and the PCT and sector databases.

7. We will ask you to provide a brief progress report on each anniversary of this approval and on completion. You should notify us when your practical work in this area is finished and send us a copy of your final report and/or a summary of your findings.

8. This project may be audited to ensure the requirements of the Research Governance Framework are being met.
Appendix 2:

Letter to Chair of Ethics Committee (amendment)
10th March 2008

Dear [Name]

Title of study: The experience of dual diagnosis in learning disability: An exploratory IPA study of people with a learning disability and their core family members

REC Reference number: 07/H0808/119

I write to inform you of a slight amendment to the procedure of identifying and approaching participants in the study named above. In the original proposal, I outlined that potential participants for the research study would be identified by the Consultant Psychiatrist of the [name of service] in which the study was being conducted. Due to the work demands of the Consultant Psychiatrist and the impending deadline of the research project for submission to the University of Surrey, it has been difficult to identify and approach a sufficient number of potential participants for the study. Therefore I plan to liaise with a clinical psychologist in the [name of service] to identify potential participants for the research study. The psychologist is also the field supervisor of the study and works in the same team in which the research has ethical approval to be conducted so there are no changes to the areas/team in which the research in being carried out.

I look forward to hearing from you soon with regard to whether this amendment is acceptable.

Yours sincerely

Joanne Coombs
Trainee Clinical Psychologist
Appendix 3:

Information sheet for participants with a learning disability
Information about the research

This study looks at: My experiences of a mental health problem and the experiences of two of my family members.

A psychologist is doing some research into people's experiences of having a mental health problem. This is to help the psychologist with her university degree. The research will look at the experiences of people who have a mental health problem. It will also look at the experiences of family members.

Dr Pickard, the Doctor at Geoffrey Harris House, has said it is ok for me to contact you. I would like to ask you to read this information and think about whether you would like to help in the research.

WHAT IS THE RESEARCH ABOUT?

The research study will look at your experience of having a mental health problem. The researcher, Jo, would like
to talk to you about your experience of psychosis / schizophrenia (name of diagnosis).

The research will also look at what your family members think. If you wanted to help with the research, you will be asked to choose two members of your family who are important to you. Jo will ask them if they would like to help with the research as well.

WHY IS THE RESEARCH IMPORTANT?

The research is important because it will help the Learning Disability service to understand your experiences better. It will tell services how to give you more help and support.

WHAT WILL HAPPEN IF I WANT TO HELP WITH THE RESEARCH?

- Jo will telephone you to ask if you want to help with the research. You can ask her any questions and she can tell you more about what will happen.
• If you say you want to take part in the research, Jo will ask you to choose two family members who are important to you. Jo will ask them if they would like to help with the research as well.

• If your family members want to help with the research, Jo will then ask you and your family members to read and sign a consent form. This form tells you about your rights if you take part in the study.

• Jo will arrange a time to come and talk to you and ask you some questions about your experiences. Jo will also arrange to talk to your two family members. Jo will tape-record the meetings so she can remember what you have said.

• Jo will also be talking to other people who have a mental health problem. She will write a report about the research. No one will be able to tell who you are by reading the report.
• Jo will then come and talk to you again to tell you what the research found. She will ask you what you think about it.

Please think about whether you would like to help with the research. It is ok if you do not want to help with the research - just tell Jo or your carer. Jo will contact you soon to ask if you want to help.

You can ask your carer to help you read and understand this information.

Thank you for reading this information.
Appendix 4:

Information sheet for family member participants
Participant Information Sheet

Information for family members

Title of study: ‘Dual diagnosis in learning disability: An exploratory Interpretative Phenomenological Analysis (IPA) study of people with a learning disability and their core family members’

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you and for your relative(s). Please take your time to read the following information carefully. Talk to others about the study if you wish and please feel free to ask any questions you have at any time.

Part 1 tells you about the purpose of the study and what will happen to you and your family member(s) if you decide to take part.

Part 2 gives you more detailed information about the conduct of the study and your rights if you decide to take part.

PART 1 – PURPOSE OF THE RESEARCH STUDY

What is the purpose of the study?

This study aims to explore the experiences of people with a learning disability who have also been diagnosed with a mental health problem. Specifically, we are looking at people who have been diagnosed with a psychotic illness in the past five years. By this, we mean people with a learning disability who have experienced phenomena like hearing voices, seeing things, feeling worried that people are ‘out to get them’ etc. There is not much research in this area and this study aims to provide an insight into these experiences for people with a learning disability and help researchers and clinicians to understand these experiences and to provide better support.

The study also looks at the experiences of family members of people with a learning disability and an additional diagnosis of a psychotic illness. This is because we know how important family members are in the care of their relatives with a learning disability. We feel that the views of family members are important in their own right and can help provide a detailed insight into such experiences.
The study looks at the experiences of a person with a learning disability who have experienced or currently experience psychotic phenomena. It also looks at the experiences of two of their family members who he/she feel are important in his/her lives and in his/her care.

**Why have I been invited to take part?**

You have been invited to take part as your relative who is under the care of the [name of location] Joint Community Team for People with Learning Disabilities has been identified as someone who may like to take part in the study. We have spoken to your relative and he/she have said they would like to take part in the study. He/she has identified you as an important family member in their life and given us permission to contact you.

We would like to invite you to take part in the study. The study involves talking to four people with a learning disability and an additional diagnosis of a psychotic illness and two of their family members (for each person). All together, 12 people will be involved in the study.

**Do I have to take part?**

It is up to you to decide whether you would like to take part in the study. Your relative has said they would like to take part in the study. If you agree to take part then we can involve you and your relative(s) in the study. If you decide not to take part, then we will ask your relative whether there is another family member he/she consider important in his/her life who he/she is happy for us to contact. If not, we would like to thank you for your time and will explain to your relative that he/she will not be included within the study.

If you decide you would like to take part, then we will ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care which you or your relative receives.

**What will happen to me if I take part?**

We will contact you by telephone approximately one week from when this information was sent to you to answer any questions you may have and invite you to take part in the study. If you decide you would like to take part, this would involve:

- Arranging a date, time and venue to conduct an interview with you. We can discuss where best to hold the interview. The interview would last approximately one hour and is fairly open and will ask you a number of questions about your thoughts and experiences in relation to your relative with a learning disability who has experienced a psychotic illness.
• The interview will be audio-recorded so that it can be transcribed and then analysed to look for themes and interesting ideas about your experiences.

• We will then arrange a time to meet with you again in approximately May / June 2008 to give you some information about the findings of the study and invite you to give feedback about what you think. This meeting will also be audio-recorded and transcribed so it can be used in the report. This is to ensure that your views have been fairly represented.

• The same things will also happen to your relative who has identified you as important in his/her life and also to another relative identified as being important.

The audio-recordings will be kept securely in a locked cabinet to which only the researcher has access. They will be kept for three years after the study has been completed. The interview transcripts will be anonymised so that neither you or your family members can be identified from the transcripts. It may also be necessary to use direct quotations from the interviews to illustrate certain ideas in the report but these will also be anonymised so no one will be able to tell who you are.

A report will be written summarising the research study and this will be included as part of an education portfolio of work at the University of Surrey and may be published in academic journals to share the findings of the research with other researchers and clinicians. The same rules about confidentiality apply here in that all personal details will be anonymised so you will not be identifiable.

What are the possible disadvantages or risks of taking part?

There are minimal risks or disadvantages to taking part in this study. However, the nature of the experiences being discussed may be potentially upsetting for you. The interviewer will give you plenty of time to think about and answer all of the questions in the interview and you do not have to answer any questions with which you feel uncomfortable. If you want to stop the interview at any time, then tell the interviewer and that will be fine. The study will require you to take part in two meetings; one hour-long interview and a feedback session of approximately 30 minutes. You can negotiate appropriate dates, times and venues with the interviewer.

What are the possible benefits of taking part?

In the same way that discussing your thoughts and experiences in relation to your relative with a learning disability and a diagnosis of a psychotic illness may have the potential to be
slightly upsetting, talking about those experiences also has the potential to be helpful by allowing you to discuss your views, thoughts and experiences.

We cannot promise that taking part in this research study will have direct beneficial consequences for you, but the information we get from this study will help give an insight into such experiences and help improve the understanding and support available from researchers and clinicians.

What happens when the research study stops?

When the research study is finished, it will be written up in a report for educational qualification and in academic journals to allow it to be circulated to other people within the field of learning disabilities and mental health. The interview transcripts and audio-tapes will be kept for three years following the completion of the study and attainment of educational qualification and then destroyed.

PART 2 – YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY

If you decide to take part in this study, you are protected by certain rights and it is important that you are aware of them before giving consent to take part if you wish to. The answers to some common questions about participant rights are outlined below:

What will happen if I start the study and then decide I don’t want to carry on?

You may withdraw your contribution from the study at any point and do not have to give a reason for doing so. Withdrawing from the study will not compromise your care and support or that given to your relative(s). If you decide to withdraw from the study, all materials (e.g. audio-tapes and interview transcripts) will be physically destroyed and no information about you or your relative(s) will be included within the study.

What if there is a problem?

If you have concerns about any aspect of the study then you can contact the researcher and / or the supervisors and they will do their best to answer your questions (contact details are given at the end of this section). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the researcher.
If there is a problem in terms of a disclosure of risk or harm made at any point during the research process, the researcher will be obliged to follow specific procedures to report the disclosure and deal with it appropriately. You will be informed of any procedures arising from this situation.

**Will my taking part in this study be kept confidential?**

The audio-tapes from the interview and feedback session will be transcribed verbatim. The audio-tapes will be kept securely in a locked cabinet to which only the researcher has access. All personal information that may identify participants will be anonymised (e.g. using pseudonyms and not real names). The interview transcripts will be analysed by the researcher and also available for viewing by the supervisors, and examiners at the University of Surrey. Interview transcripts will be included in the appendices of the report written for academic qualification and kept for personal use by the researcher and for three years by the University of Surrey. Audio tapes will be destroyed three years after the completion of the study.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the Kings College Hospital Research Ethics Committee.

In addition, the research conduct and process is being supervised by two clinical psychologists who have expertise in the fields of learning disabilities and qualitative research to ensure that the research is conducted to the highest standards and is ethical.

**Further information and contact details**

The details of the researcher conducting the study are given below:

Joanne Coombs  
Trainee Clinical Psychologist  
c/o PsychD Clinical Psychology Department  
School of Human Sciences  
University of Surrey  
Guildford
Surrey
GU2 7XH

The details of the supervisors for this research study are:

Field supervisor (learning disabilities)  University supervisor (research)
Dr Julian Morris  Dr Paul Tibbles
Chartered Clinical Psychologist  Chartered Clinical Psychologist
c/o JCLDT  c/o PsychD Clinical Psychology
Rees House  School of Human Sciences
Morland Road  University of Surrey
Croydon  Guildford
CR0 6NA  Surrey
GU2 7XH

What will happen next?

Now that you have received and read this information sheet, the researcher will contact you to allow you to discuss any elements of the study and invite you to take part in the study.

If you decide to take part, they will send you a consent form to read, sign and send back. You will receive a copy of the consent form, a copy will be kept by the researcher and a copy put in the file at the learning disability service within which your relative is being supported.

Thank you for taking the time to read this information sheet and consider taking part in the study
Appendix 5:

Consent form for participants with a learning disability
Consent form

This research looks at: My experiences of a mental health problem and the experiences of two of my family members.

My name is:

Jo, who is doing some research, has spoken to me about her research. I have agreed to talk to her and take part in the research. I understand that I will be asked some questions about my mental health, what I think about things and what has happened to me.

Please tick box to agree: 

I have said it is ok for Jo to talk to two of my family members about my mental health and what they think about the things that have happened to me.

Please tick box to agree:

I understand that if I decide I don't want to take part in the research anymore then this is ok. No one will be cross with me if I change my mind. I can stop at any time I want. I can tell my carer or someone that knows me well if I get upset and would like some help.

Please tick box to agree:

It is ok for Jo to record the meetings we have and then write it down on a computer. It is ok to write down things I have said to use in the report. I understand that no-one will be able to guess who I am by reading what I have said.
Please tick box to agree:  

At the end of the research, Jo will write a report about the information we talked about. The report won't have any information about me in it and no one will know who I am by reading the report.

Please tick box to agree:  

I know that if there is anything I don't understand, I can ask and Jo will explain it to me.

Please tick box to agree:  

I would like to take part in this research.

Please tick box to agree:  

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Please sign your name below to say you agree with the information on this form:

Signed: ...............................................    Date: ............... 

Jo will sign her name below to say she agrees with the information on this form:

Researcher: ........................................    Date: ...............
Appendix 6:

Consent form for family member participants
Consent form for family members

Title of study: ‘The experience of dual diagnosis in learning disability: An exploratory IPA study of people with a learning disability and their core family members’

Name of researcher: Jo Coombs

Please initial box:

1. I confirm that I have read and understood the information sheet dated ...... (Version ...) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected.

3. I understand that as part of the research study, the interview and feedback session will be audio-recorded and transcribed verbatim by the researcher. I also understand that all information that may potentially identify me or my family will be anonymised to protect my identity and that of my family.

4. I understand that as part of qualitative research, it may be necessary to use direct quotations as part of the research report. I give permission for direct quotations to be used in the report and any publications arising from the research.

5. I agree to take part in the above study.

........................................... ........................................... ...........................................
Name  Signed  Date

........................................... ........................................... ...........................................
Name of researcher  Signed  Date
Appendix 7:

Interview schedule for participants with a learning disability
IPA interview schedule for person with a learning disability

Thank you for coming along to talk to me today. I am going to be asking you some questions about your mental health and your thoughts and feelings. If you don't want to answer a question then that's ok. Tell me and I will ask a different question. We can stop talking at any time so just tell me if you want to stop and that it ok. I am going to be tape recording what we talk about today and then writing it on a computer so I can look at what you have said for my research. I will change your name and things though, so that no one will be able to tell who you are if they read what you have said. Is that ok?

Welcome, rapport building and putting person at ease including:
Introductions – Hello, my name is Jo, I am the lady that sent you the information and spoke to you about helping with the study. Discuss various things such as how they got here today, what they have been doing, things they enjoy doing etc.

Reiterate what we will be doing today:
Today we are going to talk about what you think and feel about living with a mental health problem. I will be asking you some questions about different things. Please try and answer all the questions as much as you can. Remember that there are no right or wrong answers, I just want you to tell me what you think about things. Tell me if there are any questions you don't want to answer. I don't mind if you don't want to answer any questions. Tell me if you want me to explain the questions any more. We can stop at any time if you don't want to talk anymore. Is that ok? Leading on to...

Reassess consent to take part:
After explaining what we will be talking about and doing today, ask whether they are still happy to take part / help with the study. Is it still ok to tape-record the interview? If say yes, can carry on.

Knowledge of diagnosis of mental health problem
Give some background information reiterating that we are going to talk about their experience of a mental health problem and gently enquire...

• Can you tell me about your mental health problem?

Prompt questions:
• What do you know about it?
• Who told you about it?
• What do you think it means?
• What does it mean to you?
• What do you think it is?
• How long have you had it?
• When did the Doctor tell you about it? What did they say?

Experience in general of living with a diagnosis of a psychotic illness

• Can you tell me what it is like having ...... (name of diagnosis in the language that the person has used to described it)?

Prompt questions:
• What happens to you?
• What does it feel like?
• How does it make you feel?
• What does it make you think?
• What do you think about it?
• Has it changed over time?
• Can you tell me what has been the most upsetting thing for you about living with .......
• Is there anything that is ok about living with .......?
• What makes it better?
• What makes it worse?
• What makes it easier to live with?
• What has helped you to cope / live with it? / Do you do anything to make it better?

Prompts include:
• People?
• Medication?
• Things they do to help it?
• What things have made it difficult to deal with?

Experiences of and relationships with services and network of care
Elicit background information about what services they receive using prompts such as asking about Dr [name of consultant psychiatrist], their carers / support workers / keyworkers etc.

Prompt questions:
• How does ..... (name of person or service) help you with your diagnosis?
• What do they do to help you?
• Is there anything that you would like them to do that they don’t do already?
• What has been the most helpful thing that (person or service) has done for you to help you with your diagnosis?
• What have been the less helpful things that (person or service) has done in relation to the diagnosis?
• What would help you even more?

Views of the experiences of their family members
Reiterate that I will also be talking to two of their family members and ask questions around what family members may think of their experiences / their view of it, including:
• Can you tell me a bit about your family?

Prompt questions:
• Who is in your family?
• Who is important to you?
• What do you like about your family?
• What do you think your family think about it?
• What do you think ..... thinks about it? (ask about each family member being interviewed separately)

Prompt questions include:
• Are they happy about it?
• Are they sad about it?
• What makes them happy / sad / ....... about it?
• How have your family helped you?
• Is there anything that your family have done that hasn’t been helpful?
Appendix 8:

Interview schedule for family member participants
IPA interview schedule for family members

Firstly, thank you for agreeing to take part in the study. As part of our PsychD Clinical psychology course I am conducting a piece of research into the experiences of people with a learning disability who have received an additional diagnosis of a psychotic illness within the past five years. I have a number of exploratory questions I would like to ask you around this topic. Please answer as fully, openly and honestly as you can, however you do not have to answer any questions you feel uncomfortable with and we can stop the interview at any time. If it’s ok, I will be tape-recording the interview (ask if ok / for consent). The interview will then be transcribed verbatim and analysed, along with a number of other interviews in an attempt to look for themes that may help me to understand the research topic a bit better. The transcripts will be kept for three years after the date of our graduation and then automatically destroyed. However, all personal or identifying details will be anonymised when the transcript is being analysed. Do you have any questions that you would like to ask or is there anything you would like me to clarify?

Experience in general

- Can you start off by telling me a bit about the background to the diagnosis, such as what diagnosis was made, what happened prior to and after the diagnosis was made?
- Can you tell me what you know / understand about the diagnosis that has been made?
- Can you tell me about what the most difficult things were for you?
- Can you tell me about any aspects of your experience that were ok for you?
- Can you tell me about how the diagnosis and any experiences that it brought affected you personally?

View of the experience of the family member with a learning disability

- Can you tell me a bit about …….'s experience of the diagnosis (name of illness diagnosed) was / is?
- What do you think their understanding of the diagnosis is in terms of what it is, how it affects them etc?
- Is there anything that you think was the most upsetting or difficult for them?
- Is there anything that you think they coped particularly well with?
- What do you think has helped them to cope / adapt?

Coping / adaptation

- Can you tell me a bit about if and how you have managed to cope with the diagnosis and the experiences it brought?
- Where do you feel you are now in relation to understanding the diagnosis?
- Where do you feel you are now in relation to coping with the diagnosis?
- What factors helped to facilitate your coping / adaptation?
- What things were not so helpful in facilitating coping / adaptation to the diagnosis?
• Is there anything that could have been done differently that may have facilitated your coping and adaptation to the diagnosis?

Relationships within the family
• Can you tell me about if and how the …… (name of diagnosis) affected relationships within the family?
• Prompts dependent upon structure of the family unit – ask questions around relationships between different members of the family.

Relationships with the wider system / healthcare profession
• Can you tell me about any help or support you received from services?
• What was the most helpful thing from services?
• What were the least helpful things about / from services?
• Is there anything you think could have been done differently that would have been more helpful?
• Is there anything that you would benefit from now?
• Miracle question – what would be your ideal service / what help and support would you have?
• What is your relationship with different services now? How has it changed over time?
Appendix 9:

Summary of the main issues arising from the discussion with the Consultant

Psychiatrist
Summary of the main issues arising from the discussion with the Consultant Psychiatrist in Learning Disabilities

Service issues

Resource constraints were identified as a major issue that mediated the level of services and care that could be given to people with learning disabilities and indeed, their families (e.g. carers assessments). The implementation of the enhanced Care Programme Approach (CPA) was identified as a significant turning point in enhancing the effectiveness of the treatment and management of mental health difficulties in people with learning disabilities. The Consultant reflected on how the historical dominance of the medical model may have led to inadequate service provision and treatment for people with learning disabilities whose mental health difficulties were managed with unsuitable medication and not regularly reviewed. This was linked to the processes of institutionalisation which underpinned a very authoritarian model of care which was characterised by limited assessment and treatment options. The ability of generic inpatient mental health services to identify and meet the needs of people with learning disabilities and mental health problems was identified as suboptimal in most cases. This was attributed to a lack of specialist knowledge and skills in working with people with a dual diagnosis of learning disability and a psychotic illness which often led to diagnostic overshadowing. The complexity of mental health difficulties in people with learning disabilities was considered to require specialist assessment and treatment and it was deemed necessary to have more time to unpick the complex interconnection of factors affecting the individual’s presentation.

Helpful aspects of the service and care

Good quality treatment and care was linked to the effective implementation of enhanced CPA, medication, well-trained staff who were familiar with the issues pertaining to and working with people with learning disabilities and mental health problems, psychoeducation about psychosis/schizophrenia and medication, psychological interventions such as targeted Cognitive-Behavioural Therapy (CBT) and educational approaches for family members. A multi-disciplinary input and team approach was also identified as being an important factor affecting the efficacy and effectiveness of the treatment and management of psychotic illnesses in people with learning disabilities. The Consultant also perceived that people were uniformly better overall when they had been
detained under the Mental Health Act and discharged under Section 117 (compulsory aftercare)

Issues in the recognition and diagnosis of mental health problems, particularly psychosis and schizophrenia in people with learning disabilities

Diagnostic overshadowing featured as one of the main difficulties that hindered the recognition and diagnosis of mental health problems in people with learning disabilities. In addition, difficulties in applying psychiatric diagnoses to people with learning disabilities in view of communication difficulties, particularly for the more subtle signs of psychosis. This was acknowledged as being linked to the low reliability and validity of psychiatric diagnoses in people with learning disabilities. Furthermore, it was suggested that certain changes and symptoms may be noticed but not recognised/acknowledged as a constellation of symptoms that form a specific illness. This could lead to the under-diagnosis of mental health difficulties in people with learning disabilities and may be linked to diagnostic overshadowing and also the abilities of people with learning disabilities to understand and convey their experience to people around them.

The experience of psychosis/schizophrenia for people with learning disabilities

The Consultant anticipated that it may be difficult for some people with learning disabilities to make sense of their experiences and that psychotic experiences may be distressing, frightening and difficult to understand. However, the Consultant stated that the experiences of people with learning disabilities may be mediated by other factors such as level of learning disability and other comorbid problems.

Issues for family members

Linked to the 'service issues' identified above, there was an acknowledgement that although carers assessments were available, they were not routinely offered to all families and/or carers. The Consultant anticipated that the onset and diagnosis of a mental health problem may be difficult for the family members of people with learning disabilities to deal
with and that such news may reactivate grief reactions linked to the initial diagnosis of a learning disability. Other anticipated reactions included denial, anger, sadness and anxiety about the future. The stigma associated with mental health difficulties was also identified as a factor that may influence their response to a diagnosis of a mental health problem such as psychosis or schizophrenia. It was also acknowledged that many people with learning disabilities are able to make significant recoveries from psychosis/schizophrenia and that the difficult or negative aspects of the experience for them and their family members may be mitigated by being able to glean positive things from the experience.
Appendix 10:

Table of superordinate and subordinate themes with supporting extracts for the
Foley family
Tables of superordinate and subordinate themes with supporting extracts for the Foley family

Key: **Superordinate theme** (bold)

*Subordinate theme* (italics)

**Course of the illness**

*Insidious onset and nature*

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<tr>
<th>Simon</th>
<th>Gillian</th>
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<tr>
<td>“As I said, the learning disability wasn’t too bad at the time and he was doing lots of things, but at that time, he was a bit funny, when he was watching telly, from that time 1999 to 2000. Watching telly, and so... Err, he said “I’m afraid of football”, he didn’t like to watch the football anymore from that time. He said he could see things on the telly that I really... I really underestimated... I thought because of learning disability. I couldn’t see it quick, see, so all along” (lines 27-34)</td>
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<td>“So the car sometimes so Simon, I asked him and he said “oh, not only here, I did it down there, when you asked me to buy something from the other street”. So I say “what is wrong?”” (lines 136-139)</td>
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<td>“You can’t call that a disability at all, that was a mistake I made from the beginning, all those times, I thought it was disability and take it for granted so. Those mistakes, I think you shouldn’t make it at all. Because that time, I didn’t take him to see the doctor early, continuing a little bit before I went to see the doctor. The doctor encouraged me that when he...”</td>
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<th>Sally</th>
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<td>“I thought now with hindsight we should have spotted it. He said he didn’t like football and I think that might have been in 1999 or something and umm... Every time, you know, the news was on and it said ‘Manchester United won’ or whatever, he’d turn, he’d turn his face so you just thought, maybe we underestimated it then” (lines 14-18)</td>
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<td>“He kind of got a sort of nervous, I don’t know what it was, he started doing a sort of mmm mmm mmm, doing his mouth like that” (lines 26-27)</td>
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<tr>
<td>“Yeah it was around that time, he didn’t eat his food and he was starting the football thing so that’s when we started to think maybe you know, something’s not right” (lines 58-60)</td>
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was there, he was normal” (lines 448-453)

“You’d be surprised. “Oh yeah I’m fine”. Oh the way Simon answers questions” (lines 150-151)

“I thought it was, you know, I dunno, yeah, at that time, we didn’t think it was…” (lines 107-109)

“I didn’t know anything about psychosis or anything and I say, “oh, probably just developing, changing” or something like that” (lines 153-155)

“Everyone else was like, they didn’t notice because it was like, unless you looked hard, you’d probably think his face was slightly different, you couldn’t pinpoint it” (lines 400-402)

“So, is difficult really, it can deceive you in any way and err, just he say “don’t worry” and then he drag the money and go to the shop for me, went to the shops, squatting on the road like that” (lines 537-539)

Gradual development

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<th>Simon</th>
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<td>“So I told the doctor and he said “oh” and to the doctor, Simon seemed fine, “oh he looks fine”, so we went and the doctor said he does not seem too bad. Same thing, I’m coming down from the kitchen and he’s saying “I’m scared of this”, so eventually, we have to go and see the doctor again” (lines 52-56)</td>
<td>“It was, kind of. It’s like if someone said the situation, if someone had told me from beforehand, the situation’s going to end up like this I probably would have been a bit like ‘oh my gosh, that’s awful’ or think it’s scary or something but because it’s so gradual, everyone got used to it. I mean it’s very, because we didn’t really know it was a mental illness” (lines 269-273)</td>
<td>“One day, Simon seems fine and another day, it’s a different matter” (lines 127-128)</td>
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| “I don’t know, it’s not like you can rush it. You have to wait six weeks or something before any medication can kick in and it is an experimental condition in that you know, you can’t force it, you have to see what happens. So that’s why Simon was in like [name of assessment and treatment unit] for like two years so I don’t think you can like... In terms of getting him
the medication and stuff I don’t see how it could have been speeded up to be honest” (lines 1252-1258)

“It went on like that, all the time” (line 161)

“At the time they were saying is he harming himself and we were like ‘yeah’ and at that time he wasn’t harming anyone else but then because he pushed me over and everything they were like ‘well, he’s harming other people’” (lines 631-634)

“People should recognise this at the early stage anyway, when the person is born disability, up to 16 and all these things, they should notice that at that time, about that, after 16, 17, developing some other things stopping things, you have to see the doctor if that’s possible because watching this, I’m seeing a monster, I’m seeing this on the telly, not sleeping, monster, I can’t sleep, I can’t sleep, all those are things that, yeah... yeah... You can’t call that a disability at all, that was a mistake I made from the beginning, all those times” (lines 442-449)

“Gradually, you could see that, no, lots of, all those times, he was developing something different which I couldn’t notice at all” (lines 460-462)

“Because we’ve got some relatives who sometimes only see him once a year like at Christmas and they were like ‘yeah, you know, over a while, Simon just kind of got worse’” (lines 641-643)

Searching for an explanation

Diagnostic overshadowing

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<th>Simon</th>
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<tr>
<td>“He said he could see things on the telly that I really... I really underestimated... I thought because of learning disability. I couldn’t see it quick, see, so all along, I put it down to learning disability. I put it down to”</td>
<td>“If someone had said to me ‘oh that’s a mental illness’ then I would have said ‘no’ you know, Most people who know him know he’s got a learning disability or that he’s a bit odd kind of thing so no-one was like”</td>
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learning disability because he wasn’t doing anything bad, just saying “I scared of the football, I hear things, I...” (lines 32-36)

‘that’s bad’ kinda thing” (lines 46-49)

“All this time, I think it’s learning disability so I think that growing up, he’s developing all of these things...” (lines 39-40)

“I mean it’s very, because we didn’t really know it was a mental illness, we just used to think he’s got a learning disability and he’s getting older and people always used to tell us that people with learning disabilities, they get older, they start to realise that their life’s not like everyone else’s” (lines 272-276)

“I took him to see the Doctor. I took him to see the doctor, the G.P. The G.P. said “oh” and because when we went to see the doctor he was alright, he’s not too bad, learning disability... So when we went to see the doctor, the doctor said, “oh, you go to church” and I say he’s ok when we go to church but he’s sitting watching the telly and saying “the monsters” and all sorts of things that haven’t happened before, but now, he’s err, all this and so I say to the doctor “I think it’s something wrong” and the doctor said “oh, well I don’t think it’s too bad, I think he needs lots of activites”” (lines 42-50)

“You underestimate at the beginning, oh, it’s only a learning disability but it’s not. The boy has a mental problem now” (lines 192-194)

“This is why when the whole thing started, that I’m hearing all this, I took it for granted and thought that it was to do with err, disability or something. Eventually, you could see that hearing voices from television was not normal” (lines 369-372)

“More than disability, yeah, yeah, yeah” (line 375)
Looking for reasons/ways to explain

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<th>Simon</th>
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<td>&quot;No, no, people get diabetics&quot;</td>
<td>&quot;So he say &quot;it’s pictures, these pictures making me seeing all these ghosts&quot;. So we take the pictures, everything out of the room and he went back to sleep. Erm, so sometime he scream and I thought it even a pussycat and go back again &quot;Simon&quot; and all night, I couldn’t get back to sleep&quot; (lines 109-113)</td>
<td>&quot;Initially like ‘oh, why did you put that poster in his room’ because if the light’s shining through the window, it could be scared so we were like ‘look, take the poster down’. They said ‘you put that in there and now he’s getting nightmares’&quot; (lines 120-123)</td>
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<td>I: Oh, diabetics. What about diabetics?</td>
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<td>SF: People can’t eat sweet things.</td>
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<tr>
<td>I: Right, yeah</td>
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<tr>
<td>SF: Sweet things</td>
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<tr>
<td>I: Mmm, hmm</td>
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<td>SF: Thing is when you fall over, you can’t get up</td>
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<tr>
<td>I: Right, ok</td>
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<tr>
<td>SF: That’s another thing</td>
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<tr>
<td>I: Is that another thing that schizophrenia…?</td>
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<tr>
<td>SF: Yeah, that’s what I think</td>
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<tr>
<td>I: Oh right, ok</td>
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<tr>
<td>SF: And mental health</td>
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<tr>
<td>I: Schizophrenia is a mental health thing isn’t it?</td>
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<td>SF: You can’t walk and that, disabled” (lines 404-432)</td>
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<td>&quot;And I think that brought the whole problem on to when he had to be admitted to hospital” (lines 392-393)</td>
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<td>&quot;Because, that’s why he was, he locked himself in the toilet and the sister said &quot;Why did you scratch the wall?&quot;” (lines 394-396)</td>
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<td>&quot;Yeah. So then we were all saying well some things on TV are a bit scary” (lines 129-130)</td>
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<td>&quot;That’s when I said to Mum that I thought Simon might have taken the matches. I thought he’d chucked them in the bin ‘cos at that point he was getting a bit erratic so I thought</td>
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"So, I think err, so I don’t know, I was thinking, ‘is it because I do everything for Simon?’” (lines 425-426)

"That’s why I thought that Risperidone must have cleared his mind” (line 413)

"But I don’t know, thinking about the whole thing I really don’t know what happened to Simon, all of a sudden he changed like that and so, you don’t know how to...” (lines 430-432)

"I wasn’t sure and I started to think well he’s hearing things and seeing things, so maybe I’m starting to smell things you know, maybe I’m just being over sensitive” (lines 490-492)

"My big sister reminded me of something, when we were younger, ‘cos we’ve lived in this house for a long time now, and we went to the post box which is just up that end he started running on the road and I was thinking I forgot about that and Jane let go of both of our hands and we were about four and we were like running and he just run out on the road and then we had to run after him and then drivers were like ‘take control of your child’ kind of thing.. That’s when, I remember that when they said he was in the Autistic Spectrum, but yeah” (lines 920-927)

"I was first born so that’s why sometimes, he sees, I don’t know whether he sees himself as the oldest but we were both the youngest and we were both given the same kind of, we were always referred to as ‘the twins’” (lines 1093-1096)
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<tr>
<th>Simon</th>
<th>Gillian</th>
<th>Sally</th>
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<tr>
<td>&quot;Erm, err... [Pause] I do some stuff. I do some stuff I don't feel good inside&quot; (lines 27-28)</td>
<td>&quot;So he said, he himself told me &quot;I was really furious. I was annoyed&quot;&quot; (lines 216-217)</td>
<td>&quot;So that time was distressing, he was suffering so much, he doesn’t want to hear it, and he’d end up crying. I don’t know if Mum told you but he’d be kneeling on the road, trying to get knocked over&quot; (lines 318-320)</td>
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<td>&quot;Makes me feel not happy inside&quot; (line 85)</td>
<td>&quot;He said to me ‘Oh well, you shouldn’t have born me at all because I’m just nothing’” (lines 236-237)</td>
<td>&quot;I was like ‘what?!’. Just shock because at that time, he was getting much worse” (lines 325-326)</td>
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<td>&quot;It makes me angry&quot; (line 94)</td>
<td>&quot;I felt very very sorry for him, I cried a lot for what he was feeling” (lines 390-391)</td>
<td>&quot;I know he was scared but now he’s not scared but ‘why are you burning your face?’ and he was finally like, and I said to mum, ‘look, he’s burning his face’ but everyone was like ‘what?!’” (lines 432-434)</td>
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<td>&quot;Umm, erm, like I like to take the blame for things” (line 176)</td>
<td>&quot;The worst thing he did, with knocking himself and all that&quot; (line 716)</td>
<td>&quot;That’s when he got up now and pushed me over ‘cos I was getting, I was like ‘oh your hands, they’re gonna hurt’ so then he pushed me over onto the floor. I was so kind of shocked” (lines 582-584)</td>
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<td>&quot;Doing something silly” (line 193)</td>
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<td>&quot;After that, Mum was like, Mum got a bit upset. All of us were just like you know, it wasn’t even like everyone was crying or anything, we were just shocked, you know, just what’s happening here?” (lines 611-613)</td>
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<td>&quot;Not happy” (line 287)</td>
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<tr>
<td>&quot;Um, it makes me feel weak” (line 479)</td>
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<tr>
<td>&quot;I feel bad when I do it, when I say it I feel bad inside” (line 504)</td>
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<tr>
<td>&quot;I: Is there anything good about it?</td>
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<tr>
<td>SF: Err, not that I can think of” (lines 1197-1199)</td>
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## Coping and adaptation

### Strategies

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<td><strong>“Erm, I try to control it”</strong> (line 99)</td>
<td>“Err, there was, difficult thing is err, when err, I couldn’t notice it quicker and I underestimate it as a disability. Or what do you mean?” (lines 378-379)</td>
<td>“So we got to the stairs and Mum was like ‘are you sure?’ but I was like ‘Look, please Mum, just come’” (lines 499-501)</td>
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<tr>
<td><strong>“I try not to get angry sometimes and feel happy inside. Sometimes I don’t do it”</strong> (lines 103-104)</td>
<td>“But when mental problem cropped in, you don’t know how to handle that” (lines 436-437)</td>
<td>“I think only because so, everyone’s been so, we’re all supportive and stuff” (lines 893-894)</td>
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<td><strong>“Think good thoughts”</strong> (line 120)</td>
<td>“GF: Err, ok for me to handle you mean? I: Mmm. Or was it all very difficult? GF: Well, yeah, ok for me to handle when he was disability” (lines 606-608)</td>
<td>“I suppose, you know, everyone’s like it can’t get any worse. We’re all Christians, you know, we pray” (lines 952-953)</td>
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<td><strong>“Yeah, I had to see a psychologist about dogs. Dogs prefer food, not me”</strong> (lines 145-146)</td>
<td>“It’s happened. He’s doing very well the way I see it, yeah. He’s coping very well because when he comes here, he’s fine, yeah, he’s fine. He talks to me and we chat and he’s really well now” (lines 660-663)</td>
<td>“At times at the beginning, I was going and taking Simon to [name of learning disability service] and then when he went to [name of specialist learning disability and mental health service], [brother’s name] was involved a lot because he drives but then at that point it was like, he needs to know what’s going on too. Then at other times, if [brother’s name] couldn’t make it to the meetings so then [sister’s name] would go, so everyone’s been there, seen what’s going on” (lines 1181-1186)</td>
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<td><strong>“Think of good thoughts, not bad. Dogs don’t bite. Dogs eat but not Simon”</strong> (lines 306-307)</td>
<td>“Err, I think it’s only by the grace of god and err, we go to church and we pray and we come home and we ask Simon to pray himself, He prays. Err, that’s it, I think, yeah. Because err, just take it, err, as gradually. Just err, take it as its happen, it happens. Nothing else, so, that’s it, yeah” (lines 681-684)</td>
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<td><strong>“I talk to him about the leisure</strong></td>
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club, at Carshalton. I go there on a Friday, it was good” (lines 740-741)

“SF: Medication?
I: Yeah
SF: Yeah
I: Can you tell me how it helps you?
SF: It makes me feel better” (lines 906-914)

“I do Sudoku and drawing and word search” (line 1560)

“Talk to [name of friend], see him” (line 1374)

Changes

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<th>Simon</th>
<th>Gillian</th>
<th>Sally</th>
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<tr>
<td>“It’s changed over ten years” (line 952)</td>
<td>“Well, they are helping Simon and while they are helping Simon they are helping me” (lines 772-773)</td>
<td>“Personally, I spot people with mental illness a lot more now, you know if I take public transport, I can generally spot them a bit faster” (lines 676-677)</td>
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<td>“Got better” (line 969)</td>
<td>“Well, now Simon got his own place and he got his carers to help him and look after him, it’s a big help” (lines 778-779)</td>
<td>“I do understand a bit more and also I’m a music facilitator so sometimes I work with people with learning disabilities or mental illness so I have a lot of empathy” (lines 969-971)</td>
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<tr>
<td>“All I know is Simon’s health is getting better” (lines 789-790)</td>
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<td>“I just you know, treat everyone as normal, as you want to be treated. It’s an illness, and if you notice signs and I think I notice signs more than the average person” (lines 998-1000)</td>
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<td></td>
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<td>“I think the way we’ve had to adapt to things is to be more, a bit more tolerant” (lines 1014-1015)</td>
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"I think, well, yeah like. I might have mentioned earlier, all of us, I don't know whether to say that it's made us nicer but we all, understand people with learning disabilities a lot more. And even with the mental illness we have a lot more empathy for it. So yeah, that's helped" (lines 1102-1105)

**Relationship with services**

**Information sharing**

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<th>Simon</th>
<th>Gillian</th>
<th>Sally</th>
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<tr>
<td><strong>I:</strong> Do you remember what Dr [name of consultant psychiatrist] said about schizophrenia?</td>
<td>&quot;Then, he went to see the psychology and then it's when she mentioned something like autism, mild autism. So I said oh yeah, when he was in juniors and in infants, one of the teachers mentioned something like this before. I said, &quot;oh&quot;, I wasn't sure but she said it's something to do with autism or something like that. But she didn't go far about it. So, then Dr [surname of psychologist] said about it and she gave us a leaflet about all these things with autism and I was disturbed I guess. All this time I didn't know&quot; (lines 73-80)</td>
<td>&quot;I: Do you feel that you were? Do you feel that you were told what it was and that it was explained to you? SF: No, I don't. I don't know. No, I don't remember that&quot; (lines 141-143)</td>
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<tr>
<td>SF: No (lines 381-383)</td>
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<tr>
<td>&quot;SF: Spoken, spoken to us I: Spoken to you SF: Yeah I: What did he speak to you about that was helpful? SF: Schizophrenic&quot; (lines 1311-1319)</td>
<td>&quot;The tablet they gave him, and I think there was a time when one of the doctors said &quot;psychotic&quot; or something and I say is this something to do with him now?&quot; (lines 92-94)</td>
<td>&quot;So we didn’t really say, ‘Simon, you’re Autistic’ and I think he only really started going, oh, you know, ‘cos he kept hearing the word’ (lines 160-162)</td>
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<td>&quot;Show me the leaflet&quot; (line 1271)</td>
<td>&quot;GF: Oh well, all that they said, I know is err, a mental problem, more or less like the mind. Erm, (pause), is</td>
<td>&quot;Is this from when he went, 'cos it's only from around [name of assessment and treatment unit]&quot;</td>
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<tr>
<td>something to do with hearing voices, sometimes, hearing voices, the voice say do this, the voice say “do this” as if somebody talking to him.</td>
<td>time when they said ‘actually, he’s suffering from schizophrenia’” (lines 232-233)</td>
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<td>I: ... So that’s as much as you were told by the doctors? GF: “Yeah” (lines 342-347)</td>
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<td>“Well, Simon told me, the doctor told him that he had developed schizophrenia, that’s what he had told him. So probably he knew, but err, hearing voices and all sorts of things so yeah...” (lines 618-620)</td>
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<td>“Yeah, yeah. I think yeah, maybe before, just around before, maybe 2005, 2004ish, around that time when one of the psychiatrists or psychologists said ‘anti-psychotic’ and I was thinking ‘hold on, what’s that?”’ (lines 248-250)</td>
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<td>“She didn’t read up on the files or anything so she stuck her oar in and said ‘You can’t do this, you can’t do that, you need to cover yourself’ and I was a bit like, what are we talking about?” (lines 1193-1195)</td>
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<td>“So in terms of seeing the psychiatrist and things like that, we’re not really, we’re sort of out of that now so I don’t know what’s going on. It’s only when they have the meeting every six months that they might mention something but they don’t mention everything that happens I’ve noticed. I don’t know whether they’re trying to save us, or protect us. It’s not like we know every little thing now” (lines 1266-1272)</td>
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### Relationship with services

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<td>&quot;The following day I have to take him to see the doctor again. So when I went and I retell the whole story to the doctor and the doctor said &quot;Oh&quot;. I phoned first and they said to bring in next week and I say &quot;I'm sorry but next week is too late&quot;. Too late&quot; (Lines 268-271)</td>
<td>&quot;I was thinking back the other day and I was thinking actually, how did I not know? I didn't check up on anything, it wasn't like I thought I needed to go and check, we trusted the doctors you know&quot; (lines 200-202)</td>
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<td>&quot;I think it's the treatment, the doctors treatment is helping him to cope&quot; (lines 667-668)</td>
<td>&quot;No, no. Not have a clue at all and it was only before he was going to [name of assessment and treatment unit] or something that they said, 'oh yeah, he's on anti-psychotic drugs' or something that I, when we went to [name of learning disability day centre], well I didn't go 'what?!' or something. Yeah that's when I was just like, 'oh, ok'&quot; (lines 210-213)</td>
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Appendix 11:

Table of superordinate and subordinate themes with supporting extracts for the
Williams family
Table of superordinate and subordinate themes with supporting extracts for the Williams family

**Key:**

- **Superordinate theme (bold)**
- **Subordinate theme (italics)**

**Experience and understanding of psychosis**

**Experience of psychosis**

<table>
<thead>
<tr>
<th>Rebecca</th>
<th>Caroline</th>
<th>Thomas</th>
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<tr>
<td>“Used to hear voices and animals speak to me when I first was ill. Seeing like leopard and he often used to ask me how you keeping and that and then I heard another voice which used to tell me do things badly like harming yourself and that. That which made me upset. Used to get me down quite a lot. I’d go high and be really happy and bubbly and then go really low and down” (lines 9-12)</td>
<td>“One of the things she’d said was that people were following her, people were photographing her and coming into the garden to photograph her, that she was supposed to be, she’d promised to help these people and she was supposed to be working. She didn’t, when you asked her where she was supposed to be working or who she was supposed to be helping she didn’t know. Night times, she would walk the floors when we’d be trying to sleep” (lines 108-112)</td>
<td>“Yeah. I mean from the word go they was out, they started to come every day and obviously she didn’t want them here, obviously it was quite obvious and I mean, for Rebecca to go down and not wash, not have fresh clothing, I mean she used to go out, have a wash, have a bath, she was really proud of herself” (lines 78-80)</td>
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<td>“It wasn’t all that great. It’s depressing a lot. Umm, I’d find it hard to speak to questions to people, difficult. I’d have to have help with someone like [name of keyworker] checking out the situation for me. Umm, that’s about it really” (lines 89-91)</td>
<td>“But we didn’t know she was hearing voices until later on. For example, my husband came home one dinner time and she’d melted candle wax and poured it into a jar of Vaseline and said that’s where it belongs. I came home one day and she was cleaning my sideboard with vinegar because I had a bottle that I had been cleaning the windows with vinegar and water in it, she was cleaning the sideboard over there with that. Also, the cream that you use for cleaning your bike, you know, for stainless steel, she was cleaning my sideboard with. She thought this house was her and her brothers, that they owned it</td>
<td>“That’s what she used to hear, all these voices and everything, saying ‘no’, some saying ‘you don’t want to do that, that’s got mould in it type of thing’ and she used to sit there bless her and she used to sit there and I’ll always remember, on the other settee and she’d sit there, put her hands around her head and she’d say ‘oh dad, my head is aching, it is really really aching, I just don’t know what to do’” (lines 87-90)</td>
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and that her Dad and I were dossing here and we should clear off. Not in those words but I'm not going to say what she said. More or less clear off and go back to where you came from” (lines 121-128)

“I wasn't taking any medication. I was hearing voices it made it worse, I was telling people to shut up and things. Wasn't my normal self. I'd have arguments with my mum and dad. It'd get them depressed as well. All have arguments and wouldn't get n very well but now it's changed” (lines 106-108)

“She was walking down the back here shouting as if she was having a conversation. We couldn't see anybody but we later found out that those were the voices she was hearing, the she was shouting. When she was shouting, she wasn't necessarily shouting at you, she was shouting at the voices that she was hearing. We also found out later that she was seeing animals and the animals were talking to were friendly. She's not talked to, don't know about Thomas but she's not talked to me about what she was hearing or seeing that was upsetting her. She did say once to her dad that she couldn't cope with all the noise. You couldn't put your stereo on. She'd come down, turn it off, you'd put it on again and she'd turn it off.” (lines 134-140)

“First changes was when she, was when err. Ooh, late February, some when in February, her birthday's in February. We said then there's something wrong. She used to stand up and sing to herself. Well, she used to love music, any time she was bored she'd be upstairs and put a bit of music on and she'd start singing up there to herself while she was tidying her room up. February I think it was, not sure if it was late February that we found out she was... That's when she went down. She used to go out and she'd come in and we'd say 'did you manage to get that darling?' and she'd say 'what? oh I forgot she said. She'd say she'd had a wash when she didn't, clothes were still on her. 'You had a bath today?' I'd say, 'no' she said, 'I'm alright'. I said to her well... She didn't used to brush Iter hair or comb her hair and we used to see nits in it” (lines 101-108)

“One of them was a male, telling me to do things, one of them was a, used to change into a woman. Depends on how bad the voices were. It used to change its voice from being happy into a man's voice and then go high into a woman's voice” (lines 163-165)

“She used to hear people in the wall, animals coming out. Not like what we lass as horrible animals, like say low and calm. She would say 'oh, they're coming at me' and she would always hear all these different noises and one saying one thing and I couldn't tell you what it was but we'll say one saying 'no' and the other one saying 'go on, do it' sort of thing and she used to hear these quite regularly” (lines 162-165)

“But I never used to like it 'cos it used to frighten me” (line

“After that she seemed to go right down... more or less just
“And umm, and umm, they couldn't believe how ill I was because I wasn't eating then neither. I used to go out of windows, climb out of windows, talk to things, talk to flowers. Sometimes talk to someone that's not there, tell them to shut up, tell people to leave me alone, 'I don't want no dinner' or I swear at them. I, I just, that's another thing I used to do as well is swear at people. Use full blown language at people and they didn't like it 'cos they didn't know it wasn't me saying all that” (lines 321-325)

"Umm, there'd be good times when you have good days and wake up feeling great when I could go out and do things, feeling good or other days when I get my animal friend come back again and that used to cheer me up. When I used to hear voices, if I used to hear the good side, I used to only hear the animal voices, it's only if I get a mix up day if I hear both of them together and the voice change it would make me have a headache” (lines 465-469)

"Never used to be me when I was ill” (line 725)

"The voices used to help me. The one with the leopard I used to see, my last place which would have been in [location], I saw a leopard, a full grown leopard but I used to be, sometimes used to keep me happy and calm and it used to talk to me at night. I often used to sit there next to a radiator with it or sometimes it'd move but when people come it used to
go away. Only I could see it so I used to think it was a special thing altogether and it was nice that” (lines 122-126)

Understanding of experiences related to psychosis

<table>
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<tr>
<th>Rebecca</th>
<th>Caroline</th>
<th>Thomas</th>
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<tr>
<td>“I didn’t actually. I didn’t know until umm, someone told me that I was very ill and how ill I was... It was quite shocking actually, that someone would tell you that you’re that poorly” (lines 251-252 &amp; 300)</td>
<td>“That one I find a bit hard to answer really, you don’ cope you just sort of muddle through” (lines 607)</td>
<td>“I don’t think she really knew what was happening really. She just didn’t see what she was doing was wrong and thought she was doing right and other people were doing wrong. She didn’t want to know” (lines 281-283)</td>
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<tr>
<td>“Trying to cope with it because it’s an everyday illness. I still find it hard now, doing things but I’m beginning to manage it ok. I’m trying to cope with it much better” (lines 417-418)</td>
<td>“I think since she’s, from the first time she had her first injection...once she’d had that injection, she realised it affected her enough to make her realise that she needed help” (lines 339-340).</td>
<td>“I think, I mean we knew she was ill, we’d said it all the way along” (lines 16-17)</td>
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<td>“But you get over it eventually. It’s taken quite a few years to get over it. It’s taken me quite a long time to get where I am at the moment. Took me quite a while when I was really quite poorly but I did get better but it takes its day to day toll” (lines 1033-1035)</td>
<td>“She’s learning about it herself I think outside of the medical group or way of working” (Lines 712).</td>
<td>“Oh, she’s come to terms. She has come to terms with it and she even admits it that she was poorly, she says ‘yes dad, I was poorly, I don’t want to go down that road again’ and openly says that to you. You know, I said well ‘now you know, you was really ill’ and she said ‘I was but I must admit at the time’ she says ‘I didn’t even know’ and I said ‘no, none of us did’” (lines 296-299)</td>
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<td>“No, no, injections help me taking control of it. Calms everything down if I’ve got an injection. Umm, don’t hear so many voices” (line 1114)</td>
<td>“I don’t think Rebecca really understood what was happening. She was getting these voices and it wasn’t what, she wasn’t really talking to me about that side of it but when she used to argue... Since she’s talked, because whenever Rebecca’s in the mood to talk, we will sit and talk and sometimes it’s both of us, sometimes it’s one of us but you didn’t, you didn’t know that she”</td>
<td>“You know, I said in that respect we really didn’t know what was going on” (line 231)</td>
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was hearing voices but what she was saying and what she's said since is that she was hearing all these voices that were going round and round and she couldn't cope with them and the everyday noise and when she used to argue with you, a lot of it wasn't she was arguing with you, she was arguing with the voices. From what I can gather, you get the two sides, it's like a battle of two people, of two people in your head, of one saying perhaps good things and the other saying bad things and then you're also getting your own thoughts that are muddled. That's how I pick it up from Rebecca, from the voices side of it" (lines 433-441)

“Mum and dad listen to me when I’m talking... saying ‘don’t worry you’ll be ok but you can’t force it Rebecca, you are ill, you’ll have this for the rest of your life’...they talk to me quite a lot of things about when I was ill” (lines 685 & 694)

“I would say probably not understanding what was happening to her. Why, you know and she must have felt terribly alone because all the time she was living here, prior to being ill she’d always wanted to have her own little place. When she became ill she believed that she and her brother owned this place. She must have felt terribly alone, wondering what on earth was going on when she was picked up” (lines 461-464)

“I said ‘how bad was I?’ and they said ‘you was very bad, half the stuff you didn’t even know what you was doing’. Some of the stuff I can recap on what I was doing, the swearing I can remember from when I was ill” (lines 698-700)

“I think since she’s, from the first time she had her first injection, although the first time it was a case of a mattress down on the floor and quite a few members of staff making it safe for them and for Rebecca and it was very distressing for everybody, once she’d had that injection, she realised, it affected her enough to make her realise that she needed help. Yes, they’d been varying the dose but she now only has it, I don’t know if it’s every four weeks or calendar

“I’ve been, I think I’ve been more relaxed, more relaxed in myself and err, and more understanding I think now. I can understand why she’s being like it, why she was there, what made her go that way, it wasn’t the fault of her own, it wasn’t the fault of us and I think we’ve tried being a parents, we’ve tried our utmost” (lines 400-402)
month but approximately that sort of time and she’s realised the difference. She also has accepted that the way to help herself is to talk and she has opened up” (lines 507-512)

“I thought I was ok you see, thought you’d be fine but then you never are when you’re that poorly. It’s an everyday thing, you don’t get over it quickly, you get over it stage by stage. Like the time I thought you could recover from it quickly but it didn’t work like that” (lines 260-262)

“I think I’ve coped with it in terms that err, knowing what the doctors have said to me, I could understand, I could correspond with them a bit more now. At first I was more or less like a lemon, you know, didn’t know what was going on. Now they’ve explained everything, you can correspond with the more in that way and I think we both have in that respect and that we can both sort things out as we go along and it’s come more closer to us and I think you’ve got more closer now as a family than we ever were and we’re more closer than ever now as a pod as I say. I think we can understand the traumatics of it, of the voices err why she was like it. You just don’t know why she went like that, we don’t know to this day and err, if we did, I don’t think we’d be on this earth” (lines 407-413)

“Counsel work yeah. Right and err you talk to them and that helped me then in the end I went on my own, first of all it was me and Caroline and then I went on my own and err, told them what was happening and more or less what we’re doing now. I said yeah I’m coping alright but if it wasn’t for my wife, I said ‘I’d have committed suicide’ and I was taking tablets at the time and then I went and saw another doctor and they said yeah you are high [blood pressure] and I think you’d better and it’s only been for my wife, I’ve been supporting and she’s been supporting me but
apart from that I don’t think I’d have gone any other way really around it. Yeah, I go quiet every now and again, it’s only me thinking, thinking out loud, that’s me I’m afraid, it’s the way I am. I don’t think I’d do any different, don’t think I’d have gone any other way” (lines 487-494)

Impact on the family

<table>
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<tr>
<th>Rebecca</th>
<th>Caroline</th>
<th>Thomas</th>
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<td>“But when mum and dad were there they thought I was telling them to shut up, they thought I was being rude” (lines 149-150)</td>
<td>“So you’re getting torn in all directions and you just feel, well, I just felt a totally failure as a parent because you couldn’t, you were struggling to get help for…” (lines 262-263)</td>
<td>“This is when I said no, it’s driving me mad and then after that I went on to depression tablets. I went down to the doctors and they kept asking how she is and I said she hasn’t changed you know. We’re lodgers more or less, [name of brother] and Rebecca, they own the house. Why don’t you go and live down pompey go back to where you come from. I said, I was on depression tablets I reckon that if it wasn’t for me wife being supported as she was, I reckon I would have committed suicide” (lines 25-29)</td>
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<td>“So yeah, mum and dad found it, mum and dad found it quite hard actually, coping with it. Because you can tell, they had all red marks under their eyes. Both my husband and I were on anti-depressants through it. Barely coping and still nothing was happening” (lines 173-174)</td>
<td>“I just said to Caroline ‘I can’t handle this’” (line 21)</td>
<td>“I was going to work with bags under my eyes and they all said ‘How’s you coping?’ and I said ‘I don’t know what to do from one day to another’” (lines 41-42)</td>
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“Well, the atmosphere was quite happy, we was quite happy, could speak to anyone there was no problem, you could go and speak to my mum and dad and they’d be happy and talk to you, watch TV. The it was like argument, shouting, cross, angry, upsetting, very tearful for all of us. It would be quite sad, get you down a lot, get depressed so it would be all that ‘The most difficult things was that you’d gone from having a home, where you’ve got a loving family set up. Compared with a lot of people, we haven’t had a lot but what we have got, we’ve only had in the last ten or fifteen years but we’ve always been a loving, caring family and got through whatever we’ve had to get through and then to have it, what felt like totally...”
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<th>Page</th>
<th>Line Numbers</th>
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<tr>
<td>759-763</td>
<td>“Yeah, talking all the time, speak to you about anything, go out with my mates, have a great time going out places, going out on the train to places for a meal out, going bowling, whatever, be fun. Fun times. Then, it was like depressing sad times, angry times, all rolled into one. Depressing times, all three of those going on, three of those things rolled into one”</td>
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<td>244-247</td>
<td>“I’ve never ever known my husband, that he actually, he actually turned around and he said that he thought he could end it all. Umm, quite early on I could really understand when you hear these bits on the news where you hear that a family’s been wiped out. I could understand how somebody could get so desperate, it’s not right but I can see how somebody could get so desperate and do that”</td>
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<td>43-44</td>
<td>“There was one day when she went into work, and she went into work and then I gets a phone call. Caroline’s at work and she’s broken down like”</td>
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<td>255-259</td>
<td>“There was one day when she went into work, and she went into work and then I gets a phone call. Caroline’s at work and she’s broken down like”</td>
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<td>916-920</td>
<td>“My brother didn’t know that much about it ‘cos he wasn’t around. Umm, mum and dad know more because they’ve been in the same room as me when I’ve flared off. They’ve been upstairs and come in my room at the same time as me and putting me to bed and I told them I didn’t want to go to bed. Or they’ll be in the same room, like in the kitchen. When we were in the same house they knew what sort of problem I was going through so they got the full whack basically”</td>
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<td>370</td>
<td>“Umm, I don’t deal well with stress anymore”</td>
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<td>194-199</td>
<td>“Was seeing my family get broken up really. Not when I said broken up, I don’t mean departure and all this sort of thing, I mean, I could see my family together but going one way and Rebecca going another way but I knew deep down in my heart that something was wrong with her and she’s going to, she’s got to have something done to her, and Caroline and she was on depression tablets at the time as well. I think, to me, seeing my family just more or less I say dissolve, just dissolving around me, I think that’s what hurts. You’ve got to more or less see it to believe it sort of thing”</td>
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<td>899-902</td>
<td>“Well, it, when she was really ill, from the family unit of us four, it sort of broke the family unit. Umm, but we, we will always be, because of the way life had been within our families, we built up this little unit of four and we’d been a close unit and we decided that no matter what happens, Thomas and I did, we would always be there as best we could and we fought hard to build onto that relationship, to build it up again”</td>
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<td>265-267</td>
<td>“I have changed. Whereas I used to, if there was any arguments going on I’d pipe up and say look, that’s your mother your talking to’ whereas now I don’t want it. I just says if there’s going to be an argument, I can’t handle this, I just walk out. I know that I’ve changed in that respect and Caroline’s changed as well”</td>
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"Tried to do my utmost with say keeping the family together" (line 390)

"Err yeah she’s not the same, we know that, she’s not the same. If anything worries her, it does worry her whereas beforehand it used to fly over her shoulder, over her head, those little things" (lines 95-96)

Services

Unhelpful aspects of services

<table>
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<th>Rebecca</th>
<th>Caroline</th>
<th>Thomas</th>
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<td>&quot;Yeah when I were poorly. Yeah ’cos I had quite a few people, ladies and gentleman coming over assessing me and umm, talking to mum and dad, speaking to them asking how they was but it was mainly about me. Sometimes I didn’t like the questions they asked mum and dad ’cos half the time I was on my own like I’m talking to you but they wouldn’t like it, they’d want mum and dad out of the room you see and I’d say ‘why can’t you talk to them without them being here’ cos I didn’t mind mum and dad being there but they said it’s about you and I said well it don’t matter, my mum and dad are ere it doesn’t usually bother me. I said it normally, I normally let my mum and dad listen to me sometimes when like I say. Don’t think they liked it, think they was a bit offensive by it. So we was just talking on our own so yeah that made it more hassle as well. So didn’t go down too great I didn’t think&quot; (lines 274-283)</td>
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<td>&quot;Unfortunately, you see, the set up within the National Health at the moment is that you’ve umm, got each department’s got its own funding&quot; (lines 23-24)</td>
<td>&quot;Well, he left and he shook his head and he said ‘that girl is ill’ and I shook his hand and I said ‘you’re the only one person’ and I said it in front of all of them and I said ‘you’re the only person that has come straight out and said there is something wrong. I said ‘everybody else, we’ve been beating our head against a bloody wall’&quot; (lines 54-57)</td>
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308
“When I was slimmer I used to climb through the window and run away and they used to have to bring me back. I was on umm, oh what they called? It was umm, they tell you something you’re not allowed to go anywhere, you’re on section. So I wasn’t allowed to go anywhere so I used to run away from, used to tell my named nurse to go away and leave me alone ‘cos when I was ill, he gave me my injection but he gave me it forced ‘cos he twisted my arm around so I wouldn’t hurt myself but he literally twisted my arm around which really hurt” (lines 503-508)

“Instead of them sitting down and talking together and working it out, they are, there’s so much backwards and forwards and this is why Rebecca and people like her are in no mans land” (lines 31-32)

“I: It really hurt?
RW: It did a bit yeah. Then when they put the injection in ‘cos I said I didn’t want to take any tablets when I was ill so... That’s what they did” (lines 510-513)

“Well, I think there’s could have gone round it in a different kind of way you know and been like, we know you’re bad, we know you’re poorly, we do know this but they didn’t say it but if they more or less see the child for what she is more so, not just look at her and say ‘she’s bad’ and I think they could have done a hell of a lot more I think. In lots of ways I think” (lines 577-580)

“The only advice we were getting from the team at [location] was take yourself out and leave the house. How can you up and leave the house at 3 or 4 in the morning? Or lock yourself in the bedroom. Now that’s not helping her and it’s not helping you because when you’ve realised there was a problem and we realised she was ill, all you want is help for your child” (lines 113-116)

“I’d like to see, not force her, but say ‘come on’ and get a bit more go into the girl. Instead of more or less sitting back and letting her get on with it herself, and err, asking as well, asking ‘cos they never used to ask any of their colleague ‘what shall we do?’ you know, how do you think we should... I reckon they should have got more into it as a group, all got together and said well look, she is poorly, we know she’s poorly, let’s try and improve or prove to her that we can help her. Not more or less sit back as I class it. To me that’s how it seemed, they was sitting back and letting us do...
“Rebecca saw several different people connected with the centre at Frimley and basically we were told from that that Rebecca was mourning. She was, she finished with her boyfriend who was years older than her and it was a bad set up but she was mourning the loss of the... we tried hard to get them to understand that what Rebecca was showing signs of wasn't just the signs you get with anybody that has a learning problem” (lines 165-169)

“No, [location], social workers I don’t think they really wanted to do anything really. They keep saying ‘yeah we’ll be right over’ and then ‘we can’t do anything more for her, what do we do?’ I said ‘get her some help, give her some more help’ but it was like talking to that wall and I said ‘right okay fair enough’ and I got so annoyed I just told them ‘I don’t think you’re doing enough’ which I don’t think in myself they done enough. She was left right out the way, they promised her, like now, they promised her to see this place, when we had the CPA meeting last Thursday and they’ll always be one short all the time. It’s always been ‘oh, we can’t make it today’ you know and it’s setting her back because she’s not got anything” (lines 527-533)

“So we phoned the police and they came out and they went away, I had explained the situation where Rebecca was falling into that catch 22 where nobody seemed to want to take responsibility” (lines 186-187)

“I said please let me know what happens, heard nothing Tuesday and then Wednesday I phoned the numbers that I’d got at [location] and none of the people that I had numbers for were either there or available, I phone again but Thursday dinner time I’d still not heard anything, I’d then got on to [name of worker], who then got back to me in the afternoon to be told that Rebecca was at [name of inpatient unit] which is a lock up mental health place. Had been there since Tuesday and nobody had told us” (lines 310-314)
"For whatever reason, the National Health system is failing them and whoever they’re caring for. It’s failure big time, it’s not little bits, it is big failure" (lines 266-267)

"Because Rebecca has come under the learning side, social services up until last year, hadn’t accepted that Rebecca needed to be in that system as well" (lines 288-289)

"The unhelpfulness and the bad feelings was all due to the fact that those who were supposed to be helping were actually putting you down. Even now when Rebecca talks, she will say she didn’t like it because although she wasn’t able to voice it herself with the voices she was hearing, she didn’t like the fact that her family, her parents were being blamed for how she was and it’s something that Rebecca has talked about since coming home and that” (lines 751-755)

"I’m afraid I’ve got no faith. As I say, they went from being here and blame and then when we first met up, one of the ones we didn’t like the attitude of was very very condescending and took your hand and was patting your hand and saying ‘you do realise Mrs Williams, she’s a very sick young woman?’ and you, I don’t agree with it but I could understand how people could hit out because I felt like hitting her and saying ‘If you’d listened in the first place’ and instead of telling you…” (lines 836-840)
**Helpful aspects of services**

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<tr>
<th>Rebecca</th>
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<tr>
<td>&quot;They umm, tried to help me in other ways, try and help us like talk to mum and dad, see what their problem is to see what else they could do but they couldn't do a lot else&quot; (lines 339-340)</td>
<td>&quot;That has been the best move out of all forms of mental health... Well, all forms of the National Health, whether it be for operations or whatever, it all forms together as well as the group that works at [name of ATU] and could interact as well without this 'it's not our responsibility' attitude, we'd have a great system again. Because we found that not only have they helped Rebecca, which is what they want, but they're interested when you go, when we take her back, they want to know how the visit's gone, how you're doing and it's good because by talking to you they're getting to know Rebecca better but also, it's an ongoing thing. Whereas we were actually told to our faces that we'd, it was our fault that Rebecca was the way she was and Rebecca only really had a diagnosis after she went to [name of ATU] and that was on her, on her care plan notes&quot; (lines 223-230)</td>
<td>&quot;Knowing there's somebody there that she can talk to... I think it's knowing that there's people there and so you feel safe and you go back and she's safe there&quot; (Lines 366-367).</td>
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<td>&quot;Yeah, by force but after that it was ok&quot; (line 517)</td>
<td>&quot;I think it's the fact that, perhaps the set up that they use at the unit. They try and find out their likes and dislikes, they try and get them into as many social activities as possible&quot; (lines 547-548)</td>
<td>&quot;Knowing what the doctors have said to me, I could understand, I could correspond with them a bit more now. At first I was more or less like a lemon, you know, didn't know what was going on sort of thing. Now they've explained everything, you can correspond with them more... and it's come more closer to us and I think we've got more closer now as a family than we ever were... I think we can understand the traumatics of it, of the voices&quot; (Lines 407-413)</td>
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<td>&quot;They're both happier because I'm at [name of specialist assessment and treatment]</td>
<td>&quot;I think [name of voluntary support group for family members] in [location].&quot;</td>
<td>&quot;I'll put my hand on my heart, they've been very very helpful. Very good and as I say, they&quot;</td>
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Although it is a carers' group and everybody that goes there, family members whatever relationship have all different illnesses, not just mental but all sorts of illnesses and going there you realise that you are not the only one that's actually struggling because when things get so bad you do feel as though you don't know where to turn and actually sitting and hearing and sometimes they would, in their way they're telling you how they've dealt with some of the bits and not to feel guilty about having time for yourself, bits and pieces like that really and accepting, going for the counseling and actually accepting that it wasn't, no matter what had happened, you couldn't have changed anything, you couldn't have done any different, and by actually sitting there and talking you realise that you couldn't have done any different” (Lines 721-729).

"I think the most helpful, the most help we've had all the way through is from all the staff at [name of ATU] because of the way they look at the situation, you can't just treat a patient” (lines 931-932)

"More or less instantly knew what was wrong with her... They more or less hit the nail on the head and we just looked at one another and were like 'they've got it' you know, I was in shock and then they explained to us what it does...” (Lines 307-308)
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<tr>
<th>Encouraged them to carry on what they're already doing with her and I do think that makes a big difference” (lines 986-990)</th>
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<td>“It’s helped a bit yeah it’s helped a lot. Without it I’d be back to square one and I’d be ill again” (lines 1118-1119)</td>
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<td>“Of course, yeah. It relaxes you more because you knew more, relaxed your mind I think, relaxed both our minds you know and err, you know, they kept us well informed, they was really good. I can’t thank them enough really, they’ve been really good. Done really well, really, really well” (lines 549-551)</td>
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Appendix 12:

Table of superordinate and subordinate themes with supporting extracts for the Harrison family
Tables of superordinate and subordinate themes with supporting extracts for the Harrison family

Key: Superordinate theme (bold)  
Subordinate theme (italics)

Understanding of learning disability and psychosis

<table>
<thead>
<tr>
<th>Matthew</th>
<th>George</th>
<th>Jane</th>
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<tr>
<td>&quot;Yes I do. To tell everything going... Round in my head is a bit funny” (line 200)</td>
<td>&quot;This is perhaps when let’s say, hallucinations started. You obviously know, people appearing from behind gravestones right, people touching him and hands appearing plus the fact is again, he became very confused in terms of birds. He developed quite a fear of birds, things like pigeons, there were things like that on his back or something of a kind. So, I think from the point of view that when these things happen, someone like Matthew with his ability, don’t really recognise that this is unusual. It’s obviously something that happens and gives them a concern but as far as they're concerned, it could be a normal thing that might happen, literally to anybody anywhere. So basically, they don’t realise that this is necessarily unusual” (lines 15-22)</td>
<td>&quot;Things have happened when he’s been imagining things” (lines 8-9)</td>
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<td>&quot;We just talking about my medication, about my tablets” (line 212)</td>
<td>&quot;He would explain what would happening as it were without realising that there was a problem” (lines 36-37)</td>
<td>&quot;Yeah. The fact that he’s got Down Syndrome, the fact that other things have come into the equation, you probably don’t notice it as much, You probably just put it down to the fact that he’s got Down Syndrome. Well, I think if he didn’t have any disability and it suddenly just happened, it might have been more noticeable. He has got</td>
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<td>Learning difficulties anyway and I think it’s just something you take for granted, that there’s something going on and you don’t necessarily realise that it is something psychotic or whatever” (lines 57-62)</td>
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<tr>
<td>“Yeah, On the scanner. I sit down. See what’s going on in my head” (line 286)</td>
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<td>“So I, one of the first hurdles was, first of all, you might not appreciate that it is something psychotic that is happening. Usually, it has to be recognised by someone who is external to them” (lines 42-43)</td>
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<td>“Yeah, I think initially. I think sometimes you take it all as being related to the fact he’s got learning disabilities so you probably don’t take any notice of the timescales because he’s always been like that. I think sometimes the way he is, I’ve noticed he’s slowed down a lot, he sleeps a lot and you don’t know whether that’s his age, the medication he’s on or what, really, what it relates to, you just accept it” (lines 67-71)</td>
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<td>“I have to take my tablets. I... In the morning, blue one, my brown one and other tablets I take it” (lines 322-323)</td>
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<td>“Well, you see, as I said to you before, they will give you the answer that they think you want. Over the many years, he has said this, this and this and people have said to him ‘that’s a load of rubbish Matthew, it’s mumbo jumbo’. So, that’s he knows, is the stock answer. Now that doesn’t mean to say that he isn’t still concerned right. He’ll say that on the basis that that’s what people say to him and he will basically say that to you” (lines 229-233)</td>
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<td>“I don’t really think that I’ve found it really difficult, because, you know, as I said, he’s always had a learning difficulty, it’s always been there. You know, another thing that you sort of deal with. I wouldn’t say that we’ve found it difficult, sometimes it’s just more frustrating than difficult because you’re trying to persuade them that there’s not a problem because you’re constantly reminding him that ‘Matthew, there’s nothing wrong’ you know, things like that. I wouldn’t say that it’s really affected me in any way at all. I don’t really see him as to the extreme you know. His mental disabilities and learning disability I don’t think are that bad that they really cause any problems or strain. It’s more sort of making sure he’s ok more than anything else” (lines 97-104)</td>
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<td>“MH: I take them this morning. Tablets I take every day.</td>
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<td>“Well, no, there’s never been any... [name of doctor] has turned to us in conversation and said to us ‘Matthew is an</td>
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| “I don’t really know actually, what Matthew’s experiences are. I think sometimes he’s actually sometimes quite umm,
<table>
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<th>I: You need to take them every day</th>
<th>enigma” (lines 247-248)</th>
<th>scared sometimes. I think like he went through stages of wanting the light on when he slept and things like that. He was imagining things and having the light left on in the corridor and things like that. I imagine things were quite...</th>
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<tr>
<td>MH: Yes I do</td>
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<td>I: Quite scary</td>
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<td>I: What do they help you with?</td>
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<td>JH: Quite scary for him at times yes. He didn’t really understood what was going on in his mind because to him it was real” (lines 133-141)</td>
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<td>MH: Umm. I don’t know” (lines 335-343)</td>
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<td>“I: Ok, good, good. Matthew, do you know what mental health means?</td>
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<tr>
<td>“I: Ok, good, good. Matthew, do you know what mental health means?</td>
<td>“Ok., can you tell me about how any of the experiences that may have happened along the years with Matthew in terms of the learning disability and the psychotic symptoms about how those experiences may have affected you personally?</td>
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<tr>
<td>MH: No I don’t</td>
<td>GH: (laughs) affected me personally?</td>
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<tr>
<td>I: Ok, that’s ok. Do you know what mental illness is?</td>
<td>I: Yes” (lines 330-337)</td>
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<td>MH: Illness?</td>
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<td>I: Yes, mental illness</td>
<td>I: I don’t know really. I don’t know, something the same as before, you just kind of accept it really” (lines 286-287)</td>
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<tr>
<td>MH: Yes I do</td>
<td></td>
<td>“I: Ok, good, good. Matthew, do you know what mental health means?</td>
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<tr>
<td>I: Can you tell me what mental illness is?</td>
<td>“I think as we said before, I don’t really think there’s been any added pressure at all because you know, Matthew’s always had learning difficulties so it’s just something, another issue that’s been added to it. So I don’t particularly think there’s been anything that’s been hard to cope with, it’s just something you just sort of accept and you go along with it” (lines 238-241)</td>
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<td>MH: Don’t know. I don’t know” (lines 370-384)</td>
<td>GH: Well, I don’t think that because he’s got a psychotic problem that it’s affected me in any different way to the fact that he had a learning disability in the first place hmmm?</td>
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<tr>
<td>“I: Ok, good, good. Matthew, do you know what mental health means?</td>
<td>I: Mmm</td>
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<tr>
<td>MH: No I don’t</td>
<td>GH: It’s perhaps if you like purely an extension, or not an extension but another aspect to be considered along with the fact that shall we say, he has a learning disability. Because</td>
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<td>I: Ok, that’s ok. Do you know what mental illness is?</td>
<td>“Umm, I think sometimes, not just with Matthew, I’ve seen how some of the carers have spoken to some of the other children I find it a bit sort of, they’re not being spoken to as a normal person, they’re being spoken down to because they’ve...</td>
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<tr>
<td>MH: Illness?</td>
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I: Can you tell me what mental illness is?

MH: Don't know. I don't know” (lines 610-632)

people with a learning disability can have challenging behaviours etc so I think it's basically all to do with the same area which you're basically looking to, to cope as it were” (lines 338-346)

got a learning disability, those sort of things” (lines 349-353)

"Well, I suppose what you pointed out, you know, sort of if someone had explained why he's imagining these things and then how you cope and how you deal with it. I suppose it's not knowing where it's coming from as well” (lines 470-472)

"I was wondering when you say you're going to be talking to Matthew, I suppose the way I see it, because he's got a learning difficulty, I sort of think, maybe it's the wrong thing to think but is he actually going to be able to explain to you what it's like for him?” (lines 653-655)

I: With you, he goes with you. Can you tell me what does Dad say when he sees Dr [name of doctor]?

MH: Dr [name of doctor] with my Dad they just talk about seeing things. I don't.

I: About?

MH: Seeing things.

I: Seeing things?

MH: Yeah. I don't.

I: You don't see things?

MH: No

I: So they talk about if you see things? Tell me again Matthew

MH: I just see things

"Well, maybe he does, but I was just wondering about you know whether he could explain to you how he feels when he's having these hallucinations and things. I suppose we don't really ask him you know. It's always accepted that that's Matthew so you don't really say to him, he's got a learning disability so it doesn't cross your mind. So you think is he going to be able to say anything to you. To me, that's normality for him, you don't know anything else, so. Interesting to know that, what he's said” (lines 659-644)
I: You do see things

MH: Yeah

I: Right, what do you see. Can tell me what you see?

MH: I saw someone at the bus stop

I: Yeah

MH: I saw them about... The mummy.

I: The mummy?

MH: Yes, (inaudible) in my tummy [gestured to stomach]

I: Tell me again?

MH: They did that to me

I: They did that to you. Oh, I see. So someone...

MH: Yeah, did that [gestured to punching the stomach]

I: Oh I see...

MH: Someone... Someone... Someone stole it.

I: Someone?

MH: Stealing.

I: Stealing

MH: Yeah and now I got a bad there [gestured to his stomach]

I: And now you've got a bad tummy

MH: Yeah

I: Oh, I see. Ok. And
when you talk about seeing things...

MH: Yes

I: What do you talk about with the doctor?

MH: I, I don't believe it.

I: You don't believe it?

MH: I don't. Load of mumbo jumbo.

I: Load of mumbo jumbo?

MH: Mmm, they are.

I: What, the doctor is mumbo jumbo?

MH: No

I: What's mumbo jumbo?

MH: I can see things.

I: Oh right. Sometimes you can see things...

MH: Yes I do

I: But it's mumbo jumbo?

MH: That's right, it's not.

I: Right, ok. And how does it make you feel when you see things?

MH: Sad. I'm so cross.

I: Sad and so cross, yes

MH: Yeah

I: Yeah. Can you tell me anything else about when you see things?

MH: No
<table>
<thead>
<tr>
<th>I:</th>
<th>So it can make you feel sad?</th>
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<tr>
<td>MH:</td>
<td>Yeah</td>
</tr>
<tr>
<td>I:</td>
<td>And cross?</td>
</tr>
<tr>
<td>MH:</td>
<td>Yeah&quot; (lines 698-808)</td>
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| "I: | Do you think the tablets, you know the tablets, the medication... |
| MH: | Yeah |
| I: | Do you think they make you feel, make seeing things better? |
| MH: | Yes, it does. It does. |
| I: | Do the tablets make seeing things worse? |
| MH: | No" (lines 846-856) |

| "I: | That's alright Matthew, that's fine. Ok. What things make the seeing things get worse? |
| MH: | I'll be scared |
| I: | So sometimes it's scary |
| MH: | Yes it was" (lines 913-919) |

| "I: | Does Dad know about these things that you see sometimes? |
| MH: | Yes he do |
| I: | Yes, can you tell me what Dad says about it |
| MH: | I think he think it a lot of mumbo jumbo. I don't believe it" (lines 937-943) |

| "I don't think he does really understand what's happened to him at all. As far as he's concerned right, umm, it's not as though he's creating a story or anything like that at all" (lines 372-373) |

| "I'm quite sure that his learning disability certainly stops him from understanding that these are abnormalities right. He says no he hasn't got a heart right, you tell him to feel my pulse or something like that. You tell him, if you can feel my pulse, that means my heart is pumping, have you got one of those right but the logic does not necessarily get through so I think from that point of view, his learning disability does stop him from understanding that it's unusual. We're always |

| The range of abilities amongst people with a learning disability is quite enormous sort of thing so I think if you're living with a child with a learning disability, you're always conscious of what are they going to be able to do, what are their aspirations going to be right, you know" (lines 361-363) |
telling him that he must have come from Venus or Mars if he’s different from the rest of us, are you from Venus or Mars Matthew? And he says ‘no’ and I say ‘well in that case, you’re basically the same as the rest of us’. It’s often things like this that he doesn’t readily accept. He doesn’t seem to have the mental ability to understand that these things..." (lines 439-447)

| "I: Does Dad know about these things that you see sometimes? | "Oh, difficult to say hmmm. You see, if you say ‘he has coped well with it’ that pre-assumes that he understands the problem and therefore he learns to cope with the problem but I very much doubt right whether he understands the problem in the first place” (lines 519-520) |
| MH: Yes he do | |
| I: Yes, can you tell me what Dad says about it | |
| MH: I think he think it a lot | |
of mumbo jumbo. I don’t believe it” (lines 949-956)

“And again, I go back to what I said before right which is that ok, if he’s also going to have a mental health problem, that’s basically an extension to a disability that’s there already. So I don’t think you change your approach to this right, if you’re coping with the fact that they have a learning disability, you’ve got to cope with the fact that they might also have a mental health problem as well. So them having a mental health problem does not mean that you cope in any different way or that anything helps you to cope more or better than with the fact that they have a learning disability. If they have a learning disability then they already have a behavioural problem and a mental health problem may only be the same as a behavioural problem. The two very much can go hand in hand so I don’t think literally, the fact that you’re coping with a learning disability, the very fact that you’re coping again with their mental health is all part of the same picture” (lines 575-584)

Family involvement

<table>
<thead>
<tr>
<th>Matthew</th>
<th>George</th>
<th>Jane</th>
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<tr>
<td>“I: Can you tell me a little about your family Matthew? Who is in your family?”</td>
<td>“Only because I’ve been in fairly regular contact with him and at that time” (lines 22-23)</td>
<td>“It’s the reassurance and I know that when he was with my sister I think she basically went onto the internet and brought up the skeleton and started explaining the body, what it’s for etc to help him understand and relate that back to what he’s</td>
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<td>MH: My dad,</td>
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<tr>
<td>I: Yeah</td>
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324
MH: Jane
I: And who is Jane?
MH: Jane is my twin.
I: Your twin sister?
MH: Yes, yes (lines 3-17)

"MH: I got a niece.
I: You have a niece?
Lovely. How old is your niece?
MH: I don’t know. I’m an uncle three times.
I: Oh, you’re an uncle three times? Lovely...
MH: Yes
I: Do you like being an uncle?
MH: Yes I do (lines 49-61)

"I: Do you see them very much?
MH: Yes I do
I: Do you like seeing them?
MH: Yeah I do (lines 71-77)

"MH: I got an ex mum "So I think one important thing, dealing with people like...
"JH: Well, I think about the caring, no, I think my sister and...

"Matthew was living with a family in South [name of location] with two others and obviously because I had lived in [name of location] and had always been in fairly regular contact with Matthew and he had sisters in [name of location] as well, we basically used to see him every week or every fortnight or something of the time. He would explain what would happening as it were without realising that there was a problem" (lines 33-37)

"I think having is family around him is helpful, kind of see us of a weekend etc and I think it must be far more difficult for those in the care home who haven’t got family who are there all the time. Although you’ve got workers in there, they’re all very different and you don’t know how they’re treating them, if one’s having a funny turn etc, plus there’s sort of one to ten, fifteen children. The fact that he has got family around him and we see him on a regular basis is beneficial as well" (lines 211-216)

"Yeah, because... It’s very interesting right because when Matthew was born, I was working in [name of country] and this was way back in the 60’s and [name of country] was rather primitive at the time and we used to keep chickens there so that we basically had fresh eggs otherwise you couldn’t get eggs in [name of country]. At that time I guess obviously he grew up with the fact that we had chickens and they used to run around, so we always used to say to him when he had this fear of birds that ‘Ah, remember, when you were a little boy that you had no problem at all and these are exactly the same’. So, that possibly right now, has sunk in or not I do not know” (lines 414-420)

"I suppose I probably don’t understand as much as my father as I suppose he’s more in contact with doctors and psychiatrists and things like that. I just get filled in by my father, so I mean I’m just assuming that some of these problems have come about because he’s been diagnosed with being lightly schizophrenic and that’s all I really know, you know, whether that’s the right sort of message I don’t really know. I just sort of accept what’s going on rather than worrying what’s behind it. I think my father’s more involved in that side than I am. I think if my father wasn’t around then someone else would take over that role” (lines 250-256)
I: Pardon?

MH: I got an ex mum

I: Oh, your mum?

MH: Yes I have.

I: Yes, what happened to your mum?

MH: Died. Died in the hospital” (lines 93-105)

I: So what do you like about your family Matthew?

MH: I do like my family are... Going home with Jane. Going home with and my Dad I do” (lines 112-114)

MH: Me and my dad went to [name of hospital]" (line 274)

I: So you and [name of other sister] might perhaps take more of a role in caring, having Matthew to stay and things like that?

JH: Yeah. Making sure he has things like clothes, making sure his toothpaste hasn’t run out and things like that. Going round and checking that everything’s ok” (lines 265-273)

I: So what do you like about your family Matthew?

MH: I do like my family are... Going home with Jane. Going home with and my Dad I do” (lines 112-114)

MH: Me and my dad went to [name of hospital]” (line 274)

I: what always worries me is that, ok fine right, Matthew is my son and I’m always going to try and get the best for him but I think what tends to happen all too frequently is that for those people who are without anyone you know to look after their interests, they miss out because the simple reason is that nobody’s looking out for them (lines 633-636)

I suppose you don’t want it to have an effect on him and his care in the home. Plus I think sometimes you feel a bit guilty because you’re not the one looking after him full time so have you really got a right to feel that? So you know, when he’s in someone else’s care in the care home, things going on that you don’t agree with but you just sort of accept. Things that I would do very differently. Things like if I did it my way then he might be more happy with certain aspects, things like that” (lines 337-342)

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MH: I do like my family are... Going home with Jane. Going home with and my Dad I do” (lines 112-114)

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I: what always worries me is that, ok fine right, Matthew is my son and I’m always going to try and get the best for him but I think what tends to happen all too frequently is that for those people who are without anyone you know to look after their interests, they miss out because the simple reason is that nobody’s looking out for them (lines 633-636)

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whole time. It's not as though we're hiding what has happened to Matthew from each other so everybody basically knows what is happening. He sees his sisters frequently so no, they've just coped. As I've suggested to you, this is just another aspect of Matthew being Matthew” (lines 786-792)

that's true or not but it was always in my mind” (lines 396-400)

"MH: Dr [name of doctor] with my Dad they just talk about seeing things. I don't” (line 700)

"I think when we were all growing up, we all sort of did things and helped out and what have you so no. No, no” (lines 413-414)

“Nothing at all. But then, because my father is so involved and my father is always there, you know and there's a problem, he'll always be onto social services or something. I haven't been invited but then I haven't felt there's a need to be involved because I know there's someone doing it, my father's always doing it. Obviously someone would take over that role if need be, so no, I haven't really been involved in social services or what's going on and things like that. No” (lines 446-450)

“I suppose I haven't really experienced any of that because my father's always dealt with it so I can't say if he had any problem with services because if there was a problem my father would be there dealing with it etc so it hasn't really affected me at all. My father's always been there to make sure Matthew's put in the right place and fought his corner for him so I haven't necessarily had any problems” (lines 514-518)
"It's down to that fact that Matthew has family who will get involved to fight his corner and get things done for him. In that sense, Matthew is quite fortunate, he has got family behind him but the ones who haven't got family are the ones who lose out. I think Matthew's lucky with my father because he knows what lines to go down to get things done whereas other people probably don't. Things related to learning disabilities, Mencap etc, where there are problems, he's prepared to put the time in so I think in that sort of sense Matthew's been quite fortunate" (lines 546-551)

Aspects of the service context

Communication and consistency

<table>
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<tr>
<th>Matthew</th>
<th>George</th>
<th>Jane</th>
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<td>“Because nobody's got an immediate access as it were to somebody who could help. So you then have to start going through care management one way or another but then if you take, well, anybody in [name of location] right and &quot;who's your care manager?&quot;, they will not know because there are so few care managers type of thing” (lines 58-61)</td>
<td>“Like the care home he's in now the owners have changed and the people have changed and it's slightly different and sometimes you feel frustrated, what's going on in there but then you feel you feel that you can't stick your nose in as it might rock the boat or cause problems for him. So that's very difficult having to stand back.” (lines 327-331)</td>
<td>“So it's those kind of things that concern me more like what's going on in the home as it wasn't like that before. They seemed to take a lot more care than they do now” (lines 621-623)</td>
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<td>“Ok, yes, quite right. Umm, but then what was happening was they said right, put him on this drug, see how they go, oh we'll give you another appointment in six months time. Then what happened is and happened over a period of years was there was a system running whereby there were trainee psychiatrists coming through for a six month period. So you go in after six months, you see one person who is picking up information from</td>
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<td>a few file notes, listens to what you're saying, says 'I think you're doing ok, come back and see us in six months', you then saw someone else&quot; (lines 89-94)</td>
<td>**“So you then have to go through and get a care manager allocated to, allocated which might take time. The care manager's got to come in, the care manager and the person with a learning disability are not going to know each other so usually, these things are only going to be brought out and get somewhere if there's someone who's obviously on a one to one basis has the confidence with the person. That person has basically got to act as an advocate” (lines 66-70)</td>
<td>**“Little things like that, which I feel the care has changed slightly” (lines 631-632)</td>
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<td>“So you then have to go through and get a care manager allocated to, allocated which might take time. The care manager's got to come in, the care manager and the person with a learning disability are not going to know each other so usually, these things are only going to be brought out and get somewhere if there's someone who's obviously on a one to one basis has the confidence with the person. That person has basically got to act as an advocate” (lines 66-70)</td>
<td>&quot;Another person, yes. So the continuity behind it was not at all brilliant etc&quot; (line 98)</td>
<td>&quot;Whereas if that person had been normal, they'd have gone away or said something so I feel that sometimes they're just a bit disregarded but maybe they've got other things on their mind so it doesn't really cross their mind. It's that personal care that I feel is lacking that was there before that isn't there at the moment. So that sort of upsets me a bit” (lines 636-639)</td>
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<td>&quot;Another person, yes. So the continuity behind it was not at all brilliant etc&quot; (line 98)</td>
<td>&quot;I probably jumped the gun a bit here because having upped his dose, we then went onto a subsequent appointment at [name of service], but [name of doctor] was not available and we saw another psychiatrist there, an Indian lady, her name escapes me right now but Matthew was there right, he was quite drowsy and basically wasn't with it at all. She panicked saying 'perhaps we've doubled his dose and maybe that was the wrong thing to do' so she basically chopped it in half” (lines 165-165)</td>
<td>&quot;No, I think before I felt some of the staff spent a bit more time with them than they do now. That's just a personal thing. Although he always seems happy, with the staff you know when he comes round so... That's how I feel sometimes” (lines 579-581)</td>
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<td>&quot;I probably jumped the gun a bit here because having upped his dose, we then went onto a subsequent appointment at [name of service], but [name of doctor] was not available and we saw another psychiatrist there, an Indian lady, her name escapes me right now but Matthew was there right, he was quite drowsy and basically wasn't with it at all. She panicked saying 'perhaps we've doubled his dose and maybe that was the wrong thing to do' so she basically chopped it in half” (lines 165-165)</td>
<td>&quot;Umm, for people with a learning disability, their life</td>
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revolves around the fact that they have to have assessments, they have to have care plans and theoretically they should be reviewed fairly regularly as well. Err, what the basically means for a person with a learning disability, their whole life to a certain extent is completely dependent upon a care plan or an assessment or something like this which is something then which is produced by a care manager or somebody of a kind. In other words, a particular person on a particular day fills out a bit of paper that basically then regulates the life potential of someone with a learning disability and you can certainly have assessments that are good and care plans that are good or assessments that are bad and care plans that are bad. You can have care plans which basically say, which get approved, this person should be getting this service, this service, that service but that doesn’t necessarily mean that another day, another person in another office is going to offer the money to allow that person to even be able to follow their care plan. So from that point of view, it’s all very much, can be very hit and miss” (lines 657-659)

“So there’s an awful lot of things in the life of a person with a learning disability that is not joined up” (Lines 682-683)

“Well, I suppose the most helpful, at least what is helpful right now is that at least we have one psychiatrist involved as opposed to a different one every six months” (lines 889-890)
"Well, ok you say what is the least helpful... I suppose another area has been that it could have been quote helpful if care management had also been aware of the problems that we were having, Matthew's psychotic problems. But then again as we said before, people do not have an allocated care manager. All they do get these days is an annual assessment providing it happens annually. Theoretically these things should happen every twelve months but you can't guarantee it always is. You can again never guarantee that the same person is doing the annual assessment as well" (lines 989-904)

"Well, I don't know. There's another thing that right, on one hand you've got Social Services and care managers and on the other hand you've got psychiatrists who aren't part of this, you've got Matthew's GP, again, a third party and it's a question shall we say in lots of areas it would be helpful if these three items could get closer together. Whether that's a practical possibility or not I don't know. One of the problems with GP's these days is that you never know which GP you're going to see. This time may not be the one you're going to see next time. GP's right, how many of them have done a lot of work with people with a learning disability?" (lines 975-989)
“One of the things, I wouldn’t say it’s a problem as such but with living in a residential care home there’s obviously a care home manager but then other staff and it’s not the same person doing the same thing every day, every week. Things get done by a different person and different times on a different day. And they could well be that, appointments come along for the hospital or for the psychiatrist or things like that and you can’t always be sure that his keyworker in the home is available and on duty on a particular day at a particular time when basically he has a hospital appointment or an appointment anywhere type of thing. I think the big thing with appointments is to try and maintain continuity and I think from that point of view, it’s important…” (lines 1032-1040)

“Matthew does not have an allocated care manager, but that’s not unusual, nobody could claim to have one particular person. So I suppose for the liaison point of view, there’s no ongoing liaison with care management. So I think this is not just something that happens to myself and Matthew, you talk to anybody who’s got a relationship with somebody with a learning disability and they’ll tell you that care managers do not exist right” (lines 1045-1050)

Resources

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<th>Matthew</th>
<th>George</th>
<th>Jane</th>
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<td>&quot;It’s one of these things right where whether you like it or not, the government is cutting back on its funding for learning disability services. I think in &quot;</td>
<td>&quot;Umm, I suppose in an ideal world, more opportunities to be available for them and with all the cutbacks they just seem to be leaving them to fend for</td>
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actual fact they automatically reduce the annual funds to such services by something like two and half per cent a year. But by the same token, instead of giving them a cost of living increase of 208, 209, they're giving them an increase of 1 per cent. You know and the cost of living is around about 3 or something like that, what are people supposed to do?" (lines 509-514)

"You can have care plans which basically say, which get approved, this person should be getting this service, this service, that service but that doesn't necessarily mean that another day, another person in another office is going to offer the money to allow that person to even be able to follow their care plan. So from that point of view, it's all very much, can be very hit and miss" (lines 665-669)

"So the system is one in which, well, the resources would never be there to provide for them I don't think" (lines 868-869)

"Again it rather comes back to the fact that changing his day services has involved a change in financing and extra finance. So despite the fact that it probably would have been helpful if his annual assessments had picked up the fact that a change in day services would have been to his benefit, it doesn't necessarily mean that that would have been acted on. Because if there's themselves. You know, all the day centres are closing down and if they want to go to day centre's they're expecting them to pay for them and all that and most of them are on benefits, so it's those sort of things. I think more things being available, and they're not for them to do or get involved in, it's all money. You know, he's lucky to be going to the farm and that's all down to money and social services agreeing to pay that. He's fortunate where he's in that situation where they have, but a lot of people are not fortunate enough to be in that situation" (lines 539-546)

"I think they need stimulation, they need to be doing things, it makes their lives better and what have you so I think at the moment Matthew is doing alright now they have got him into the farm. You know, when he wasn't there he was sitting at home doing nothing or they go to the day centres and there's nothing for them to do, you know, they're not being stimulated so in that sense I think more needs to be done but it's all down to money" (lines 552-556)
money involved, even though it's part of an assessment of care plan, just because it's there does not mean to say it's going to happen” (lines 917-912)

“Nothing immediately comes to mind. One area, it's an area that is still outstanding is an issues right now is outstanding between myself and social services concerns his day care which is really all to do with his financing, financing. Right now, he only gets day care for four days per week and his care plan says he should have day care for five days a week but only four days to date has been financed” (lines 1011-1015)
Appendix 13:

Table of superordinate and subordinate themes with supporting extracts for the Jayawardene family
Tables of superordinate and subordinate themes with supporting extracts for the Jayawardene family

Key:  
Superordinate theme (bold)  
Subordinate theme (italics)

Changes over time

Progression of illness

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<tr>
<th>Tamara</th>
<th>Geoffrey</th>
<th>Victoria</th>
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| “Yes, it started off umm, we were living in Salome in Sri Lanka and she had a problem, we were just kids then. Mum and Dad used to run round and take her to doctors or whoever and umm, then we came to England and umm at that point it all changed. I would actually stay with her every evening and she wasn’t, she was not stupid in that sense in the sense that she was still going to normal secondary school here in England and she did not come last in math’s so I knew that she had a brain which was logical and umm, therefore, umm, her behavioural tendencies were illogical to the casual observer but to her in her mindset it was totally logical. So she would like, throw tantrums and stuff when she was a teenager. We eventually got her sectioned because she did get extremely violent if she didn’t get her own way. It’s the spoilt brat umm scenario and umm, so she would get sections and eventually got hospitalized in [name of hospital]” (lines 18-26) | “Oh right, as far as I know, I’m going on what I’ve heard, obviously from my parents when they were alive, umm, basically she was suffering from blackouts and fits when we were in Sri Lanka, that’s where we come from and umm, they had then, we moved to London and as far as I know, they diagnosed err, a tumour and they operated to remove the tumour and after the operation did they realise that it wasn’t a brain tumour, it was part of her brain so before the operation she was going to a normal secondary school and at that time she was suffering from blackouts and other behavioural problems, I’m not sure what the nature of those was. After that the blackouts stopped but not the behavioural problems. That’s really as much as I know in terms of her background, I mean, obviously over the years she was in a locked up institute and umm obviously, where she is now which is fairly open and also when she lived at home, she was going to a day centre kind of thing which kept her busy” (lines 27-36) | “I do know exactly, up until 1998 say, 1999, what was going | “I guess, because now I live in Scotland and she would come
through her head and ummm, that basically is it and ummm. So I know how she thinks, I think she's, if you draw a graph, horizontal, vertical, she reached a plateau where the graph rises and then it settles off and I think that at this moment in time and a few years before today it has flattened off so she is mentally stable in that sense, she knows where she is at and she knows what she can do and she knows what she can't do. So she has plateaued on that graph. So it's not, it's going to make something amazing to make her erratic if you know what I mean?" (lines 43-48)

"At first, initially, she was taken to be merely epileptic but as soon as she started throwing the violent tantrums, I don't think epileptics throw violent tantrums, they tend to either sit or lie and shiver. I'm not sure but I think that's it but she started throwing violent tantrums and when I say violent tantrums, I mean violent tantrums" (lines 85-87)

"The diagnosis of her behaviour has to be forthcoming from Mum and Dad so there was a gradual change ummm over the years like from say when she was 13 and going upwards from there leading to her being sectioned where she became violent and you couldn't trust her in the house which is why she became sectioned but ummm, something happened... We go back to the previous question and something had happened and I do believe that there was some sort of surgery being put onto her and that, basically backfired" (lines 98-102)

"Yeah because she changed completely after mum died. Dad died in 1982 and mum died in and visit me for the weekend and after the first day or so she'd deteriorate really and she would deteriorate and she would start talking rubbish really and would become paranoid and would start thinking about people doing things to her. So I guess those sort of things I know about and I don't think that has really changed very much but yeah" (lines 53-56)

"You can see her getting worse and worse and you can only imagine what's going on in her head, she's talking about so and so's done this and so and so's done that and you know, you're thinking it's all rubbish" (lines 140-141)

"Ideas, yeah paranoia, yeah, she always has this thing about neighbours doing things to her when we were younger anyway and I'm not sure if she still goes on about neighbours now because where she lives now she can't see neighbours as much" (lines 146-148)
1986 and I was working in [name of location] at the time in a menswear store, got the phone call. The first thing I did because I'm still nurturing her was get on the train, back to [name of location] and then get a taxi from [name of location] to [name of hospital] and umm, shove her in the taxi to take her to [name of hospital] and coming, driving through the grounds, I just said to her 'Uma's died', Uma being mum. Uma's dead and umm, that was it but from that point onwards she knew she couldn't have her own way because it was mum who she would actually try to get around but she now knew that she couldn't get around me so at that point, from that point on she became totally different, quite placid, even though, she would throw her little tantrums or whatever at [name of residential home] but it was from that point onwards and I would say, a few years later, if mum had been alive, well, if mum could see this, she wouldn't believe it. That you can exert discipline on Tamara and she would accept it whereas beforehand, it was Tamara who was exerting her own power, real power on whatever situation there was which is why I haven't, I've lost touch with Tamara and the last time she came up here was 1999" (lines 203-214)
"Oh she is yeah because when we had these meetings when she was still in [name of hospital] with the Social Workers and they would bring out the drawings the paintings that she’s done and it was always in black and white, there was no colour, was black and white and then you could see the progression, eventually she was now painting with colour. Now, use blue for sky whereas before it was white and umm, she would paint actually in colour and she was now in some way sort of accepting something around her, around her environment that it is no longer black and white and it became more colourful so effectively she was sort of blossoming psychologically and err, it sort of stopped there and I’m not sure what she’s like now I haven’t seen her” (lines 306-312)

"Well, I’ve lost touch now but the last time Tamara came home was 1999 and umm, she hasn’t been on the phone, I know she’s been on holidays with [name of residential home] at least once if not more and err, she sends postcards and what have you and used to send me birthday cards as well but those have stopped so I think psychologically again she has umm, err, what’s the word, she has, she has got to, she has understood her position in the family and within herself, she’s leveled it out and so that’s, yeah there’s nothing, no” (lines 563-567)

"She, we’ll go back to that brain operation, I keep calling it brain operation, I don’t know what happened, I really don’t know but she is fully aware that she has a disability, she always has
been but the fulcrum was her mother, our mother dying”  
(lines 287-289)

“I think with the Social Services and all that umm (pause). She knew she had her brothers and sisters, sort of around and her uncles, cousins whatever around. She must have stabilised because she used to phone incessantly, when I say incessantly I mean once a week or when she phoned, she would phone her cousins and in [location] and [location] and then phone here and I realised like a couple of years ago, they were saying a few years ago umm, Tamara stopped phoning. Now I’m thinking right, she’s accommodating her own mindset into some sort of level that she doesn’t need to phone because phoning and talking achieves nothing because what can you achieve? You can’t give her money over the phone or, that’s basically what she was asking for I think, you can’t give presents over the phone etc and I think she’s aclimatised herself to that aspect of behaviour so now she’s, I think she’s probably now a recluse. I could be totally wrong but in her mind I think she’s a recluse umm, that’s it” (lines 360-368)

Service changes

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<th>Tamara</th>
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<td>“Yes, I think that was the beginning of a change for the better when umm, when she was in [name of hospital] properly, which has probably been demolished by now, it was under lock and key, it wasn’t like going into hospital and umm, you had to sort of be let...”</td>
<td>“I think she’s coped quite well with, where they live in the open environment I think. She didn’t cope very well at all when she was in a secure ward in a hospital” (lines 156-157)</td>
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into the ward and which means that a key has to be inserted and turned and bla bla but umm, but once she left that environment and got into the bungalow, she was much free-er. They wouldn't let anyone go into the bungalow so they had to show that they were quite stable sort of thing but it was nice. It did change her because I go to see her and you know, suddenly there was freedom for her because in the ward, if you went to see Tamara in the ward, you had to stay in the ward, it was under lock and key but once she was in the bungalow, you could walk out of the bungalow, into the grounds, sit on the bench and just sit there. We wouldn't actually talk but we would just sit there for like 45 minutes and hardly a word would pass but umm, it was again it a spirituality, she's got an inbuilt spirituality as well as the logic and I think one goes hand in hand somehow and she realised that she didn't have to talk or say anything, same as myself. Just sit there and have a couple of fags so we did that for like 40 minutes and then go back to the bungalow which you couldn't do, a sense of absolute freedom for her, it must have been to be able to walk out. That wasn't the only time, so if I wasn't there and she wanted to go out then someone would have taken her in hand sort of thing and gone with her but no, it was definitely the sense of freedom which was just sort of processed her mind into thinking sort of differently” (lines 493-508)

“Umm, no I can't. I think they've been very helpful over the period, over the ages as far as they can be” (line 512)

“Adapting, ooh, err, when she was in the secure ward, apart from when she was trying to escape, most of time she was
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<th>Being quite good there because I think she realised that she was better off than quite a lot of the other patients there and she was actually playing fairly intelligent games there like scrabble and cards and stuff and therefore the nurses in theory treated her in better because she was able to do more. She quite quickly learnt that and that sort of helped her too I think being in that environment, oh and when they moved out into the community, that's been quite good as she's been more independent and stuff. Umm, yeah” (lines 179-185)</th>
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<td>“Now that I’m almost 50 and I’m thinking back, they could have done, but back in those days, thirty years ago it wasn’t the same scenario. Today, the social services etc are completely different to what they had been umm, back then so I wouldn’t have umm, I would have umm said anything or asked for anything” (lines 416-418)</td>
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<td>“Yeah, she’s got her own space, her own things, err you know, surrounding her, things she likes, videos and stuff so from that point of view she likes it, likes going on the bus and I think she goes on the bus to her therapy and stuff, art therapy. All that side of things, it’s a bit more like a normal life compared to living in a secure hospital kind of thing, where she has patients screaming around and I think where she is there aren’t many patients around her” (lines 189-193)</td>
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<td>“They were moved out of the dormitories, the wards into the bungalows and err, she was there and from that point onwards, her psychological state became better.” (lines 481-483)</td>
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<td>“Umm, especially where she is now, I think it’s quite good that they do tend to do, activities, the fact that where they are, they do seem to have quite a lot of open space, so they’re not err, encroached by anyone and they have quite a bit of independence, like they have to wash their own clothes and look after their own room so, yeah” (lines 257-260)</td>
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<td>“Umm, it was frustrating because the manager of [name of residential home] for example, the management kept changing you know like every couple of years and umm, there was a case of some, I was still involved</td>
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<td>“Umm, they seem to know her, on the different occasions, I’m not really sure it’s always the same people, they’ve been, they seem to know her quite well from that point of view, they know her dislikes and likes, so</td>
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with her at the time, it was a case of re-initiating the management as to Tamara’s problem. To be honest, I didn’t like it because everyone coming in after a period of time were coming in fresh but they’re coming in and by which time now, they’re clients, they’re not patients anymore, so they’re coming in and dealing with clients who they’ve had no experience with and umm, they’re starting a fresh which I think, politically is probably wrong but I think it is wrong. You have to have a continuous relationship with your clients otherwise, otherwise, it just can’t stop and start, stop and start, stop and start because it affects the client more than it affects say, the manager. The manager is ok, he knows what he is doing or she is doing and umm, so as far as he or she is concerned, they are just walking into another job, whereas the client is concerned, they’ve just lost someone and now they have to deal with a new person so the client has to start all over again but the manager doesn’t have to do that. The manager starts, not all over again but they simply start but the clients, they have to start all over again, get the relationships going and all that” (lines 571-583)

from that point of view it’s good” (lines 322-324)

“Well, whatever you know really. I guess for me, it’s the move out into the community that has been a big help but apart from that, I don’t really know. She’s always had art therapy and I’m not really sure whether that helps her or not because whether that increases her imagination or not but I don’t know any other specific services and what they do really” (lines 380-383)
### Wider societal changes

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<td>Mmm, I took it as said, as read. As you're growing up and apart from that, the bad things I got in to. There was nothing really, actually, well there was I suppose. We're going back to the 1970's, yeah 70's when there, when racism was actually quite high so I actually had to calm myself because every weekend I'd go with Tamara on a Saturday into the [name of location] town centre and just walk with her but she'd walk with a stoop and if you can imagine an ape walking with the two hind legs, two arms, now if she had stopped any further, she would have been walking like an ape and that's bad enough but what compounded it was the fact that we were Asian. Now, we were getting abuse left, right and centre you know, on the way to the [name of shopping centre], you know the [name of shopping centre] don't you?&quot; (lines 237-244)</td>
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<td>Well, that's where we were going to and umm, from youths basically a load of Caucasians and I could see the looks, I could see them looking but they're not going to do anything, anything physical because they've not got the maturity. The youths in their teens would be abusive and there were times when I would want to lash out at them and I'd know, because if I separated myself from Tamara then she would become vulnerable so I had to take it in that sense. So, that wasn't physical abuse like standing between her and my father, it was sort of thinking, no, don't do it, just swallow it and carry on.</td>
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on as normal, if there could be, if there is such as thing as normality in that sense of the word in the situation with... Does that answer the question? “ (lines 248-254)

“Yes, yes, that is totally correct but that was back in the 70’s and society has progressed a little bit more now and umm, err, so like when she was coming up to Yorkshire for a few days over the Christmas period, you know, there was nothing and umm. I do remember one time when I was still working in London when I used to be a taxi driver there and umm, and a coloured guy would come into the car and we would start, we were about the same age and the question, I remember him asking me, something like ‘Is it me or have they stopped being racist?’ because he’d gone through the same thing, he didn’t have a handicapped sister or anything but he was simply black and umm he’d been racially abused and he was just wondering because we were about 30 at the time and umm whether it’s because they’ve got older or whether it’s because society has changed and I put it down to society has changed, they’ve been enlightened a little bit to people’s circumstances but I think, they would have had a different reaction if the handicapped person had been Caucasian, but at the time, back in the 70’s that was the reaction but there wouldn’t have been the slander or whatever, the abusive reaction had they been Caucasian so if you fast forward the clock umm, people like, disabled people in wheelchairs, you know they would have been looked, frowned upon back then
but now no, everyone goes out of their way to accommodate disabled people and you know, does that answer the question?"
(lines 261-274)

“I’ve no questions, it’s just the observation that I’d made at some points. Now, you’re talking to me on the phone now and ideally we’d be talking face to face I suppose, but thirty years ago, this wouldn’t have happened. That is the observation. You can’t be critical because this is the economic or political situation at the time, so, how things have moved on is unbelievable. Totally, you wouldn’t have been talking to me thirty years ago”
(lines 614-617)

Impact of learning disability and schizophrenia at multiple levels

On Tamara

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<tr>
<th>Tamara</th>
<th>Geoffrey</th>
<th>Victoria</th>
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<tr>
<td>“Because in the courthouse did to me” (line 865)</td>
<td>“The fulcrum was her mother, our mother dying” lines 288-289</td>
<td>“I don’t think she thinks about it at all. I know that she knows she’s missing out on certain things” (line 123)</td>
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<tr>
<td>“I had the brain operation” (line 819)</td>
<td>“She’s always gone, you know with her own tide and I don’t think, the only thing, like normal things, if someone upsets her then she you know, goes back at them but there’s nothing fundamentally upsetting her” (lines 346-347)</td>
<td>“Oh, I don’t know, like getting married or starting a family or something. She knows she can’t do those things, she knows she can’t do it. Whether she knows but I don’t know if she accepts that she can’t do those things. I know that she really wanted children and she can’t do that so emotionally, it’s hard, I can only imagine it but I think she knows she’s missing out but…” (lines 127-130)</td>
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<tr>
<td>TJ: Ah, ah, ah, the brain operation</td>
<td>“Well, the only thing she’s learnt, again, I go back, the only thing she’s learnt and coped with is her mother’s death. That basically is it because then she”</td>
<td>“I knew she knew things that she missed, was missing out on life, it was quite hard. I wasn’t sure whether to take the baby down to see her or not you”</td>
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<tr>
<td>TJ: The brain operation at the courthouse</td>
<td>I: The brain operation at the courthouse? Can you tell me about that Tamara?</td>
<td>TJ: Oh yeah I must be in trouble then</td>
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**TJ:** *Mmm, mmm*” (lines 455-461)  

*“I: What other things make you happy?*

**TJ:** *Umm, err, mmm. What’s that now... Ah, I know, shopping, shopping by myself”* (lines 484-486)  

*“The management kept changing you know like every couple of years and umm, there was a case of some, I was still involved with her at the time, it was a case of re-initiating the management as to Tamara’s problem”* (lines 571-573)  

*“Yeah, just because it, because there was quite a lot of things that she could do for herself but wasn’t allowed to do for herself, with living in a secure hospital umm, it brought her much more out, to a normal way of life if you like so I think from that point of view it’s much better for her umm because it was, in her eyes as well, a lot more independence and she had her own space. Basically, like when she was living at our old house, when we were growing up, she had her own room and jam packed full of gadgets and everything she could ever think of. You know, she can do her own washing, she can go out, it’s like a house, a big house, it’s not a hospital with bars and very clinical looking. So I mean it’s chalk and cheese really moving out into the community. It’s got a front door, not like a hospital at all”* (lines 405-412)  

*“Erm, probably more contact with the family as we haven’t been able to visit as much. I think that she would benefit from family contact. Where I’m in Scotland so that doesn’t help either, whereas when I was still in say, Milton Keynes, I would still be able to drive down umm, whereas up in Scotland it’s that much harder”* (lines 456-459)
### On family member's perceptions of Tamara

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<tr>
<th>Tamara</th>
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<tr>
<td>&quot;I knew that she had a brain which was logical and umm, therefore, umm, her behavioural tendencies were illogical to the casual observer but to her in her mindset it was totally logical. So she would like, throw tantrums and stuff when she was a teenager. We eventually got her sectioned because she did get extremely violent if she didn’t get her own way. It’s the spoilt brat umm scenario&quot; (lines 22-25)</td>
<td>&quot;I haven’t got a clue what she thinks in between, you know, when we’re not there, you know, after we’ve gone, what she’s thinking” (lines 202-204)</td>
<td>&quot;Yeah I think like she would throw tantrums if she didn’t get what she wanted but obviously I know with bringing up a child, you don’t give into those because otherwise they’re controlling you the whole time. It felt like the whole time she was in control of everything because, because if she didn’t get what she wanted she would create a big fuss. It got to the point where she would just get what she wanted anyway so” (lines 275-279)</td>
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<td>&quot;So she would frequently blame the neighbours and I think that’s because she stopped… Again, she’s very logical, must have realised at some point that she can’t blame the family so now she realised she’s got to blame someone else so now she starts to blame the neighbours and it’s totally, totally irrational because she’s blaming the neighbours for something that well, doesn’t exist” (lines 114-118)</td>
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<td>&quot;Which really isn’t good. The whole concept of what I’ve learnt from the experience with her is don’t spoil them, don’t give them, children, whoever, don’t give them what they demand if the demand is unrealistic. If the demand is realistic, I’m thirsty, give me a drink of water, give them a drink of water, yeah, there you are and then come down, two minutes later, I’m still thirsty, can I have some water? Yes, there you go. Now, ten times later, as a parent you’re going to say you can’t be thirsty, I’ve just given you half a gallon of water. At this point, tantrum and that is basically it in that&quot;</td>
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sense that she was spoilt which is not surprising, spoilt by mum which basically after dad died what happened. You must stop spoiling her, you mustn't spoil her and the term spoil isn't quite correct, it's more like don't give in to her demands of any child's demands, doesn't have to be mentally handicapped or anything like that but just don't give in to demands” (lines 188-196)

“But she'd walk with a stoop and if you can imagine an ape walking with the two hind legs, two arms, now if she had stopped any further, she would have been walking like an ape and that's bad enough” (lines 240-242)

“From that point onwards, although she was aware that she was disabled, she could still think straight and always did think straight but when mum died she realised that she could no longer behave the way she used to behave before Mum died so Mum was basically giving into her all the time but she is fully aware of her disability but she will, I'm sure and I'm sure she has done, taken advantage of that disability as the bluff so she will throw a tantrum or whatever, I think she'd kicked in a TV set at [name of residential home] once a few years ago but she will put that down to her disability which means that she is absolutely logical, she knows what she's doing. I know that sounds stupid but she will, because she can't get her own way, she will do something and when apprehended or asked for a reaction, she will actually say 'I don't know what I'm doing, I'm disabled' or how every she enunciates her disability, she will blame that aspect of her
disability as the reason for her previous action so effectively, she actually knows what she's doing” (lines 293-302)

“Again, the same amount, she knows she is mentally handicapped but she, it's not one of the things, you can't know you're mentally handicapped if you know you are mentally handicapped, I don't think that is possible. Physically, if you have your left leg amputated, you can look at your left leg and your stump and know you haven't got a left leg. That's different to the psychological mental side when someone is actually aware that they are mentally handicapped, it's a contradiction in terms. You've lost a leg, fine, you can't walk on that leg. Now, if you're mentally handicapped, you're handicapped but you're not aware of being handicapped, you shouldn't be aware, logically. This is my opinion now, but logically, you shouldn't be aware of being handicapped if you are handicapped mentally because that throws everything out of the window because if you're aware that you're mentally handicapped then you cannot be mentally handicapped, yeah?” (lines 317-325)

“So, she's aware and she's I think she is probably still using that facet of her handicap to try and get her own way. All these down in [name of residential home] down there, they know. She is actually quite contained when she's been up here and stuff” (lines 329-331)
On family members and the family unit

"Just to my brother and sister. I have not been for a long, long time. Twenty years" (line 48)

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<tr>
<th>Tamara</th>
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<tr>
<td>&quot;GJ: I'm tall but I'm very slightly built and I weigh nine stone and my father he was a founder of a boxing club back in Shalom. Now, the most difficult thing for me to do was physical, it was to stand between my father...[became upset]&quot;</td>
<td>&quot;I: Is it difficult to talk about? It sounds like it's very difficult for you to recall some of those memories?&quot;</td>
<td>&quot;In some ways, at some times in the past, it's helped in some ways because she's a focal point in that sense, for Christmas or discussions and stuff. You had to get together to do things or whatever and that which if it wasn't for her, I'm not sure whether these things would have necessarily have happened as much&quot; (lines 292-295)</td>
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<td>I: Are you ok to continue or would you like to move on to another aspect of the interview?</td>
<td>GJ: Sorry about that</td>
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<tr>
<td>GJ: No, that's absolutely fine and it's understandable if you're beginning to talk about things that haven't been thought or spoken about for a very long time. Would you like to perhaps either carry on with this part of the interview or...</td>
<td>I: Ok, ok.</td>
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<td>GJ: This is the first time, no one knows about this.</td>
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<td>GJ: Absolutely no one... That I would have to stand between my father and Tamara to stop him punching her so I was taking the punches. I'd forgotten all about that until now and umm... I don't think anyone has ever asked me about that and you're the first person</td>
<td>I: Right, ok</td>
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"I: So do you like seeing your brother and sister?

TJ: Umm, yeah I do but umm. I don't want them to come just Geoffrey. I don't want them to come down here if (inaudible)” (lines 70-73)  

"And she's not slight, she's really quite hefty but because I've nurtured her all those years and I could see her problem wasn't her fault but at the same time, my father can't reconcile himself to Tamara's problem. Now, he wasn't stupid or demented in that sense, he just couldn't reconcile it. Now I sort of compromised and when he got physical, he really lost his temper effectively that's just it, he lost his temper for whatever reason and he'd start lashing out at her. There was one thing though, my mum, it's an ordinary terraced house sort of thing and umm, she would be on one side, Tamara would be at the foot of the stairs and dad would be a couple of paces away from Tamara and he's big and I could tell before he started lashing out that he was going to start lashing out here so I'd be stood in between and it didn't stop him lashing out and I thought the only way to stop him lashing out at Tamara is to hit me. He'd want to hit Tamara, not me so at that point he'd stop and I'd take the beating, the physical side of him. The flipside of it is that Tamara got away with it. She didn't get hurt in any way and she actually got away with whatever she wanted and Dad was reacting to her and I got punished for it. Big problem there psychologically, because Tamara now has got her own way. I've taken the brunt of it.” (lines 169-180)  

“No. I, umm, I don't think so because I was always shielding her so essentially my brothers and sister, they weren't, what's the word, they weren't being...” (lines 134-160)  

“Everyone's very independent and my two older brothers because they weren't in the house very much, everyone didn't really spend a huge amount of time together because the time that was spent in the house, quite a lot of it from what I remember, quite a lot of it was her with her temper and everything being calmed down and doctors and things. So from that point of view, you didn't really have a brilliant relationship with everyone so obviously when you're older, you're that much, you're a bit further as well so she sort of in some ways kept us closer if you like, because the parents aren't there, you've got to help out and share the responsibility for like” (lines 295-301)
inflicted by the umm, by Tamara's condition so they weren't being bombarded in that sense because I was forever shielding her, trying to keep her calm so I don't think so, my sister might think differently which is why you should talk to her" (lines 435-438)

"a weekend, you have to in case she's violent and she has done a few things over the years to me, like she has grabbed me from the back by my hair so I would never leave her, be alone with her at my place. Trying to work out what she's thinking as well, which is quite hard because you might not know, if she's taking a turn for the worse then we try to, it's obviously quite hard and quite unpredictable. You have to make sure that there's no knives around, nothing that she could you know, harm with. That's probably just me being paranoid but obviously from past experience, there have been previous times when she's done something. That's been the only difficulty as such. Obviously growing up it was quite difficult because you couldn't do lots of stuff, things always got ruined, there would be my brother and my dad holding her down. We could never go anywhere in case she started. Couldn't have friends round and things. It always seemed like she knew what she was doing because as soon as she got what she wanted, she would calm down. Not much else really, of difficulty" (lines 65-77)

"TJ: I like only my mum and dad
I: You like only your mum and dad
TJ: Not my brothers, not so much
I: Not your brothers so much?
TJ: I should be nice to my sister, my sister nice" (lines 109-117)

"Because I don't recall at any time her lashing out at any of her brothers and sister and umm, she probably did do it and I've probably got a really bad memory and umm, but my sister's got a very good memory but I don't think so" (lines 447-449)

"To be honest I haven't really had to cope, it's not affected me directly apart from you know, when, when we do bring her up, having to do it in short bursts because we can't bring her up for like a whole week you know because she would just get too wound up after a couple of days and she would just start talking nonsense and stuff and then you're not really sure if you're safe. With what's going on in her head, you can't really tell what's going through in her"
<table>
<thead>
<tr>
<th>&quot;I: Can you tell me what you liked about your mum and dad?</th>
<th>&quot;I: Ok, what things do you think have helped you to manage over the years in terms of the caring role that you've taken on for Tamara, what do you think has helped you to manage and to cope?</th>
<th>&quot;Yeah, umm, I mean, managing is probably the right word in the sense that only having her come up for short visits, you know, checking what sort of things like sharp knives are around and you know, glasses and things that she can hurt you. Just things like that really&quot; (lines 223-225)</th>
</tr>
</thead>
<tbody>
<tr>
<td>TJ: Just they looked after me&quot; (lines 135-137)</td>
<td>GJ: I don't know Joanne because it wasn't that cut and dry. I don't know because it's something you sort of fall into, it's like water flowing out of a fountain&quot; (lines 395-399)</td>
<td>&quot;Driving, driving was another one because one of the incidents where she was that I was driving and my husband was sitting in the passenger seat and she was behind me in the driver's seat and then she suddenly grabbed hold of me while I was driving and tried to strangle me so now whenever we put her in the car now, she's always in the front, next to the driver rather than behind so it's harder for her to try and do anything. There are just little things like that that we've just dealt with automatically umm, really&quot; (lines 229-234)</td>
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<td>&quot;The reality is that they were not aware of what was happening, you know what families are like, they keep themselves to themselves, they won't divulge unless it is</td>
<td>&quot;To be honest I haven't really had to cope, it's not affected me directly apart from you know, when, when we do bring her up, having to do it in short bursts because we can't bring her up</td>
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"To be honest I haven't really had to adapt apart from visits and things like that. Other than that, I don't think it's really affected me directly, or even indirectly apart from that" (lines 210-216)
absolutely necessary so there comes, in that little scenario. Hypothetically, yes they could have done if they knew” (lines 551-553)

for like a whole week you know because she would just get too wound up after a couple of days and she would just start talking nonsense and stuff and then you’re not really sure if you’re safe. With what’s going on in her head, you can’t really tell what’s going through in her head so in terms of adapting, I’ve not really had to adapt apart from visits and things like that. Other than that, I don’t think it’s really affected me directly, or even indirectly apart from that” (lines 210-216)

“Yeah, I would say so. Though when she was younger, it was just generally, didn’t matter who it was at it was just generally towards the family. I mean, she did get spoilt, in terms of she got more of what she wanted and treated differently really to the other children when we were growing up because she was always a priority, so whatever she wanted or needed came first but I mean there wasn’t anything like we suffered for it, it was just something that we just accepted that that was the norm” (lines 248-252)

“Err, I would say yes probably. I think umm, it’s probably more of a personal perception rather than the reality, perception wise I would say that, I don’t know, the other children, the other four would always take a back seat so you didn’t really, like my oldest brother was just out of the house as much as possible and therefore, their relationship with say, my father probably wasn’t as good as it could have been because they weren’t spending very much time there. I don’t know if there’s anything else really” (lines 268 – 272)
Appendix 14:

Analysis of themes not included in the main analysis section for the Foley family
Analysis of themes not included in the main analysis section for the Foley family

The superordinate and subordinate themes arising from the analysis of the Foley family interview transcripts are delineated in the table below:

<table>
<thead>
<tr>
<th>Superordinate themes</th>
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<tbody>
<tr>
<td>Course of illness</td>
<td>• Insidious onset and nature</td>
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<tr>
<td></td>
<td>• Gradual development</td>
</tr>
<tr>
<td>Searching for an explanation</td>
<td>• Diagnostic overshadowing</td>
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<td></td>
<td>• Looking for reasons/ways to explain</td>
</tr>
<tr>
<td>Experience of negative emotion</td>
<td></td>
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<tr>
<td>Coping and adaptation</td>
<td>• Strategies</td>
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<tr>
<td></td>
<td>• Changes</td>
</tr>
<tr>
<td>Relationship with services</td>
<td>• Information sharing</td>
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<tr>
<td></td>
<td>• Relationship with services</td>
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The themes highlighted in **bold** were included in the main analysis section. The other superordinate and subordinate themes are discussed below:

**Course of illness**

*Insidious onset and nature*

The experiences related to schizophrenia as described by members of the Foley family conveyed undertones of the insidious onset and nature of schizophrenia. The term *insidious* can be described as something which operates harmfully in a subtle manner using deceit to entrap people. Both Gillian and Sally described how they did not know that the subtle changes and behaviours that Simon exhibited were linked to a mental health problem or that they may have been linked to schizophrenia more specifically.

*Gillian:*  *At that time he was a bit funny, when he was watching telly... he said ‘I’m afraid of football’, he didn’t like to watch the football anymore from that time. I really underestimated... I couldn’t see it quick. (Lines 29-34).*

*Gillian:*  *Gradually, you could see that, no, lots of, all those times, he was developing something different which I couldn’t see at all (Lines 460-462).*
Sally: I didn't think... If someone had said to me 'oh that's a mental illness' then I would have said 'no' (Lines 46-47).

The above extracts highlight the insidious nature of the onset of schizophrenia for Simon in that the subtle signs he exhibited were underestimated in terms of their wider implications and not immediately linked to the development of a mental health problem. Gillian described how she “didn't know anything about psychosis” (lines 153-154) which suggests that a lack of knowledge about the signs of schizophrenia may have made it more difficult to attribute Simon's behaviours to the onset of a mental health problem. This theme is linked to the superordinate theme of 'searching for an explanation' and subordinate themes of 'diagnostic overshadowing' and 'looking for reasons/ways to explain' as the family engaged in a process of hypothesis testing and looking for reasons that may explain his behaviour, such as that it was related to Simon’s learning disability or to other external factors.

There was also a sense of deceit which underpinned the insidious nature of the development of schizophrenia which was expressed by all members of the Foley family. Gillian and Sally described a series of events in which Simon had tried to mask some of the harmful things he was doing in the context of schizophrenia both from his family and from healthcare professionals:

Sally: I don't know if mum told you but he'd been kneeling on the road, trying to get knocked over and we only found out because the newsagent at the top of the road told us... But we didn't realise he was doing all this (Lines 319-321; 338).

Sally: I said 'did you burn your face?'. He was like 'no' (Line 396).

Gillian: We went to see the doctor. Simon gave the speech again 'I'm not going to do it again, I just want to...' so he says 'ok'. So when we come home, same problem. (Lines 182-185).

Gillian: So, is difficult really, it can deceive you in any way (Line 537).

Interestingly, the language used by Gillian externalised the schizophrenia in a way which attributed the deceit to the influence of schizophrenia rather than locating the deceit within
Simon. There are a number of other examples of the externalisation of schizophrenia which convey a sense of ‘being done to’, particularly in Simon’s account in relation to the experience of negative emotion. There is also a sense of the signs and symptoms of schizophrenia needing to be picked up by people around the person, such as family members though this can be difficult when the signs are being masked or hidden and when there is a lack of knowledge about what constitutes a mental health problem such as schizophrenia. The masking of harmful behaviours was linked to ‘the experience of negative emotion’ theme as Simon, Gillian and Sally all expressed difficult, negative emotions in the context of the harmful behaviours that occurred in the context of schizophrenia.

Gradual development

Linked to the insidious onset of schizophrenia, there was a sense that the illness developed and escalated gradually over time with concordant escalations in the responses of the family members and healthcare professionals around Simon. In her account, Gillian mapped out both the gradual unfolding of the symptoms of the illness and the ongoing responses of services in response to the behaviours as the illness escalated. She described the oscillation of the illness in the early stages and how “one day Simon seems fine and another day, it’s a different matter” (lines 127-128). This oscillation is paralleled in the initial responses of the healthcare system as she described a period of consulting the General Practitioner and being reassured and sent away with recommendations that Simon should increase his daily activities. The escalation of Simon’s behaviours was mirrored by an escalation in the responses of services after Simon had moved from harming himself to harming others as described by Sally:

Sally: After that, we just thought that was not good so mum was like we need to go to [name of service where Simon’s psychiatrist was based] so we went but leading up to that point, the psychiatrist was like ‘oh you know’... ‘I treat people with a worse condition than what Simon has’ (lines 615-620)... and at the time he wasn’t harming anyone else but then he pushed me over and everything they were like ‘well, he’s harming other people’ (lines 632-634)... So, they said he should go in [to inpatient assessment and treatment unit] (Lines 637-638).
The gradual development of the illness was also sensed by those around Simon, including extended family members as Sally described how family members had said "yeah, you know, over a while Simon just kind of got worse" (lines 642-643). There was a sense that the gradual development of the schizophrenia mediated the negative impact of gravity of the diagnosis:

Sally: If someone had told me from beforehand the situation's going to end up like this I probably would have been a bit like 'oh my gosh, that's awful' or think it's scary or something but because it's so gradual everyone got used to it (Lines 269-272).

This extract also conveys a sense of coping gradually at each stage which was shared by Gillian:

Gillian: Just take it err, as gradually. Just err, take it as it happens, it happens (Lines 684-685).

Although the insidious nature of the course of the illness may have somewhat hindered the identification of schizophrenia, the gradual development of the illness and of the responses from services was seen as a necessary part of the process rather than as a negative part of their experience, as described by Sally:

Sally: There wasn’t ever a point where any of us thought ‘why aren’t they doing this?’ or ‘why aren’t they doing that?’ because it’s not like, I don’t know, it’s not like you can rush it. You have to wait six weeks or something before any medication can kick in and it’s an experimental condition in that you know, you can’t force it, you have to see what happens (Lines 1250-1255).

In reflecting on the gradual development of the illness, Gillian stated that "people should recognise this at the early stage" which conveys a sense of the perceived importance of early recognition and intervention which may help to prevent the escalation previously described which characterised the Foley family’s experiences.
Coping and adaptation

Strategies

Each member of the Foley family described a number of strategies which they had found helpful in learning to cope with the experiences that schizophrenia brought into their lives. Simon described a range of strategies that he had found helpful including cognitive and distraction techniques ("think good thoughts not bad thoughts", line 522) engaging in activities ("I do sudoko, drawing and word search", line 1560), medication, talking about what upset him with his family ("I tell them what upsets me", line 1631) and with the workers and education about schizophrenia ("Show me the leaflet" (line 1271)... "they wrote it down" (line 1279)). For Simon, there was a sense that coping with schizophrenia meant trying to exert a sense of control over it:

Simon: I try to control it
I: Mmm
Simon: I try not to get angry sometimes and feel happy inside. Sometimes I don’t do it (Line 103)
I: Sometimes you feel angry inside but you don’t do anything?
Simon: No I don’t do it out. (Lines 99-108).

Simon made reference to a number of people who help him in these various activities, such as his family, psychologists and psychiatrists in the learning disability team and the staff in the supported living placement.

Simon, Gillian and Sally all shared a sense of the importance of family support in helping them through difficult times.

I: Do your family help you with the schizophrenia?
Simon: Yeah
I: Can you tell me how they help you with the schizophrenia? What do they do to help you feel better from the schizophrenia?
Simon: Err, talk to me
I: And you also tell them about what upsets you and then what do they do?
Simon: They sort it out (Lines 1620-1627).

Within this extract, Simon conveys how talking to his family about the schizophrenia is helpful for him, particularly by explaining things to him if he has become confused or is unsure about a situation and there is a sense of Simon being able to rely on his family. The involvement of each family member in providing ongoing support to both Simon and other members of the family as a means of coping over time is echoed by Sally:

I: What’s helped him, and what do you think the things were that helped him to cope and adapt and kind of get through it?
Sally: I think only because, so, everyone’s been so we’re all supportive and stuff (Lines 891-894).

Sally: Then at other times if James couldn’t make the meetings then Jenny would go, so everyone’s been there... everyone in the family’s involved. (Lines 1184-1188).

The continued involvement of each family member in sharing responsibility and taking an interest in Simon’s care had been a large factor in helping Simon and Sally to cope with the gradual development of the illness and the experiences and contact with services that this brought.

The importance of religion, prayer and faith was also highlighted by Gillian (“I think it’s only by the grace of God and err we go to church and pray and we come home and we ask Simon to pray for himself” Lines 681-682) and reinforced by Sally (“I suppose you know, everyone’s like it can’t get any worse. We’re all Christians you know, we pray” Lines 952-953). The resolute nature of Sally’s approach to coping with the difficult experiences that have occurred as conveyed in the first sentence lend credence to the idea of using these experiences coupled with their faith as a way to build resilience. This is also shared by Gillian, however, the final, resolute resilience conveyed in her account when thinking in hindsight from her current position is different from the immense sense of struggle and difficulty conveyed when describing being initially faced with a mental health problem:

Gillian: Well, as I said, he’s helping himself because he has no choice. It’s happened (Lines 660-661)
Gillian: Just take it err, as gradually. Just err take it as it happens. (Lines 683-684)

I: Was there anything that happened to Simon that you managed to cope quite well with or you know, was ok for you?
Gillian: Err, ok for me to handle you mean?
I: Mmm, or was it all very difficult?
Gillian: Well yeah, ok for me to handle when he was disability but with the mental health problem it made it really difficult (Lines 606-609).

This extract conveys a sense of surprise from Gillian about being asked about her own coping and adaptation and there are a number of possible hypotheses or interpretations of her response to this type of question about her own needs. Firstly, it is possible that Gillian was not expecting this as I, as the researcher had not made it clear to her that aspects of the interview would be about her own experience rather than all about Simon. This would have direct implications for the evaluation of the study in itself. Secondly, it is possible that the surprised response from Gillian which led her to clarify the question was because she had not been asked about her views or needs before. Though these hypotheses are not mutually exclusive and there may be other interpretations of this interaction, the second interpretation of Gillian’s response is perhaps more pertinent to the current research question which suggests that being asked about their own experiences, views and needs may be a new experience for family members and one which they approach with an element of surprise and perhaps even with caution as it is something they may not have experienced much, if at all before. The other salient aspect conveyed in the above extract highlights the significant difficulty experienced in trying to cope with and adapt to the onset of a mental health problem which is seen as being a challenge over and above coping with a relative with a learning disability. This is built upon further throughout Gillian’s account (Lines 185-190) which demarcates the significant difference and difficulty represented by the onset of a mental health problem which was difficult to cope with and adapt to in comparison to a learning disability. This point is also discussed in the ‘diagnostic overshadowing’ theme. This may suggest that although the family had already learnt to cope with and adapt to Simon’s learning disability over the years, that the onset of a mental health problem may have
required a different set of skills or additional skills in order to manage the difficult experiences it brought. Interestingly, the deep sense of struggle and difficulty that is conveyed in Gillian's account which underlies the process of adapting to a mental health problem is quite different from the resolute stance adopted by both Gillian and Sally in describing the trajectory of experiences in hindsight from their current 'here and now' position.

Changes
Overall, the accounts from Simon, Gillian and Sally connote a number of positive changes over time in relation to their experiences with schizophrenia. In the context of discussing what had helped him, Simon was able to acknowledge the positive change in his experience of schizophrenia over time:

I: Ok, has the schizophrenia stayed the same over ten years or have there been or has it changed over ten years?
Simon: It's changed over ten years
I: Has it got better or worse?
Simon: Got better (Lines 949-952).

Although this conversation did not arise spontaneously from Simon, there is concordance among the accounts of each member of the Foley family in that they have witnessed positive changes over time:

Gillian: Yeah, but because he has improved a lot in himself I feel happy now. (Line 702)

Gillian: At last he's getting better. (Line 706).

This extract from Gillian demonstrates how improvements in Simon's well-being have had a concordant positive impact on her own sense of happiness and well-being, though there is also a sense that there has been a long and difficult journey to get to this point and that there may still be some way to go. This fits with the previous themes of 'insidious onset and nature' and 'gradual development'.
Similarly, Sally highlighted subsequent changes in the way she conceptualised and approached difficulties such as mental health problems. Her experiences of dual diagnosis of learning disability and schizophrenia in relation to Simon had fostered an enhanced sense of vigilance or recognition around mental health problems ("Personally, I spot people with mental health problems a lot more now" Line 676), increased understanding and empathy ("We don’t just dismiss people with learning disabilities anyway. Also, umm, mental illness because yeah we kind of understand a bit more. I can only relate to Simon’s...” Lines 982-984) and more patience and tolerance of people with learning disabilities and mental health problems ("I think the way we’ve had to adapt to things is to be more, a bit more tolerant” Lines 1014-1015). The use of the word “we” also implies that from Sally’s perspective, these changes may extend to other members of the family too. There is also a recognition that the learning and changes are specifically connected to her experience of Simon’s difficulties which implies an understanding that there may be variation in the experiences of different people.

There was agreement between Simon, Sally and Gillian that one of the main positive outcomes had been the move to supported living accommodation in that this had enabled Simon to become more independent. There is a sense that this outcome may not have happened if Simon had not been in contact with services for his mental health difficulty, therefore, this was viewed as being a helpful outcome for Simon and his family.

**Relationship with services**

**Information sharing**

Throughout each of the accounts, there are references which convey a sense of surprise about certain elements of Simon’s diagnosis or care which suggest that there may have been a lack of information sharing or transparency at some points during the course of Simon’s care and the family’s engagement with services:

*Gillian: I think there was a time when one of the doctors said “psychotic” or something and I say “Is this something to do with him now?”. (Lines 93-94).*

*Sally: It’s only from around (name of inpatient assessment and treatment unit) time when they said actually “he’s suffering from schizophrenia”. (Lines 232-233).*
Sally: Just around before, maybe 2004, 2005ish around that time when one of the psychiatrists or psychologists said “anti-psychotic” and I was thinking hold on, what’s that?. (Lines 248-250).

I: Do you remember what Dr Patterson said about schizophrenia?
Simon: No. (Lines 381-383).

The sense of surprise conveyed in the above extracts underlines the importance of remaining transparent about the way the service works and the decisions made at each stage of care. It also reinforces the importance of remaining mindful about the taken-for-granted knowledge that professionals hold and the impact of not informing a family about the nature of a suspected or confirmed diagnosis and of this information being picked up almost by accident, particularly where specialist terms such as ‘psychosis’ or ‘schizophrenia’ may be used which may conjure certain images or ideas that may be related to e.g. stereotypical depictions of these difficulties in the media. Alternatively, it is possible that information about the nature of the diagnosis had been shared with Simon and his family but that they had not retained this information, as is common for patients consulting with their general practitioner. This is particularly salient in relation to people with learning disabilities who may find it difficult to retain information, particularly regarding a complex diagnosis such as schizophrenia. This raises questions about the ways in which health professionals convey information to people with learning disabilities and their family members in a way which facilitates their understanding and remain open to questions throughout the duration of their contact with them. Indeed, some family members may find the diagnosis of a severe mental health problem such as schizophrenia very difficult and may actively, whether consciously or unconsciously, seek other explanations or dismiss such news.

Despite the possible lack of transparency, information sharing and psychoeducation about schizophrenia was seen as being one of the most helpful elements of the care provided, particularly for Simon:

Simon: Show me the leaflet
I: Show you the leaflet? What’s the leaflet about?
Simon: Schizophrenic. (Lines 1271-1275)
I: What's the most helpful thing that Dr Patterson has done?
Simon: Helpful that Dr Patterson?
I: Yeah
Simon: Spoken, spoken to us
I: Spoken to you?
Simon: Yeah
I: What did he speak to you about that was helpful?
Simon: Schizophrenic. (Lines 1305-1319)

This extract suggests that psychoeducation about the nature of schizophrenia had been helpful for Simon and also for his family, as indicated in Simon's use of the term "spoken to us".

Relationship with services

Despite the occasional absence of information sharing, the family's relationship with services was characterised by trust and faith in the ability of professionals in Simon's network of care, as delineated by Sally:

Sally: I was thinking back the other day and I was thinking actually, how did I not know? I didn't check up on anything, it wasn't like I thought I needed to go and check, we trusted the doctors you know. (Lines 200-202).

This extract conveys a sense of unquestioning faith and trust in services. This somewhat unquestioning and unchallenging approach may be linked to an underlying power differential between family members and professionals as part of the wider health care system. Traditionally, the patient versus expert nature of healthcare espoused by the medical model has meant that service users and carers may have a model of healthcare which locates power within the healthcare system and the professionals that work within them. The service-user involvement movement where the views and input of service users and carers are sought to inform and improve healthcare services is a relatively new philosophy and one which may be a new idea for people who had been used to the historical model of healthcare. This may help to explain the tentative response by Gillian to
questions about what her views and experiences were as this may be a relatively new way of thinking for some people.

Despite this, there is evidence within Gillian's account of a more critical and challenging approach to working with professionals within Simon's network of care. Gillian describes how in response to a particularly difficult incident that had occurred in the family home, she challenged services to provide a more efficient response to her request for help:

Gillian: The following day I have to take him to see the doctor again. So when I went and I retell the whole story to the doctor and the doctor said “Oh”, I phoned first and they said to bring in next week and I say “I'm sorry but next week is too late”. Too late. (Lines 268-271).

This underscores the importance of the healthcare system remaining open and responsive to feedback from people with learning disabilities and their family members and/or carers.
Appendix 15:

Analysis of themes not included in the main analysis section for the Williams family
The superordinate and subordinate themes arising from the analysis of the Williams family interview transcripts are delineated in the table below:

<table>
<thead>
<tr>
<th>Subordinate themes</th>
<th>Superordinate themes</th>
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</thead>
<tbody>
<tr>
<td>Experience and understanding of psychosis</td>
<td>• Experience of psychosis</td>
</tr>
<tr>
<td></td>
<td>• Understanding of experiences related to psychosis</td>
</tr>
<tr>
<td>Impact on the family</td>
<td>• Unhelpful aspects of services</td>
</tr>
<tr>
<td>Services</td>
<td>• Helpful aspects of services</td>
</tr>
</tbody>
</table>

The themes highlighted in bold were included in the main analysis section. The other superordinate and subordinate themes are discussed below:

**Experience and understanding of psychosis**

*Experience of psychosis*

Rebecca, Caroline and Thomas all provided detailed descriptions of the nature of the changes in Rebecca that marked the onset and course of psychosis, although at the time they were unaware that such changes were linked to psychosis specifically. Thomas described the initial changes he recognised which were initially subtle and linked to the things that Rebecca had previously enjoyed, for example, Rebecca enjoyed listening to music but began singing out loud to herself. After this, the family noticed a number of other changes which marked a rapid decline:

*Thomas: After that she seemed to go right down... more or less just stare out of the window... she used to see people, thinking they were coming for her...* Caroline noticed one or two things as well. (Lines 113-117).

*Caroline: She was walking down the back here shouting as if she was having a conversation. We couldn’t see anybody but we later found out that those were the voices she was hearing, that she was shouting.* (Lines 125-127)

*Caroline: She'd got this idea that whatever I was feeding her was rotten and mouldy... When I say about the weight loss, this happened within a few months.*
There was a sense that the psychotic experiences showed themselves and affected Rebecca in a number of different ways. For Rebecca, looking back from her current position, she noticed a number of changes in herself which affected her and those around her:

Rebecca: They couldn't believe how ill I was because I wasn't eating then neither, I used to go out of windows, climb out of windows, talk to things, talk to flowers. Sometimes talk to someone that's not there, tell them to shut up, tell people to leave me alone... Use to use full blown language at people and they didn't like it 'cos they didn't know it wasn't me saying that. (Lines 321-325).

The above extract highlights how the changes had a negative impact on Rebecca and those around her and this is discussed further in the 'family - impact' theme. Interestingly, Rebecca's use of the term “they didn't know it wasn't me saying that” perhaps suggests that the changes in her character and behaviour when she was acutely unwell left her unrecognisable to herself and her family. Indeed, Rebecca later commented “never used to be me when I was ill” (line 325) which highlights the gravity of the change in character for Rebecca. It also raises questions about how the sense of self and identity is affected during this time and the impact of psychotic experiences on identity once the symptoms are being well managed.

Though the illness had a profound negative effect on some members of the family, as discussed below, Rebecca was also able to acknowledge some positive elements of the psychotic experiences:

Rebecca: The voices used to help me. The one with the leopard I used to see... used to keep me happy and calm... Only I could see it so I used to think it was a special thing altogether and it was nice that. He often used to calm me down a lot when I was depressed. (Lines 122-126).

The pleasant aspect of the psychotic experiences was in fact helpful for Rebecca in some ways.
Understanding of experiences related to psychosis

Each member of the Williams family expressed a sense of now knowing what was happening or that the changes were specifically related to psychosis. Though Caroline and Thomas were aware of a number of changes that may have indicated that Rebecca was ill, Rebecca was unaware of the changes in her behaviour and character and of the fact that these were related to an illness:

Rebecca: I didn’t actually. I didn’t know until umm, someone told me that I was very ill and how ill I was... It was quite shocking actually, that someone would tell you that you’re that poorly. (Lines 251-252 and 300).

Thomas: I don’t think she really knew what was happening really. She just didn’t see what she was doing was wrong and thought she was doing right and other people were doing wrong. She didn’t want to know. (Lines 281-283).

Each member of the family embarked on a gradual journey to understand the illness. Rebecca and Caroline expressed how they coped with the illness on a day to day basis and that their coping and understanding was built up gradually over time (Rebecca: lines 1033-1035 and 417-418; Caroline: line 607). There was a sense that an understanding of the experiences related to psychosis was gradually built up over time and continued to build and grow as they reflected on the experiences between themselves and in the research interview. Each member of the family attributed different experiences and points in time as being significant in developing their understanding of the psychotic experiences. The beginning of medication was identified as a significant turning point from when Rebecca began to be able to make sense of and reflect on the psychotic experiences. This is commonly referred to as ‘developing insight’ in some medical and psychiatric contexts.

Rebecca: No, no, injections help me taking control of it. Calms everything down if I’ve got an injection. Umm, don’t hear so many voices (Line 1114).

Caroline: I think since she’s, from the first time she had her first injection...once she’d had that injection, she realised it affected her enough to make her realise that she needed help. (Lines 339-340).
There was a sense that medication and talking had helped Rebecca to "come to terms with it now" (Thomas, line 296). For Caroline and Thomas, the liaison with specialist learning disability and mental health services and individual and couple counselling was identified as being instrumental in helping them to understand the illness. An extract from Rebecca described how the family continued to develop their understanding through a joint process of reflecting on the meaning of previous experiences:

Rebecca: Mum and dad listen to me when I’m talking... saying ‘don’t worry you’ll be ok but you can’t force it Rebecca, you are ill, you’ll have this for the rest of your life’...they talk to me quite a lot of things about when I was ill

Interviewer: What sort of things do they talk about when you were ill?

Rebecca: I said ‘how bad was I?’ and they said ‘you was very bad, half the stuff you didn’t even know what you was doing’. Some of the stuff I can recap on what I was doing, the swearing I can remember from when I was ill (Lines 685-700).

This extract conveys how the family may jointly co-construct their understanding of the meaning of the psychotic experiences and the impact that this had on the family and that this process may continue over time. In addition, it was viewed as important for Rebecca to be able to construct her own understanding of the experiences independent of the medicalised view:

Caroline: She’s learning about it herself I think outside of the medical group or way of working. (Line 712).
Appendix 16:

Analysis of themes not included in the main analysis section for the Harrison family
Analysis of themes not included in the main analysis section for the Harrison family

The superordinate and subordinate themes arising from the analysis of the Harrison family interview transcripts are delineated in the table below:

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subordinate themes</th>
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<tbody>
<tr>
<td>Understanding of and relationship to learning disability and psychosis</td>
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</tr>
<tr>
<td>Family involvement</td>
<td></td>
</tr>
<tr>
<td>Aspects of the service context</td>
<td>• Communication and consistency</td>
</tr>
<tr>
<td></td>
<td>• Quality of care</td>
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<td></td>
<td>• Resources</td>
</tr>
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The themes highlighted in **bold** were included in the main analysis section. The other superordinate and subordinate themes are discussed below:

**Family Involvement**

Each member of the Harrison family expressed the extent and importance of family involvement in Matthew’s care. Matthew began his interview by mapping out the members of his family and identified how he liked spending time with his family.

*Matthew: I do like my family are. Going home with Jane. Going home with and my Dad I do. (Line 114)*

The family involvement ranged from helping with aspects of care, such as attending appointments, liaising with services, providing information and reassurance about psychotic phenomena and being involved in aspects of care in the residential home. There was a division of roles between family members, with Matthew’s father, George adopting a proactive role in liaising with services and “fighting the system” to get things done for him and Matthew’s sister, Jane and other sisters providing more of a caring role:

*Jane: Well I think about the caring role, no, I think my sister and I sort of quite often have Matthew at weekends and I think that my father is more involved in things like doctors, dentists, psychiatrists, more involved in that side of it rather than the other*
There was a sense of family involvement over the course of the lifecycle and this was linked to the theme of 'understanding of and relationship to learning disability and psychosis' in which the family had accepted and adapted to Matthew's learning disability over time. The involvement of the family was viewed as being very helpful for Matthew specifically and for people with a learning disability more generally:

*Jane: It's down to the fact that Matthew has family who will get involved to fight his corner and get things done for him. In that sense, Matthew is quite fortunate, he has got family behind him but the ones who haven't got family are the ones who lose out.* (Lines 546-548).
Appendix 17:

Analysis of themes not included in the main analysis section for the Jayawardene family
The superordinate and subordinate themes arising from the analysis of the Jayawardene family interview transcripts are delineated in the table below:

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subordinate themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes over time</td>
<td>• Progression of illness</td>
</tr>
<tr>
<td></td>
<td>• Service changes</td>
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<tr>
<td></td>
<td>• Wider societal changes</td>
</tr>
<tr>
<td>Impact of learning disability and schizophrenia</td>
<td>• On Tamara</td>
</tr>
<tr>
<td>at multiple levels</td>
<td>• On family member’s perceptions of Tamara</td>
</tr>
<tr>
<td></td>
<td>• On family members and the family unit</td>
</tr>
</tbody>
</table>

The themes highlighted in bold were included in the main analysis section. The other superordinate and subordinate themes are discussed below:

Changes over time

Progression of illness

Both Geoffrey and Victoria summarised the extent of their background knowledge about the development and progression of Tamara’s behaviour which was not specifically related to either learning disability or to schizophrenia:

Geoffrey: Yes, it started off, umm, we were living in Salome in Sri Lanka and she had a problem, we were just kids then. Mum and Dad used to run around and take her to the doctors or whoever and umm, then we came to England and at that point it all changed... So she would like throw tantrums... We eventually got her sectioned because she did get extremely violent if she didn’t get her own way... and eventually got hospitalised in (Name of long-stay hospital for people with learning disabilities7). (Lines 18-26).

7 The name of the long-stay hospital for people with learning disabilities referred to in the interview transcripts of the Jayawardene family has been removed to ensure anonymity. The long-stay hospital was closed when there was a move from institutional to community care for people with learning disabilities.
Victoria: She was suffering from blackouts and fits when we were in Sri Lanka... we moved to London and they diagnosed a brain tumour and they operated to remove the tumour and only after the operation did they realise that it wasn't a brain tumour, it was part of her brain so before the operation she was going to a normal secondary school and at that time she was suffering from blackouts and other behavioural problems... The blackouts stopped but not the behavioural problems... Over the years she was locked up in an institute. (Lines 27-35).

In mapping the progression of Tamara's behaviour over time, there is also a sense of searching for a reason or trigger to explain the perceived deterioration in her behaviour. Tamara (lines 455-461 and 819), Geoffrey (lines 287-289) and Victoria (lines 27-36) all made reference to a brain operation which was highlighted as being a possible catalyst for the perceived deterioration in behaviour which led to hospitalisation in an institution.

Some of the perceived changes outlined were linked to wider service and societal-level changes, such as the move from institutionalised to community care for people with learning disabilities which was described as being helpful for Tamara to enable her to reach a stable "plateau":

Geoffrey: She's reached a plateau where the graph rises and then it settles off and I think at this moment in time and a few years before today it has flattened off so she is mentally stable in that sense, she knows where she is at and she knows what she can do and she knows what she can't do. (Lines 43-48).

Geoffrey: When we had these meetings when she was still in (name of long-stay hospital) with the social workers and they would bring out the drawings and the paintings that she's done and it was always in black and white, no colour... then you could see the progression, eventually she was now painting in colour... she was now in some way sort of accepting something around her, around her environment that it is no longer black and white and it became more colourful so effectively she was sort of blossoming psychologically and err, it sort of stopped there. (Lines 306-312).

The interpretation of the change in Tamara's drawings to depict a sense of acceptance on her part parallels the description of the progression of the illness to a now stable plateau. 

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Interestingly, it was not possible to ascertain a sense of Tamara's perception of her current position in relation to the illness and her sense of how she felt she was currently. This would have provided more information about concordance or discordance between the views of members of the Jayawardene family.

**Service changes**

As delineated above, service-level changes such as the move from institutionalised to community care were perceived to have had a positive impact on Tamara and this was experienced by all members of the Jayawardene family who were interviewed:

*Geoffrey: Yes, I think that was the beginning of a change for the better when umm, she was in (name of long-stay hospital) properly, which has probably been demolished by now, it was under lock and key...but once she left that environment and got into the bungalow, she was much free-er... Suddenly there was freedom for her... It was definitely the sense of freedom which was just sort of processed her mind into thinking sort of differently. (Lines 493-508).*

The contrast between being “under lock and key” and of having “freedom” provides a strong illustration of the experience of institutionalisation contrasted with more space and freedom which was perceived to have a beneficial effect on Tamara's well-being. This was built upon in Victoria's account:

*Victoria: It brought her much more out to a normal way of life if you like so from that point of view it's much better for her umm because in her eyes as well, a lot more independence and she had her own space. Basically, it's like when she was living at our old house, when we were growing up, she had her own room. (Lines 405-412)*

This was also recognized by Tamara:

*I: Ok. So, Tamara, can you tell me what things make you feel happy?*

*TJ: Living outside*
I: Living outside? Oh right

TJ: Outside with my family. (Lines 431-437).

There was concordance between Tamara, Geoffrey and Victoria’s accounts in their shared sense that the move to the community had been beneficial for Tamara and contributed to a sense of a ‘normal’ life.

Wider societal changes

The helpful service-level changes detailed above were linked to a perception of change in attitudes at a wider societal level in relation to learning disability, mental health and to ethnicity and diversity. This subordinate theme was mainly alluded to in Geoffrey’s account, however, elements of Tamara’s and Victoria’s account support this theme as an important change over time, for example, in reference to the move from institutionalised to community care which was linked to a wider change in attitudes towards the treatment of people with learning disabilities and with mental health difficulties. Geoffrey made reference to the significant changes in the perception and treatment of traditionally marginalised groups of people such as those with learning disabilities, mental health problems and those from minority ethnic groups, through a process of reflecting on his own experiences of discrimination and reflection on the process of taking part in the research study:

Geoffrey: We’re going back to the 1970’s, yeah 70’s when there, when racism was actually quite high so I actually had to calm myself because every weekend I’d go with Tamara on a Saturday into the (name of town) town centre and just walk with her but she’d walk with a stoop and if you can imagine an ape walking with the two hind legs, two arms, now if she had stopped any further, she would have been walking like an ape and that’s bad enough but what compounded it was the fact that we were Asian. Now, we were getting abuse left, right and centre you know... but that was back in the 70’s and society has progressed a little bit more now... I do remember one time when I was still working in London when I used to be a taxi driver there and umm, and a coloured guy would come into the car and we would start, we were about the same age and the question, I remember
him asking me, something like 'Is it me or have they stopped being racist?' because he'd gone through the same thing... I put it down to society has changed, they've been enlightened a little bit to people's circumstances but I think, they would have had a different reaction if the handicapped person had been Caucasian, but at the time, back in the 70's that was the reaction but there wouldn't have been the slander or whatever, the abusive reaction had they been Caucasian so if you fast forward the clock umm, people like, disabled people in wheelchairs, you know they would have been looked, frowned upon back then but now no, everyone goes out of their way to accommodate disabled people. (Lines 261-274).

Geoffrey: It's just the observation that I'd made at some points. Now, you're talking to me on the phone now and ideally we'd be talking face to face I suppose, but thirty years ago, this wouldn't have happened. That is the observation. You can't be critical because this is the economic or political situation at the time, so, how things have moved on is unbelievable. Totally. You wouldn't have been talking to me thirty years ago. (Lines 614-617).