

**Major Research Project**

**“The experiences of primary caregivers of people with learning disabilities  
who have committed an offence: a narrative study”**

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*“Sometimes it seems as if the invitations to worry,  
to diagnose, to pressure and to police  
our children are more prevalent than invitations to cherish them”*

(Tron Dinneen, 2004)

*“Institutional ways of being and doing give different rights to different people as  
regards speaking and being worthy of being listened to. All this is largely hidden. It is  
so obvious that it is not easy to notice”*

(Mair, 1998)

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### Abstract

Background and aims: The experiences of primary caregivers of adults with learning disabilities who have committed an offence is a largely neglected area within current literature. However, primary caregivers have an integral role in the provision of care of adults with learning disabilities and this has implications for service provision and rehabilitation. Our understanding of both learning disability and offending behaviour is affected by societal, cultural and political narratives and these have impact on a primary caregivers meaning making. Having identified a gap in our current understanding, this study aims to develop an understanding as to the storied experience of primary caregivers in order to inform clinical practise and raise awareness of the challenges faced.

Methodology: A qualitative approach was selected for this research. A purposive sample of five primary caregivers (three females and two males) was recruited through two NHS services and one community based contact. Field interviews were conducted with each participant, audio-recorded and transcribed. Narrative analysis was used to analyse the transcripts, focusing upon the content of information shared, the way in which the narratives were performed and the contextual factors which may influence story co-construction.

Analysis and findings: The narratives shared by participants are presented on a group level. Results are divided into two areas. Firstly the primary caregivers stories are presented chronologically in order to orientate the reader to the context in which primary caregivers were operating. The stories refer to 'life before the offence', 'the offence', 'life since the offence' and 'future stories'. Secondly attention is given to the underlying emotional content of the storied experience, with four predominant emotions identified; Frustration, Anger, Grief and Fear. This gives an emotional underpinning through which we can interpret the emerging plots and subplots, with consideration of the similarities and differences within these. Four plots were identified: 'Understanding', 'Proximity to offspring', 'Relationship with self and others' and 'Commitment to care giving role'. These narratives highlight both the temporal nature of the caregiving role and how it may be affected by service responses to the individual with learning disabilities and their families. The findings are considered in regards to their clinical relevance and implications for service provision. The strengths and limitations of the study and suggestions for future research are presented along with personal reflections.

## **Chapter 1: Introduction and Literature Review**

Emerson and Frosh (2004) argue that when conducting qualitative research it is essential that the researcher is transparent about their theoretical stance and interest in a particular topic area. With this in mind I wish to begin by sharing my motivation for undertaking this study, which has been borne out of my own personal and professional experiences.

I am a white, English woman who was raised in a predominantly working class family. There is a history of both offending behaviour and mental health difficulties within my family and I believe that there is a strong family narrative that the best way to manage is to not talk about these issues. Following university, I was employed in a medium secure unit for adults who had learning and communication difficulties. I was often frustrated by the way in which staff perceived parents as either 'collusive' or 'neglectful' and how these assumptions went largely unchallenged within the system.

Both my personal and professional experience has led to a belief that families within which offending behaviours occur are having to contain a great deal of anxiety and can feel judged by the way in which society and services respond to them. I believe that the views of parents of individual's with a learning disability are vital for the development of sensitive and successful care services (Madden, 1995), particularly when issues of risk and safety are involved. However, parents of adults with learning disabilities have had a relative lack of attention paid to their experiences. Families may welcome an opportunity to voice their own stories about their experiences over time, as potential counter-narratives to the dominant narratives which may judge or reject them.

### *Theoretical underpinning of this study*

The lens through which I shall attempt to understand the experiences shared by the primary caregivers in this study is Narrative theory (NT). This is a constructionist approach, which argues that it is through our ability to narrate our lived experiences that we come to understand who we are as individuals, evaluate our actions and predict our future outcomes (Crossley, 2003; Atkinson, 2007). The narratives we tell about ourselves are deep rooted, spanning across generations and reflective of our social context and cultural status (Chase, 1995; Duchardt, Deshler & Schumaker, 1995).

NT views identity in terms of the internalised stories we tell about individual life events and our life as a whole (McAdams et al, 1997; Stueve & Pleck, 2001). Identity is fundamentally temporal in nature (Gergen & Gergen, 1997) and the way in which

an individual comes to view themselves is reliant upon their ability to understand and relate experiences to one another across the lifespan. NT recognises that individuals have multiple aspects to their identity and these will become more prevalent at different points in life and in different contexts (Somers, 1994).

All of the stories we tell about ourselves are valid but may not be viable if they do not match our lived experiences. For example, unexpected or traumatic events can upset the continuity of an individual's storied life as individuals lose touch with their values and sense of identity (Begum, 2007), acting as a 'biographical disruption' (Bury, 1982) to the way in which we understand our own identity. Furthermore, if the social narratives told about us are 'erroneous' - that is, if they over simplify or fail to adequately represent the storied experiences of people operating within these spheres - our ability to be in the world will be accordingly problematic (Gavin, 2005).

By adopting a social-constructionist narrative approach for this study I hope to be able to story experiences that may transcend reductionist labels or dominant discourses. It is important to be clear as to the language that I have selected for use in this research, given the power that this holds in challenging and constructing shared meaning (Crossley, 2003).

#### *Language selection*

I have selected the term 'primary caregivers' as it encompasses all individuals who have adopted a traditional parental role towards another. Whilst the literature is heavily biased in its attention towards mothers, this research aims to give equal focus to the experiences of fathers, whilst acknowledging the different social narratives associated with each role.

Secondly, previous authors have highlighted the difference in opinion regarding how individuals with underlying cognitive impairments should be referred. Currently, the self-advocacy groups for these individuals promotes the term 'learning disability' and so for this reason it will be used here. Elliman (2011) highlights a conflict between the views of parents and the individuals themselves, with parents commonly advocating a 'person-first language' approach.

For this research I have chosen to adopt a 'person-first' approach. This is because this study is concerned with experiences and views of primary caregivers and so it is intended as a mark of respect that I use terminology they prefer. I also consider the 'person-first language' to be more in line with the narrative ethos of this research, as it implies that there are other aspects of the person which can be focused upon (Bagatelli, 2010). For these reasons the term 'individuals with a learning disability' will be used throughout this literature review.

Similarly, in line with the narrative view that individuals cannot not be defined by only one aspect of their character or behaviour (Somers, 1994), the term 'individual who has committed an offence' has been selected over the more paternalistic term of 'offender'. I also acknowledge that the term 'offence' (and associated variations) is a socio-political term which is dependent upon an individual having been convicted by a court of law. Any behaviours which are deemed high risk or socially unacceptable, but for which an individual has not been convicted, are referred to as 'challenging behaviours'.

### **Literature Review**

The literature search was conducted over a 20 month period and followed a systematic approach designed to elicit the key terms relevant to this study. A breakdown of the full literature search strategy is available in appendix A.

The following literature review is presented in two halves. Firstly, an exploration of some of the social narratives of both parenthood and learning disabilities is provided to orientate the reader to the context in which primary caregivers may be operating within British society. The second half of the literature review is focused upon the challenges faced by primary caregivers when their child has a diagnosis of learning disability or is convicted of an offence.

### **Understanding the context in which primary caregivers are operating**

The experiences of primary caregivers are at the centre of this study and so it is important to analytically consider the cultural, political and historical contexts within which parents are acting and being appraised by themselves and wider society (Kall, 2009). These will not only have influence upon us as readers but also on the primary caregivers themselves. The joint psychological and social perspective offered by NT (Crossley, 2003) is particularly well suited to this task as it addresses how stories have developed in varying and changing contexts over time.

### **Narratives around parenthood**

It is recognised that within the literature definitions of family construction vary, but predominantly they are based upon Anglo-American middle-class, heterosexual constructs (Gavin, 2005). This has important repercussions when considering the previous literature on parenting and how roles are divided between parents, particularly given the social narratives which exist around gender and care giving.

### ***The influence of gender on primary caregivers' experiences***

Parenting is a gendered social experience (Scott & Alwin, 1989; Starrels, 1994). Gender is both culturally and biologically defined (Fivush et al, 2000) and needs to be

understood not just within the limits of a parents physiology but also within the social context in which the different aspects of male or female identity are highlighted (Fivush & Buckner, 2003). Within the context of parenting different cultures within society hold varying views as to how to prioritise the multiple sub-roles associated with the overall 'parent role' as well as narratives as to how these sub-roles should be divided upon gender lines. As such, these roles become gendered, viewed as being 'feminine' or 'masculine'.

For example, traditionally within Western society fathers have been expected to place greater emphasis on the sub-roles of 'provider', 'tutor' and 'rule enforcer' whilst mothers take responsibility for the sub-roles of 'caregiver' or 'nurturer' (Starrels, 1994). Such roles are subtly reinforced through the way British society is structured (for example 'mother and baby' groups and maternity entitlement) and there remains an enduring expectation that mothers are the most equipped to provide care for their child (Kall, 2009). Whilst there have been significant challenges to the gendering of these roles, most notably through the feminist movements (Chodorow, 1994; Fivush & Buckner, 2003) and the gay rights movement (Patterson, 2006), there remains a pervading societal belief as to the roles men and women are expected to undertake and the capabilities of individuals who attempt to cross these gender divides. Fathers run the risk of social derision or stigmatisation should they be observed to perform the more 'feminine' parenting roles, whilst mothers may be considered 'cold' or 'unfeeling' if they adopt a more masculine approach to parenting. One of the predominant strands to emerge around general parenting roles and societal expectations is the notion of 'unconditional' parental love.

#### *Notion of 'unconditional' parental love*

The expectation that a parent should love their child unconditionally is such a fundamental assumption within our society that it is rarely questioned. However, it is important to highlight this assumption, as it has important repercussions for the way in which a parent may appraise themselves or feel appraised by society. Indeed, Kall (2009) argues that the notion of 'unconditional love' is considered so imperative to the role of motherhood that those mothers who do not explicitly demonstrate it are automatically labelled as 'bad' mothers. Expected demonstrations of unconditional love are usually subsumed under the idea of 'always being there' for their child.

Whilst many primary caregivers may fulfil this aspect of their role without question, critical incidents, such as their offspring committing an offence, may cause the primary caregiver to feel anger, shame or resentment to their child. This may be experienced as a threat to the notion of 'unconditional love' and subsequently their identity as a parent (Kall, 2009). As such there is a social investment for parents to act in a way that is associated with the notion 'unconditional love', in order to defend against negative appraisal of their parenting ability. However, there are other

societal duties which parents are expected to fulfil which may conflict with a parent's ability to love their child unconditionally, the most notable of which is the expectation that parents will act as moral guiders.

#### *Parents as 'moral guiders'*

Parenthood is not only cultural but it is also political (Kall, 2009). Within British society there is the expectation that it is the parents who hold responsibility for the moral development of their child (Koffman, 2008). Whilst the limit to parental influence has been noted within the realms of social cognitive psychology (Bandura, 1991), with the wider societal and peer influences highlighted (Riess, 1965), the enduring discourse remains that undesirable behaviour is the result of poor parenting (Kall, 2009; Koffman, 2008).

Such is the strength of this narrative that it can be seen in almost every aspect of daily social life in the UK, from media reporting on 'hoodie culture', throughout the school system and to government legislation such as Parental Treatment Orders (Crime and Disorder Act, 1998). However, parents report feeling scapegoated for their off-springs behaviour, citing failures within society such as education and social care as the real cause of the problem (Koffman, 2008). This can lead to resentment and disengagement with services, as parents feel unfairly blamed for behaviours demonstrated by their child (McNab & Kauner, 2001). This may be particularly applicable as their child ages and seeks to establish their independence away from their family.

#### *Maturation as a marker for adulthood*

A further expected parental 'task' identified in Western based literature concerns the parental encouragement and development of 'individuation' amongst their off-spring, i.e. 'growing up' and 'leaving home' (Haley, 1976). Traditionally, within the realm of psychoanalysis, a child being able to separate from their parent and become a totally independent being was seen as the mark of maturation into adulthood (Freud, 1958). More recent research has challenged the issue of independence, arguing that mutual independence is a more accurate way of understanding the adult child-parent relationship (Peterson, 1993). However, the privileging of independence and separation remains a predominantly Anglo-American construction and one which may be limited in its viability in multi-cultural Britain (Gower & Dowling, 2008).

How primary caregivers position themselves in regards to the narrative of independence will influence the future stories they tell about themselves and their child. This remains a gravely under researched area (Gower & Dowling, 2008). An unexpected life event may further serve to disrupt these future stories and the way

in which an individual defines their primary caregiver identity, if it means that the adult child is unable to separate as expected or a separation is enforced upon the family when neither desired nor anticipated. It is easy to see how a diagnosis of 'learning disability' or an adult child being convicted of an offence may create either of these challenges (Hayley, 1976; Sheehan, 1997).

### Narratives of Learning Disability

In order to understand the way in which primary caregivers make sense of their experiences it is important to recognise some of the societal narratives which exist around the diagnosis of learning disability and proposed links between the diagnosis and offending behaviours. Particularly pertinent are the ways in which learning disability is defined and understood and its proposed links to criminality.

#### *Medical narratives and social narratives*

The term learning disability is a social construct linked to the skills valued by Western society, such as literacy, numeracy and communication skills (McPhail & Freeman, 2005). Diagnosis is based upon the medical model which situates difficulties within the individual and labels those who fall below the measured 'norm' for these skills as being 'cognitively inferior' or 'disabled'.

Service research has focused upon developing our understanding of aetiology and epidemiology of conditions, with the systemic and psychosocial factors surrounding disability often overlooked (Whitehurst, 2011) The medical focus in diagnosis has been criticised for overemphasising an individual's impairments and difficulties and ignoring their individual strengths (Clements, Focht-New & Faulkner, 2004). In response to this, the Social Model of Disability (Oliver, 1983), aims to promote a social acceptance of impairments and emphasises the need for society to adapt in order to minimise or remove the social structures which create disability (Oliver 2004; Shakespeare, 2006). When the model first came to prominence in the early 1980s it was applied specifically to physical disability. However, in more recent decades it has been expanded to include individuals with learning and developmental disabilities (e.g. Walmsley, 1997; Baron-Cohen, 2002; Elliman, 2011).

A major criticism of the social model is that it attributes too much of the cause to society and does not give enough consideration to the impairments that individuals experience and the interplay between the two (Elliman, 2011). Currently, the most accepted definition of learning disability in the UK attempts to incorporate both medical and social factors, requiring both impairment in intellect (IQ less than 70) and social functioning, both of which were evident prior to adulthood (Department of Health, 2001).

*Historical narratives*

Our narratives, although ever changing, are rooted in history (Gavin, 2005) and this is equally as true for individuals labelled with a learning disability as it is for others within society. It is less than a century since learning disabilities (or 'mental deficiency') was first recognised under law in England and Wales and the way in which individuals are defined has been subject to constant review and dispute, with terms such as 'feeble-minded', 'mentally deficient' and 'intellectually disabled' being used. This has created a fractured narrative whereby individuals are constantly having their identity re-defined by individuals around them with little room for consideration as to the individual definitions they prefer. There is a concern that by placing a label upon a label, that services may lose sight of the individual underneath and their needs and preferences.

A link to criminality has been posited throughout the history of learning disabilities. Indeed, Terman (1911) wrote: 'there is no investigator who denies the fearful role of the mental deficiency in the production of vice, crime and delinquency... Not all criminals are feeble-minded, but all feeble-minded are at least potential criminals' (p. 11, cited in Lindsay, Taylor & Sturmeay, 2004). Terman may be recognised by some readers as the author of one of the earliest IQ assessments and his comments may be indicative of the political motivation involved in identifying individuals who did not meet the privileged norm. It is also worth noting that he was writing two years ahead of the Mental Deficiency Act (1913), giving further indication as to the political agenda behind identifying and labelling individuals as deficient. This has created a subsequent history of segregation, derision and fear from wider society, creating a fractured narrative which has had an impact upon individuals' sense of self (Blackman, 2003).

*Current narratives concerning criminality*

Interest in the interface between offending behaviour and learning disabilities pervades today. However, more recent research has focused not on establishing a causal link between condition and behaviour, but in identifying the challenges individuals with learning disabilities may encounter within the criminal justice system (Hayes, 2007) and determining appropriate treatment pathways post conviction. It is encouraging that the increasing interest in the rights of individuals with 'learning disability' in the Criminal Justice System (CJS) has resulted in government legislation designed to protect the individual and ensure fair service treatment ("Valuing People", Department of Health 2001; the Mental Capacity Act, 2005) (Cant & Standen, 2007).

Research indicates that individuals with learning disabilities have often demonstrated an escalating pattern of challenging behaviour prior to police

involvement (Law et al, 2000) and that families have been required to manage and contain the majority of this. Recognition of the complex nature of learning disability and offending has led to the wide acknowledgement that professionals require extensive training to work with learning disabled offenders (Hayes, 2007; Cant & Standen, 2005) and yet this view does not appear to have been extended to the educational needs of families and primary caregivers (Tsang et al, 2002). It is implied that families should 'just know' by nature of their relationship how best to support their family member and they risk vilification if unable to do so. Furthermore, the not entirely unfounded concern that their offspring may be removed from them because of their behaviour may prevent some primary caregivers from raising concerns in the early stages, which in turn may contribute to offending behaviours escalating. Increased understanding as to the experiences of primary caregivers is needed to inform service provision.

### **Impact of a lived experience on primary caregivers**

Having looked at the context and narratives in which primary caregivers are operating, we now move to look at the impact that both parenting an offspring with a learning disability or an individual who has committed an offence may have on primary care givers' experiences.

#### **Learning disability and the parental experience**

The last 30 years has seen increased emphasis on de-institutionalisation (Todd & Shearn, 1996a) and it is estimated that approximately two thirds of all individuals with a learning disability currently live within a family setting (Kelly et al, 2009). However, despite this, very little attention has been given to understanding the impact this may have on family life, with a notable absence of parental opinion reported in the literature (Todd & Shearn, 1996a; Kelly, 2005; Clarke and Thompson, 2009). Recent research has begun to consider the temporal nature of parental identity and the factors associated with learning disabilities which may mediate this. This includes a focus upon the stress parents may experience by nature of their role as well as consideration as to how services can best support primary caregivers.

#### ***Changes in parenting role identity***

In acknowledging their child's impairments, primary caregivers are required to re-evaluate their assumptions about their role as a parent and their future stories regarding their child (Kelly, 2005). This can also have a practical implication as parents may need to make alterations to daily life, which impact upon their identities associated with other roles such as work status (Hubert et al, 2007). Parents can find themselves living lives which are incongruent to their expectations and at odds to the lives being lived by their peers (Todd & Shearn, 1996a). From a narrative perspective, this can serve as a form of 'biographical disruption' (Bury, 1982) which potentially

may have a detrimental impact upon an individual's identity and emotional state. Feeling separated or isolated from others can increase an individual's stress (Faust & Scior, 2008) and feelings of resentment which opposes unconditional love narratives.

Todd and Shearn (1996b) were one of the first to explore parental attitude towards the caregiving role as a factor determining parenting identity and emotional responses in parents of individuals with learning disabilities. Through a thematic analysis they identified two key subgroups of parents who differed in their appraisal of their independence and autonomy in their parenting role. They used the term 'captivated' parents (those who found meaning in their roles and did not express a longing for an alternative lifestyle) and 'captive' parents (those who felt restricted as parents and wished to have lifestyles more in line with their peers) to categorise these two groups (Todd & Shearn, 1996b). Whilst attempts to understand the ways in which primary caregivers may experience their role are helpful, the dichotomous nature of these two categories tells us little as to the process through which individuals come to position themselves. Given the temporal nature of identity (Gergen & Gergen, 1997) a more nuanced experiential continuum of meaning making, generated by parents themselves may be more beneficial to the advancement of our understanding. This will be particularly useful in understanding the emotional responses primary caregivers report at different stages in their role.

#### *Emotional responses*

Attempts to understand parental experiences have historically taken a positivist, 'medicalised' stance with theories and models - such as the cognitive model of stress and coping (Lazarus & Folkman, 1984) - being applied, with the lived experience somewhat ignored (Hassall, Rose & McDonald 2005). It is widely assumed that parenting an individual with a learning disability is a 'stressful' and 'distressing' experience (Walden, Pistrang & Joyce, 2000) which, whilst accurate in some cases, does not provide a deep insight into a complex experience.

Factors proposed to influence distress outcomes include marital stability (Faust & Scior, 2008), carer's appraisal (Todd & Shearn, 1996) and the level of education and income of the carer (Walden et al, 2000). In particular, the health and physical care needs of the individual with a learning disability and behavioural problems have been found to be associated with stress experiences (Faust & Scior, 2008; Walden et al, 2000). Todd and Shearn (1996a) argue that limitations on the carer's opportunity for self-focused or extra-parental activities are a major contributor towards carer stress. Furthermore authors examining parents of individuals with learning disabilities who do experience high levels of distress have found that this appears to be less to do with their child's impairments and more in response to the way in which society isolates and stigmatises them (Solomon, Pistrang, & Barker, 2001). As Fergusson (2001) so succinctly argues, "it is not a specific set of parental reactions to disability

that is inevitable but the influence of social contexts in shaping those reactions” (Fergusson, 2001, p.375).

However, the assumption that parenting an individual with a learning disability is inherently negative has been challenged in more recent literature (Walden et al, 2000). As one participant in Marshall and Long’s (2010) study highlighted, in receiving her child’s (autism) diagnosis she was able to gain a new perspective on the dynamics within her family, which ultimately enabled her to feel forgiveness for past relationship difficulties. Furthermore, family members have also highlighted the mutual caring and companionship which can develop when an adult child remains living at home (Hubert, 2006). It should not be assumed that individuals with learning disabilities are incapable of, or unmotivated to, provide both emotional and practical support to others. The balance of responsibility and support is not automatically weighted on the parent or registered carer, particularly once the individual with a learning disability reaches adulthood or middle age (Prosser & Moss, 1996). In considering where to direct support, services providers need to consider the individual needs of both client and carer and the relationship between them both.

#### *The interfaces between parents and services*

There can be no doubt that recognition of the needs of carers is increasing, with government legislation pertaining to the provision of additional support (Disabled Persons Act, 1986; Carers (Recognition and Services) Act, 1995) meaning that carers have an established place in service development. Examples of good professional-parent partnerships are increasing in the literature (Madden, 1995) and I think most who work in the field would be able to draw upon personal experience of ‘getting it right’ in terms of supporting and involving parents in continuing care needs. However, the experiences of individuals does not necessarily translate into service provision as a whole and should not be used to assume that services are adequately structured to maintain a focus upon carers needs in addition to those of clients.

What is apparent is that the burdens experienced by primary caregivers, whilst complex and varied, include emotional, social and financial aspects of care (Tsang et al, 2002). Services currently appear better equipped to respond to the latter two concerns, with the systemic and psychosocial factors often misunderstood or under-recognised (Whitehurst, 2011). Despite a growing consideration for the variety of cultures which exist within modern British society, services can be inadvertently insensitive to families’ different social norms or cultural beliefs due to a lack of knowledge (Hubert, 2006). This in turn can lead to family members feeling invalidated, blamed or ignored by the very services designed to support them. It has been found that cultural variability has a huge impact upon an individual’s construing of their care giving identity (Walden et al, 2000; Begum, 2007) and that it is not possible to generalise experiences from one cultural, religious or even geographic community to another.

In regards to accessing the necessary professional support, parents can report feeling 'judged' or 'blamed' (McNab & Kauner, 2001). Often this message may be received implicitly through professional questions regarding relationships and home circumstances (Tron Dinneen, 2004). The social discourse that parents should be able to love and guide their offspring through whatever difficult circumstances may influence some parents to feel inadequate if problems arise for which they require additional support. Similarly, many families report that the situation at home needed to reach crisis point before services responded to their requests for help (Faust & Scior, 2008), which could compound families' feelings of failure or frustration. As a result, families may come to rely on informal sources of support from extended family and friends (Prosser and Moss, 1996). However, this too can be problematic as in some cases it may lead to feelings of resentment within informal support networks, if one person feels that the balance of responsibility is unequally distributed (Prosser & Moss, 1996). Unsurprisingly, primary caregivers can feel reluctant to involve their other adult children in the caring of their child with learning disability, as they may feel that this would be a burden to them and prevent them from living the lives that they hoped for their non-disabled children (Dillenburger & McKerr, 2010). These challenges may only intensify if behaviours are such that they warrant intervention from the CJS.

### **Impact of offending on parental narratives**

Research into the impact of offending upon the families of offenders is still in its infancy but there have been notable contributions made from Australia (Scott, 2005), the USA (Kall, 2008), the UK (Condry, 2007a; 2007b) and Hong Kong (Chui, 2010). Through her ethnographic research, Condry's study found that common reactions to the offence included shame, 'contamination' (whereby relatives are held accountable for the offence through their genetic link to the offender), guilt, anger and shock (Condry, 2007a). These responses have also been reported in studies by Tewksbury and Levenson (2009), Scott (2003), Hallbäck (2004) and Kall (2009). However, the way in which primary caregivers make sense of their lived experiences in order to manage their emotional response requires more detailed research.

### *Coping responses*

Early attempts to understand the impact of offending on families focused upon the development of a prescriptive model to explain the emotional journey parents experienced, complete with expected timescales for each stage (see Withers, 2000). However, such models are overly simplistic as they do not highlight factors which influence the process of meaning making, and reflect the systems' attempt to pathologise individual responses. Furthermore they reinforce the idea that there is a 'right' way to respond, which can lead to additional and unnecessary distress for primary caregivers whose emotional responses do not follow a prescriptive pattern.

A more detailed understanding of the process through which parents of individuals who have committed an offence make meaning from their experiences is provided by Hallbäck (2004) who conducted a unique phenomenological exploration into the experiences of mother's attending a gestalt therapy group. The purpose of this group was to assess the benefit of providing the mothers an opportunity to share their stories about their child's offending and help them to re-organise their narratives in a less distressing way (Bauer & Toman, 2003). Hallbäck conducted her study four years post-group and found that the majority of her participants had found the group helpful in dealing with their negative emotions around the offence and making meaning of their subsequent experiences.

Further developing our understanding of how individuals may interpret their personal narratives about their life in order to make it feel more manageable or understandable is the 'Act/Actor' adjustment proposed by Condry (2007a). The 'Act' adjustment refers to ways in which the family member may alter their perception of the offence itself in order to minimise its impact (for example, reframing 'murder' as 'manslaughter'). The 'Actor' adjustment occurs when family members alter factors about the offender themselves, for example focusing on upon the fact that they have been under the influence of alcohol or experienced mental health difficulties at the time of the offence (Condry, 2007a). These adjustments are not a conscious mechanism and may reflect social narratives regarding the seriousness of certain acts over others. A diagnosis of learning disability was not listed as a form of 'Actor' adjustment in Condry's study, although this may well be reflective of her sample, and it is not difficult to imagine how one may attribute an individual's offending to this diagnosis.

### *Offending and learning disabilities*

The complex nature of the individual's condition has made suitable service provision difficult, which in turn has led to a lack of community services (Cant & Standen, 2007). This means that what service provision there is remains disjointed, with no clear channels of communication between inpatient and community support (Cant & Standen, 2007).

It is not uncommon for CJS to divert the individual to secure services, which are inappropriate for the person's needs (Hayes, 2007). The detrimental impact that inappropriate service environments may have on the individuals' mental health or behaviours can lead to the individual being 'trapped' in the system (Hayes, 2007), Indeterminate sentence lengths may contribute to primary caregivers feeling that their parenting identity is either lost or suspended as they are prevented from fulfilling their parenting duties in traditional ways and cannot make longer term plans regarding the future for themselves or their child (McCann, McKeown & Porter, 1996).

The literature search identified a solitary article which focused specifically upon the experiences of parents of offenders with learning disabilities. Humbert, Flynn, Nicholls and Hollins (2007) interviewed five mothers who were attending a monthly support group whilst their sons received treatment for sexual offending. The study identified the challenges mothers experienced in reconciling their own feelings of anger, anxiety and stress at the offence, with their continuing desire to fulfil their maternal role in supporting and protecting their son. This was coupled with an overwhelming frustration at services for their lack of support and understanding (Hubert et al, 2007).

What is interesting, however, about Hubert et al's (2007) research is that the offenders in the study were all under the age of 16 and had all experienced sexual assault themselves. Their age and the impact that their 'victimisation' had on the mothers is most strongly focused upon. That the mothers were able to attend a support group in the first place is unusual in the UK. Children and victims are deemed deserving of sympathy and are excused from their behaviours and - perhaps by extension within this dominant discourse - so are their parents.

### **Need for further understanding**

Whilst it is encouraging that studies conducted by Hubert et al (2007) and Condry (2007) are raising awareness of the challenges faced by primary caregivers, our understanding of the dual impact that both learning disability and offending may have upon parents is limited. What is lacking in the bulk of this research is how parents have made sense of their experiences over time. Early theories of parental response to having a child with a disability are over simplistic and reflective of the dominant discourse which values 'perfection' and devalues those who differ from the norm. Similarly, models proposed to predict the pattern of emotional responses experienced by families affected by offending (Withers, 2000) are overly deterministic and tell us little of individual meaning making.

The dominant narratives around both disability and offending can overshadow parents' stories about their child's strengths (Tron Dinneen, 2004) or their own abilities to provide care (Begum, 2007). By adopting the dominant narratives within a system we risk pathologising parental experiences and in turn fail to acknowledge the complex and meaningful way parents come to understand their lived experiences and negotiate their emotional reactions to it. Services ignoring or invalidating parental experiences can lead to feelings of hopelessness or failure on the part of the parent (Tron Dineen, 2004) which can in turn reduce involvement in services and families receiving the right support (O'Connor & Paley, 2009; Whitehurst, 2011).

In recognition that our current understanding is limited, this study has two main research questions:

- What stories do primary care givers of individual's with learning disabilities and have committed an offence tell?
- How are these stories told and understood?

## **Chapter 2: Methodology**

### **Qualitative Methods**

It has been argued that traditional scientific methods of enquiry limit our understanding of the social world by precluding those whose experiences do not fit the traditional positivist methods of research (Booth & Booth, 1996). It is in response to this criticism that qualitative methods, under the banner of the 'excluded voice thesis' (Farber & Sherry, 1993) aim to provide a platform for those groups who have hitherto been misrepresented or ignored. By utilising a qualitative research design, individuals with a specific lived experience are afforded a better opportunity to share their experiences (Liamputtong & Ezzy, 2005) and may feel a greater sense of control over what they can disclose (Reinharz, 1992), whilst researchers are afforded a greater opportunity to understand a specific social phenomena (De Fina, 2009).

To date, there have been limited studies aimed at understanding the lived experiences of the primary caregivers of offenders and no studies looking specifically at the lived experiences of primary caregivers of adult offenders with learning disabilities. Qualitative analysis was therefore chosen as a method of enquiry for this study as it provided opportunity for this under-researched and sensitive area to be explored in depth (Liamputtong & Ezzy, 2005). When considering the different qualitative approaches available, I needed to consider an approach which reflected the underlying research questions and the study's epistemological stance (Pearce, 2009).

### **Epistemology**

This research project is built upon the belief that services have previously constructed the narratives around offending behaviours without giving adequate opportunity for family members to be involved in the co-construction of these narratives (Mair, 1998). As such, there is a positivist belief that the family members will have their own stories within themselves which the research is trying to access. However, it is in the accessing of these stories that more constructionist views becomes increasingly dominant as it is recognised that the language an individual uses in order to share their narratives is important (Riessman, 1987). As Lyons and Chipperfield, (2000) explain "interviewers and interviewees are co-producers of narratives" through the way in which the two interact and so no one narrative can be viewed as an 'absolute truth'. In line with Seale (1998), the researcher considers the field interviews conducted for this research as 'data as a topic' because the content reflects the co-constructed nature of the reality in which the story is created. It conveys the values of the narrator and the society in which the narrative is constructed and understood (Witten, 1993). The stories shared will be influenced by

many factors, not least the way in which the participants view the researcher (Goodley, 1996). Furthermore, the stories shared cannot be viewed as absolute truths because the temporal nature by which meaning is understood will change over time and in response to new experiences and relationships; as such the story an individual shares may differ significantly one year, a week or even a day later if told again or to a different audience (Pearce, 2009).

### **Why use NA in this study**

The type of qualitative analysis selected for this research was reached after careful consideration of a number of different analysis methods and how these linked to the study aims. This research aims to explore and illuminate the individual stories which may occur within a shared phenomenon but does not wish to reduce these experiences into a theory, which may fail to allow for the shifting nuances of people's experiences. As such it was considered that Grounded Theory (GT) would not be appropriate as it did not fit with the study aims. A NA method was chosen because it examines how people make sense of their lived experiences but also how they make sense of an experience *within the context of their whole lives* and the other events within this (Smith & Sparks, 2009). As such it differs from other qualitative forms of inquiry, such as Interpretive Phenomenological Analysis (IPA) or Thematic Analysis (TA) as it does not seek to analyse experiences in isolation. At the same time as highlighting the struggles and triumphs individuals may have experienced in their role as parents of adults with learning disabilities who have offended, NA also offers opportunity to explore the process through which parents come to make sense of their experiences (Marshall & Long, 2010). It is considered particularly well suited to studies which aim to explore the impact of politico-social discourses on the self (Weatherhead, 2011) because it offers the reader opportunity to re-evaluate their own assumptions about the lived experience of others and the world around them (Goodley, 1996). This is important in relation to the research question as the participants will have had to make sense of both their role as a parent to an adult with learning disabilities and their role as a parent to an offender.

Fergusson (2001) argues that narrative accounts of parents of intellectual disabilities can expand our understanding both of what 'disability' means and what it means to parent. This study aims to further our understanding of an area of human experience which has, to date, largely been under recognised within the literature. It may also allow for an in-depth exploration of the political context within which stories are told and understood (Weatherhead, 2011) which is important given the sensitive topic nature which is itself politically defined.

## Study Design

### Sampling Strategy

The purposive sampling strategy for this project reflects the study's narrative aim of giving a platform to the voices of individuals with a lived experience. In keeping with recommendations for other forms of qualitative analysis (Smith, Flowers and Larkin, 2009) it was anticipated that a purposive sample of 5-8 participants would be required. Wells (2011) argues that "the number, five, is sufficient for most studies involving complex analyses." (Wells, 2011: p.20) and, given the demands of qualitative analysis and the amount of data provided in one interview, a maximum of 8 was set as this was deemed practically manageable whilst still providing in-depth information (Wells, 2011).

### Inclusion/ exclusion criteria

The participants for this study were the primary caregivers of adult males with a learning disability who had been convicted of an offence. Within this study 'primary caregiver' included any individual who considered that they had been primary caregivers at the time of the offence, irrespective of their formal biological relationship with the client. The relationships took the form of biological parents, adoptive parents, and grandparents. In all cases the primary caregivers were also the recognised next of kin for the client.

The purposive sample was determined following careful consideration of the inclusion/ exclusion criteria. Firstly, I was mindful of the current literature highlighting the amount of primary caregivers seeking support from mental health services (Scott, 2003). It was important that sensitivity was taken to minimise the impact of this research on the participants own recovery process and, for this reason, primary caregivers were not approached if they self-disclosed that they were seeking counselling for their experiences at time of interview. Similarly, I felt it was important that all court proceedings needed to be completed as it was considered potentially damaging for participants to be asked to reflect and make sense of a process which had not yet reached a conclusion and for which the outcome may have been beyond the participant's control.

Secondly, because narrative analysis is reliant upon a participants ability to verbally communicate and express themselves, primary caregivers who themselves had a known diagnosis of Learning disability or communication disorder were not approached. Although McFarlane and Lynggaard (2009) advocate the use of Narrative therapy with individuals with learning disabilities, the time constraints of this study unfortunately made their inclusion in this case impractical. Consideration as to how individuals with learning disabilities may be involved in future research is given in the discussion section. All participants were required to have a good

understanding of English in order to participate, although care was taken in order to ensure that the information shared and the questions posed in interview were of easily accessible language.

### **Participant Recruitment**

#### **NHS Service Involvement**

Two medium secure units were involved in this study. The Eric Shepherd Unit (ESU) and the Broadlands Clinic (BC) are both NHS commissioned services providing assessment, treatment and rehabilitation to adult males who have a learning disability (and associated mental health or complex needs) and whose level of risk taking behaviours require a high level of support. All its clients are detained under the Mental Health Act (1985), and a number of its client's have committed offences which have necessitated their admission to hospital.

The units were approached to help facilitate this study after attempts to identify a purposive sample elsewhere proved difficult. They expressed a willingness to understand the needs of their client's families in more depth. The Field Supervisor for the study is a Consultant Clinical Psychologist currently in post at the ESU. Ethical approval for this study was granted through National Research and Ethics Service (NRES) (Appendix B).

The clients in the service are referred to as 'clients' throughout study. Therefore, the term client also refers to an adult male with a learning disability who has committed an offence.

#### **Selected Participants**

Of the 54 clients currently residing at the ESU and BC, 8 were deemed suitable by the service to be approached for consent to contact their primary caregivers. Of these all 8 gave informed consent and subsequently four primary caregivers (of three clients) agreed to participate.

In addition, the contact details of two mothers, who met the study criteria and whose sons were currently living in the community, were passed to the researcher through a colleague working outside the NHS. Ethical approval to approach these individuals was granted through University of Hertfordshire Ethics Board (Appendix C) The families were informed of the study aims and one primary carer agreed to be interviewed, making in total five primary caregivers of four clients being interviewed. My difficulty in engaging primary caregivers to talk echoes that experienced by Kall (2009), although I cannot comment on the reasons primary care givers appeared reluctant.

## **Procedure**

### **Recruitment**

There were two levels to the initial recruitment approach through services. At the request of the NHS services, suitable clients were approached and asked for their permission to invite their primary caregivers to participate. These clients were identified by, Dr Christopher Bennett, who is the Consultant Psychologist for the ESU and the secondary supervisor for this study and Dr Peter Langdon, Consultant Psychologist for the BC. In both services a second opinion as to client suitability was sought through either the Psychiatrist or Social Worker who knew each client well. Suitability was determined by considering the potential consequences that involvement in the project may have on the client's mood, behaviour or continuing support needs.

Once identified Dr Bennett or Dr Langdon met with the client and explained the purpose of the study and asked for consent. It was agreed that it was most appropriate for this to be completed by the Psychologists who knew the client well in order to minimise disruption to the clients daily care routine. Information sheets and consent forms explaining this process were written by myself in consultation with a Consultant Speech and Language Therapist, Jill Coote (Appendix D and E). These were presented to the client and a period of one week was given to allow for client's information processing difficulties and also minimise any possible concerns regarding coercion, as stipulated within the NRES approval.

The second level of recruitment was to approach potential participants via letter (see Appendix F). Along with the invitation letter, an information sheet outlining the purpose of the study was also sent (Appendix G). Contact details for the Chief Investigator were included in this information pack. It was acknowledged that some of the potential participants may have reading difficulties and so I telephoned each person one week after the letter had been sent out. This telephone call was to offer potential participants opportunity to ask any questions they may have about the study prior to deciding whether they wished to take part. No further contact was made with participants after the telephone calls unless instigated by the participants themselves.

### **Interview Procedure**

At each participant's request, all interviews took place in their own home. As all participants lived further than an hour from the researchers home, a colleague accompanied the researcher to all interviews but waited in the local vicinity. This was in line with the risk management protocol approved by NRES.

Prior to the interview it was explained to participants that we would meet on a one to one basis. However, only one interview (Audrey) took place without any other people being present. During two interviews (Maurice and Debbie) another family member or close friend was present for at least part of the interview but did not participate in the interview itself. For the final interview, the decision was taken to interview Mark and Rachel jointly, at their request, out of respect for their self-defined roles as active and joint decision makers in their son's care (Seale et al, 2008).

It is acknowledged that the joint interview is 'qualitatively different' (Arksey, 1996) because it offers insight into how individual narratives are constructed and negotiated within systems (Seale et al, 2008) and that, in this sense, the moments at which Maurice and Debbie were joined by others may have altered the co-construction of their narratives and this was considered during the analysis process. Furthermore, this has a degree of ecological validity as it echoes narrative construction and performances occurring within active social contexts.

#### Narrative Interview Schedule

As this was an innovative study no pre-existing published interview schedule existed. In order to guide the interview, the researcher constructed a list of prompt questions in a semi-structured interview format. This ensured all participants were invited to share the same areas or topics whilst still allowing them flexibility in terms of the depth to which topics and experiences could be explored and understood (Murray, 2003). The flexible format for the interview also served to minimise my agenda dominating the data collection (Leggett, Goodman & Dinani, 2007) reflecting the co-constructed nature of the story-telling process (Lyons & Chipperfield, 2000).

The outline of the semi-structured interview was developed through consultation with the field supervisor and principle supervisor (Appendix H). In line with the research question '*what stories do primary caregivers tell?*', it was designed to encourage exploration of key themes of the individuals narratives such as 'key events', 'significant people', 'stressors' and 'the future' (Crossley, 2003). As the central question to all NA remains in what way events have impacted upon an individual's sense of self (Weatherhead, 2011), the interview was structured to encourage participants to comment upon the impact that they feel events have had upon them, their offspring and their family in several key areas (Riessman, 2002).

#### Transcription

"Accurate transcription is a fundamental first step in data analysis" (Dickson-Swift, 2007; p12) and, within a week of each field interview, a verbatim transcript was produced. Although all efforts were taken to ensure as much information from the

original audio recording was documented, it is suggested that transcription itself is an interpretive act (Riessman, 2002) and so must be seen as a 'partial and selective' representation of actual events (p.11). For three of the four interviews, this transcription was completed by the chief researcher. A professional transcription service was used for the final transcription, with participant consent, and after confidentiality agreement had been signed by the service (Appendix I). The audio material was anonymised, with each recording simply being labelled by a letter code. Both the audio files and the written transcripts were password protected.

The point at which other individuals may have entered or left the field interview was documented in the transcript.

### **Ethical Considerations**

As previously stated, participants in this study were recruited via both NHS and Community based samples and so ethical approval for this project was gained through both the National Research Ethics Service (NRES) and the University of Hertfordshire Ethics Board. Following the British Psychological Society code of ethics for research (BPS, 2009) the ethical considerations for this project are covered below:

#### **Consent**

There were two levels of consent required for this project, designed to minimise power imbalances and to ensure transparency in client care. Consent was sought from the clients to approach their primary caregivers in order to ensure transparency and to minimise the impact the research may have on their familial relationships (Stalker, 1998). Similarly, the participants cover letter explained that the client's had been consulted and were aware of their primary caregiver being approached (Appendix F). All participants were required to sign an informed consent form (see Appendix J) once they had agreed to participate.

Of course, this double consent issue in itself posed an ethical consideration in the sense that primary caregivers, who may have wished to have taken part, may have in effect been silenced by their offspring not giving permission for them to be approached. This concern was discussed with both the services involved and at the NRES meeting. However, the services felt that their priority needed to remain in protecting the ongoing care needs of the client and established therapeutic relationships and so for them to be involved clients must be consulted.

#### **Information**

A number of measures were taken to ensure the ethical nature of the information sharing process. All information, including the client and participant information sheets, consent forms and debrief information was purpose written for the study. This was checked by a Consultant Speech and Language Therapist in order to ensure that the language used would be appropriate and accessible for the clients. All parties (clients and primary caregivers) were informed of each others involvement or potential involvement to ensure that no deception occurred.

Information about the study was shared with clients in a familiar environment and by a person who they knew well. This was to minimise client anxiety or distress in regards to the study (Gilbert, 2004). In line with a precedent already used within the services, a time period of one week was given to allow client's time to consider their options without fear of coercion. Finally, written information was left with the clients for them to refer back to (Gilbert, 2004).

### Confidentiality

The participants for this project were all the primary caregivers of adult males who were currently residing within the two medium secure units in Hertfordshire Partnership NHS Trust. In line with trust policy, all information about the clients in the service was secured either on password protected computer systems or in locked filing cabinets and was not made available to the chief investigator. As chief researcher for this project, I did not have contact with the clients or their records at any time.

Prior to interview, each participant was assigned a number code (e.g. 1,2,3) in order to anonymise their contact details and consent forms. Post interview participants were assigned a letter code (e.g. AA, BB, CC) under which their interview data was stored. All information was kept in a locked filing cabinet or password protected document which only I could access.

Although Plummer (2001) argues that total anonymity cannot be guaranteed for participants undertaking qualitative research, a number of steps were taken in order to ensure that participants were afforded privacy. This included the changing of names of other family members and places and ensuring that the way in which results were presented did not make identification of participants easy. Furthermore, the formal nature of the relationship between client and primary caregiver and specific details of the offence were omitted from the study write up.

### Avoidance of Harm and Risk Management

There were three key areas which needed to be considered in order to manage the risk of harm for this study. These were: minimising distress to the client, the participant and reducing the physical risk of the researcher. Firstly, as all clients

currently reside in medium secure services, their level of risk was under constant review. The decision as to whether a client was suitable to be approached was made in consultation with the Consultant Psychologist and unit staff who knew the client well.

As the project was exploring how individuals make sense of stressful and difficult experiences it was possible that painful emotions would be evoked during the interview process. If not dealt with sensitively, this could serve to have a recapitulating effect on earlier emotional distress or be distressing in and of itself. As all participants in the study were not currently seeking support through the NHS for their experiences, consideration needed to be given as to where participants may be able to access additional support should it be deemed necessary. It was anticipated that, in the first instance, clients would be directed to their General Practitioner for support. To manage this, as a matter of course I made a telephone contact to all participants one week after the interviews (in agreement with participants) for a debrief and to discuss any arising concerns. At this point all participants reported feeling happy with how the interview had been experienced and did not report any ongoing concerns. Similarly, it was possible that, on reflecting upon their offspring's care and treatment, the participant may raise concerns which warranted further attention or action. Both the information sheet (Appendix G) and debrief sheet (Appendix K) contained contact details for Patient Advice and Liaison Service (PALS) and participants were informed that if they raised concerns regarding client care I was ethically obliged to raise these with the service.

Finally, in regards to my own safety throughout the project (Dickson-Swift et al, 2007), I was accompanied to the vicinity of interviews by a colleague in order to manage any physical risks associated with home visits and I had a network of support including my research supervisors and trainee colleagues who made themselves available to discuss any concerns I had regarding my emotional reactions to the stories shared.

### Participant Debrief

After each interview was completed the participant was asked if they have any questions about the project and how they felt. A follow up telephone call was also arranged, with the participants' agreement, for approximately one week after the interview. This was held at a time agreed with the participants and was aimed at giving an additional opportunity to discuss any concerns or offer a feedback. It also served to validate participatory experience by highlighting their importance in the project (Dickson-Swift et al, 2007). The researchers contact details were made explicit on the debrief form (Appendix K) and the participants were invited to contact the researcher at any time to discuss any concerns or questions.

### **Participant checking of results**

In line with the epistemological view that stories are co-constructed, member checking was not deemed appropriate given that the results presented are reflective of the researchers understanding and do not purport to be an 'absolute truth'. However, in order to guard against the researcher making intuitive leaps in analysis which could contaminate the results (Leggett et al, 2007) credibility checking of analysis was conducted between the chief investigator and research supervisor who has expertise in NA.

All participants reported a wish to be informed of the findings of the study and it has been agreed that a letter will be sent with a final summary of findings once these have been confirmed. This is important in order for participants to feel validated in their contribution (Dickson-Swift et al, 2007) and has the potential to serve as a unifying document in helping participants feel that they are a part of a shared collective (White, 1995) and less isolated by their experiences.

### **Analysis Process**

Unlike other forms of qualitative analysis there is no one set method for conducting NA (Riessman, 1993). In order to analyse the field interviews in sufficient depth I was guided by the narrative researchers Riessman (1987; 2002), Minister (1991), Greenburg and Angus (2004) and Lieblich, Tuval-Mashiach, and Zilber (1998). However, NA is similar to other forms of qualitative analysis as it is an iterative process whereby the different levels of analysis may be utilized simultaneously (Riessman, 2002).

Narrative researchers do not consider plots or subplots to be cross-sectional representations of an individual's experience. They are instead viewed as temporal representations, reflecting the variable and shifting nature of contextual experiencing, within which individual's may oscillate dependent upon understanding in any given circumstance or emotional experience (Greenberg & Angus, 2004). As such an individual may experience the same theme in multiple ways, as depicted by their reported behaviours, interactional style and language selection, at different points in their narrative. Within a narrative paradigm, each theme is seen as an individual plot, with associated subplots, in order to reflect the dynamic nature of the experience. Two individuals may experience the same plot very differently despite the audience assuming similarities between their narratives (Polkinghorne 1988).

In order to ensure that each field interview was analysed in equal depth the following process was undertaken for each interview.

### Reflective Journal

Emerson and Frosh (2004) highlight the impact that the researcher's own assumptions and biases may have on the analysis process and, for this reason Yardley (2008) argues that transparency throughout the analysis process is essential for strengthening the credibility of result findings. In order to aide this, a reflective journal was kept by the researcher and entries made both prior and post to each field interview and post the transcription process. Three of the four interviews were transcribed by the researcher and reflections made at the end of this process. For the fourth interview (Mark and Rachel) a transcription service was used. The researcher listened to the audio interview three times and completed a quality check on the transcription. Reflective notes were made for this interview at this stage.

Each transcript was then read through three times, initially for thematic content, then with a focus on the performative aspects of the stories co-construction and finally with a specific focus on the contextual issues which may be present. Reflective notes were taken after each stage of the analysis.

### Reading for Content

In order to answer the research question *what stories do primary caregivers tell about their experiences?* each story was read initially for content so as to identify the individual events that primary caregiver had experienced and to gain what Lieblich et al (1998) termed 'the feel of the life'. This is the overall global impression that the reader takes from reading the narrative. When reading for content the issue of emplotment (Emden, 1998) was important in terms of how the individual plots were woven throughout the telling of the larger life story. In particular the sequence of events (eg. whether presented chronologically or not) and the point at which individual plots or subplots entered or left the narrative were noted, as this gives insight into how plots were prioritised and linked for the individuals' meaning making (De Fina, 2009).

In identifying the plots and subplots emerging through the primary caregivers interviews I was also mindful as to how the narrator appeared to be positioning themselves within each subplot at the time of interview as this may have had influence on the information they wished to share

### Reading for Performance

The language used in interviews is never emotionally neutral (Rapley, 2001) and individuals convey more meaning than their words alone through the way in which they perform and interact with the researcher during the interview. In line with the

research question *how are these stories told?* it was of paramount importance that attention was given to the way in which participants shared their stories. Readings for performance was guided using Greenberg and Angus (2004) writing on the emotional content underpinning narratives and Riessman's (2002) performative questions:

- *Why was the story told in that way?*
- *In what kinds of stories did the storyteller place themselves?*
- *How do they locate themselves in relation to the audience and vice versa?*
- *How did they strategically make identity claims through their narrative performance?*
- *What other identities are performed or suggested?*
- *How did I respond? How did this influence the development of the story and its interpretation?*
- *How could it be interpreted differently?*

#### Reading for Context

Lyons and Chipperfield (2000) argue that all interviews should be seen as taking place between three parties; the interviewer, the interviewee and the audience (wider society) as no social interaction can be seen to be taken separately from the cultural and political climate within which it was cultivated. Given the moral, political and social implications of the stories being shared, it was therefore important that contextual factors were considered when analysing these interviews. Furthermore, it is important to be mindful that the contextual factors privileged by the researcher may differ from those privileged by the interviewee and consideration needs to be given as to who or what may be influencing the stories participants chose to share. When analysing the interviews I therefore considered the 'Ghostly audiences' (Minister, 1991) of each story, for example, who else might the participants also have been sharing their story with - on an individual or wider societal level - even though they did not have a physical presence in the room.

#### Reading for contrasts and comparisons across stories

Once each level of analysis had been completed, a global impression (Lieblich et al, 1998) for each participant was written along with a summary of the themes emerging from each field interview. The final stage of analysis then involved looking for comparisons between each participant's storylines. From this, final storyline

definitions (including plots and sub-plots) were determined. Each transcript was re-read at this stage with each plot in mind.

### Credibility and Rigour

Narrative analysis does not purport to provide definitive 'truths' but rather one tentative and shifting interpretation of a social phenomenon. As such, results are not assumed to be replicable and so the concern of the qualitative researcher is not with validity or reliability of results (as it would be with quantitative research). The strength of qualitative research is determined through criteria such as credibility (i.e. how plausible are the interpretations being made) and rigour (i.e. to what extent can the interpretations be supported by the original data?) (Yardley, 2008). Qualitative researchers are required to be transparent in their analysis process in order for the strength of their findings to be judged. For this reason a copy of the analysis process for Debbie's field interview and her complete interview transcript are included in Appendix M and N. Debbie has given additional consent for it to be used for examination purpose and only to be included in the examiners' copy of this thesis.

### Creating the narrative text

The narrative text is the transcript of a field interview conducted for the purposes of this research. As such it is not a naturally occurring story (De Fina, 2009) but a purposeful interaction between researcher and participant. When analysing the narrative text it was, therefore, important to recognise the contributions of both members of the story construction and so researcher comments, questions and non-verbal encouragements were recorded. When including context from the narrative text in the results section, direct quotes were embodied within each paragraph. The reader will note that whilst direct quotes are used within the body of the text they, and any reference to the performative aspects of story co-construction, are given in the past tense. This is to reflect the study's epistemological stance that the stories were created in a specific moment and circumstance and so cannot be assumed to be present day reflections.

### Chapter 3: Findings

#### i) Demographic description:

The final (anonymised) five participants and four clients were as follows:

	A	B	C	D	E
<b>Participant</b>	Maurice	Audrey	Debbie	Rachel	Mark
<b>Offspring</b>	Michael	Gregory	Jamie	Matthew	Matthew

To protect confidentiality, demographic details are presented as a group. All participants were self defined as white British, from working class and middle class backgrounds and aged between their mid forties and late seventies. Three were biological parents and two adoptive parents. On average each participant was talking about experiences dating between eighteen months and three years post conviction.

#### ii) Results of narrative analysis

The results of the narrative analysis have been subdivided into two sections. The first section focuses upon the stories told by primary caregivers about their experiences and are presented chronologically in order to orientate the reader to the sequence of events. Individual accounts have not been given in this section for two reasons. Firstly, given the public nature of the offending and the names of the care units through which participants were recruited, anonymity could not be ensured with the sharing of individual accounts. Secondly, inline with the epistemological perspective of this study, stories are understood to be both supported and constrained within socio-political contexts and so I am particularly interested in collective accounts that perhaps gather counter-narrative impetus to challenge 'dominant' stories held within services. Plummer (2001) argues that stories that are shared by groups have more political power and are harder to dismiss than stories told by individuals. However, although I emphasise collective stories, there are a few idiographic stories which highlight the variations in experiences and these are acknowledged under the relevant headings.

The second section presents the emerging plots and sub-plots which were developed through the co-construction of their narratives. Again, these are presented at a collective level, with comparisons drawn across individuals' experiences of each theme.

Throughout the results section the reader will see references made to the current literature available and an interpretation of how these findings sit within the current research base. Whilst this is not in accordance with traditional methods of presenting

separate results and discussion sections, it fits better with the narrative nature of this research whereby storied results are discussed within a contextualised scenario. This method of presentation also adheres to precedents established by other qualitative researchers (Coyle & Rafalin, 2000; Dickson-Swift et al, 2007). Clinical implications and suggestions for service provision are highlighted in the conclusion section.

### **The stories:**

I felt it was important to record the events family members reported going through in order to orientate the audience to the experiences and challenges facing primary caregivers. For this reason, I begin with a summary of the stories told. During the analysis I considered the performative aspects of each story's co-construction and the order in which information was shared with me, as this is linked to an individual's meaning making (De Fina, 2009). For reader clarity, however, in this write up, the experiences reported have been divided into four chronological sections; 1) Life before the offence, 2) the offence, 3) Life since the offence, and 4) future stories.

#### 1) Life before the offence

##### *Early life: Home experiences*

All four clients were reported to have been socially isolated as children, experiencing difficulty in maintaining friendships or being ostracised by their peers because of their behaviour (Blackman, 2003). Three of the four clients had siblings living at home with them whilst growing up and their primary caregivers all reported that the client and their difficulties had a direct impact upon these siblings. Debbie stated her frustration that her other son experienced difficulty at school through association with his brother even though "*he was always a good little boy*" whilst Rachel raised concerns that "*I think you have to think about siblings really because it's quite – they get left out really don't they? the whole equation really and we probably get more sympathy than they [do]*". These comments reflect those of Rawson (2009) who highlights the lack of current literature attesting to sibling's experience. Maurice was the only participant to raise concern that the relationship he had with Michael may negatively impact on his ability to form a relationship with Michael's sister. He reported feeling a greater degree of ambivalence towards this other care giving role, fearing that he would be unable to cope with the increased pressure given the stress he was already experiencing in regards to his son.

##### *Early life: School experiences*

All five primary caregivers reported that concerns were raised around their child's behaviour whilst at school, with only Audrey reporting that additional support was provided by the school to help manage these concerns. The remaining four primary

caregivers reported feelings of resentment, either at the schools failure to respond or their negative attitude towards their child. Commonly the clients were labelled as '*lazy*', '*stupid*' or '*trouble*'. Debbie and Maurice both reported feeling so frustrated at the actions of the school that they sought outside assistance, in Debbie's case attempting to take legal action against the school and in Maurice's case enlisting the help of local counsellors. In hindsight both Debbie and Maurice attributed their child's offending to be in some way linked to the treatment they received at school, with Maurice reporting a belief that '*that was the beginning of the rot*' and Debbie attesting that the school attempted to sabotage Jamie's future opportunities.

#### *Mental health service involvement*

Similarly, all participants reported having sought support from mental health services prior to their son's offending, with varying degrees of input being received. Audrey reported that whilst help was there (for anger management), it was Gregory who was reluctant to engage and so continuing treatment ceased. Mark and Rachel told a story about Matthew's reluctance to engage with mental health services and a belief that Matthew had '*known what to say*' in order for professionals to believe that their concerns were attributed to '*carers' fatigue*'. Debbie told a similar story, having had Jamie's behaviours explained as '*there's nothing wrong, it's just your parenting skills*', whereas Maurice was dismissed with '*yeah he's alright there's nothing wrong with him*'. In all cases a diagnosis was only reached after the offence had been committed.

#### *Escalation in challenging behaviour*

Without exception all participants reported that they had had ongoing and increasing concerns with regards to their son's behaviour. This is in line with previous research highlighting the degree of challenging behaviour families have often been containing prior to police contact (Law et al, 2000). However, there was a significant difference in the way in which these stories were shared, with Rachel, Mark and Debbie appearing to find it easiest to access and share the difficult experiences that were happening at home. However, for the remaining two participants these concerns were more gradually revealed throughout the interview, having initially only been alluded to during the opening discussion as to why their son was in hospital. It appeared that as a rapport and sense of trust between us was developed, more painful experiences could be acknowledged (De Fina, 2009). Inevitably, the selection and 'performance' of particular stories are thus integratively linked to the context and interviewing relationship.

When behaviours were acknowledged there was a tendency amongst participants to present these in a very factual way, using legal terminology, or in a way which could be seen to minimise the seriousness of the offence. Reflecting the previous findings of Faust and Scior (2008), three primary caregivers, Maurice, Mark and Rachel, expressed the fear that their son's physically aggressive behaviour may result in an

injury to themselves or others and shared stories of times when they felt they had prevented this injury from occurring.

### *Interacting with the police*

In regards to police contact, Maurice stated that he had found the police to be helpful in managing the immediate physical threat of Michael's behaviour but that he had not understood why the police took the eventual action of prosecuting him when they did. Debbie appeared to have adopted a deliberate strategy of attempting to work with the police "*so that they help you*", but recalled specific events where this had not worked and a belief that in these instances "*the police try to wind you up so they can get you too*". Mark and Rachel stated that they felt the police had done nothing to support them, sharing one story of a time when police refused to enter the home themselves for fear of Matthew's aggressive behaviour and an incident at the police station where "*they just treated us like scum*" (Rachel).

Regardless of the detail with which these stories of early life were shared with me, in all story telling there was a performative aspect of the narration which created the sense of, not just frustration, but also foreboding that the primary caregivers were experiencing; the sense that at any time the behaviours could increase and they had no avenues of additional support or confidence in the police's ability to protect them or their son. Although all participants voiced similar views, it was Audrey who perhaps voiced their shared concerns about life before the offence most succinctly, pointedly stating "*I think we were constantly worried*".

## 2) The offence

### *Precipitating events to offence*

Maurice and Audrey both highlighted the deaths of the clients' mothers as potential precipitating factors for the offending, with Audrey sharing a view that "*he was obviously acting out and everyone acts out in some way when they lose somebody that they love.*" Interestingly, Debbie, Mark and Rachel told tales of bereavements occurring during Jamie and Matthew's teenage years which coincided with increased concerns around their behaviours. The different ways in which individuals with learning or developmental disabilities process and respond to bereavement has been subject to increasing research (Hollins & Esterhuyzen, 1997; MacHale, & Carey, 2002; Bonell-Pascual et al, 1999; Blackman, 2003; Clements et al, 2004) and the comments of the primary caregivers in this study highlight the need for improved understanding in this area.

### *Types of offences*

The index offences for the four clients were arson, harassment, a sexual offence and possession of a dangerous weapon. However, all primary caregivers reported that their offspring had demonstrated a number of other serious challenging behaviours prior to their arrest. These included arson, assault, theft, substance abuse and property damage. Despite the ongoing concerns reported by all, the primary caregivers did not report the index offence to have felt either inevitable or predictable. For example, Mark, Audrey and Rachel all expressed a fear at the possibility that Gregory or Matthew may have offended and yet felt that they had no pre-warning as to the type of offence that was committed. In all narratives except for Debbie's, this uncertainty created a sense that the offending behaviour continued to exist in the present and that it may re-occur in the future.

### *Navigating the criminal justice system*

As previously stated, a diagnosis for all four clients was only reached after the index offence was committed, with Matthew, Michael and Gregory all remanded in prison prior to being moved to hospital. Audrey stated that she had found information regarding the CJS (and particularly the prison service) to have been easy to access and useful in helping her to manage her anxieties, but questioned whether Gregory himself had been able to understand the process. She attributed her ability to find out information to her willingness to ask questions rather than the information being freely given. Maurice reported being unclear himself as to the process through which Michael was moved from prison to hospital, and he expressed a belief that Michael blamed him for the move as he had sought the guidance of a local Member of Parliament prior to the hospital admission. He reported that hospital staff had commented to Michael that *'your dad got you in here- he wrote to the MP'*. This appeared to be an ongoing issue within their relationship. Like Audrey, Debbie stated that although she had been able to access the information she required, she felt she had repeatedly come across a lack of understanding in regards to Jamie's disability amongst CJS professionals, which had the potential to create more difficulties for Jamie as procedures were not structured in a way that was accessible to him, nor sympathetic to his needs. Finally, Mark reported a similar grievance with the way in which the law is structured, stating he felt this served to victimise families and block the individual's opportunity to access necessary support and information. He cited the Data Protection Act (1998) as being particularly unhelpful as it prevented him from being able to advocate for his sons needs.

### 3) Life since the offence

#### *Being within the care system*

The four primary caregivers whose sons were currently detained in hospital all reported feeling that the level of support their son received was of a good standard and that they themselves had benefited from the work done by staff. Maurice and Audrey raised some concerns that they did not necessarily agree with all the decisions made by the hospital in regards to their sons' care, but that they felt that they knew who to talk to in seeking clarification. Audrey stated her biggest concern was the way in which family members were not given information as a matter of course and that she often had to seek out clarification. She stated her concern was not for herself but for other family members who may not be as confident in asking questions. In contrast, Rachel and Mark reported feeling that they were kept fully informed as to the decisions which were being taken in regards to Matthew's care and that their input was sought on care planning issues.

Audrey also highlighted the lack of privacy that was created, due to staff having to be present during visits and how this impacted negatively on her feeling that she could talk freely with Gregory about '*family things*'.

#### *Avenues of support*

Neither of the two clinics currently provide a support forum for clients' family members and, when asked, there was disagreement amongst the participants' narratives regarding the benefit of such a service. Maurice reported that he felt he would have '*little to offer*' people, explaining that he was probably too "*old in the tooth*" to have anything in common with other parents. However, he went on to state that he thought his wife may have had more to offer and so his comments could be seen to be reflective of the wider societal view that mothers are more equipped to discuss their children (Stueve & Pleck, 2001; Kall, 2009). Audrey stated her full favour for such a support forum, stating that she felt more needed to be done to help families and a belief that this would be more helpful if it came from the primary caregivers themselves rather than the professionals because "*to talk to an individual who is going in actually the same situation you are*" would help to combat some of the isolation they feel in their role. Her comments echo the findings of Todd and Shearn (1996a) who found that parents often prefer informal support networks.

In the absence of formal support networks, participants reported that they had been able to access a number of informal avenues of support. These included the church, the local community and work colleagues. All participants reported having the least support from other family members and a subsequent degree of familial isolation, although there was a recurring theme of primary caregivers not wishing to share the extent of the difficulties with other family members for fear of burdening them with the responsibility of looking after their son. There was a sense in Debbie, Maurice and Rachel's story that they felt their families had their own lives to live and so did not want to disrupt this through asking for help. Audrey and Mark on the other hand expressed confusion about why family members had reacted towards the difficulties

by distancing themselves from them and consequently withdrew from asking them for more support.

The stories reported in this study echo the work of Prosser and Moss (1996) who highlight the difficulties families can experience in agreeing on the type of support needed and who should be responsible for providing this. Although the participants in this study reported a sense of not wanting - or not being able - to share the responsibility with others, Todd and Shearn (1996a) warn against this being interpreted to mean that participants felt a sense of well-being within the carer role (Todd & Shearn, 1996a).

#### 4) Future stories

##### *Future care needs*

Maurice, Audrey and Rachel all perceived a need for their child to require never-ending care, which created an anxiety about what will happen to their sons after their death. Audrey reported that this anxiety influences all the decisions she currently makes as she is constantly thinking about what can be established for Gregory when she is not here, whilst Maurice expressed the view that he believed that Michael would end up "*in either prison or an institution*" in the long term. Both Rachel and Mark acknowledged the belief that Matthew will require life-long care, but there were significant differences in their reported concerns around this. Whilst Rachel reported a fear that her children will be left to care for Matthew after they were gone, Mark stated his concern was not for after they have passed, but rather the impact that Matthew may have on his and Rachel's later years, based on an expectation that services will eventually withdraw from Matthew's care. Both Mark and Rachel stated that their (self labelled) pessimistic view of the future was based upon the negative experiences of caring for Matthew without help in the past; they stated an expectation that they may feel differently once Matthew is moved to a lower secure hospital and they have chance to increase their confidence in spending time with him and improving their relationship.

In contrast to this, only Debbie reported a view that Jamie would not require long term care or support. She sighted the current improvements in his behaviour and previous input from professionals, along with her own parenting style as the reason that Jamie's behavioural difficulties could now be anchored in the past.

##### *Future relationships*

Two primary caregivers talked specifically about the possibility of their sons forming future adult romantic relationships, although their views on this appeared to vary significantly. Debbie stated that she expected Jamie's future to include him having children, a wife and "*to be just like everybody else*". Rachel on the other hand stated

that she worries about the detrimental impact that being a parent may have on Matthew's anxiety and also the impact that Matthew himself may have on his children. She stated a view that *"this is just the start of it for us really we've got a whole life like this where we're going to worry about him and relationships"* and that *"I hope he doesn't have children, isn't it awful?"*. Although Rachel's wishes are borne out of a concern for her son's wellbeing, comments such as these also have important cultural resonance, given the societal prejudices which exist in regards to individuals with learning disabilities having children (Conder et al, 2010) and the involuntary sterilisation procedures which have been conducted on individuals with learning disabilities in the past (and continue to be used in some cultures and countries to this day; Aunos & Feldman, 2002)

The concern about future relationships was also present in Maurice's narrative, although not directly related to Michael himself. Maurice expressed a concern that the difficulties Michael experiences may be due to a genetic component and reported an anxiety that Michael's sister may have children with similar care needs.

### **Plots and subplots**

The following diagram outlines the relevant plots and subplots identified through the NA. The reader will note that emotional experiences have been identified as existing outside these plots. Greenberg and Angus (2004) argue that "it is often the rise and fall of emotional themes – and the conflicting desires, intentions, goals and purposes they represent - that provide the connective thread that weaves together the disparate experiences and events to create a meaningful and coherent whole: a storied experience" (pg 331). For this reason, the shared emotional experiences of the primary caregivers are provided as a canvas onto which the plots and subplots can be mapped. Furthermore, it is recognised that, just as no experience can be understood in isolation from what has come before, no subplot can be understood without an appreciation of the interplay between it and the other subplots present within the same experience. Plots are therefore defined as permeable (Frank, 1995) and this interaction across plots is represented by the dashed line marking the 'boundary' between the plots and subplots.

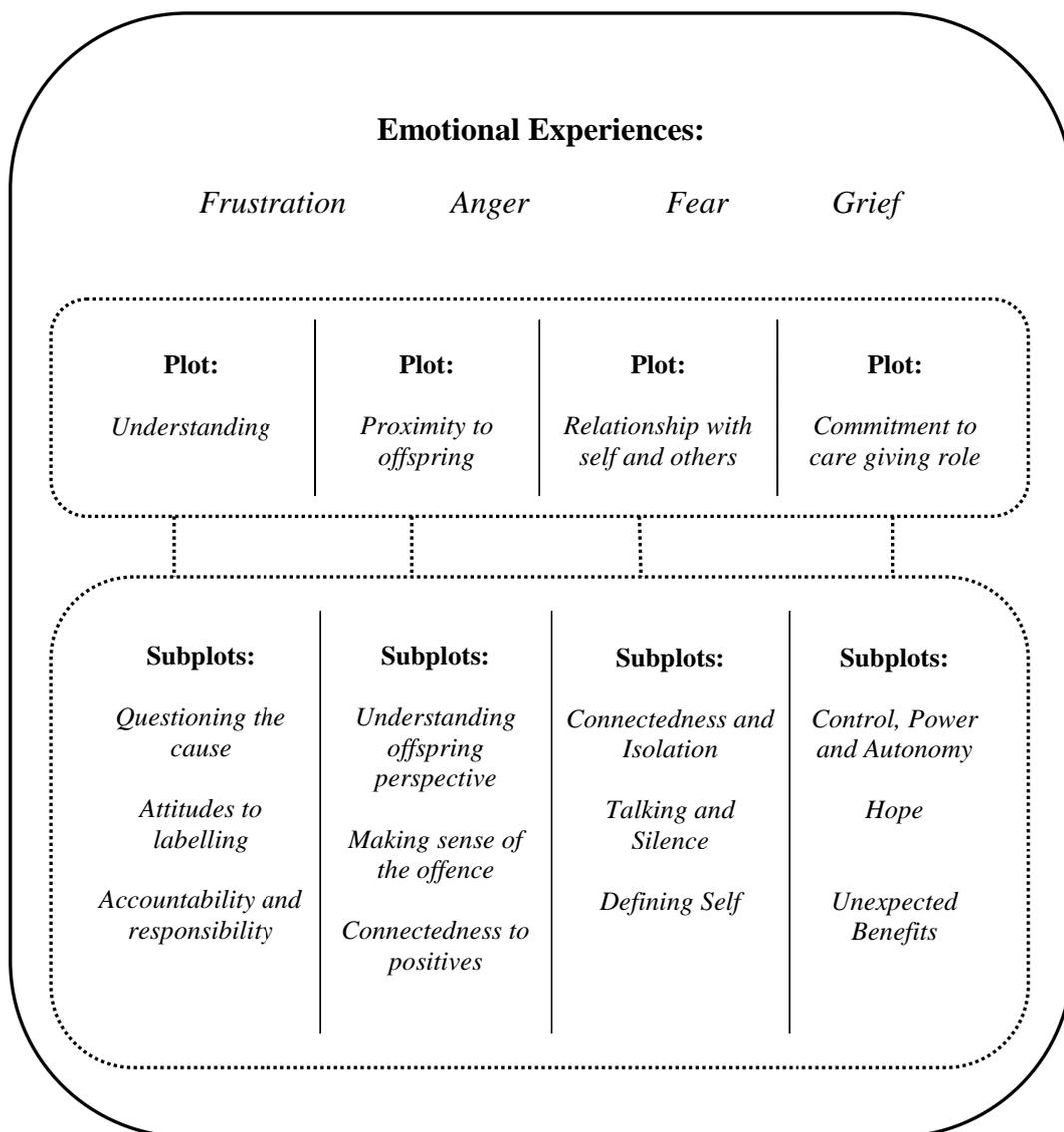


Diagram 1: Plots and subplots identified from primary caregivers narratives.

The remainder of this chapter is concerned with exploration of these plots. Each plot will be introduced, followed by a breakdown of each related subplot.

**Emotional Experiences**

Unsurprisingly, given the sensitive nature of the experiences being discussed, there was a strong sense in all the interviews that the primary caregivers had to manage a multitude of emotional experiences, some of which they reported as having the potential of ‘pushing them under’. These emotions appeared to have a pervasive effect, both implicitly and explicitly, upon all the stories shared and require attention

in their own right in order to understand the emotional landscape (Greenberg & Angus, 2004) within which the primary caregivers were operating. The four predominant emotional experiences evident in the sharing of these primary caregivers stories were 'Frustration', 'Anger', 'Fear' and 'Grief'. It is acknowledged that there were other emotional experiences (e.g. guilt or shame) described by participants in their stories and reference to these will be made where appropriate. However, there were clearly four predominant emotional experiences that were identified in the participants' stories and these will now be discussed in detail.

### Emotional experiences: Frustration

All primary caregivers in this study referred to the events surrounding the offending as 'stressful' to varying degrees, with frustration being the emotion most associated with this. Within the research literature, stress has been the most focused upon response of parents of individuals with learning disability (Faust & Scior, 2008), particularly when the individuals demonstrate challenging behaviours (Walden et al, 2000) or within the families where an offence has been committed (Condry, 2007a). Although it is acknowledged that there are additional socio-cultural and economic factors which mediate this stress (Fergusson, 2001) there remains a dominant assumption within the literature (and society at large) as to the inherent frustration primary caregivers will experience by nature of their role. For Debbie, Mark and Maurice this appeared to be their primary concern and a key challenge to their ongoing narratives.

Debbie explicitly discussed the frustration she had experienced and stated it had been evident from throughout Jamie's early life, up until the end of his court proceedings. This appears to have been linked to both his challenging behaviour and her attempts to procure a diagnosis. To highlight the extent of her experience she shared with me a story of the physical impact that this had and the subsequent reaction from health professionals to initially understand her symptoms from within an individualised and medical framework. The systemic and emotional understanding of her experience was only posited later on and she was reassured by this as she took her doctor's recognition that she was '*under enormous pressure*' as validation of her feelings of frustration.

In contrast, Mark referred to the stress he was experiencing rather implicitly with the statement that '*all parents should be given medication*' to cope with their experiences. This comment is particularly interesting given that, of all participants, Mark seemed to adhere to the idea that society was the cause of the difficulty - and yet he was requesting an individualised and medical solution to his distress. There was a sense in his narrative that he viewed the problem to be so overwhelming and to have such an endemic cause that he was incapable of effecting any change alone (Koffman, 2008). In response to his frustration, and the associated feelings of exhaustion and hopelessness, Mark was requesting an external 'cure', which would

help him escape from his emotions, seemingly indicating a sense that his own resources are and were inadequate.

Maurice was able to talk about the stress he experienced with regards to Michael's behaviour at home and repeated police contact. He reported a physical desire to 'leave' the family home ahead of times when he knew there would be problems, echoing Mark's frustrations at not being able to manage what was happening around him. Acknowledging that *'It's helped me, him not being here... it's helped it's it's er helped... alright when he went to prison it wasn't nice but that has, that has... It's certainly given me less stress, put it that way'*, Maurice was quick to return the focus on Michael's experience, rather than dwell upon his own, stating *'all this has been stressful for him too remember'*. Through comments like this he served to unite him and Michael in their experience but also ensures that the focus remains on Michael throughout and deflects away from Maurice's emotional experiences. When considering how Maurice performed within the next emotional experience to be discussed (anger), it appears that his re-focusing on Michael serves a purpose of helping to spread out the stress and associated anger he feels, and this way of managing may have had a protective function in the maintenance of his relationship with his son.

#### Emotional experience: Anger

A second emotional experience identified through the NA was anger. This has been found in previous studies to be a common emotional reaction to both learning of a child's learning disability and/ or offending (Scott, 2003).

The anger Maurice experienced in response to Michael's aggressive behaviour was only gradually acknowledged and expressed. His narrative developed slowly throughout the interview and he appeared to 'jump' from point to point without a clear chronological order. He seemed to talk 'off topic' a lot but always brought himself back to my question without prompting. He began with a somewhat emotionally detached description of Michael as having a *'temper'* but built upon this throughout the interview through the use of terms such as *'abusive'* *'violence'* and *'dangerous'*, finally ending with a more vitriolic description of Michael as *'a vicious little bugger'*. It appeared that the more Maurice talked, the more his confidence in his narrative increased and the more able he felt to access the strong emotional elements underlying this. Of all participants, it was Maurice who reported that he did not talk about the issues with others and so one assumes that perhaps his emotional response was still unprocessed, as he had not given language to his experience (Dickson-Swift et al, 2007).

In contrast, Debbie was very able to access and articulate her emotional experience, and in particular her anger. She directs this outwards towards the people and services that she holds accountable for Jamie's behaviour, at times seeming to

excuse his actions and focus upon the ill treatment she felt he was responding to. In return, she reported feeling that teachers and health professionals were *'horrificed'* by her approach, deeming her to be a *'terrible mother'*. Such a reported view could be seen as reflective of a wider societal and political discourse which holds parents accountable for their child's moral development (Koffman, 2008; Kall, 2009). In analysing the text we cannot say with any certainty whether Debbie's assumptions of the judgements of others are accurate, but the fact she raises this as a possibility could be seen to reflect that Debbie herself is aware of, and reacting against, this dominant discourse.

She referred briefly at the end of her interview about her own regrets that her school did not recognise her own special educational needs and this appears to offer an alternative explanation as to why Debbie may have felt so strongly that she needed to respond positively towards Jamie and direct her anger at the system. I wonder whether Jamie's experiences may have had a recapitulating effect for her in terms of her feelings of anger and resentment towards the education system for not recognising her needs as a child. Contrary to how she was apparently labelled as *'antagonistic'* by the education system, her shared lived experience with Jamie may have made seeing alternatives to the attributions they made more difficult.

Finally, a number of times throughout our contact Mark expressed that *'all our grievances are from before he went in [to hospital]'*. He uses the metaphor of a castle to describe the families battle to receive treatment stating that the *"mental health service as far as I can see it's like a prison, like a big castle, it's impossible to get in and once you're in it's impossible to get out"*. However, despite his reported satisfaction with current levels of care, Mark's anger remained evident throughout the interview, through his criticalness of the way in which mental health services and social services are structured and the reasons he gave for why they had been able to access help. This created a sense of Mark being in a place of reluctant acceptance in that he wanted to have help from the system, but he could not let go of the resentment he felt at the systems earlier failure to support him and his belief that this made the problem worse. He appears to attribute his family being able to *'break into the castle'* as being down to *'luck'* and meeting a *'Maverick'* who *'won't follow the rules'* rather than due to the system being structured in any helpful or supportive way. It appeared that his anger at earlier service dismissal had an energising effect on the way in which he views his current support and the way in which he anticipated services response to him in future. By remembering and re-experiencing his anger from the past he can defend against the possibility of services dismissing him or his family in the future.

#### Emotional experiences: Fear

Fear was expressed in all five narratives and appeared to cover two key areas; fear *for* their son and his future and fear *of* their son and his behaviour towards them.

Parents of individuals with learning disabilities have been found to report high degrees of fear in response to their child's challenging behaviours (Faust and Scior, 2008). At the same time, the uncertainty as to what the future will hold for their child can make parents feel fearful of their future life trajectory (Kelly, 2005).

Rachel reported being afraid of Matthew, despite his assertions that he didn't think he would ever hurt her, and reported feeling that she could not visit him without Mark because she was *'frightened to be alone with him'*. Despite this fear she stated she was committed to being involved in Matthew's long term care needs. Aggression of child towards parent is an area of family dynamics which has been largely ignored in the literature (Peek, Fischer & Kidwell, 1985; Paterson et al, 2002; Bobic, 2004). Even within family violence services there is an expectation that, as Paterson et al (2002) expresses, 'mothers are not responsible for the violence but are important to the solution' (p.92) and that it may be 'less appropriate' for mothers to be able to leave the home due to their own victimisation because they have a parental duty to fulfil. Aware of the societal pressure which exists which values maternal duty over personal safety (Bobic, 2004), when analysing the narrative text I wondered how able Rachel might have felt to be able to voice an alternative desire not to support Matthew given the fear she associated with him. Rachel stated that the risk Matthew posed had been acknowledged by other family members who had advised her to call the police (advice also given to Debbie) or *'chuck him out'* but that she felt unable to do this because *"there's something wrong with him he's ill 'I'm not just throwing a child out that's ill' because he's my child and so you're sort of torn really because you think 'well that would do something' it would come to a head but then you're getting into very dangerous territory there if people just chuck their kids out"*.

Rachel's dilemma was between wanting to feel safe from Matthew and wanting to nurture and support her son; ultimately she prioritised her maternal role, continuing to support Matthew at home until his arrest. In contrast, Debbie reported a fear as to what may happen to Jamie (and herself), should he be sent to prison and this appears to have influenced the way in which she interacted with people around her. Her assertion that *'I cannot think of anything worse than calling the police on your own child'* further highlights the predicament parents (and particularly mothers) may find themselves in, when traditional avenues of safety seeking appear blocked, because of societal expectation or undesired consequences.

#### Emotional experiences: Grief

The fourth emotion which appeared to dominate the stories shared by participants in this study was grief. Although all three mothers in the study referred to the sadness that was associated with their sons' experiences or current situation, Audrey was the only participant to talk explicitly about the grief she experienced in response to Gregory's offending, subsequent imprisonment (Scott, 2003) and hospital admission (Kelly, 2005). However, she does this mainly by talking about the experiences other

parents must be going through, stating *"it's sort of bereavement really when somebody's sort of.... So called locked away, which they are really"*. By attributing her emotions to others she was able to begin to explore them from a detached and 'safe' distance. Although Audrey was able to explicitly name the emotion of grief she appeared to need to place strict control on it and this created a sense that exploring it further may have threatened her continuing ability to cope. She defended against this throughout our interview, either changing the topic if it became too 'close' or by sharing stories of the strategies she uses to stop people *"giving her too much sympathy"* because she *"cannot cope with it- I can give it to others but can't take it myself"*.

As previously stated, two of the primary caregivers had experienced bereavement in the immediacy before the offence occurred and the extent to which the offending may have impacted upon their own grief process was not explored in this study. However, both Audrey and Maurice talked about bereavement rituals, such as putting flowers on the grave, and how their offspring's' incarceration had disrupted this for them as they were now expected to continue these rituals on their son's behalf. Both clients were reported to have had bereavement counselling in their respective care units, which Audrey and Maurice reported had been helpful for them also as it meant they felt less pressure to support their son through this.

### **Plot 1: Understanding**

As Kelly (2005) argues, learning of a child's disability can cause life to move into a different trajectory, which had not necessarily been anticipated. The impacts of this trajectory on the individual is dependent upon how well they can make sense of events and assimilate these into their whole life story (Bury, 1982). Meaning making has important implications for a person's ongoing way of being in the world and it is therefore unsurprising that the first plot identified by the primary caregivers reflected their attempts to understand what had happened. The associated subplots pertaining to the primary caregivers meaning making have been labelled 'Questioning the cause', 'Attitudes to labelling', and 'Accountability and responsibility'.

#### **Subplot: Questioning the cause**

The issue of the origins of their child's learning disability was a particular concern for both Rachel and Maurice and had impacted on their ability to understand why their family had been affected in the way it had. It would appear from his narrative that Maurice's need to understand the cause of his son's learning disability had implications not just in regards to his relationship with Michael, but also his relationships with other family members across his life span. He states explicitly his belief that *'it's in the genes'* and shared with me stories both of researching his ancestors *'to see where it may have come from'* and stories of wanting to prevent

future generations from experiencing similar disabilities to Michael, by advising his daughter to '*check up*' if she were to become pregnant. Maurice's story echoes some of the motivations given by participants undergoing genetic testing in a study by Statham et al (2010), but as can be seen in his position in the next subplot, he's not concerned about a 'label' as the majority of the Statham et al study reported to be. Indeed, Maurice's comments regarding the actions his daughter should take, may be more reflective of what Blackman (2003) refers to as 'society's death wish' towards those with disabilities, a remnants of the Eugenics movement of the early 20<sup>th</sup> century, through which society attempted to eliminate 'imperfection'.

Rachel too questioned a genetic cause, listing a number of other members of her family who had experienced mental health problems and questioned whether Matthew's disability had come '*from my side*' of the family. However, she also shared a previously held concern that his problems may have been due to her peri-natal depression and her subsequent relief that Matthew's eventual diagnosis was not linked to this. Both of her early assumptions appeared to implicate Rachel as the cause of her son's difficulties and the diagnosis appeared to have gone some way towards negating this, although she retained the belief that it probably had some genetic links.

Unlike Maurice and Rachel, Audrey was able to give a concise explanation of Gregory's cognitive difficulties, linking it to problems he experienced during surgery required as a child. She stated that '*so many babies*' had the same problem in treatment, indicating that his learning disability had been anticipated, but her assertion that it's '*better now*' for children seemed offered to reassure herself that this would not occur for others in the future. What is also interesting is that she did not question the cause of the physical disability in the same way that Rachel and Maurice did. It is possible that this may be because Audrey knew medically what caused it, or because as Gregory is not her biological relative it may not have had the same implications for her.

#### Subplots: Attitude to Labelling

There were two types of labels which the primary caregivers were considering throughout their narratives - the diagnostic label (e.g. learning disability) and the offender label (e.g. 'sex offender', 'arsonist', 'paedophile' etc). In all cases it appears that it was the offender label which got their son the help they were asking for, but it was now the diagnosis label which primary caregivers chose to focus upon throughout the interviews. Two of the participants in the study, Audrey and Maurice, did not give a formal name to their child's learning disability, and one of these, Maurice, did not name the offence for which Michael was convicted. However, in both instances Maurice was able to discuss key factors around the diagnosis (such as Michael's IQ) and the pattern of his behaviours which constituted his offence, creating a sense that the labels themselves were not as important in his meaning

making as the individual factors. Debbie, Mark and Rachel all gave name to their child's diagnosis but did not name the offence for which Jamie or Matthew were charged.

The only parent to report resistance to the diagnosis was Mark. Based on his own lived experience of having a medical diagnosis, which excluded him from certain groups and activities, he explained that *'I didn't want him to be labelled because then you are written off'*. However, as his narrative progressed there was a shift in his attitude towards the diagnosis and he doubted whether his previous position was helpful or not. He questioned *'Well yeah because if he'd been er caught early on as what – he would have been tagged which I didn't want him to be but it would have been better, if he'd have been tagged he then would have been in the system and it would have been dum dum dum dum'*.

The two biological mothers in study reported welcoming the formal diagnosis - and indeed seeking it themselves - because it provided them with answers to earlier life experiences (Marshall & Long, 2010). As Rachel stated, *'I was relieved to know that you know – I know you don't like to have names of things but there was a reason why he was like that'*. As a result of this understanding Rachel reported an increased sense of empathy towards Matthew and was able to view his challenging behaviours at home with more objectivity. Similarly, having a formal diagnosis appeared to have value for Debbie because it served to increase her confidence in explaining Jamie's difficulties to others (Staham et al, 2010) and protected her from the possibility of being held accountable for her son's behaviours (Hemphill, 1996). For her, *'Diagnosis is everything because then you have the understanding'*. However, what is interesting in Debbie's narrative is how her attitude to the diagnosis has altered over time as Jamie's challenging behaviours have lessened. Her initial relief at receiving the diagnosis appeared to have dissipated and as she told her story to me there were elements which indicated her attempts to 'write out' the diagnosis (and offender label, which she has always denied) and focus upon her belief that Jamie will be *'just like everybody else'* in the future.

All primary caregivers appeared to focus upon the psychiatric label over and above the offender label and one wonders whether the diagnosis was the easier label to talk about and could perhaps be used to 'explain away' the offender label. Inherently, by labelling Gregory, Audrey labels herself through association (Condry, 2007) which may further influence the participants' reluctance to label the offending behaviour. The fact the offender label remained unnamed within the majority of the narratives may be reflective of a fear of stigmatisation (Condry, 2007). It may also be a consequence of the way in which society views and condones different types of offending. For example, Rachel's comments that she worries Matthew may be wrongly labelled as a *'paedophile'* due to being in hospital with people who were, reflecting a wider societal narrative in regards to the acceptability of certain offences over others (Gavin, 1995). Furthermore, Audrey asked *'do I have to tell you why he's*

*in? Does it help? He, he was in for a sexual assault'* which implied a need for an additional permission or justification to discuss such a sensitive topic, despite this being the reason for our meeting.

#### Subplot: Accountability and Responsibility

Hemphill (1996) has previously raised concerns that psychiatric labels may be used to excuse (violent) behaviour and this appeared to be evident in the primary caregivers' stories. In particular, when talking about Gregory's time in prison, Audrey stated. *"and of course he was also in the unit where those people also had really been sexual offenders[my emphasis]"* indicating that she did not view Gregory as a 'real' offender, that he should not be classified as such and should not be held accountable in the same way. It would appear that for Debbie and Mark, this view that their sons are not accountable resulted in them feeling that they were being apportioned a greater deal of responsibility than they were willing to accept. This was most evident throughout their childrens' earlier years, prior to the offence, with both having reported feeling that professionals were quick to attribute cause to their parenting styles –*'they put it down to me'* (Debbie) - or parental anxiety – *'they thought we were the ones with the problem'* (Mark). This appears to have left an indelible mark on the way in which they are able to interact with services due to anger they feel at this initial response.

However, the primary caregivers in this study were not impervious to the social narratives around parental responsibility (Koffman, 2008) and many shared stories regarding how they had questioned their role in the offending. This took the form of both failing to prevent the offence and allowing challenging behaviours to escalate until they reached the point of offending. For example, in regards to the offence itself Audrey stated that *'I think possibly myself, I could have been- I mean I don't feel guilty about it at all. No guilt about it whatsoever- um but I think in hindsight I think the the night it happened um.. I was a little bit unhappy about him'* whilst Maurice questioned whether there was anything he could have done in Michael's earlier life which could have prevented events escalating. Even Debbie, who performed with great certainty throughout her narrative, voiced the concern that her actions may have allowed the situation to continue to the point that it did. This uncertainty appeared to be an ongoing challenge for the primary caregivers to manage and linked to their fear regarding their child's future.

Attributing the underlying cause of the offending to her son's anxiety and cognitive difficulties, Rachel appeared to want to take responsibility for her son, because of their genetic bond. This created a dispute between herself and Mark as to the degree to which she should hold herself to account. After she voiced the belief that the cause of the learning disability was from her, Mark appeared to respond to this unspoken anxiety stating *'No, no I just think you know I think maybe you've used up*

*all yours and this is coming from mine'*. Whilst he did not dispute his wife's proposed genetic cause, he appeared to want to reassure her that she should not be held responsible for their son's difficulties. This comment also served to highlight his place as Matthew's parent who holds equal responsibility for his child's upbringing and appeared to both reassure Rachel and reinforce the sense that they were *'in this together'* and *'neither could cop out'*.

## **Plot 2: Proximity to Son**

The circumstances around their son's arrest and hospitalisation highlighted stories about how close, physically and emotionally, the primary caregivers felt to their son throughout their whole life story and how this was impacted upon by individual events. The subplots associated with the emotional and physical proximity primary caregivers discussed have been labelled 'Understanding offspring perspective', 'Making sense of the offence' and 'Connectedness to positives'.

### **Subplot: Understanding son's perspective**

The difficulties people with learning disabilities may experience in communicating their inner thoughts and emotions may lead to their family members having to make assumptions about their world view (Madden, 1995; Clements et al, 2004). In this case it has led to the primary caregivers having to make assumptions about the motivations for their child's offending and question the factors which may have contributed to this. This initially appeared to have created an emotional distance between the primary caregivers and their sons as they did not feel able to access their son's inner world.

For four of the participants (Maurice, Mark, Audrey and Rachel) it was the offending which was instrumental in them feeling able to develop their own perspective into their son's understanding of the world. Prior to this they reported they had felt they had limited ability to access this. In these three stories, there was a paradox apparent whereby as the physical distance between the primary caregiver and offspring increased so their emotional relationship became closer. It should be noted that these three stories were marked by the apparently high levels of physical aggression displayed within the home environment and so highlights the importance of safety within primary caregiver - offspring relationships. Overtime, and with support from care staff, Mark and Rachel reported feeling that they have developed a good understanding, particularly with regards to knowledge about diagnosis and feeling able to engage Matthew in talking about his thoughts and behaviours. Conversely, Maurice stated that there were a number of issues that he had yet to *'go there'* in terms of talking to Michael about what had happened. He stated that he had his suspicions as to how Michael saw things, but his own reluctance to discuss this

meant that a lot was still unexplored between them and his understanding of his son remained relatively limited.

In contrast, Audrey was very explicit about what she felt needed to happen in the future to prevent Gregory from returning to hospital. She based this on what she felt he *'needed'* and stated that she was not prepared to compromise on this, directing his care staff about what they needed to put in place. Her performance during the interview indicated that she was less confident in how to interact with Gregory and put her plans into action. For example, on each occasion that Audrey would share her wishes with me she would first state what she was trying to do and the rationale behind it in a very confident and assertive manner. However, when she then gave an example of how she had communicated this to Gregory her demeanour became far less confident and the volume and clarity of her speech would drop, so that it was very difficult for me to hear exactly what she had said. I have interpreted this sudden contrast in her performance as indicative of a lack of confidence in how to interact with Gregory, based on her limited knowledge of his perspective and a concern that others (including me) may judge her for this.

Debbie reported the most confidence in her understanding of Jamie's perspective and the reasons behind his offending. However, she reported that this was the result of deliberate efforts on her part to *'come along side'* Jamie when he was twelve years old. She stated a belief that this was the correct thing for a parent to do but recognised that not all parents have been able to do this stating *'an awful lot of parents I've met have no clue what it means to be their son or daughter'*. Interestingly, Rachel confirmed Debbie's belief throughout her narratives regarding life before Matthew went into hospital, repeatedly stating that *'we had no idea he thought like that'* and *'this has only come out since he's been in there [hospital]'*.

There appears to be a need for primary caregivers to be able to recognise others' perspectives but also to know who this perspective belongs to. Whereas Mark attributed Matthew's offending to the confusion that exists in the space between Matthew and the rest of society, Debbie attributed the difficulties to the way in which the social world has targeted and harassed her son. When Mark stated that Matthew believed that *'everything he's done it's all self defence as far as he's concerned. Because everyone was out to get him'* it is clear that Mark did not fully agree with this view; he showed an appreciation for Matthew's understanding and positioning without feeling the same degree of persecution or hostility towards the world. For Mark, he and Matthew remained distinct individuals, although they were emotionally closer due to Mark's ability to understand Matthew's perspective.

#### Subplot: Making Sense of Offence

Understanding why their son's behaviour escalated to the degree it did, impacted upon the emotional closeness primary caregivers reported having with their son. Initially, finding an answer to this question was confused by their child's impairments, preventing them from being able to reflect on or communicate their motivations (Clements et al, 2004). In all stories their son's vulnerability was proposed as the main contributing factor for the offending and this vulnerability was deemed to stem from their cognitive impairments. The issue of drugs and alcohol was also raised in two stories but linked to their vulnerability in peer groups. From this perspective it was considered that the primary caregivers were making a strong association between vulnerability and offending.

Comments voiced by both Mark and Debbie reflect the key principles underpinning the Social Model of Disability (Oliver, 1983) in that it is the way in which society is structured that creates their child disability, rather than their child's cognitive impairments. As Elliman (2001) highlights, it is common for individual's whose impairments make social interaction difficult to feel discriminated against or ostracised, which in turn can lead to feelings of hostility and anger aimed towards the social world. It would appear that for both Mark and Debbie, the social model provides explanation as to why Jamie and Matthew committed their offences; society let them down and, as Mark so succinctly put it, "*he [Matthew] was just standing up for himself*". After a lifetime of de-valuing experiences Jamie's aggression could be perceived as a response to losing a positive sense of self - due to the prolonged negative response Debbie reported he had received from others (Clements et al, 2004). This highlights not just their vulnerability but also the damaging effect that the social world can have on young men with learning disabilities (Reiff et al, 1997).

When considered together, the stories shared regarding the primary caregivers ability to make sense of the offence appear to fall along a continuum. Over time it appears that Mark and Rachel's confidence in their making sense of the offence has strengthened as they have been able to develop a deeper level of understanding regarding Matthew's impairments and how they link to events. For example, they were able to posit a rationale for how other people's treatment of Matthew may have been received as patronising. As such they were able to mentalise about Matthew's perspective at each point in the story. Maurice did not appear to have yet reached this stage, and was still questioning his assertion that it was because '*he thought he needed help*' but did not understand why Michael acted as he did and did not know what type of help Michael had hoped to access. Finally at the point of telling her narrative, Audrey remained in a place of confusion as to why Gregory committed the type of offence he did. Although she highlights his vulnerability and questions the role of the victim in the offence she continues to struggle in her understanding stating, '*well I can't make sense of it... um at all. I can't understand.*' and '*[the] solicitor said on both sides and we may never know for a fact what actually what happened. How it came about. And I think they're absolutely right.*'

Subplot: Maintaining connectedness to positives

As Ho (2004) succinctly explains ‘being labelled as having learning disabilities can affect other people’s perceptions and expectations of that child” (p.88). As a result, primary caregivers may be acutely aware of how their child is being perceived by others and may strive to ensure their child is still seen as an individual rather than being defined by their condition or behaviour alone. Furthermore, Tron Dinneen (2004) has previously highlighted the concern that an over emphasis on a child’s impairments can cause parents to disconnect from the individual aspects that they value in their offspring, which in turn can make their relationship with their child more difficult. For the participants in this study, their son’s offending behaviour has further exacerbated the negative way in which he may be perceived by them or others due to the systemic focus upon the offending behaviour and its risk management. There was evidence in the way all the stories were shared of the primary caregivers trying to ensure their child was represented as a whole person rather than as simply an ‘offender’ or ‘learning disabled’. For example, in reading back the narrative text from Mark and Rachel’s interview, it is notable how frequently this alternative view of Matthew or his difficulties was given and how there were two key ways in which this occurred. Either a strength of Matthew’s, such as his loyalty to others, would be explicitly highlighted (usually after discussion of the more challenging aspects of his behaviour) or the behaviours themselves would be ‘repackaged’ to have a positive use were they to be demonstrated in a different circumstance. For example, after sharing with me the way in which Matthew would ‘grind them down’ to the point of ‘bullying’ them into giving in to his particular topic of interest, Mark presented the alternative view that ‘*Maybe he should be hired by the secret services to interrogate people- he’d be fantastic!*’.

What is of further interest is that it appeared to be the accessing of a diagnosis which facilitated Mark and Rachel being able to connect to the positives around their son. This is contrary to previous literature which highlights parental struggles in remaining optimistic in the face of diagnosis (Kelly, 2005). As Rachel explained, having a diagnosis allowed for the realisation that “*he wasn’t a bad person, it was something that wasn’t his fault really*” and this in turn made them recognise the alternative identities that Matthew held; if he was not inherently bad then other aspects of his character needed to be acknowledged. This highlights the way individuals may use labels in order to externalise causality inferences and responsibility regarding behaviour and raises important ethical questions as to at which point an individual can become ‘responsible’ for their actions.

Whereas Mark and Rachel together appeared to be able to hold a shared flexible view which acknowledged both Matthew’s strengths and weaknesses, it appeared from others’ narratives that not all participants were able to do this. For example,

Debbie appeared to have taken a very dichotomous position in relation to Jamie's difficulties, holding on to positives about Jamie as global truths, and negatives as belonging to the person who said them (i.e. internal to them) and not applicable to her son. However, whilst this served as a benefit for Debbie in protecting and nurturing her sense of connectedness to Jamie (Tron Dinneen, 2004), it had a pervasive effect of distancing them both from others around them, as services (schools and police) labelled her as collusive and became dismissive of her views. Given the amount of negative feedback she received one begins to question why Debbie held her position so vehemently and what it would mean for Debbie were she to take a more holistic view of Jamie. It appeared that any acknowledgement of Jamie's difficulties would be to validate the criticisms she feels Jamie and she have been subject to throughout Jamie's life and so she continued to deny them, focusing on the strengths that Jamie and she had in order to discredit the ghostly audiences (Minister, 1991) from the past.

Assuming that being able to view the positives about their child is a factor influencing proximity (Tron Dinneen, 2004) one questions how proximal primary caregivers can be to child if a connection to positives is lost? Certainly, the participants in this study all told stories of trying to remain connected to their child's positive attributes and project them to others, and all demonstrated this throughout the story construction with me. Recognition of the needs of primary caregivers to protect and project their child's positive attributes is important as it offers an alternative discourse to how parents may be perceived as collusive or over involved. There is a current trend within the literature, which is reflected in Government legislations such as 'Valuing People' (Department of Health, 2001) and 'Valuing People Now' (DoH, 2009), to place greater emphasis on seeing individuals in a holistic sense and the stories told by the participants in this study would support the need for services to be more explicit in their attempts to do this as it has implications not just for client care but also the family around them.

### **Plot 3: Relationships with self and others (identity)**

Too heavy a focus on one aspect of our life story can cause an individual to lose touch with other aspects which they may once have valued or which may provide resources for coping. This has been found particularly true for parents of individuals with learning disabilities when the predominant focus has been upon a child's difficulties and differences (Hubert et al, 2007). As identity is dependent upon the ability to relate to others, and this is dependent upon the stories we tell about ourselves (McAdams et al, 1997; Pearce, 2009), a traumatic or troubling event will affect our life stories and consequently the way in which we see ourselves in relation to others, who may or may not share these experiences.

The subplots pertaining to the primary caregivers relationships with themselves and others have been labelled 'Connectedness and isolation', 'Talking and silence' and 'Defining self'.

#### Subplot: Connectedness and isolation

Isolation is a key concern for parents of individuals with a learning disability (Solomon et al, 2001; Whitehurst, 2011) and the stories shared in this study only serve to highlight this concern further. Maurice, for example, talks of his isolation not just within society but also his own family as he provides support for Michael. Like Rachel, he expresses a desire not to '*burden*' others with something that he sees as his issue and responsibility, but also acknowledges that other family members have expressed hostility and resentment toward Michael, which leads him to believe they would be unwilling to help, even if they were aware of Maurice's need for additional support. There are similarities between the stories told by Maurice and Debbie as, despite the numerous characters which appear throughout the narrative, Debbie presents as a lone figure within her story. Like Maurice, at times she was separated physically from other family members, and she made conscious decisions not to share her anxieties with others for fear that the situation may worsen. Her assertion that "*All the other parents were the opposite*" highlighted her sense of being isolated from other parents because her experiences differ so widely from theirs. Wanting to have her view validated or understood by others presented a challenge for her, which led to her feeling alone in her struggle. Rachel too talked about being '*the only mother*', highlighting how Matthew's behaviours served to isolate her within her role by making her distinct.

There are echoes of narrative theory of connectedness (White & Epston, 1996) when Debbie talks about needing to be supported by other people who have lived through what she was going through, rather than just by professionals. It is implied that you cannot know how to help someone unless you have a lived experience of the problem, a view which appeared to be shared by Audrey as she talked of her desire for a support service to be established '*not by professionals*'. To combat her sense of isolation, Debbie appeared to be searching for allies throughout the narrative and talked of her need for support which was not forthcoming because, as she herself explained "*there's just no understanding anywhere Becky and it trips you up all the time... you know?*". She attributed this lack of understanding to the complex nature of Jamie's condition and explained that the result of this is that '*it feels personal. You know, it feels like nobody else is going through this, only you*'. Furthermore, she talked of wanting the health professionals to view the problem as she saw it and not as '*criminal behaviour*'. In re-reading her interview it appears that Debbie is still searching for validation for her actions in order to feel more connected to others.

Rachel and Mark's comments regarding the strength and reassurance they find in one another echoes the findings of Olsson and Hwang (2001) who argue that spousal

support helped mediate the individual stress associated with supporting an individual with a learning disability. However, Debbie's story that her husband '*just makes it all worse*' highlights the potential detrimental effect that a spouse may have in managing this stress, if the type of support needed is not negotiated or offered between couples (Margolin, Gordis & John, 2001).

#### Subplot: Talking - silence

A contributing factor to the sense of isolation or connectedness that participants felt was their ability to share with others and talk about the problem. There was a strong family narrative within Maurice's story regarding not talking about experiences or difficulties, marked not only by Maurice's own previously discussed reluctance to share his anxieties with his friends and family members, but also his acknowledgement that his wife did not share her experiences with him. Whilst this appeared to have left Maurice questioning his understanding of family life, there was a sense that he was unsure whether he really wished to know what occurred. For example, he shared his concern that his son may have been '*blackmailing*' his wife prior to her death, and the views of another family member who blamed Michael for his mother's ill health. It is interesting that Maurice had not been motivated to discover the answers to these questions in the same way he had been motivated to research his family history. Despite the uncertainties Maurice voiced, it appeared that continuing to not share these with others served a functional purpose in enabling him to continue to support Michael. The answers may have confirmed his fears and served to increase the feelings of anger which he was already struggling with. One question whether Maurice would be able to support Michael effectively if his anxieties regarding Michael's treatment of his mother were confirmed. Furthermore, the fear that if people know what has happened may make people withdraw from them, might prevent primary caregivers from talking (Skone, 1989; Condry, 2007) - and Maurice certainly limited the amount of information people outside the family could access. During the interview he closed down topics of conversation as to what people know, particularly the offence, by stating that he tells them '*he's in hospital*' and they then know to '*leave it at that*'.

In contrast Audrey, Mark and Rachel shared stories of talking about their experiences with others in their close community, with no negative repercussions being reported. However, it should be noted that in their stories the element of choosing to talk or not was limited by their offspring's offence appearing in the local paper. It was of note that although they felt willing to talk, they had established certain rules which allowed this to happen. For example, Audrey limits her talking to the practical aspects of support, as the emotional aspect of her experience appears to serve as a threat to her identity as a '*coper*' because '*I'll fall apart*'. As previously stated, when emotions are discussed it is limited to how other people must be feeling and the help they should receive. Rachel noted the cathartic nature of talking, telling me at the

end of the interview, *'And thank you, you've had to listen; we've quite enjoyed getting it off our chest haven't we? It's been like therapy!'*

Finally, it is within Debbie's narrative that we see most clearly how an individual's relationship with a particular theme alters over time and in response to key events. She begins by referencing her need for help and talking with healthcare professionals. However, as the help Debbie felt she needed was not forthcoming and Jamie's behaviours began to escalate, she became less willing to talk about the problem, fearing that it may make the situation worse because *'I couldn't really tell people about that... I was always worried that if I told professionals that somehow they would get him'*. At this point talking about the problem is limited to times when she felt she may have found an ally (such as her life coach or solicitors). She actively excluded people, such as her husband, from her experience by *'hiding'* what was going on, because *'he would have made it so much worse, so I keep very quiet about those things'*. At this point talking appeared to be both exposing and threatening for her. However, by the end of her narrative her relationship to the theme of talking had changed again and she appeared to have found *'value'* in sharing her experiences with others as *'a lot of people come up to me and it's a relief to hear my story because then they think 'wow, we've been through something similar' and that makes you feel better'*. What facilitated this change in Debbie's relationship with talking was the decrease in Jamie's challenging behaviour and a belief that the offending can be anchored in the past and does not present a current threat to her. However, the remnants of her previous concerns that the actions of others may have a negative impact upon her ability to cope were evidenced by her whispering during certain parts of her story in case she was overheard by her husband. Indeed, such is the change in her relationship to this subplot that, not only does she now find talking helpful but she has created a platform through which she can regularly tell her story to hundreds of people.

#### Subplot: Defining self

The terms *'parent'* or *'primary caregiver'* are social positions by which an individual's relationship with another is influenced by the social narratives regarding the expected behaviours and outcomes associated with that role (Stueve & Pleck, 2001). For Audrey, who inherited the role of primary caregiver to Gregory later in life, her challenge has been in how to integrate this new identity and social demands into her pre-existing model of self. An additional challenge exists in how to communicate this new identity to others, who expect her to fulfil her role as a caregiver according to their own assumptions. For example, she feels that Gregory wants her to treat him like his mother did, whilst Audrey wishes to support him in a more *'detached'*, disciplined way. Whereas initially this was a dilemma just between them, Gregory's admission to hospital has complicated this as the number of people holding different expectations as to how she should act have increased. This appears to have

magnified the pressure she feels for her preferred position to be made explicit to people now involved in Gregory's life. However, as there is no pre-existing name for this new role as the traditional roles of 'mum', 'aunt' or 'next of kin' do not adequately reflect how she sees herself, Audrey is limited in her success at communicating her new identity to others. Furthermore she experiences her role as a relative of someone in care as dismissive of her previous professional role which she wishes to protect. She is challenged with having to navigate through a system of dominant social narratives, none of which fit with her lived experience. Whilst she cannot give a name to her new identity, she attempts to defend its component parts strongly through, for example, prioritising pragmatism over the sharing of her emotional experiences.

Mark's identity as a father also appears to have been redefined throughout the narrative, particularly by Matthew since his admission to hospital. However, in contrast to Audrey, this re-definition appears to have moved Mark into a position more easily recognised by himself and others as being in line with that of a 'dad' as Matthew has sought more guidance and support from him (Stueve & Pleck, 2001). Mark attributes this change in Matthew's attitude towards him, to his admission to hospital and the reporting that Matthew now appears to view hospital staff in the way Matthew once viewed him (as the 'enemy'). There is a sense that Mark questions the permanency of his new role, given the pessimism he feels as to what will happen in the future. Whilst it is a position he values, it is not yet one which he feels completely comfortable in, for fear that it may be snatched away.

For Maurice, it was his identity as dominant male which was challenged as Michael's dominant aggressive behaviour served to highlight his self-perceived frailty associated with his aging. It served also to undermine his masculinity, as evidenced in the sharing of his story of standing up to Michael's threat of physical aggression with the response *'you aint big enough to do that boy, you'll never be big enough to do that'* and his attempts to convince me that he could have stood up to the headmaster of Michael's school because *'this was 20 years ago remember'*. Having navigated the threat Michael's behaviour appears to have had on Maurice's identity, there appeared to be a secondary threat to his identity as an authority figure, through his dependency upon a service (for Michael's care), which he does not fully understand and does not have the language to fully access.

#### **Plot 4: Commitment to primary caregiver role**

In talking with the primary caregivers I felt no doubt as to their commitment to remaining in their child's life. However, there appeared to be differences in the factors and societal narratives which influenced this commitment. For example, within Audrey's narrative, there was a sense that she had a 'Christian duty' to ensure Gregory was cared for and this both influenced her assertion that she would not

*'abandon him'* and her confusion as to why other family members were not showing him the same level of support when *'they are Christians too'*.

In this final section the subplots associated with primary caregiver commitment to their role will be discussed. These subplots have been labelled 'Control, power and autonomy', 'Hope' and 'Unexpected benefits'.

#### Subplot: Control, power and autonomy

Feelings of disempowerment have been reported to be common in parents of individuals with learning disability (Solomon et al, 2001) and people who have committed an offence (Condry, 2007). Within this study there was evidence of traditional gender roles influencing the degree of power and autonomy the primary caregivers reported.

Firstly, the notion that a mother's love is unique and irreplaceable was raised by Audrey's comment that it's *'different for mothers'* and I myself expected the mothers in this study to report feeling a sense of power because of this uniqueness. However, Rachel stating *'as a mum it's harder'* (to see your child in distress), highlighted how simplistic my original view was. In Western society there is a social narrative that dictates a 'mother knows best' when it comes to her child's care. Whilst Rachel may be aware that she holds this position she has also been vocal in the limits of her knowledge about Matthew's care needs and she has been empowered to seek advice and guidance from professionals. She shared stories of having been able to challenge professionals on their approach and negotiate with them until she felt she reached a position of equal power in contributing to Matthew's care package. Over time it appears to have become easier for Rachel to manage the disagreements which occurred between her, Matthew and the professionals involved in his care - as she has felt that her position as his mother has been respected, even though she has acknowledged her own limitations within the role.

Audrey too reported feeling that she had been able to engage the services in a dialogue as to the rationale behind their care packages. However, she appeared almost apologetic about this stating *'it's because I'm nosey'* that she had been able to do this, which created a sense that she felt scrutinised in her role and ability to provide care. She extended her feeling to the rest of her family, stating her resentment at the invasion of privacy that occurs within service. The feeling that her whole family was being scrutinised served as a direct challenge to her sense of autonomy and although she continued to challenge the system and create a dialogue, her apologetic stance in this highlighted her uncertainty as to the limits to her control.

Maurice too appeared to adhere to the social narrative of mothers being unique and irreplaceable, sharing how his wife took the main responsibility for care giving prior to her death. By deferring to his wife's experience it limited his understanding of what occurred at home, which in turn impacts upon his confidence and commitment to his care giving role, because he does not feel he has the knowledge to negotiate with professionals or advocate on Michael's behalf. Although it was clear that there were certain points of Michael's care he disagreed with, he would negate his concerns by deferring to the power of the system, for example when stating '*he does craft which I think is a little bit young for him but anyway apparently there is a reason*'. Throughout the narrative this created a sense that although Maurice feels that Michael will benefit from certain things, he does not feel confident to push these through and will not challenge the system for fear that he may lose support. Currently he feels he can only continue to fulfil his care giving role from a distance and so his need for care services limits his ability to challenge them.

It is worth noting that Maurice's use of more emotional language increased after a short break in the interview, at which point the following exchange occurred:

M *As I say I'm...I've probably been telling you a lot of stuff you don't even wanna know or use I expect cos you//*

B *//not at all//*

M *You'll edit out as and \*laughed\**

B *It's all very helpful.*

Maurice's comment that I may '*edit him out*' highlights an expectation that I, as a professional, may dismiss or, at best, undervalue his experience. Previously (and subsequently) in the interview he positioned me as being a professional and talked at length about professionals ignoring his concerns or failing to respond. I believe that my reassurance that his story was '*very helpful*' served to indicate that I was prepared to hear Maurice's story and this in turn allowed a deeper degree of emotional connection with his story to be accessed and shared. Trust is vital in facilitating the sharing of stories (Booth & Booth, 1994), particularly those of a sensitive nature (Dickson-Swift et al, 2007), or when the participant feels uncertain as to what the researcher may do in response to their sharing.

For Maurice and Mark there was evidence of the traditional definitions of fathers as 'providers and guiders' (Starrels, 1994) being taken away from them through service involvement. By taking legal responsibility for their child's care, the fathers appeared more limited in their traditional roles than the mothers, who appeared to have found a way of remaining 'nurturing' and 'caring'. On reading back the transcripts from Mark and Maurice's interviews, I wonder whether there was a sense of currently

feeling redundant and whether this impacted upon their confidence in being able to fulfil their parenting role in future. As Mark stated *"we're being selfish because we need to build our confidence up in first"* and the question remains how the fathers would be able to develop this confidence, whilst their sons remained in hospital.

#### Subplot: Hope

Related to the degree of power and autonomy individuals reported is the penultimate subplot, hope. This section explores the stories that primary caregivers told and the hope about the future which appeared to have sustained them throughout their experiences. Both gender and life stage issues appear to have influence upon the degree of hope that primary caregivers reported, although it must be noted that the sample size in this study and this finding may perhaps not transfer beyond this study sample.

In general, the male participants reported more pessimistic views about the future, whilst the two biological mothers reported the greatest degrees of optimism. Throughout his narrative Maurice used terms such as *'at the moment'* when referring to improvements in Michael's behaviour and the unit's reports that he was *'doing well'*. It appeared that Maurice doubted the permanency of such improvements and, coupled with his previously discussed lack of autonomy, this created a sense of his life being *'built on sand'*. Similar to Mark, his pessimism appeared to have an energising effect in that it motivated him to continue to engage in services, as he did not believe that time alone would make things alright.

In contrast, both Rachel and Debbie appeared the most optimistic in regards to Matthew and Jamie's futures, with both reporting an expectation that it will be less marked by aggression and that their increased emotional bond will be sustained. In re-reading their transcripts I wonder whether their hope was central to the protection of their maternal role in that it enabled them to feel able to continue to support and *'be there'* for their sons. Of the two, Debbie appeared to deny any possible future challenges, whilst Rachel continued to reflect on the challenges that needed to be overcome for a positive outcome to be reached. It is important to remember that Rachel shared her story in the presence of Mark and so it is possible that their individual contrasting relationship with hope may have had a mitigating effect upon shared reporting (Stueve & Pleck, 2001).

Finally, in regards to life stage issues, increasing age was an issue raised by both Audrey and Maurice and may have been a barrier to the degree of optimism they both experience about the future. Their concerns regarding who will take care of their offspring after their death echo comments made by participants in other published research (Prosser & Moss, 1996; Dillenburger & McKerr, 2010). As Audrey shared with me *'And however young I might feel, the clock's ticking on and you just don't know Becky, do you'*. But Audrey appears to be taking a very pragmatic

approach towards managing this anxiety whilst Maurice reports a desire not to burden others with it.

#### Subplot: Unexpected benefits

The final subplot relates to the stories of unexpected benefits shared. It is important to be aware of the variable nature of contextual experiencing and how these can challenge the assumptions made by wider society about a particular lived experience. Despite the difficulties reported by primary caregivers in this study, not all stories shared by primary caregivers in this study were problem-saturated and the unexpected positives experienced appeared to strengthen primary care givers commitment to their care giving role.

As previously explored, comments made by four of the primary caregivers echoed those reported in Kall's (2009) study in that the offending behaviour had apparently increased the emotional bond they felt with their child. This certainly appeared true for Maurice. In addition, it also appeared to have increased the emotional connection they felt with others, particularly with people outside of the immediate family unit. For Debbie, Jamie's offending has lead to a complete change in her professional life as, having discovered that '*Sharing this all makes sense, it's its valuable*' she was motive to start a profitable business helping other in similar situations to understand their child and find positive strategies.

Rachel and Mark reported that their standing in the community had also increased because they felt that people around them have rallied and respected the way they dealt with the very public difficulties. Rather than experiencing stigmatisation as other parents of offenders in other studies have reported (Condry, 2007; Tewkesbury & Levenson, 2009), they felt that they had been able to establish a better network of friendships in the community precisely because they were '*that couple with the mad son*'.

#### **Chapter 4: Conclusion**

This research was focused upon hearing the stories told by primary caregivers who had a unique lived experience. In this final section I offer a discussion as to the clinical relevance of the study findings with suggestions for service delivery. I will then discuss the strengths and limitations of this study, as well as future research opportunities. I end with my personal reflections on this process. However, to begin with, I provide a summary of the main findings in relation to the two main research questions.

*What stories do primary care givers of individuals with learning disabilities who have committed an offence tell?*

The primary caregivers in this study shared stories which predominantly focused upon the ways in which their relationship with their son had been altered by the offending behaviour. There were a number of challenges and benefits identified. Challenges included developing an understanding of their child's world (which in some cases had felt relatively inaccessible until the offence occurred) and how to ensure the positive attributes about their child were not subjugated in the face of the more dominant narratives around offending and risk management. However, in meeting these challenges, participants reported an increased emotional bond with their child (Kall, 2009). Important to the process appears to be the primary caregivers' ability to mentalise their child's perspective. In some of the stories shared there was evidence that this increased understanding had been facilitated through the help of professionals involved in their son's care and implications for service provision are discussed later in this chapter.

Knowing the cause of both the learning disability and the offending behaviour had important implications not just for how the primary caregiver saw their current situation but also the future stories they told about themselves and other family members. This was particularly evident if the cause identified ways in which they could prevent future generations from experiencing the same difficulties (Staham et al, 2010). Being able to access information as to their son's treatment and the broader care system had important implications for counteracting the feelings of powerlessness that the primary caregivers reported (Drysdale, Jahoda & Campbell, 2009). This in turn helped them to feel more equipped to provide support.

A major challenge for the primary caregivers within this study was the social isolation they experienced as a result of their offspring's offending behaviour. Isolation within primary caregiver experiences can increase emotional distress (Todd & Shearn, 1996a) and the need for support. However, societal implications, such as a fear of stigma or concerns that the situation may worsen, appeared to limit how safe primary caregivers felt to talk at different points in their narrative (Skone, 1989) and

this in turn increased their sense of loneliness. Four primary caregivers appeared to have imposed rules which facilitated their ability to talk and these related to socially desirable outcomes such as 'helping others' and being seen as open and honest by the wider community. These four participants all reported less emotional distress as a result of establishing informal networks of support.

#### *How are these stories told and understood?*

The four predominant emotional experiences highlighted by participants in this study were 'Frustration', 'Anger', 'Fear' and 'Grief' and these create the emotional landscape (Greenberg & Angus, 2004) of the narratives. Whilst the presence of these emotions aids our understanding as to the emotional lens through which primary caregivers may make sense of their experiences, what is of equal note is the absence of other emotions that may have been anticipated, such as guilt and shame (Scott, 2003). These emotions, which have been previously been reported by parents of offenders, were not focused upon as heavily by participants in this study. Whilst this may be due to factors such as the small sample size, one wonders whether the diagnosis of learning disability has a dissipating effect on these feelings as the disability is responsible for their son's behaviour and not their parenting style

#### Clinical relevance of findings and suggestions for service provision

When considering the implications for service provision and development I have remained mindful of the differing needs of clients, primary caregivers and the service providers. However, primary caregivers remain the focus of this study and conclusion chapter.

#### *The importance of involving primary caregivers*

Services and clients need caregivers as family connections are crucial for emotional well-being (Barber, 1997). The knowledge primary caregivers have about their child is unique and the contribution they can make to care planning should not be underestimated (Drysdale, Jahoda & Campbell, 2009). In particular, primary caregivers are crucial to the ongoing development of our understanding around offending behaviour, particularly given that challenging behaviours are often reactive to life events such as bereavement (Blackman, 2003). As O'Connor and Paley (2009) state 'failure to recognize the broad and unique needs of these individuals and their families can lead to multiple treatment failures, consequent worsening of symptoms and high personal societal costs' (p 232; cited in Whitehurst, 2011). The development of good channels of communication between all members of the system is, therefore, of no small importance. An important question is how this can best be achieved?

*Fostering 'sensitive partnerships'*

In order for primary caregivers to feel able to engage with care services, attention must be given to how best to engage them. Given the logistical difficulties with maintaining regular physical contact, and the legal restrictions which may further complicate this, services need to give consideration in how best to facilitate the maintenance and strengthening of parent-adult child relationship. Primary caregivers require a careful and flexible approach, tailored to their individual needs - and professionals need to be prepared to adapt this approach, in response to caregivers' feedback (Madden, 1995). I believe the frustrations and concerns raised in regards to previous service contact further support the view of Madden (1995) who argues that services should be aiming to provide 'sensitive partnerships' as opposed to the more intrusively termed 'interventions', in order to ensure that all parties in the system feel able to engage with support.

All of the primary caregivers in this study shared stories of feeling misunderstood, dis-engaged, or de-rolled. This had a detrimental impact upon their sense of autonomy and hope for the future as they struggled to be able to make long term plans or restore their confidence in their caregiving ability following police contact. Furthermore, the subplots of isolation and connectedness reported by the primary caregivers needs to be recognized with services increasing their efforts to help parents feel part a collective (White and Epston, 1996). Both Audrey and Debbie discussed how inaccessible their experiences were to individuals who did not have the same lived experiences. Tron Dinneen (2004) highlights the benefits to parents in inviting them to discuss their role. Participants in Faust & Scior's (2008) study reported finding talking about their experience for research validating and affirming, although they acknowledged that it had evoked some painful feelings. There is, therefore, a strong argument for the development of carer led support groups, which allow primary caregivers to share their experiences and support one another. Although the message from participants in this study was that these needed to be run by people who '*had lived it to*' (Audrey), services may have an important part to play in the practical aspects of group facilitation, such as advertising. Consideration should also be given as to the necessary pathways of communication between these groups and services.

Furthermore, although it was not an aim of this research, the comments from Rachel that that '*we've quite enjoyed getting it off our chest haven't we? It's been like therapy!*', give insight into the type of approach which may be most helpful for primary caregivers. The process of allowing people to tell their stories has clear benefits to meaning making and reducing emotional distress (White and Epston, 1993). Services should consider incorporating sensitive narrative approaches into their liaison with family members.

*A holistic approach to systemic care*

The current way in which the medical model dominates service provision within the NHS may not be helpful because of its over emphasis on medical ways of understanding disability and its lack of attention to understanding the lived experiences of people with learning disabilities and their families (Solomon et al, 2001). Few primary caregivers in this study used the diagnostic label and so it could be argued that it should not be given as a blanket explanation to all problems and behaviours (Tron Dinneen, 2004). Holistic formulations using carers' individualised appraisals of 'strengths' and 'vulnerabilities' may be more meaningful for both primary caregivers and clients (Tate & Pledger, 2003). Engaging with people in this way will make it far more likely that they will feel understood and consequently better able to manage their own emotion and help with their child's 'rehabilitation'.

The narrative approach may help participants identify personal resources that can be used to help them manage their negative experiences and stress. It also provides opportunity for primary caregivers to remain connected (or in some cases re-connect) with their child's strengths and positives. Services need to focus upon the client's unique outcomes, which challenge the dominant focus upon clients as dangerous (Tron Dinneen, 2004), in order to assist risk management and to help parents remain connected to positives by focusing on strengths and have to best utilize

*The need for safety*

None of the participants in this study reported secondary victimisation in response to their child's offending, which is in contrast to the previous audits conducted by Tewksbury & Levenson, (2009). However, this may be due to the small sample size of this study or the fact that two of the offences did not attract media attention. However, the stories shared by Maurice, Mark and Rachel demonstrate the victimization primary caregivers can sometimes experience from their child. Services do need to recognise the anxiety and fear some primary caregivers experience in regards to their child's behavior and prioritise developing a place of physical and emotional safety for both parties. The stories of Mark, Maurice and Rachel indicate that only once this has been achieved may primary caregivers feel able to make decisions as to the continuation of their care-giving role.

*Involvement in care planning*

When talking with the primary caregivers in this study I was concerned by how little information they appeared to have in regards to the statutory requirements for ongoing care and monitoring of their son. When primary caregivers discussed the

future for their sons post-hospital, all stated that either '*I don't know*' what's available or reported that they were guessing as to the way in which services may be structured. Previous research has highlighted the detrimental impact on an individual's sense of autonomy and hope when their ability to make long term plans is compromised (McCann et al, 1996) and services need to ensure that primary caregivers are kept informed of both the legal framework within which their son will be expected to remain (for example, Multi-Agency Public Protection Agency reviews) and the potential care pathways that may be utilized for step-down care. Four primary caregivers placed particular emphasis on their anxiety as to how much of this care may befall to them and how much support they could expect to receive. Transparency in long term care planning is essential to manage parental anxiety (Drysdale et al, 2009).

The stories shared also highlight the need for a collaborative approach in the developing of effective management strategies, so that parents feel that they understand and agree with the rationale behind a particular approach and feel empowered to implement it (Hassall & Rose, 2005). It has been argued that individuals can only feel autonomous if other people allow them to be (Hayley, 1976). If services are not transparent enough with information, primary caregivers may be limited in their sense of power and autonomy, which may limit the degree to which they feel they can access services.

#### *Early interventions: implications for schools, social services and the CJS*

The need for services to engage with parents at the earliest stages of behavioural concerns being raised is of key importance, given the previously proposed link between a perceived failure on the part of services to provide this and increased parental stress (Dillenburger & McKerr, 2010). All the participants in this study reported a prolonged history of feeling that their needs and concerns were dismissed by professionals. For most of the participants the associated feelings of resentment and frustration continue to influence their appraisal of service involvement and their confidence in support in the future.

Comments about difficulties in early life (e.g. school) and the attributions primary caregivers gave regarding these experiences and the future difficulties they encountered has resonance not just for the care system but also education and social support. The comments made by the primary caregivers in this study support the need for schools and social services to consider tailoring the curriculum to ensure access to each child's individual needs are assessed. Integration into the school system and attainable goals may help foster pro-social adolescent attachments, given the association between educational difficulties and paths towards conduct disorder.

Furthermore, the stories shared by both Debbie and Maurice regarding the police and CJS highlight the need for improved knowledge in regards to both learning and developmental disabilities. This echoes arguments presented elsewhere in the literature (Hayes, 2007; Cant & Standen, 2007). Key areas noted in this study include police response to families when their son is in custody and the need for court staff to consider the ways in which the restrictions placed upon an individual may be interpreted. However, the comments made by Debbie and Rachel in regards to the limits of a parents understanding of their child also highlight the need for services to work with families in order for both parts of the system to develop a deeper understanding of the individual's behaviour and appropriate management strategies.

#### *Implications for later life care*

The concerns raised by both Maurice and Audrey as to the provision of care for their sons after their death highlights the importance of including primary caregivers when considering whole life planning for individual's with learning disabilities (Prosser and Moss, 1996; Walden et al, 2000; Dillenberger & McKerr, 2010). Services need to be sensitive to the anxieties of primary caregivers not only in what may happen to their child after their death, but also in terms of later life planning. Similarly, services need to consider how to support families in maintaining an emotional connection should the elderly caregiver be unable to travel to visit or need health care support themselves. Establishing good networks of communication with external services is of vital importance in order to ensure they can help facilitate the continuation of the parent-child relationship.

The importance of this is further highlighted by all the participants reporting an increase in their son's challenging or offending behaviour following the death of a close family member. The way in which individuals with learning disabilities make sense of bereavement is of no small importance when considering service provision (Bonell-Pascual et al, 1999; Blackwell, 2003; Clements et al, 2004). Although knowledge and interest in this area is increasing, consideration needs to be extended to the experiences of other family members, given the way in which primary caregivers own grief experiences may be disrupted or subjugated by meeting the needs of their son with learning disability.

#### Methodological Considerations

##### *Strengths*

A main strength of this study was that it is innovative and explores a lived experience which has hitherto been under recognized within the literature. As such it contributes to our understanding of an important area of human experience which has implications for service provision and development. Furthermore, the narrative

approach, with its focus upon the psychological and social factors in meaning making (Weatherhead, 2011) allows for the development of counter-narratives to the dominant discourses, which in turn can challenge the pathologising of human experiences (Mair, 1998). In doing this, this research aimed to hear the experiences of both men and women and consider the differences between their narrative and the social context which may be influencing this. Fathers are grossly under-recognised in the research literature (Condry, 2007a) and so it is a strength of this study that they were included here.

Boeije (2004) believed that joint interviews undermined the validity of the interview as individuals may be disinclined to answer truthfully in the presence of a partner or outsider witness whom they would continue to see post interview. Although this may be a legitimate concern if taking a realist epistemological stance, a more social constructionist view point is that one cannot make claims as to the validity of one type of interview over another as there is no one 'truth' to which it can be compared to (Rapley, 2001; Seale et al, 2008). I believe that my agreeing to interview Rachel and Mark together, and accepting that other people known to the participants were present during all the interview process facilitated the co-construction of the narratives. Whilst it undoubtedly posed challenges for me in terms of analysing the content, considering the ways in which the story development was affected by their presence or absence, I believe it was beneficial in ensuring the participants felt that they were in control of the interview process and not being dictated to by the researcher as to who could attend or what could be discussed.

### *Limitations*

There were a number of limitations within this study. Firstly, the sampling strategy for recruitment may have introduced selection bias in two ways. In the first instance the double consent requirement in the recruitment strategy was ethically conservative and this may have restricted sampling access and recruitment. However, not asking the clients for permission to invite their primary caregivers to participate may have marginalised the informed opinion of people with learning disability, which I did not wish to do (Gilbert, 2004). In the second instance, all clients in this study were male. Although primary caregivers of female individuals were not actively excluded from the study, the fact that one of the medium secure services only catered for men biased the recruitment. The social narratives around male and female offending differ considerably (Gavin, 2005) and so the experiences and attributions of primary caregivers of females remains an unexplored area which is in need of attention (Hayes, 2007).

Linked to this is a recognition that all participants were from the same ethnic and cultural background, which was also shared by the researcher. This limits the understanding of how this phenomenon is experienced and made sense of by people from different ethnic or social backgrounds (Begum, 2007). Further research is

required to explore the meaning making of primary caregivers from multi-cultural backgrounds as this will have implications for service delivery.

A second limitation of the study is the procedure for data collection, which may have limited the degree to which participants were able to share their stories. For example, each participant was only interviewed once and, with hindsight, a more in-depth exploration could have been achieved through repeated interview design. Cotterill (1992) proposes that multiple interviews allow for a deeper level of trust to be developed, which facilitates the co-construction of more private narratives. Furthermore, it allows the tracking of narrative changes and developments over time, which may assist with narrative therapeutic efforts. I feel that this approach could have enabled more of the emotional content behind the stories to be shared, particularly in regards to the exploration of feelings such as guilt or shame which may have been being defended against in the stand alone interview context.

Finally, I must acknowledge my own limitations as a researcher and how these may have impacted upon the co-construction of the stories and the data collected. Johnson and Clarke (2003) highlight the conflict researchers from clinical backgrounds can experience over dual roles when conducting research and I feel this was certainly something I struggled with.

#### *Suggestions for further research*

This research was conducted with a small group of individual's and as such the findings cannot be used to generalize experiences to all primary caregivers. Further research is required to develop our understanding. In addition to the suggestions made above I think there are a number of future research opportunities identified through this study. The interview schedule in this study covered a broad range of experience and there may be scope for more in-depth questioning to develop 'thicker' stories which can inform service provision (for example, studies focusing on the experience of supporting an offspring through the Criminal Justice System; Talbot & Riley, 2007).

Furthermore, this research focused upon the narratives of primary caregivers and as such the narratives of the individuals with learning disabilities themselves have not been explored. This is an important area of the literature which needs to be addressed for two reasons. On a political level, individual's with learning disabilities have a history of being marginalized or subjugated and there is a need for researchers to recognize the vital contribution they can make to our understanding (Gilbert, 2004; Talbot & Riley, 2007). Secondly, from a research perspective I am not aware of any studies investigating how individuals with learning disabilities may view their relationships with others following conviction from an offence. Exploring this area will offer valuable insight which could inform systemic care packages. Over

recent years there has been a growing interest in the use and benefits of NA in hearing the voices of individual's with learning disabilities (Gilbert, 2004; McFarlane & Lynggaard, 2009), it may be of great benefit for the research aims of this study to be repeated with the clients themselves.

### Personal Reflections

This has felt a very personal project and I would like to honor that by dedicating the remainder of this chapter to my personal reflections on the process. During my initial interviews I was uncertain as to how involved I should be in guiding and shaping the topics discussed. Somewhat naively I feel I hoped that primary caregivers would just 'talk' in detail given the opportunity and had not been prepared for the extent of my role in exploring issues with clients. Furthermore, I felt uncomfortable at times when I felt I had more knowledge about the legal and medical framework in which their son's were being treated than the participants appeared to have and I struggled to know whether to share this information at these times. Concerned that my doing so may alter the focus of the interview I remained silent but I am aware that my own struggle with this may have influenced the story co-construction on some level.

The method of analysis chosen for this study presented me with many challenges, not least knowing how to manage my anxiety in response to there being 'no set way' of interpreting the data (Reissman, 1993). Whilst this appealed to my rebellious identity, the conformist aspects of my character struggled with a fear of getting it wrong. This was associated with a fear of doing a disservice to my participants by not giving their narratives the correct degree of consideration and analysis. However, I found the social and psychological perspective NA afforded me (Weatherhead, 2011) hugely satisfying and beneficial in my understanding of this topic area.

In conducting this research I was challenged to hear stories on a human level and to be allowed to connect to them on a human level too. I felt on occasion that the participants were positioning me in an identity that I did not want and that this created a distance between us which I felt excluded me from their experiences. Maurice's comment that '*I'm only talking about you type of people*' stung me as I had felt critical of the professionals he was discussing and hurt that I could be categorised negatively by my professional label.

Conversely, I was also aware of the uniqueness of the interview process and how this afforded me greater opportunity to connect with the participants lives than I may have been in a clinical setting (Dickson-Swift et al, 2007). All the interviews took place in person's house and I was invited to look at family photos, pet the family pet and drink their tea, which created a friendly and welcoming attitude. However, this created conflict in me because I was aware of the temporal nature of my involvement with the family and the fact that our contact would likely end on the

completion of this study. I didn't want to appear voyeuristic to their experiences or their lives and, at times I felt it.

I had expected to have to disclose more about myself than I did (Dickson-Swift et al, 2007), but in fact only Audrey asked me any personal details (whether I was a mother and my experience of prison), which perhaps reflected other primary caregivers as positioning me as 'professional' and thinking that they could not ask. I wonder how this affected the level of disclosure participants felt they could give and the power imbalance between us.

In undertaking this study I hoped to illuminate the storied experiences of primary caregivers who I felt had hitherto not been afforded adequate consideration within adult learning disability services. I hoped that by creating thick descriptions of the stories care-givers bring, these could feed into services in order for their accounts to be heard and responded to. The process of conducting research can have a profound effect upon the researcher (Dickson- Swift et al, 2007) and I feel that this has certainly been the case for me. Hearing the participants' stories has made me question my own life narratives and the future I anticipate (Crossley, 2004). Although I am not currently a parent, I hope that it will not be long before I start my own family and this research has made me consider what it means to be a parent, both on an individual and societal level.

As such I consider it to have been a privilege to be witness to these stories and to the individuals' lives. It was a big ask for them to share this with me and I am deeply grateful to them for this. (Patai, 1991; Sullivan, 1998). However, the question I am left with is what do I, as both a clinician and a human being, do with this privilege? In contrast to the warning heeded by Dickson-Smith et al (2007) I believe that I stated that the undertaking of this project has made me more sensitive to the needs of primary caregivers and less likely to be dismissive of their experiences in future.

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**Appendix list:**

A = literature search strategy

B= LREC Approval letter

C= UH ethics approval letter

D= client info

E= client consent

F= participant invite letter

G= participant information sheet

H= interview schedule

I= transcription service agreement

J= participant consent form

K= participant debrief sheet

L= Transcript of field interview for 'Debbie'- removed from final submission

M= Audit of analysis for 'Debbie'- removed from final submission

## **Appendix A: Literature search strategy**

I approached the literature search by focusing on search terms that were designed to elicit the main studies in the area being investigated. It should be acknowledged that these terms are themselves shaped by a dominant discourse around conceptualising some people as having inherent 'learning disabilities'. I have alerted the reader to the implicit constructed nature of this term by using quotation marks around these terms. Ideally, one should have access to alternative and less deficit focused descriptors to search as well.

When conducting the literature search the following terms were selected;

- 'parents and intellectual disabilities',
- 'parents and learning disabilities',
- 'Offenders with learning disabilities',
- 'learning disability and offending',
- 'narratives of parenting',
- 'narratives of offending',
- 'narratives of learning disabilities',
- 'offenders and their families',
- 'offending and society',
- 'narratives of care giving'
- 'narratives of motherhood'
- 'narratives of fatherhood'

The following databases were selected:

- Web of Science
- PsycINFO
- Ingenta
- Google Scholar (online search engine)

In addition I was also a member of a purpose formed support group established with three others from my cohort who were using Narrative Analysis (NA) in their major research projects. A number of papers were exchanged between members.

**Appendix B: LREC approval letter**

**Hertfordshire REC**

Victoria House  
Capital Park  
Fulbourn  
Cambridge  
CB21 5XB

Telephone: 01223 597733  
Facsimile: 01223 597645

19 October 2010

Ms Leah Hull  
Doctorate in Clinical Psychology  
University of Hertfordshire  
Hatfield  
Hertfordshire  
AL10 9AB

Dear Ms Hull

**Study Title:** **The Experiences of Primary Caregivers of Offenders with Learning Disabilities. A Narrative Study.**

**REC reference number:** **10/H0311/37**

Thank you for your letter of 05 October 2010, 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 Alternate Vice-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, subject to the conditions specified below.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research (“R&D approval”) should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation’s involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### **Approved documents**

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		22 July 2010
REC application		22 July 2010
Supervisor CV - Dr Nicolas Wood		22 July 2010
Investigator CV - Leah Rebecca Hull		22 July 2010
Field Supervisor CV - Dr Christopher Bennett		22 July 2010
Letter from Sponsor	University of Hertfordshire	22 July 2010
Evidence of insurance or indemnity	UMAL	01 August 2010
Covering email from Leah Hull		17 September 2010
Response to Request for Further Information	from Leah Hull	17 September 2010
Protocol	2	17 September 2010
Participant Information Sheet: - Appendix B - Client Information and Consent Sheet	2	17 September 2010
Participant Consent Form: Appendix F - Carer's	2	17 September 2010

Consent Form		
Email from Leah Hull		07 October 2010
Response to Request for Further Information		05 October 2010
Participant Information Sheet: Appendix E Carer's Information Sheet	4	05 October 2010
Letter of invitation to participant - Appendix D Cover letter to participants	3	05 October 2010

### 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.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

<b>10/H0311/37</b>
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<b>Please quote this number on all correspondence</b>
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Yours sincerely

**Mr David Grayson**  
**Alternate Vice-Chair**

Email: [Anna.Bradnam@eoe.nhs.uk](mailto:Anna.Bradnam@eoe.nhs.uk)

*Encs:* “After ethical review – guidance for researchers”

*Cc:* Dr Nicholas Wood (Academic Supervisor)  
University of Hertfordshire  
Hatfield  
Hertfordshire  
AL10 9AB

Professor John Senior (Sponsor Contact)  
Pro-Vice chancellor (Research)  
University of Hertfordshire  
Hatfield  
Hertfordshire  
AL10 9AB

Ms Natercia Godinho, R&D Manager (NHS R&D Contact)  
Cambridge and Peterborough Foundation Trust  
Douglas House  
18 Trumpington Street  
Cambridge  
CB2 8AH

**Appendix C: Letter of Ethical Approval from the University of Hertfordshire**

**SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE  
APPROVAL**

**Student Investigator: Leah Hull**

**Title of project:** The Experiences of Parents of Offenders with Learning Disabilities.

**Supervisor: Nicholas Wood**

**Registration Protocol Number: PSY/03/11/LH**

**The approval for the above research project was granted on 7 March 2011 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.**

**The end date of your study is 31 July 2011**

**Signed**

**Date:** 7 March 2011

**Professor Lia Kvavilashvili**  
**Chair**

-----  
**Psychology Ethics Committee**

**STATEMENT OF THE SUPERVISOR:**

**From my discussions with the above student, as far as I can ascertain, s/he has followed the ethics protocol approved for this project.**

**Signed (supervisor):** .....

**Date:** .....

  
**Appendix D- Client information sheet**



**INFORMATION SHEET - Study of the experience of parents of people with Learning Disabilities who have offended.**



**Why is the research being done?**

Being a parent of someone with a learning disability can sometimes be challenging.



It can be harder for parents if the person with a learning disability has been in trouble with the Police. We would like to ask these parents some questions. We will ask them what it is like to be a parent, why they think things happen and what can be done about it. This will help us to understand their difficulties better and see if we can help.



### **What will I be asked to do?**

The people doing this research are studying at a University and they would like to ask you if it is ok to speak with your parents. They will not ask you any personal questions, just whether it is ok or not to talk to your parents.

If it is Ok to talk to your parents you will be asked to fill in a form. You will not be asked to do anything else. Filling in the form will take about 15 minutes. The person visiting you can help you with this.



Your parents will then get to chose if they want to speak to us. They can say 'no' if they want to.



### **What will happen if there is a problem?**

If you find any of the questions upsetting we will ask you if you would like us to tell anybody for you. If you would like we could tell a professional.

If we think it is important to tell a professional, we will discuss this with you and explain the reasons why.



If you find that you are having difficulty with the form you can ask to take a break. If you decide that you do not want to carry on, you can ask to stop.

## What are the benefits of taking part?



*You will help professionals learn how to support the parents of people with learning disabilities.*

## Who will be able to see my results?



Your form will be kept in a locked cupboard. The research team will be the only people who will see your form.

The questions your parents are asked will be written on a computer. Your name and your parents name will not be on the computer. The research team will be the only people who will see the results.



## Do I have to take part in this research?

You do not have to take part in this research. If you do not want your parents to be asked any questions then that is fine. It will not affect your care in any way.



### **Can I find out the results?**

We will not be able to tell you the results. However, if you would like us to, we can send you a summary of what the study tells us about helping parents.



If you want to ask any more questions about this research you can contact Becky Hull, on [phone number] or ask your carer to do so for you. **THANK YOU**

### **Questions to be asked to confirm informed consent**

1. Can you tell me what the research is about?
2. Can you tell me what you will have to do?
3. Can you tell me how long it will take?

4. Can you stop at any time?

5. Will anybody be able to see your form?

6. What will happen if there is a problem?

7. Have you got any questions?

**Appendix E: Client consent form**

To let us know whether you would like to take part in our research project we would like you to fill in this form.

Your name is? \_\_\_\_\_



Please tick

Have you looked at the information sheet?

YES

NO



Have you talked to someone about the project?

YES	NO
-----	----



Do you understand what the project is about?

YES	NO
-----	----



Do you understand that it may become necessary to inform a professional if you or someone else is not safe?

YES	NO
-----	----



Is it ok to ask your parents to be asked take part in the project?

YES	NO
-----	----



Would you like to be sent a summary of the results?

YES	NO
-----	----

I the undersigned have read the information about this study and give my consent to take part. I understand that I can withdraw at any time and that this study might not help me but may help other people.

Volunteer signature.....Date.....

**Appendix F: Participant invitation letter**

Becky Hull  
c/o Cathy Lambert  
School of Psychology  
University of Hertfordshire  
College Lane  
Hatfield  
Herts  
AL10 9AB

13<sup>th</sup> January 2011

address

Dear Mr

I am a Trainee Clinical Psychologist at the University of Hertfordshire. I am writing to you to let you know about a research project I am conducting through the Eric Shepherd Unit which you may wish to participate in. Your Son, XXXXX, has given permission for me to contact you about this research.

The research is exploring the experiences of the parents of adults with learning disabilities who have committed an offence. I believe that this is an area which is not given sufficient attention or understanding and I hope that the research will give a voice to those who have had this experience.

I have enclosed some further information about the project. If you are interested in taking part or have any further questions, please feel free to contact me using the details on the sheet.

Many thanks for your time and consideration and I look forward to hearing from you.

Yours Sincerely,

Becky Hull  
Trainee Clinical Psychologist

**Appendix G: Participant information sheet**

**INFORMATION SHEET - A study of the experience of parents of people with Learning Disabilities who have offended**

**Why is the research being done?**

Studies have shown that being a parent to someone with a learning disability can be challenging. This is particularly true when the person with a learning disability commits an offence. At the moment we do not know a lot about how parents of people with learning disabilities make sense of the child's offending behaviour and the impact this has upon them. It is really important for us to find out so that services can offer families of people with learning disabilities the right support.

To help us do this we would like to talk to parents of people with learning disabilities who have been in trouble with the police so that we can understand how Parents make sense of their experiences and what they feel would be helpful.

### **What does taking part involve?**

A researcher from a university will contact you to arrange a convenient meeting time. The researcher will ask you questions about what it is like to be a parent of someone with a learning disability. They will also ask you about the impact of your child's offending on you, how people have responded to you and what you think would have helped. You will be able to talk about the issues that matter to you. If you wish you can also bring photos or objects to talk about.

### **Who can take part?**

Any person who considers themselves to be a parent of someone with a learning disability who has been in trouble with the law.

### **Do you have to take part?**

No, taking part in this study is entirely up to you. It will not affect your child's care in anyway.

If you decide to take part but do not want to answer all questions you do not have to. Also, if you change your mind about taking part after answering the questions you can ask for your interview not to be used.

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

All information collected during the course of this research will be kept strictly confidential. You will not be named when the results of this study are reported. We will not share your interviews with your child. A copy of the studies overall results may be shared with your child if they request but they will not know which comments are yours.

The information you have provided to the researcher will be treated in strictest confidence. However if you reveal evidence of serious bad practice by staff, the team would be obliged to refer the matter to senior managers in order to put things right. We will let you know if we are going to do this.

**What if there is a problem or something goes wrong?**

If you have any concerns either regarding the care your Son is receiving, your treatment during the research or the research in general then the complaints procedures are as follows:

**Who do I talk to if I have any concerns about the care my Son or Daughter is receiving?**

If you have any concerns regarding the care your son receives at the Eric Shepherd Unit/Broadlands Clinic Becky will discuss with you what you can do. If you have concerns but do not wish to share these with Becky, the Hertfordshire Partnership Concerns and Complaints details are as follows:

Patient Advice and Liaison Service (PALS) (01727) 804629

The service is open between 9.00am and 4.00pm Monday to Friday. At all other times you can leave a message on the PALS answering machine, and you will be called back as soon as possible.

You can email PALS: [pals.herts@hertspartsft.nhs.uk](mailto:pals.herts@hertspartsft.nhs.uk)

If you would like to give feedback regarding the unit's care directly to the Trust then you can write to the PALS and Complaints Manager or the Chief Executive at HPFT, 99 Waverley Road, St Albans AL3 5TL.

Phone (01727) 804705 or email: [complaints@hertspartsft.nhs.uk](mailto:complaints@hertspartsft.nhs.uk)

**Who do I talk to if I have any concerns about my treatment during the research or the way the research is being conducted?**

This main investigator is Becky Hull, Trainee Clinical Psychologist. If you have any concerns you can contact her directly on [07736300481] or via email: [leah.hull@ntlworld.com](mailto:leah.hull@ntlworld.com)

Becky is being supervised in this project by Dr Nick Wood, Chartered Clinical Psychologist. If you have any concerns about the project or Becky you can contact him directly on [01707-284767] or via email: [n.1.wood@herts.ac.uk](mailto:n.1.wood@herts.ac.uk)

**Can I receive a copy of the findings?**

If you would like to receive a copy of the findings, please write your postal address in the space below:

.....  
.....  
.....  
.....  
.....

## **Appendix H: Semi-structured interview schedule**

### **1. Can you tell me your understanding as to why your son is currently in the Eric Shepherd Unit?**

- How do you understand/ define his behaviour?
- How do you understand the purpose of the Eric Shepherd Unit
- Do you feel they need what the Eric Shepherd Unit provides?
- How would you explain to friends where your son is?

*[This question is designed to explore how the parent views and understands their son's behaviour. The language and terminology used by the parent is important for the researcher to be able to connect to the parent's story]*

### **2. Can you tell me about the process that led your son to being in the Eric Shepherd Unit?**

- Do you understand how events are linked?
- When did the process start?
- When did you first have concerns?
- When did others first have concerns?
- How would you explain to friends what has happened?

*[This question is designed to explore a parent's understanding of the CJS process as well as charting the history of their son's behaviours. It allows for parents to discuss the historical and systemic factors around their son and their experiences. It may also elicit their own emotional reactions]*

### **3. What do you feel needed to have happened to have prevented you and your son reaching this point?**

*[This question explores what the parents felt was needed but may not have had. It allows for consideration of their own actions but also the actions of others, for example services, police, social support]*

### **4. What impact has this had on you?**

- On your family?
- On your relationship with your son?
- On you relationship with others?

*[The question is left open to allow for both negative and positive impacts to be explored]*

### **5. What factors do you feel have influenced how you have managed this impact?**

- What has been helpful?

- What has been unhelpful?
  - What would you have liked more/less of?
  -
- 6. What do you feel needs to happen now for things to be different for you?**
- For your son?

*[Thinking about hopes for the future, reparative measures and risk management]*

University of  
Hertfordshire



Appendix I: Service level agreement with transcription service

Doctorate in Clinical Psychology  
University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

This non-disclosure agreement is in reference to the following parties:

Leah Rebecca Hull ('the discloser')

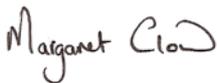
And

*Transcription service* ('the recipient')

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed: 

Name: Margaret Clow

Date: 7<sup>th</sup> May 2011



Major Research Proposal

Student No:

**Appendix J: Participant consent form**

Participant Name \_\_\_\_\_

Please read the statements below carefully and tick to indicate your agreement.  
You can still participate in this study without ticking yes to everything.

I have read the information sheet

YES	NO
-----	----

I understand what the project is about

YES	NO
-----	----

I understand that my child's care will not be affected by my taking part/ not taking part in this research

YES	NO
-----	----

I understand that I can withdraw from the study at any time

YES	NO
-----	----

I understand that my interview needs to be audio recorded

YES	NO
-----	----

I understand that this recording will be kept in a secure place for three years

YES	NO
-----	----

I understand that any sensitive data I provide (photographs, newspaper clippings, etc) will be destroyed or returned to me after the research is complete.

YES	NO
-----	----

I understand that a professional transcription service may be used to transcribe my interview.

YES	NO
-----	----

I agree for a professional transcription service to be used

YES	NO
-----	----

I agree for my direct quotes to be used in the study write up

YES	NO
-----	----

I understand that I will be able to view the study findings if I wish 

YES	NO
-----	----

**I agree to take part in this study**

YES	NO
-----	----

**Signature of participant.....Today's date.....**

Signature of researcher.....Today's date.....

**Appendix K: Participant debrief form**

21<sup>st</sup> Jan 2011

Debrief Sheet

**Thank you for taking part in this study. Your interview will help us to understand the experiences of parents of people with Learning Disabilities who have offended and to think about what support might be needed.**

**What happens now?**

Your interview will now be written up. In one weeks time the researcher will contact you to check that you are ok and to answer any more questions you may have. The researcher will contact you:

On [day and date ] at [time of day] via your [telephone/ email]

If you wish to get in touch with the researcher before or after this time then please feel free to do so via the contact details at the end of this sheet.

**Can I receive a copy of the findings**

Yes, once the research has been conducted, the researcher will contact you to share your results with you and ask your opinion. If you do not wish to comment you do not have to.

Once the study is completed the researcher will send you a copy of the overall findings if you would like to receive it.

**Who do I talk to if I have any concerns?**

This main supervisor is Becky Hull, Trainee Clinical Psychologist. If you have any concerns you can contact her directly on [phone number] or via email:

[leah.hull@ntlworld.com](mailto:leah.hull@ntlworld.com)

Becky is being supervised in this project by Dr Nick Wood, Chartered Clinical Psychologist. If you have any concerns about the project or Becky you can contact him directly on [phone number] or via email: [n.l.wood@herts.ac.uk](mailto:n.l.wood@herts.ac.uk)

If you have any concerns regarding the care provided by the Eric Shepherd/ Broadlands Clinic you can contact:

Patient Advice and Liaison Service (PALS) (01727) 804629

The service is open between 9.00am and 4.00pm Monday to Friday. At all other times you can leave a message on the PALS answering machine, and you will be called back as soon as possible.

You can email PALS: [pals.herts@hertspartsft.nhs.uk](mailto:pals.herts@hertspartsft.nhs.uk)

If you would like to give feedback regarding the unit's care directly to the Trust then you can write to the PALS and Complaints Manager or the Chief Executive at HPFT, 99 Waverley Road, St Albans AL3 5TL.

Phone (01727) 804705 or email: [complaints@hertspartsft.nhs.uk](mailto:complaints@hertspartsft.nhs.uk)

Thank you!