Placing a child with learning disabilities into out-of-home care: Parents' and caregivers' decision making processes and 'breaking point': a grounded theory exploration.

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ABSTRACT

Research suggests that parents of children with learning disabilities are particularly vulnerable to stress and that parental distress impacts negatively on family functioning, parenting roles and relationships, behaviours, socialisation and the psychological well-being of both parent and child; as a consequence many parents reach ‘breaking point’ and will choose to place their child in out-of-home care. However, the research literature outlining this process is limited.

The purpose of this research was twofold: to explore the process leading to ‘breaking point’ in parents and caregivers of children with learning disabilities and how this impacted on the decision making process leading to out-of-home care, and secondly, to formulate a grounded theory of this process and its consequences.

The study used a social constructionist grounded theory methodology. Fourteen participants were interviewed and three participants completed a qualitative survey. The sample included two birth fathers, twelve birth mothers, one adoptive mother, one sibling and one guardian. The level of their child’s learning disability varied from mild to severe. In all cases, the child had additional diagnoses, such as autism, fragile-X syndrome and Down’s syndrome.

A grounded theory was constructed from the data outlining the basic psychosocial process which led to ‘breaking point’ and the decision to place the child in out-of-home care. Parents developing awareness of their child’s disability combined with social prejudice, contributed to the development of a *negative parental identity*. To defend against this, parents created a *compensatory good parent identity* and in doing so convinced themselves that they could cope with *the 24/7 child*. This increased stress, caused relationship breakdowns, financial difficulties and mental health problems. Parents faced additional stressors when *screaming to be heard* by professionals as they sought guidance, diagnosis and support. Eventually *breaking point* was experienced as they became overwhelmed. This initiated the decision making about out-of-home care. Once the move occurred, a process of *adjusting* and managing the *loss of role* was entered, linking to *evaluation* and constant *monitoring of care*. In this sense parental responsibility was never relinquished and parental roles were redefined.

The findings outline a lack of support, information and guidance for parents and families based on their experiences of prejudice and dismissal of concerns by society, professionals and on occasion family and friends. Suggestions for future research and research limitations are explored. The implications for practice and more generally for counselling psychology are also considered.

INTRODUCTION

It is estimated that 1,191,000 people in England have a learning disability, of these 21% are known to learning disabilities services (Emerson, Hatton, Robertson, Roberts, Baines, Evison and Glover, 2011). In the UK, 6 in 1000 babies, (approximately 4,800 per year), are born with a severe or profound learning disability (McGrother, Thorp, Taub and Machado, 2001). At least half of these adults with learning disabilities live with their families and 29,000 live with parents aged 70 or over, who may not be able to manage in their caring roles. Only 1 in 4 are supported by local authorities who are involved in seeking alternative housing (Mencap, 2013).

The definition of learning disability

When understanding disabilities, it is beneficial to outline the variations of disabilities and how they overlap and relate. Lenhart (2000) divides developmental disabilities into categories. Firstly, cognitive impairments, which include learning disorders and communication disorders i.e. mental retardation, dyslexia and attention-deficit hyperactivity disorder; secondly, sensory and physical impairments such as blindness and mobility; thirdly genetic disorders such as fragile-x syndrome and Down’s syndrome; finally, neurological disorders such as epilepsy and autism. These categories can overlap and individuals can have a disability which fits into more than one category.

Learning disabilities have a number of causes such as brain damage before birth (for example through exposure to alcohol, drugs or malnutrition), through damage at birth (e.g. premature birth), or because of a serious illnesses in early childhood such as meningitis (Middleton, 1995). Hamdan, Gauthier, Araki, Lin, Yoshizawa, Higashi, Park, Spiegelman, Dobrzenieck and Piton’s (2011) research suggests that in 5% of cases learning disabilities have a genetic origin, although the genes involved are mostly unknown. McLaren and Bryson (1987) found that for moderate to severe learning disabilities, 20 -30% of cases related to prenatal causes, 11% were associated with birth causes, 3 -12% were associated with postnatal causes and 30 -40% of causes were unknown; in cases of mild learning disabilities the aetiology is less clear with up to 63% of cases having an unknown cause. Learning disabilities are life-long and impact on processing, understanding and communication (National Centre for Learning Disabilities, 2011).

Learning disability is classified under the term ‘mental retardation’ within the International Classification of Disease tenth edition (ICD-10), (WHO, 1992). However Salvador-Carulla and Bertelli (2008) argue that this term is outdated and the term ‘mental retardation’ was removed from American legislation in 2010. The recently published Diagnostic and Statistical Manual of Mental Disorders-fifth edition (2013) (DSM-5) has replaced the previous classification of ‘mental retardation’ with the term ‘Intellectual Developmental Disorder’. The World Health Organization is revising its International Classification of Disease and Related Health problems manual, and proposes to reclassify ‘mental retardation’ as ‘Intellectual Disabilities’ in its publication due in 2015 (Department of Health, 2010). The term ‘learning disability’ was adopted by the NHS in 1997 (Hodges, 2003), and will therefore be used throughout this report.

The ICD-10 uses Intelligence Quota (IQ) scores, assessments of adaptive functioning and age of onset to aid the diagnosis of learning disabilities. The DSM-IV-R relied on IQ scores alone for the purpose of diagnosis; this has been revised in DSM-5 to reflect the complexities of the diagnosis. Diagnosis is now based on assessing a) conceptual domains such as reading, reasoning and memory b) social domains such as social judgement, empathy, ability to retain friendships and c) the practical domain such as caring for one’s self. IQ scores can be used to understand the disorder but these additional elements mean that functioning in other areas is also considered.

The UK care system for people with a disability

In the UK, parents of children with any disability may rely on local authority resources and are entitled to an assessment of need undertaken by a social worker (Burns, 2009). These assessments ensure that children (and their families) are known to social services, resulting in the child being classified by the local authority as either a ‘Child in Need’ or ‘Looked-After Child’. This classification ensures that children (and families) are monitored and that the correct support is offered. This allows for the allocation of respite care, domiciliary care and modifications to the home. Information sharing can also be provided at this time regarding disability allowances for the child. In the UK the authority assessment outcomes are subject to budgetary restrictions and although individualised, the outcomes provided are similar due to the availability of services and resources. In 2003, a survey by Mencap found that 40% of children with learning disabilities had not had this assessment and of the 60% who had, 20% were allocated short respite breaks. There were no statistics available on the number who lived in residential settings. Under the Children Act (2004), 'Children in Need' are those diagnosed with any disability who continue to live with parents and / or family and are defined as needing a service under Section 17 of the Children Act. Some children live away from home in residential facilities i.e. in health or educational settings. Such settings can be funded privately and are not contributed to by local authorities. In these circumstances the child remains as a 'Child in Need', although they are not living with their parents.

'Looked after Children' is the term used for children whose care is funded by local authorities; these children live away from their parents i.e. in out-of-home care and in some cases may be fostered. In these circumstances, the 'Looked after Child' is supported through voluntary arrangements whereby local authorities do not gain parental responsibility for the child and the responsibility remains with the parents. In these circumstances the child's welfare will be assessed by social services; consequently it may be concluded that parents are not able to fully care for their child's needs at home. Reasons for such an outcome are varied and could relate to the parents' health, the family environment, safeguarding concerns or the parents' inability to manage which can be due to a number of factors such as family resources, motivation, their own intellectual ability or mental health issues. This service is covered under Section 20 of the Children Act (2004). In some cases, 'Looked after Children' are covered by statutory arrangements under Sections 31 and 38 of the Children Act, where Interim or Full Care Orders are acquired through the Court system to remove a child from the parents' care. This is put in place when the child is deemed by social services to be suffering, or likely to suffer, significant harm. In these circumstances the local authority takes parental responsibility for the child, although this does not relinquish the parents' parental responsibilities.

All ‘Looked after Children’ are reviewed regularly through statutory reviews, under the Reviews of Children’s Cases Regulations (1991); these reviews aim to provide a system where the care of the child remains central. The Children Act (2004) built on this but aims to further improve children’s lives based on ‘Every Child Matters: Change for Children’ (2004).

Out-of-home care

The responsibility for caring for someone with a learning disability has moved away from hospitals to the community wherever possible, and people with learning disabilities often live at home; Beadle-Brown, Mansell, Whelton and Hutchinson (2006), state that 59% of people with a learning disability live at home and 41% are supported by local authorities (which may include out-of-home care). Out-of-home care is categorised as any environment whereby the person is supported to live. This includes residential care or school environments and supported living. Residential care is often viewed as ‘institutional care’ where individuals are provided with 24-hour care and usually live with others who have similar disabilities and needs. Residential schools include education as well as the 24-hour care support and are focussed on supporting school aged children. There is a gap in the research regarding the benefits of out-of-home services for individuals with learning disabilities, with considerable difficulties in measuring outcomes i.e. evaluating the level of care. Sloper (1998) suggests that these difficulties may relate to the differing viewpoints that the parties involved (parents, families, social care, service user, stakeholders, organisations) may hold. For example social care may evaluate services depending on the improved safety for the child, whereas a parent may evaluate a service based on comfort and care. Therefore there is a lack of understanding about why decisions are made in favour of some services over others, such as respite care compared to long term out-of-home care, and about whose choice this actually is.

Parent- child relationships

Parent-child relationships have been found to be negatively impacted upon when a child has a disability; at diagnosis parents often experience shock, numbness, sorrow, confusion and denial (Kearney and Griffin, 2001). Carpenter (2005) suggests that upon diagnosis, parents are actually grieving the ‘loss’ of the ‘perfect’ child. Historically, children with disabilities were institutionalised, whereas currently the majority of families are committed to caring for their child themselves at home. Research indicates that parents of disabled children are particularly vulnerable to stress (Slaper and Turner, 1993; Dyson, 1997; Redmond, Bowen and Richardson, 2002; Warfield, 2005 and McLennon and Urictiuk, 2008). Davis (1993) suggests that when a child has a learning disability, the rate of disturbance in families rises to 30-35% as opposed to 10-15% in families where a child does not have a disability. Slaper and Turner (1993) found that 70% of mothers and 40% of fathers of severely disabled children reported high levels of stress and distress compared to peers. Within the psychological and sociological literature, it is evident that parental distress and family functioning impacts on the disabled child, for example their behaviour, social development, cognition and their psychological well-being (Middleton, 1995). Understanding these factors may aid the development of therapeutic interventions, support, research and practice, which is why this area is of relevance to counselling psychology.

LITERATURE REVIEW

The social construction of parenthood

Social constructionism considers how phenomena and individual experiences are developed through the social contexts in which the individual lives; as such an individual’s beliefs and reactions are embedded within social, cultural, economic and historical contexts (Apple and Golden, 1997). Fundamentally, an individual’s behaviours and experiences are guided by the society in which that individual lives. When considering the social construction of parenthood, the subtle and explicit cultural messages regarding parenting roles and styles therefore impact and guide the parenting process. For example, cultural norms and expectations impact on child rearing practice such as whether a baby is hugged every time it cries (Keshavarz and Baharudin, 2009). Triandis (2001) suggests that cultural differences in value bases impact on how the parent and others interpret parenting, for example conceptualisations of parents as ‘good or bad’. The context of society constructs lived experiences and the interpretation of these experiences. For example within a collectivist culture the importance of interdependent relationships, sociability, harmony and the family is a theme, while individualistic cultures emphasise independence from others (Descartes, 2012). Parenting styles within cultures will therefore vary.

The social construction of learning disabilities

It has been suggested that there are cultural differences in how learning disabilities are constructed, experienced and diagnosed; learning disabilities appear to be more prevalent in Western societies due to the high value placed on literacy and numeracy within the educational system (Nuttall, 1998). A study by Tews (2008) indicated that Chinese parents generally attribute a learning disability to the child’s lack of discipline; the difficulties in learning and functioning are attributed to an imbalance of yin and yang. However, agrarian cultures i.e. those that do not need to focus on literacy and numeracy such as farming communities, do not generally class learning ability as a measurement of adult adequacy (Nuttall, 1998). Devlieger (1998) suggests the notion of learning disability is evidence of an individualistic obsession with self-reliance. Such arguments illustrate how the label of disability is socially constructed and represents a lack of fit between differing cultures. Dudley-Marling (2004) suggests that cultural constructs influence the educational, medical and psychological discourses around learning disabilities and that ideology around individualism focuses on difference being problematic. When a child does not conform to the cultural norms, the focus tends to be on ‘what is wrong with the child’ rather than considering 'what is wrong with the system in which they are learning’. Gee (1990) suggests that what stops society asking this second question is due to the cultural constraints and constructs around disability that are created by the context of such historically embedded values and beliefs.

Postmodernists such as Gergen (1990), argue that social relations serve to construct individuals’ views of themselves and their identities, as well as acknowledging that individual identities are context dependent. These perspectives aid the understanding of how learning disabilities are socially constructed specifically within the prominent domain of the education system. Dudley-Marling (2004) argues that learning disability is thus defined by the deficits within performance which have been constructed by the educational institution, rather than by focussing on distinct and individual strengths in other areas. McDermott and Varenne (1999) suggest that learning disabilities are only defined by the evaluation of the level of learning achieved and thus have developed from the framework of educational constructs and meaning-making. Dudley-Marling (2004) suggests that learning disability is like any other personality trait or identity and relies on the social context to give it meaning, which in turn gives the learning disability an identity of its own.

Historical context of learning disabilities

During the 19th Century, educational and medical professionals believed that disability was due to the parent (mainly the mother) being ‘poor’ (Ferguson, 2002). It was suggested that the morally deficient mother bred idleness (Barnard, 1865). This blame was rooted in the belief that the disabled individual and mother were a social burden on the economy and that mothers had deviated from the social code. This prompted legislation for specialised asylums and residential schools in an attempt to move children away from their parents. Professionals assumed parental responsibility within the asylums in the hope that this would break the cycle between ‘poor’ parents and disabled children (Ferguson, 1994), which aided the development of special education in public schools at the turn of the century (Tropea, 1993). Brockley, (1999) argues that the asylums were forged to protect the community from the ‘menace of the feeble-minded’, a perspective which continued until the early 1900’s.

In 1905, Alfred Binet and Theodore Simone introduced the use of IQ tests within education to group children by intelligence (Scheerenberger, 1983). The eugenics movement and Social Darwinism were taking shape at this time and from this it was suggested that learning disability was due to inherited elements which weakened the species. Within the past thirty to forty years professional research has shifted, but it is suggested that such historical perspectives remain embedded within the current cultural and social conceptions and meaning-making of disability today, as evidenced by current models of disability.

The medical model of disability

The debates between the medical and social models of disability have impacted on the ways in which families and children are viewed by society and professionals (Finkelstein, 1980; Driedger, 1989; Bury, 1996 and Campbell and Oliver 1996). Within the medical model ‘need’ is based upon the child’s impairment and the prevention of the disability. Crow (1996) argues that within this framework an individual’s functional limitations (impairments) are seen as the root cause of any disadvantages experienced which can only be rectified by medical treatment or cure. The medical model suggests that family stress is a direct and inevitable result of the child’s impairment and focuses solely on the deficits of the person with the disability (Burns, 2010) i.e. rather than linking stress to social elements such as stigmatisation or focussing on the positives of the disability. This medicalised view was modified in the 1970’s due to an increase in human rights and politicalisation (Driedger, 1989) whereby the voices of people with disabilities were heard and recognised by the public; this put pressure on political figures and professionals to explore new ways of thinking and supporting individuals with disabilities. An example of this is provided by Simon Brisenden, a man with disabilities who argued against the medical model and whose views were highly influential in terms of the way in which disabilities are viewed. Brisenden (1986) suggested that isolating ‘facts’ in the form of a list of general physical or intellectual characteristics was limiting. This gave a distorted view of disabled people as a category of “rejects, as people flawed in some aspect of humanity…the medical model of disability is rooted in an undue emphasis on clinical diagnoses… leading to an inhibited view of disabled individuals… instead we need to build up a picture of what it is like to be a disabled person in a world run by non-disabled people” (Brisenden, 1986: 173).

The social model of disability

Such debates encouraged the development of the social model of disability which applies a broader view of disability and considers factors such as personal and social attitudes towards impairment and acknowledges inadequacies in support (Barnes, 1990; Campbell and Oliver, 1996). Within a social model, disability itself is seen as being constructed by the society in which the person with a disability (and their family) lives, and in order to remove discrimination, there needs to be a change of approach and thinking in the way that society organises its views of disability and disabled people. With this in mind, the social model strives to acknowledge individual variations in the constructions of disability; for example, parents’ constructions of, or expectations about, how disability impacts on how they are able to manage their child’s welfare and their own stress (Oliver, 1990).

During the past forty years, the philosophies which inform policy, research and services for families of children with disability have undergone significant changes in response to social perspectives and a focus on equality. Factors influential to these changes include the human rights movement, the generation of theoretical models of stress and coping within family systems (Lazarus and Folman, 1984), the focus on children’s rights (Education Act, 1994; Children Act 1989; 2004) and the rights for those with disabilities (The Disability Discrimination Act, 1995; The Human Rights Act, 1998).

PARENTAL STRESS

Parental stress has been found to be higher in parents of children with intellectual disabilities (Slaper and Turner, 1993 and Gerstein et al., 2009). Although some families have been found to show more resilience and to thrive in these circumstances; this may be due to relationship stability (Dyson, 1997), and coping strategies for managing stress levels (White and Hastings, 2004). There is a wealth of research identifying the variables involved in parental stress, which are discussed later within this section, for example the type of disability involved (Stein and Jessop, 1989; Silver, Westbrook and Stein, 1998), dual diagnoses (Neece and Baker, 2008), the levels of support available to parents and families (Oakley, 1992; Rogers, 2007), the availability of family resources (Oldmand and Beresford, 2000; Warfiel, 2005), gender differences of the parents (Olsson and Hwagn, 2008) and family relationships (Keating, 1997).

Models of parental stress

Belsky's (1984) process model outlines how a parent's developmental history and characteristics contribute to parental behaviours and reactions to their child. This model involves cognitive constructs such as self-esteem, which influence parental behaviours such as how often they praise their child. Belsky's (1984) model assumes that parenting stress is experienced as part of the psychological well-being of the parent. For example in order for parents to achieve improved self-esteem, they have to manage their stress (which makes them feel good and thus impacts on their sense of well-being). Such studies encourage a focus on how stress is managed and experienced and how such factors could impact on parental behaviours and reactions to their child. Abidin's (1992) parenting stress model suggests that increased parenting stress results in negative parenting, whereas The Parent-Child Interactive Stress Model, (Mash and Johnston, 1990), suggests that child characteristics are the main factor in parent-child stress, while also acknowledging the importance of environmental factors such as lack of bedroom space and parental cognition or parenting practice. These link into how parents understand and perceive their parenting role, which impacts on their evaluation and expectations as parents in terms of seeing themselves as 'good or bad' parents. This theory focuses on the parent-to-child relationship and links parental stress to parent-child conflict.

The cognitive model of stress (Lazarus and Folkman, 1984) has provided the basis for much research into parental stress (Quine and Pahl, 1991; Sloper et al., 1991). This model focuses on the individual's appraisal of the stressor; Quine and Pahl's (1991) study found that the participants' cognitive beliefs impacted on their adjustment and acceptance of their disabled child and influenced their level of stress i.e. how parents process the experience of parenting and coping seemed to affect the degree of stress.

Webster-Stratton (1990) suggests that low socio-economic status and breakdown of relationships significantly impact on parental stress. This research suggests that negative parent-child interactions increase parenting stress, for example when the child presents challenging behaviours the parent may internalise this as their fault or externalise it as the child's fault. Both responses contribute to parenting stress due to the undesired behaviours presented and the focus of blame, which remains unresolved. The Abidin model (1992) emphasises the behavioural determinants of parenting stress and indicates specific parental characteristics which interact with stressors. These include; individual characteristics, work, environment, parental relationships, life events, child characteristics and development, daily struggles and cognitive coping strategies.

Parental adjustment

Studies on personal adaptation and parental stress suggest that this varies according to the type of disability or chronic disease diagnosed; Stein and Jessop (1989) compared mothers' views on psychological adjustment relating to their chronically ill child. The children were diagnosed either with asthma, meningomyocele / hydrocephalus, seizure disorders, or haemoglobinopathies. Stein and Jessop found no significant difference between the type of chronic illness and the psychological adjustment to this and the impact of the illness on the family (except for financial impact). Silver, Westbrook and Stein (1998) assessed parents' self-reported psychological distress relating to varying chronic health conditions in children by using telephone surveys on large samples and found that children's functional limitations related to an increase in parental distress compared to the child's chronic illness. In this study, parental distress was assessed through the self-reported Psychiatric Symptom Index (1976) which rated the parents' level of twenty-nine common psychiatric symptoms. Such studies guide new knowledge but outline a gap as they do not allow for the depth of individual exploration about the adaption and stress experienced in childhood illness and how this guides decision making. It is argued this could be more thoroughly achieved through a qualitative methodology to understand the processes involved.

Holroyd and McArthur (1976) used questionnaires to explore the effect of diagnosis on the families of children with autism or Down's syndrome and found that mothers of children with autism reported significantly more psychological problems than parents of children with Down's syndrome. Results indicated that severity of the child's functioning was the significant factor in determining a negative effect on the family. However it is important to consider the differences between these diagnoses; Autism is a spectrum disorder where the triad of impairment, according to Bartak, Rutter and Cox (1975), affects areas of social relationships and interactions, language and communication, and finally activities and interests. With Down's syndrome, there may be impairments of cognitive ability and physical growth characteristics. Because conditions affect functioning, it is therefore not surprising that the child's functioning was identified as the significant factor. It is not clear from these findings how the level of the child's functioning was measured i.e. how the researchers compared the severity. Other factors to consider relate to how the parental adjustment and relationship with a child is affected in light of the social constructions about the disability. For example Down's syndrome is a genetic disorder (Beeghly and Cicchetti, 1997) whereas there remains a lack of certainty relating to the aetiology of autism. In addition questionnaire responses are generally standardised so it is not practically possible to explain points in the questions that participants might misinterpret (McLeod, 2006). Nonetheless some advantages link to the standardised way that large portions of information can be collected.

Hanson and Hanline (1990) conducted a longitudinal investigation into parental stress and adaptation of mothers of children with Down's syndrome, hearing impairment or neurological impairment. They found that parents' adaptation did not differ according to the type of disability. However, there were significant differences across the groups with respect to reported stress for mothers who had children with neurological impairments. The validity of comparing these different diagnoses is questionable, as the effects of these distinct diagnoses are vast and dependent on the severity of the impairment or syndrome. It may have been more beneficial to compare parental stress within the different groups rather than between the groups. There was also a lack of clarity regarding what the neurological impairments were. Nonetheless, findings indicate that parents of children with cognitive or neurological disabilities are likely to experience significantly higher levels of parenting stress than are parents of non-disabled children or physically disabled children (Dyson, 1997; Kearney and Griffin 2001; Redmond et al, 2002).

Parental adjustment and stress has also been associated with the severity of the child's learning disability; Hassall, Rose and McDonald (2005) found that the more severe the learning disability the more 'strain' there is on parents and family. From the literature, it appears that specific characteristics rather than disability type correlate with increased parental stress. For example, the child's inability to communicate verbally (Frey et al., 1989) the child's neurological functioning (Hasall et al., 2005) and the presence of challenging behaviour (Hodges, 2003).

Other forms of disability which significantly impact on parental role adjustment and stress include psychological disorders such as schizophrenia. When an adult-child i.e. a child who is aged over eighteen, is diagnosed with schizophrenia, the caregiver burden generally falls to the parent (Milliken, Herbert and Northcott, 2003). Many studies into parental stress use quantitative methodologies, however Milliken et al. (2003) used a qualitative study to explore how mental illness impacts on parents' emotional experiences and suggested that parents need to psychologically shift identities in order to manage and adjust; parents had expected to raise their child towards independence, but due to the psychological disorder the parent faces sudden uncertainty around their child's ability to manage independently in adult years. Instead the parent is obliged to continue with active care-giving and strives to keep their child safe, resulting in parental stress exacerbated by the grief parents experience as they react to the changes in their child (Reinhard, 1991). Parents can feel in endless turmoil in their care-giving roles with shame, guilt, depression and frustration reported as common experiences (Milliken and Rodney, 2003).

Teschinsky (2000) emphasised that the emotional stress on parents of adult-children with psychological disorders is heightened and leads to tension and conflict for the caregiver as they become marginalised by society and in some cases by their extended family, and the stress is heightened by the social constructions and associated prejudices surrounding mental illness.

Dual diagnosis

Neece and Baker (2008) suggest that when a child's learning disability is accompanied by other disorders or health conditions, this significantly increases the stress experienced within the parental environment because the outcome (dependent on the diagnoses) means multiple issues are presented and these influence parental roles and styles of parenting.

CONDITION	THESE CONDITIONS ALL INCLUDE SOME DEGREE OF LEARNING DISABILITY AND ADDITIONAL FACTORS DISTINCT TO THE CONDITION
Angelman Syndrome	Neurodevelopment disorder. Main signs are learning disability, jerky movements, a tendency to seizures and a happy, sociable personality.
Cornelia de Lange Syndrome	Developmental growth, small stature, hearing impairments, heart defects, seizures, feeding problems, behaviour problems i.e. self harm, aggression.
Dandy Walker Syndrome	Abnormal development of the foramina through which the cerebrospinal fluid exits from inside the brain to the outside surface. Balance, co-ordination and mobility are common problems
Down's Syndrome	Chromosome Disorder with characteristics of small chin, protruding or oversized tongue, shorter limb, poor muscle tone, health concerns, hearing loss, obstructive sleep apnea and thyroid dysfunctions.
Lissencephaly	(Smooth Brain) Neuronal migration disorder. Causes developmental delay and seizures.
Smith–Magenis Syndrome	Is due to an abnormality in chromosomes and results in behavioural problems, mild to severe learning difficulties and sleep disturbances.
Williams syndrome	Has physical, emotional, behavioural and mental difficulties including hyperactivity in early years, hypersensitivity to noise, problems in social and personal relationships, elfin facial features and heart problems

Figure 1 – Example of health conditions which also include a learning disability. Adapted from Mencap (2011)

Neece and Baker's (2008) research focussed on learning disabilities and autism, which is especially significant to parents' stress due to the additional difficulties the child faces in terms of impaired social interaction skills. The child who has Autism (and learning disabilities) demonstrates a lack of intuition about others, with parents often seeing the child as ‘hard to reach’. This is further exacerbated in autism due to possible speech delay, play problems i.e. play not ‘conforming’ to social norms and lacking creativity and social focus (Bartak, Rutter and Cox, 1975). Such factors exacerbate parents’ reported stress (Neece and Baker, 2008). In addition because autism affects a child’s information processing, their ability to organise and be creative may be affected, resulting in them ‘taking things literally’ or ‘saying things how they see them’ even if this is culturally unacceptable to others (Kanne, Randolph and Farmer, 2008).

Learning disabilities and challenging behaviour

Hodges (2003) suggests that challenging behaviour is frequently diagnosed in those with learning disabilities with between 5-15% of this population regularly demonstrating severe challenging behaviours. Challenging behaviour refers to “behaviour of such an intensity, frequency or duration that the physical safety of the person, or others, is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities” (Emerson, Barrett, Bell, Cummings, McCool, Togood and Mansell, 1987:195). With this definition of challenging behaviour it is not surprising that challenging behaviour is a common reason for local authorities to fund out-of-home services, due to the difficulty a parent may experience in keeping their child or others safe.

Hodges (2003) stresses the importance of understanding challenging behaviours as a communication about a person’s ‘inner-world’. However, while understanding these communications is essential, it is important to understand the impact that challenging behaviour has on others. Challenging behaviour may be a common feature of developmental disabilities, although it is noted that similar behaviours also occur in non-disabled children and likewise may be absent in some children with developmental disabilities. Nonetheless, research has suggested that challenging behaviour is more consistent and enduring in those with developmental disabilities and contributes to parental stress and lower levels of wellbeing in comparison to parents with non-disabled children (Matson, Gardner, Coe and Sovner, 1991). Challenging behaviours may also have negative consequences for the child in terms of peer rejection (Coie, Lochman, Terry, and Hyman, 1992). Factors which contribute to challenging behaviour include problems in communicating, which can be exacerbated by factors such as living in disadvantaged areas, coercive or poor parenting interactions (Reid, Webster-Stratton and Hammond, 2007), parental conflict and psychopathology (Patterson, 1992) and low expectations of the child (Bixknell and Conboy-Hill, 1992). These factors impact on the relationships between the child and parent, due to stress, which then contributes to unsatisfactory parent-child relationships. The unsatisfactory nature of the parent-child relationship affects the parents' sense of identity as 'a good parent' and forces them into a role where they see themselves as limited in terms of their parenting abilities. It is clear that these unsatisfactory relationships are complex, and may reinforce the challenging behaviour (in the child) which then further diminishes the parents' sense of self and increases stress, maintaining a cycle.

Research suggests that children's challenging behaviours contribute to significantly high levels of hopelessness (Padencheri and Russell, 2002) and lowered levels of optimism (Baker, Blacher and Olsson, 2005) in parents. Woolfson (2004) identifies the significant role these psychological factors play in the parental adjustment to a child's disability. Floyd and Gallagher's (1997) longitudinal study involving 336 families compared parental accounts of caring for children with intellectual disabilities or chronic illnesses (both with and without challenging behaviours). They used questionnaires relating to resources and stress to correlate parental stress and strain associated with caring for their child. Significant behaviour problems were found to be more important than disability or illness type, when determining high levels of parental stress and coping. This study also noted gender differences, mothers reported greater levels of stress and depression than fathers, specifically linked to worries about the children's future care because of the challenges faced in managing their challenging behaviours. Literature into depression and gender suggests an association between increases in mother's negative perceptions of their children and thus their ability to manage their child's behaviours (Gelfon and Teti, 1990). Overall, literatures suggest that lower levels of child behavioural problems relate to a greater parent-child emotional reciprocity and co-responsiveness (Deater-Deckard and Petrill, 2004).

Relational factors

During times of stress parents may take their frustrations out on each other or those around them including their children (Redmond et al., 2002), which can lead to marital problems, difficulties with parent-child or sibling relationships, sibling rivalry, parentification (when a child takes on the parental role*)* and even child abuse. Lavin (2001) suggests that parents often avoid dealing with marital issues by focussing their attention on the needs of their child or other children. This potentially creates a hostile relationship between parents and contributes to unhealthy bonds between the parent and child which may affect the quality of care-giver stress and parental identity.

Conversely Keating (1997) found that many parents with a learning disabled child experience a strengthening of their relationship. However, a study by Contact-a-Family (2003), a UK charity for parents of disabled children, explored the relationships between parents and concluded that 24% of couples required couples counselling due to depression, financial difficulties and housing problems. This survey was based on 2000 postal and web-based self reports. 84% of respondents were female, 12% male and 4% did not record gender. In 67% of cases the child was cared for by both parents, 7% by a single parent and 3% were in another situation such as in out-of-home care (12% did not respond). Data indicated that 23% of those surveyed believed having a disabled child had brought them closer together, with 19% suggesting it had no impact on their relationship. However 31% of respondents felt that raising a child with a disability had caused problems in their relationship, with 13% believing it caused major issues and 9% linking the child's disability to their separation. Stress or depression was reported by 88% of respondents. Self reports give an indication of the relational issues involved, however caution is needed when interpreting these findings as these difficulties could also be experienced by parents with non disabled children. Nonetheless, the findings do allow for exploration into relational dynamics and the researchers also consulted with parents at conferences and workshops to explore their experiences further.

The family therapy literature suggests that siblings of disabled children may experience similar reactions to their parent, such as fear for the learning disabled sibling's future in light of health and developmental issues, grief, anger, and guilt (Batshaw, 1991). Siblings can feel confused and wonder if they can 'catch' the disability, or can have beliefs and fears that they caused the disability by wishing the parents didn't have a new baby (Batshaw, 1991). Research exploring family dynamics suggests that some siblings may feel jealous or left out because the disabled child requires (or gains) more support (Pearson and Sternberg, 1986). These family relationships can impact on parental stress and the care that the child with disabilities receives. For example, parental sensitivity and atunement to the child depends on their ability to accurately recognise and interpret their child's behaviour, body language, facial expressions and speech.

When the child is disabled, their ability to communicate their mental state may be compromised by the presence of functional and sensory impairments. Thus the disability can affect the child's ability to request support; for example when afraid they may not cry. The literature on Down's syndrome is illustrative of this process; there are conflicting views regarding the underlying problem for children with Down's syndrome and how the disability affects their learning difficulties, which Anderson (2001) suggests links to the relatively slow speed at which their brain processes information. The consequence of this slowness is that the child achieves many of their developmental capabilities, but this is delayed by deficits in their ability to report what they think, feel and know. Beeghly and Cicchetti (1997) suggested that the mothers of children with Down's syndrome use fewer internal state words in conversation such as those relating to feelings and emotions because the child doesn't appear to respond to their words. This then decreases the information exchange between parent and child which impacts the child's learning; they do not have opportunity to experience parents' expression of these emotions and feelings, thus do not develop their own understanding of thoughts and feelings as a consequence. Solomon and George (1996) found that mothers of children with Down's syndrome were significantly less sensitive to their children (compared to a control group) due to the child being less communicative / attentive to their mother and less lively.

Similarly, Baron-Cohen, Leslie and Frith (1985) suggest that autistic children lack a 'theory of mind' due to both their disability and parental reactions towards them. This deficit causes significant problems in subsequent social relationships and communication, which starts within the family when parents and siblings only respond to the child's given signs. Charman, Swettenham, Baron-Cohen, Cox, Baird and Drew (1997) argue that the autistic child is less likely to look at the face of someone exhibiting distress or to show facial concern in response partly because they are delayed in doing so due to their disability and partly because they have not been consistently encouraged to do so by the parent. Hoppes and Harris (1990) suggest that these communication deficits contribute to parental stress which in turn affects parental sensitivity and emotional availability towards the child.

There is a gap in the literature regarding actual learning disabilities and relationship dynamics, with much focus being placed on Down's syndrome and autism. From these studies, it is suggested that parents with a child who has a learning disability may also experience increased difficulty in understanding their infant's signals. This means they have to work harder to understand the interactions, which affects the mutual pleasure in mother-child interactions, with additional diagnoses further exacerbating the parent's experiences. Because of this, Nind and Hewett (1994) suggest that mothers may become overly stimulating or directive in their interactions. When the child experiences their needs as being unrecognised, misunderstood, inconsistent or ignored they become more distressed which amplifies further attachment behaviours, adding to the caregiver's distress and frustration (Howe, 2006). A vicious cycle then ensues which further impacts the parent-child relationship.

Moran, Pederson, Pettit and Krupka (1992) point out that children in need of sensitive care, in effect challenge the parent's ability to provide this level of care. Their research found that with a group of developmentally-delayed children, levels of maternal sensitivity and security of attachment were significantly low. Barnett et al., (2003) found that some parents are unable to develop an internal representation of their child's actual abilities rather than the wished for abilities and were less likely to provide an experience of secure attachment for their child (Atkinson et al., 1999).

Dickman and Gordon state that “it is not the child’s disability that handicaps and disintegrates families; it is the way they (the family) react to it and to each other” (1985:109). Parent-child relationships can additionally be influenced by social elements such as experiencing stigmatisation.

Stigma

From a sociological perspective, it is argued that stigmatisation is due to individual and societal assumptions about individuals who are then devalued within that society (Goffman, 1963). Link and Phalen (2001) define stigma as a process which labels and stereotypes individuals (or groups of individuals who share the label), leading to discrimination against them and loss of status. A study by Contact-a-Family (2006) found that 70% of parents, who care for a child with disabilities believe that public acceptance of the disability is poor or unsatisfactory and it is this acceptance (or lack of) that contributes to enhanced levels of stigmatisation and discrimination. Discrimination is distinct from stigmatisation, although the two are often confused; discrimination relates to a person *acting* on a belief, for example treating someone differently or bullying them due to their disability. Stigma is based on negative assumptions towards the person with the disability, for example staring at, or pitying someone with disability (Ablon, 2002). Goffman (1963) introduced the concept of ‘courtesy stigma’ which Mehta and Farina (1988) termed ‘stigma by association’; this occurs when someone is stigmatised for affiliation with an individual or group; for example the parent of a child with a disability, due to their relationship with the child.

The effects of stigma should not be underestimated according to Beresford (1994) because they are experienced alongside the stress and adjustment processes which individuals are undergoing; although research into this process is currently limited within the learning disability field. Research by Scambler and Hopkins (1986) divided stigma into two domains, ‘enacted’ stigma such as outright discrimination or exclusion including staring, and ‘felt’ stigma such as internalisation of feelings of shame and fear i.e. feeling embarrassed when the child does something in public. With these findings in mind, it is argued that both enacted and felt stigma impact on parental identity, stress and strain. Gray (2002) suggests that mothers are more likely than fathers to experience stigma; which may be due to social constructions of motherhood, as mothers potentially experience more internalised guilt over their child and therefore are more sensitive to social reactions (Anderson and Elfert, 1989).

Parents' gender

Research on parental experiences of parenting have generally focussed on mothers' experiences; Bristol and Gallagher (1986) suggest that some reasons for neglecting the fathers' experiences relates to difficulties gaining access (i.e. males are less likely to take part in research), and potential historical bias due to social expectations for mothers to promote child development. The limited studies including fathers indicate that parents of children with disabilities do not differ in their perception of stress, although mothers and fathers differed in the types of stress they experience (Hadadian,1994). Although the literature on parental stress has historically focussed primarily on mothers' experiences, in recent years this deficit has been acknowledged and some studies into fathers' experiences are coming to the fore.

Dyson (1997) explored mothers' and fathers' views of parental stress using a family scale survey and concluded that while parents of disabled children experienced greater stress than parents of children without a disability, the difference between genders was not evident. Olsson and Hwang's (2008) Swedish study surveyed sixty-two mothers and forty-nine fathers of children under the age of five with intellectual disabilities and compared these to a larger group of parents with children who were of typical development. It emerged that fathers of those with intellectual disabilities scored higher on the depressive symptoms scale compared to fathers in the control group. These findings contradict earlier findings which suggest that fathers generally report lower levels of depressive symptomology than do mothers (McGrother et al.,1996). It has been suggested that this may relate to fathers working and having other commitments following the child's birth (Heller, Descamps and Hondekiji, 1998). Additionally men are less likely to talk about their feelings and potentially may disguise their depression (Schoenberg, 1993). Literature supports this and suggests that mothers are more likely to focus on family care with fathers focusing on the wider world (Pelchat, Lefebure and Perreault, 2003).

Family resources

Material, personal and social resources have been found to relate strongly to parental well-being. For example family resources such as income and work commitments influence a parent's ability to manage day-to-day stress and strains (Warfield, 2005). This is supported by Friedrich et al. (1985) and Krauss and Seltzer (1993) who concur that a family's social climate (i.e. their assumptions, mood and relationships as a family unit) is associated with effective coping strategies and reduced stress. Elements which impact on parental stress within the family often relate to inadequate income. Gordon, Parker, Louhran and Heslop's (2000) quantitative study suggests that families of disabled children often have lower incomes, yet require extra finance for services or resources which are not covered fully by disability benefits. Many mothers would like to work outside of the home but are prevented from doing so due to a lack of provision for caring for their child and the inflexibility of services such as hospital appointments. Stress can also come from parents' perceptions regarding employers' attitudes towards issues such as taking time off to look after an ill child or to attend appointments. Research has shown that some parents have been refused promotion because they have spent time caring for a learning disabled child (Smyth and Robus, 1989).

Implications of stress

Seltzer, Almeida, Greenberg, Savla, Stawski, Hong and Taylor (2009) explored levels of stress in parents of disabled children from a psychosocial and biological perspective. Their in-depth study used daily telephone interviews (n=82) with midlife parents (parents mean age 57) of adult children with disabilities (children's mean age 29 years) who lived at home with parent carers. Results were compared with a closely matched sample of parents of non-disabled children, to explore the daily experience of parenting. Biological markers in the form of salivary cortical samples were obtained during stages of the study to explore whether parents had deregulated diurnal rhythms and cortical expression (biological markers relating to stress). These levels were related to the interview outcomes and analysed in light of what had occurred that day (specifically related to the time the parents had spent with the child and the parents reported level of stress). Results indicated that parents of children with disabilities had elevated levels of stress in their saliva as well as negative effect and physical stress symptoms were reported daily. The self-reported findings were supported by the diurnal rhythm of cortical expression, which was significant when parents of a child with disabilities spent more time with their child i.e. the time spent with the child per day was significant to the self-reported stress and the biological record of stress. The findings suggested that daily stress can accumulate over years leading to a pattern of deregulation of cortical expression which relates to chronic stress. These researchers found that the diurnal pattern presented was actually associated with chronic strain consistent with the chronic nature of parents' care-giving responsibilities over decades. One critique of this study is that the researchers were unable to separate parental well-being from the child's disability. For example it cannot be ruled out that parents had poorer well-being and higher stress responses prior to the onset of their child's disability which my effect the outcome of findings. Nonetheless, the researchers were able to compare groups of parents of children both with and without disabilities, which goes some way to enhance the validity. Secondly, the researchers did not analyse sub-groups based on the child's age or severity of disability. However, their in-depth multiple dimensional study, suggests that caring for a child over a long duration affects the body and even when the participant did not report feeling stressed, the biological evidence indicated that stress hormones were prevalent and were higher than in the control group. This indicates that long-term stress builds biological markers over time.

The health implications of stress are well researched, although within the disability field much of this is focused on carers of individuals with dementia; studies tend to be focused on the exploration of caring roles and stressors. Kiecolt-Glaser et al., (1987) explored chronic stress experiences in carers of individuals with Alzheimer's and the effects on the immune system. They found higher self-reports of loneliness and psychological distress in caregivers compared to the controls. This linked to increases in viruses affecting caregivers; even several years following cessation of the care-giving role, individuals experienced more viruses. This research suggests that choric stress weakens the immune system thereby impacting general health over long periods of time.

Further studies have explored stress and health; Glaser, Sheridon, Malarkey, MacCallum and Kiecolt-Glaser (2000) used antibodies in response to pneumococcal bacterial vaccine i.e. how participants respond / recover biologically to illness. The results of this study suggest that caregivers demonstrate deficits in antibody responses, suggesting that chronic stress affects antibody levels which impacts on healthy resilience at a cellular and enduring level.

Bauer, Vedhara and Perks (2000) explored salivary cortical levels (markers of stress) of adult carers for those with dementia, as well as using a control group and exploring socioeconomic, gender, ethnicity and employment status. This study suggests that cortical expression is raised in carer-givers i.e. those who showed high cortisol levels also showed acute stress as a result of their care-giving roles. Furthermore Bauer et al. (2000) suggest that such immunological changes occur rapidly with the onset of stress. Caregivers tend to experience more health issues such as respiratory tract infections, which take significantly longer to heal, compared to controls (Vitaliano, Persson, Kiyak, Saini, Echeverria. 2005). Such research, on the effects of chronic stress in caregivers, suggests that health is most significantly affected when the stress is embedded at a social level i.e. such as in a caring role which is enduring, compared to someone who experiences less enduring life events which contribute to stress (Pearlin, 1989). Such chronic stress links to physical and psychological health problems (Forbes, While and Mathes., 2007) and Pinquart and Soresen, 2003). Pariante, Carpiniello, Orru, Sitzia, Piras, Farci, Del Giacco, Piludu and Miller (1997) suggest that caring for a child with disabilities is also associated with poorer cellular regulation and poorer immunity as a result. In summary, such research indicates that caregivers are at an increased risk of health issues including depression, stress and, anxiety (Pearlin, 1989 and Reese, Gross, Smalley and Messer, 1994.). Chronic stress affects organ health, speeds up the signs of aging, influences mental health such as depressive symptoms and negatively impacts psychological well-being (Seltzer *et al,* 2009). McGrother et al. *(*1996) cross-sectional study found that parents of those with a disabled adult reported 40% more limiting health disorders than the general population, and depression was four times more common among female carers.

‘Breaking point’

Breaking point is a concept interrelating stress, strain and burnout and for the purpose of this study, ‘breaking point’ is defined as the critical point when family caregivers’ efforts in being able to care have reached a maximum with respect to available resources (Annerstedt, Elmståhl, Ingvad and Samuelsson, 2000). There is to date no research into the process of 'breaking point' for parents of a learning disabled child, but a study by Annerstedt et al.(2000) into ‘breaking point’ indicates its significance. This study analysed caregiver burden and the ‘breaking-point’ for caregivers of patients suffering from Alzheimer type dementia and vascular dementia; ‘breaking point’ was identified as the critical time when care became insufficient and/or inadequate. This study was based on a sample of seventy-nine partners of individuals with Alzheimer’s and who were being considered for relocation into group-living units. The participant’s gender and social class did not significantly impact on the participant’s caregiver burden and stress. A multiple regression analysis indicated that the amount of care-giving time the participant gave each week, combined with their impaired sense of own identity, misidentifications, clinical fluctuations, and the nocturnal deterioration of the patient, were the key predictors for reaching breaking-point. Care-giving burden linked to general strain, isolation, disappointment and emotional involvement, which correlated with the patients' diagnoses, abilities, and symptoms.

Availability of Support

Considerable attention has been paid to identifying reasons for parental stress with a strong correlation between parenting and the availability of support (Hassall et al., 2005). Rogers (2007) a mother of a learning disabled child explored the social pressure mothers face when they ‘fail’ to produce ‘perfect’ babies. She suggests that parents feel loss, shock and disappointment upon diagnosis and argues (drawing on personal narratives and in-depth interviews) that formal and informal support is the most powerful tool; without this the child with the diagnosis can disable the whole family. Without such support Doig et al. (2008) suggest that elements of frustration build, including stress, exhaustion and ultimately ‘burnout’. Oakley (1992) identified that when parents are exhausted and ‘burn out’, they fear that they may harm their children. Oakley’s research is based within a sociological and feminist perspective and explores motherhood and social support. While not focused on the disability field, her findings suggest that any parent can fear negative consequences towards their child if they are under chronic stress, with some parents subsequently harming their child (intentionally or unintentionally). Burns (2009) found that 64% of learning disabled children within residential settings are on Care Orders, meaning the child has been removed from the parents' care via the courts system due to social services deeming the child to be at risk of significant harm, therefore out-of-home services or extra support become vital.

Respite and out-of-home care

Doig, McLennon and Urictiuk's (2008) grounded theory exploration of parents' experience of seeking respite care for children with special needs identified that parents spoke of reaching 'breaking point' due to strain and frustrations of caring for their child without breaks. This study interviewed both mothers and fathers about their experiences and the process of seeking respite care. Their fight for services was evident and their own sacrifices to get support were noted, for example parents incurring considerable travel costs. Although this study identified 'breaking point', it did not focus specifically on what constituted the process of 'breaking point'. The study did identify that respite care was sought in anticipation that it would reduce stress by ensuring parents gained time away from the constant care of their children. The study concluded that the experience of seeking respite services was negative and stressful with parents 'jumping through hoops' and 'shouting the loudest' to gain the support they required. McGill, Tennyson and Cooper (2006) researched the experiences of families seeking residential schools. Parents recalled negative and stressful experiences prior to placing their child in a residential school, and related this to limited services available. A survey by Mencap (2001) found that 48% of exhausted families receive no help with respite or care, and that children usually enter the care system when parents are no longer able to cope with the burden of caring.

Decision making

Decision making has a premise that eventually a final choice will be made (Reason, 1990). In the case of decision making about out-of-home care, the choice itself can be that of action i.e. physically changing circumstances such as choosing out-of-home care, or that of opinion whereby the choice is made to not do something i.e. for the child not to leave home and to remain cared for by the parent. Decision making is based within an individual's value system and is regarded as a continuous process formed by interactions within the immediate environment (Scarnier, Schmader and Lickel, 2009). In the psychological literature, decisions and reasoning are laden with emotional interpretations, and are viewed as either rational or irrational. Kenji and Shadlen (2012) suggest that decisions are analysed in light of evaluating the cost and benefits, which is known as Rational Choice theory, therefore individuals seek to maximise benefits and reduce costs. One criticism of rational choice theory is that it assumes all individuals consciously calculate and anticipate the consequences of every action and decision. Hecher (1997) suggests that it ignores the concept that people generally act impulsively, emotionally, and through force of habit. As such, decision making involves biases and can cause individuals to make decisions which are perceived by others as irrational.

There is currently a gap in the literature relating to parents' decision making within the learning disability field; it is suggested that parents experience both practical and moral dilemmas when questioning their decision making, based on the available alternatives; such as caring for their child themselves versus external support. Parents facing this dilemma are forced to recognise that morally neither choice is satisfactory (Milliken et al., 2003). To manage this, it is suggested that they progress through phases of internal moral deliberation which is based on judging the welfare of everyone, which is a moral act as it aims to produce the greatest 'good' for everyone (Schofield et al., 2011). Negotiation may be needed in these cases and parents may have to act as moral agents to meet their own and their child's needs. However when parents are constrained they can lose their ability to act as they morally would like to due to lack of choice. As unresolved moral dilemmas are experienced, parents may withdraw and accept their inability to make valid moral decisions and act on their choices (Schofield et al., 2011).

Adaption: when a child is no longer cared for by a parent

Social construction of parenthood, is generally based on the assumption that parents will morally judge situations and seek to prioritise their child’s needs; such a social construct means that society will judge actions and outcomes as being based on a correct or incorrect decision (McCarthy et al., 2000). Kielty’s (2007) research with non-resident mothers who were estranged from their child’s father, found that mothers had to adapt to the loss of a child (who now lived with the father) in order to psychologically manage both the loss of their child and the loss of their care-giving role. The study identified that mothers experienced loss, grief and anger combined with guilt and regret which affected their self-esteem and identity resolution. Studies into the parental experiences of loss of a child, such as those going into foster care or being placed for adoption, have outlined the challenges and difficulties parents face, which include outcomes such as loss and anger (Schofield, Beek, Sargent and Thoburn, 2000; Höjer, 2007). Such studies suggest that parents whose children are in foster care are at increased risk of experiencing stigma, which impacts on how they perceive themselves. Doka (1989) suggests that despite the loss that parents experience when their child is supported in foster care, their reactions and grief about this loss is not acknowledged or supported socially, which Doka describes as ‘disenfranchised grief’. Doka (1989) suggested that the stigma surrounding this combines both legal and social elements, which then exacerbate the parent’s grief. For example parental responsibility may be removed by the court when a child is in foster care, especially if the parent has been deemed to pose a risk to the child and the care system or foster carers take the guardianship role. The research in this area is limited with a significant gap relating to learning disabilities and parental responses towards out-of-home care. However, given research in similar fields, it is not unreasonable to suppose such stigma and parallels in parental experiences will be present when managing both the loss of the child and the parental role.

RESEARCH RATIONALE AND AIMS

The literature illustrates the scale of psychological distress faced by the parents of a learning disabled child; the experience and management of parental stress, the impact of diagnosis, strain on relationships and effects on psychological and socio-economical well-being, all of which are relevant to the field of counselling psychology. The aim of the current research is to explore parents' experiences and the psychological impact of parenting a child with a learning disability, the process of stress and 'breaking point' and how this impacts on the decision making process for out-of-home care. There are significant gaps in the literature regarding what is known about this process; it is hoped that forming an explanatory theory of this process will aid understanding and therefore help to inform treatment interventions. Methodologically, a qualitative approach seems the most appropriate method to explore these processes.

Firstly by using a qualitative approach these life experiences have an opportunity to be discussed and explored (Bradley, Curry and Devers, 2007). Secondly, the grounded theory methodology allows the processes, meanings and experiences of individuals to be shared and constructed (Kitto, Chesters and Grbich, 2008). As such, when exploring parenting roles and potential stressors, the methodology encourages participants to share their stories, which Wynn and Money (2009) suggest gives a richness of detail into the area of investigation which is currently lacking. These experiences are important to understand due to the complexities of the processes present; by using a constructionist approach, the research aims to make sense of the experiences, beliefs, assumptions, views, prejudices and knowledge of the participants (Andrews, 2012). Understating these elements within a constructionist framework, pieces together statements to allude to and enhance meaning making (Charmaz, 2000). Understanding how such experiences influence decision making and parenting roles has scope to potentially aid parents, families, professionals, service users and organisations. Increasing knowledge of the processes of decision making at all stages, and the processes involved in reaching 'breaking point', may be influential in terms of the design of adequate support programmes and early interventions that will aid the immediate and long-term psychological wellbeing and health of parents (and the child), when making and living with the decisions they make about their child.

The research aims to inform those working to support parents, which may enable them to address this process, reduce stress and anxiety, and potentially enable parents to provide better care for their child (at home if they want) and to reduce ‘care burden’ on the social services care system. From another perspective, learning about the decision making processes and ‘breaking point’ could speed up referrals for out-of-home care with increased understanding i.e. to prevent the anxiety of reaching ‘breaking point’. Psychological support could assist parents through this process prior to, during and following the decision making process.

METHODOLOGY

DESIGN

This is a qualitative study which adopts a social constructionist grounded theory methodology (Charmaz, 2006). Data collection was via semi-structured interviews and a qualitative survey.

Rationale for qualitative methodology

Both quantitative and qualitative research methodologies contribute to the psychological literature. Quantitative research focuses on illustrating phenomena through numeric symbols and statistical analysis (Babbie,1999), whereas qualitative research offers a more rigorous data collection process with a lengthy data analysis procedure (Creswell, 1998). Both forms of research have strengths and limitations, therefore researchers endeavour to evaluate which approach is most appropriate for their aims and objectives. Guba and Lincoln (1998) suggested that qualitative designs promote an expansionist stance, gaining knowledge through the connotations, processes and meaning which participants communicate. A qualitative design was chosen for this research for the following reasons:

i. As a trainee counselling psychologist, I acknowledge that qualitative methods ‘fit’ with my personal and longstanding research interests. Mills, Bonner and Francis suggest that when choosing a methodology, “researchers must choose a research paradigm that is congruent with their beliefs about the nature of reality. Consciously subjecting such beliefs to an ontological interrogation in the first instance will illuminate the epistemological and methodological possibilities that are available” (2006: 2). To elaborate, my belief about what constructs ‘reality’ relates to an assumption that concepts and habits are based within social systems, therefore concepts, beliefs and ‘reality’ are consciously and unconsciously socially constructed.
ii. Additionally a qualitative approach was felt to be appropriate considering the sensitive area under examination (Frey and Oishi, 1995).This methodology allows an exploration of the processes, meanings and experiences of individuals (Kitto, Chesters and Grbich, 2008); it generates theory grounded in the participant’s experience, and links well to the research aims.
iii. It allows the participant to ‘tell their story’ which Wynn and Money (2009) suggest gives the researcher richness of detail in the area of investigation.

Rationale for Grounded Theory

Creswell (1998) outlines five paradigms of qualitative research design; biography, case study, ethnography, grounded theory, and phenomenology, which all have differing philosophical origins and are tailored within specific genres of inquiry. For this study, a grounded theory methodology was considered the most appropriate approach as it allows theory to be generated in an under-researched area, focusing on actions and processes rather than experience alone. Furthermore, grounded theory has been used to explore stressors and coping strategies (Morrow and Smith, 1995) in previous research domains. Grounded Theory is distinguished from other qualitative methodologies due to its focus on theory development (Strauss and Corbin, 1994). Grounded theory also fits well within the epistemological position of the researcher. Charmaz suggests that “data does not provide a window on reality, rather the ‘discovered’ reality arises from the interactive process and its temporal, cultural, and structural contexts" (2000: 524). Constructivist grounded theory actively positions the researcher in a role of author, with a goal of reconstructing the participants' shared experiences and their meanings behind those experiences. As such, the researcher is responsible for interpreting the participants' experiences and for 'giving a voice' to these constructed experiences (Charmaz, 2006). These processes are inductive initially (as ideas are constructed from the data) and then become deductive (as the researcher develops hypotheses) which lead to analysis occurring in light of these developing hypotheses (Morse, 2001).

Epistemology

Historically, grounded theory originated with the work of sociologists Glaser and Strauss (1967). Glaser's underlying epistemology is one of social interactions, and focuses on theory 'emerging from the data'. Charmaz (2000) however argues that Glaser and Strauss assumed the existence of an external reality and contends that a constructivist approach to grounded theory is possible because research outcomes are determined by the researcher's co-constructed experience and meaning making, gained from the 'stories told by participants'. This offers a much needed next step within this research methodology which, she argues, keeps the participant present throughout.

Epistemologically, grounded theory methodology acknowledges the interrelationships between researcher and participant whilst acknowledging the subjective nature of this dynamic (Pidgeon and Henwood, 2007). This promotes the importance of researchers' understanding that they are a part of the research and not objective observers; the researchers' values, experiences and beliefs should be acknowledged by themselves and made transparent to their readers as these will inevitably impact on the research findings (Guba and Lincoln, 1989; Stratton, 1997). Charmaz argues that there are multiple realities in the world and that generalisations are "partial, conditional and situated in time and space" (2006:141). Therefore co-constructing data with participants and recognising the subjectivity that influences their lives, and that of the researcher, is a key principle. For this reason Charmaz argues for the importance of focusing on participants' narratives rather than presenting an abstract account of their experiences. Charmaz' (2006) methodology is viewed as a flexible set of principles and practices aimed at construction rather than discovery, which is applicable in this study as one of my interests is in how participants construct their experiences of parenting a child with a learning disability and how social constructions of disability and parenting impact on these constructions. Additionally, I am interested in exploring how these constructions influence decision making.

Social constructionism

It is important for grounded theory researchers to appreciate the distinctions between the underlying epistemology of their chosen methodology; Young and Colin (2004) suggest that social constructionism is based on social, rather than individual factors, whereas constructivism suggests that individuals construct their experiences via cognitive processes. Social constructionism attempts to make sense of the social world, for example individual constructs, beliefs, assumptions, views, prejudices, experiences and knowledge, with the premise that these elements are constructed as opposed to created (Andrews, 2012). Constructivist approaches fit with an interpretative tradition for example focusing beyond how an individual views a specific situation or experience, to one of construction and interpretation of that experience (Charmaz 2000; 2002). Constructionist analysis pieces together these interpreted actions and meanings demonstrating how a statement alludes to the experience. Charmaz (2000) argues that constructivist approaches assume that both data and data analysis are socially constructed within both the participants' and the researcher's values and cultures. It is noted that this method depends on the researcher's views with researcher reflexivity and transparency being key throughout the process as "theory *depends* on the researcher's view; it does not and cannot stand outside it" (Charmaz 2006:130). Adopting a constructivist approach for this research (based on Charmaz) requires the researcher to remain alert to the differences which may be expressed by individuals. The samples size affects this, as small samples have the potential to disconnect the researcher from wider social contacts and situations due to limiting the amount of information and experience shared (Collican, 2005).

METHOD

There are a number of concepts to consider within a grounded theory design. Firstly, the area of interest is chosen to explore the perspective and experience of one or more groups within the substantive area (Scott, 2009). In this study the area of substantive interest is learning disabilities, parental experience and decision making. The action orientated research question 'Placing a child with learning disabilities into out-of-home care, parent and caregivers decision making processes', was chosen with the purpose of exploring the decision making process around out-of-home care and the experiences that impact on this process. Secondly theoretical sensitivity relates to the concept of the researcher's insight into the research area which includes a consideration of their awareness of the nuances and the complexities of participants' world and experiences. Charmaz (2006) suggests that researchers remain sensitive to data and encourages the researcher to immerse themselves in it, by moving back and forth between data, categories, theoretical sampling and analysis, in order to develop theoretical sensitivity.

Literature review

The treatment of the literature needs to be considered; within the classical grounded theory approach it is suggested that the literature review takes place later in the analysis to prevent the researcher from contaminating, stifling or inhibiting the emerging data (Glaser, 1992). However, Charmaz (2001) argues that it is more realistic for researchers to explore the existing research literature in advance of data analysis as this aids a more critical stance. For the purpose of developing this research proposal and generating the interview questions, a brief literature review was conducted. This allowed the identification of existing findings which shaped the semi-structured interview questions and outlined gaps in the literature which this study aimed to address.

The literature offered the opportunity for considering methodological weaknesses of earlier studies (Hill et al., 1997), for example comparing the appropriateness of methodologies used. To manage the impact of pre-existing knowledge gained from the literature and from my own experiences working in this field, I documented my expectations about what might emerge from the data to identify possible biases before the research began. A reflective diary was kept throughout, as well as field notes and these were reflected upon during the research process.

Interview Schedule

Interviews are defined as “a purposeful conversation in which one person asks prepared questions (interviewer) and another answers them (respondent)" (Frey and Oishi, 1995:01).The rationale for using interviews links to the advantages of this method; firstly, interviews are useful for untangling complex topics and narratives because the researcher can adapt or rephrase questions if necessary to aid clarity and to ensure the participant understands the questions (Bryman, 2001). Secondly, Opdenakker (2006) suggests that there are advantages when participants answer spontaneously to the question, rather than taking time to reflect and consider their response; thus the responses given generally provide a richness of detail. In line with this, non-verbal cues can be acted upon. For example, the participant may become distressed, or particularly enthusiastic about a specific question, all of which can provide additional information to the researcher.

Charmaz suggests using open-ended questions will “encourage un-anticipated statements and stories to emerge” (2010: 26). The use of open-ended questions allowed individuals to respond in varied ways for example giving as much or as little explanation as they choose about the given topic of interest (Wimmer and Dominick, 1997). This is a suitable way to explore sensitive topics with a flexible focus, which provides large amounts of detail about a given topic more easily than other methods, for example a questionnaire (Frey and Oishi, 1995).

In line with Charmaz (2010), a pilot study was not required to support the development of interview questions because the questions were developing through an iterative process as the research progressed. Five broad open-ended questions were developed:

Question 1 - Can you tell me something about your experience of parenting a child who has learning disabilities? This question served as an introduction; Kvale (1996) describes how introductory questions can be used to start an interview and interesting points raised can be clarified later in the process. The broad nature of the question encouraged the participant to settle into the interview; Foddy (1993) suggested that using an open question can be useful as the first things mentioned by the participant could be the most important to them and therefore gives the researcher an opportunity to explore these further.

Question 2 - Can you tell me something about the decision making process during this time, leading to your son / daughter moving to out-of-home care? This question was directly related to the research aims and served to gain specific information but was deliberately framed as an open question; Foddy (1993) suggests open questions are useful because they allow respondents to express themselves in their own words.

Question 3 - Can you say something about your emotional well being prior to this decision? This question linked to encouraging exploration of the psychological effects of the decision making process. Not surprisingly this question proved to be the most difficult for participants to answer. Therefore time and space was given as they considered their responses, which Kvale (1996) suggest is beneficial when exploring sensitive areas.

Question 4 - Can you say something about what was going on for you at the point at which you decided to place your child in out-of-home care, or why you are considering this? This open question allowed for cognition and practical elements relating to decision-making to be explored i.e. whether factors such as relationship breakdown or financial issues were present.

Question 5 - Is there anything else that you would like to add about the factors that led to this decision?

Following Charmaz (2006), prompt questions were also used to guide discussions and encourage participants to give more information following the initial questioning. Throughout the analysis the themes which arose during interviews contributed to additional interview questions for example a question relating to support systems was added. Lofland and Lofland (1984), suggest that interviews can be modified to focus attention on developing areas of importance, or researchers can choose to remove questions which have proved unproductive for the goals of the research.

At the request of prospective participants, a qualitative survey was later introduced. The reasons some participants gave for preferring a survey included a) preferring to write an account, b) geographic location, c) wanting to include family members and d) not having time for an interview due to caring responsibilities. Tourangeau and Yan (2007) identified the benefits of using surveys for sensitive areas of research opposed to face-to-face interviews because some participants may be unwilling to discuss certain topics but may be willing to provided written responses.

Sampling strategy

A purposive sampling strategy was adopted initially with the inclusion criteria that participants had to have a least one child (of any age) with a learning disability who was living in out-of-home care or for whom out-of-home care was being considered. There was one explicit exclusion criteria, which was that the participant's child must not have been accommodated on a Care Order into out-of-home care as this meant the decision for out-of-home care was not necessarily that of the parent. As the analysis developed, a theoretical sampling strategy was then adopted

Charmaz (1990) suggests that theoretical sampling should be utilised when key concepts are discovered in attempt to develop these concepts and refine developing categories. For example, a mother who was not considering out-of-home care was interviewed to enhance understanding i.e. what the differences were for those who do not decide on out-of-home care.

Participants

i. The sample comprised seventeen participants aged eighteen or over, two birth fathers, twelve birth mothers, one adoptive mother, one sibling and one guardian (the cousin of an adult-child with learning disabilities)
ii. Fourteen individuals were interviewed; on two occasions joint interviews were conducted (one mother & daughter and one husband & wife). The duration of the interviews ranged from thirty minutes to two hours. The combined duration of all the interviews equated to over eleven-and-a-half hours of recorded discussions.

iii. Three participants completed a specifically designed qualitative survey. Six surveys were requested by individuals throughout the research period and three were returned. The survey consisted of the same questions as the semi-structured interviews. Survey responses varied between 500 and 2000 words in length.

iv. Research recruitment started in January 2012 (following receipt of ethical approval). At this time, participants were able to contribute through interview. From January 2013, the qualitative survey was introduced and from this period, participants were offered to contribute by interview or survey.

For the participant summary table see appendix C.

During the research period, over forty phone calls and emails were received from parents who had become aware of the study and wanted to share their stories or make recommendations. Some of these declined to be interviewed or did not meet the inclusion criteria. Feedback on the research was positive and, over two-hundred emails were received from those contacted by the researcher. I participated in four face to face meetings with out-of-home care providers and disability support services who wanted more information about the study and wanted to share their thoughts and suggestions. These responses seem to indicate that the research area was one which individuals and support services saw as important. Many of these individuals provided contact details for other services which were able to support the study via recruitment. Feedback suggested that the research could support change for families, which indicated that those who phoned or emailed (and are familiar with the field of learning disabilities) had experiences of the decision making process being a struggle. These points of contact and discussions were summarised, as field notes, and contributed to additional information which guided memos and aided analysis.

PROCEDURE

Ethical considerations

This research gained ethical approval from the University of the West of England's research committee prior to recruitment. Prior to interviews the potential risks and benefits of participation were discussed. This was done through a phone call prior to the interview, and reiterated at the start of the actual interview. Information about the study was provided and discussed at these times to ensure that participants were informed prior to giving consent to participate. The qualitative survey included the same information and was available to be read on the researcher's website and in all cases the researcher communicated this over the phone or via email before emailing the survey to those who requested it. It was explained that the opportunity to talk about or document experiences may be personally beneficial as it may give a chance to reflect on experiences; however it was stressed that this process of reflection could be potentially distressing. During three interviews, participants became distressed and I suspended the interview and turned the recorder off. Feedback from participants indicated that they had not expected to find the experience as emotional and challenging as it was. With my counselling experience and experience of working with families in this area, I was able to support participants as we took a break. I remained calm and empathic and reminded participants they could discontinue participation without consequence. However all wanted to continue following a short break; participants expressed a desire to finish their story as they wanted to use their experiences to help others. At the conclusion of each interview, participants stressed that the experience had been useful; many stated that they had not realised the significance of the journey. As part of the de-briefing for interviews and survey, participants were provided with a de-brief sheet with contact details for support agencies such as the Samaritans, Mencap and The Challenging Behaviour Foundation, should they wish to access support as a result of taking part in the study. Additionally, I offered all involved the opportunity to contact me should they wish to discuss anything; two participants made contacted via email following the study to add a written summary of what they had discussed during their interviews. They gave consent for comments to be summarised and analysed in the same way as their interviews.

Recruitment

There were four main approaches involved in recruitment:

i. ***Direct contact to out-of-home organisations*** - I phoned, emailed or wrote to more than fifty out-of-home settings across the UK to request permission to recruit within their setting. The request was to display the research poster within their organisation. Five organisations consented to this.

ii. ***Direct contact to support services*** - I phoned, emailed and wrote to over two hundred individuals who worked within support services in the area of learning disabilities. These included charities such as local Mencap groups, The Challenging Behaviour Foundation, Contact a Family, parenting support groups, People First and other similar charities. The request was to display the research poster within the organisation and to support recruitment in any way possible. From this 172, emails and phone calls were returned as services agreed and sought to aid recruitment by displaying the research poster, sharing information through their mailing lists, Facebook pages, forums and newsletters.

iii. ***Via word of mouth / networking*** – Firstly, I asked participants to encourage friends, colleagues or family to read the recruitment leaflet / poster or website. Secondly, given my experience, I used professional contacts to aid 'word of mouth', this included liaising with multidisciplinary professionals (psychologists, social workers, speech and language therapists, occupational therapists, psychiatrists, nurses), to aid recruitment.

iv. ***Using a specific website*** - I registered and designed a research website (www.learningdisabilityresearch.co.uk) to aid recruitment, which also linked to a designated twitter and forum page; this interface was designed as a 'reference' tool for participants. The website allowed participants to see all of the information sheets to help them decide if they wanted to take part.

    a) The internet provides a huge audience and an ideal noncommittal way for somebody to explore the research in more depth. The website benefited from the various online search engines through a targeted Search Engine Optimisation (SEO) strategy. SEO utilises content optimisation techniques to highlight the relevance of the website to its audience and the search engines, enabling potential participants to find out about the research project through sites such as Google.

b) Other (well known) organisations added the web-link to their website.
c) The website allowed updates and news to be shared.
d) The website allowed for the qualitative survey to be accessed by anyone at any time.

The website statistical analysis concluded that from 1st January 2012 to 26th September 2013 there had been 842 visitors to the site. The average duration of visits lasted 1 minute and 29 seconds; these peaked during recruitment drives. (See appendix B6)

Interview process

Participants were interviewed at a private location, either at their child's out-of-home placement (with the correct prior approval from the out-of-home provider), at the University of the West of England, at the participant's home or at another suitable and agreed location. Interviews lasted between 30 to 120 minutes and were audio recorded. Full health and safety and risk assessments were conducted prior to interviews.

Transcription and data protection

In line with British Psychological Society and the University guidelines on data protection, data was stored in password protected files on a password protected computer system. Audio recordings were transported in a locked case, before being uploaded to a computer immediately after interviews, with identifying details being removed at the point of transcription. Identifying information for the qualitative surveys were removed on receipt at a secure university email address. All written documents were anonymised and each participant was assigned a unique ID number. Written notes were stored in a locked filing cabinet and once comments were transferred to computer, paper notes were shredded. Consent sheets were scanned and uploaded on a PC, before being shredded. During the recruitment phase, consent phase and following the interview, participants were reminded they could request that their data be removed at any time before submission without giving a reason. Each participant was given a reference number; notes and recordings were given this reference, thus if participants wish to withdraw all data would be deleted. One participant requested to see the transcript of her interview and together we checked it for accuracy, but no one withdrew their data. Four participants were contacted to aid the development of the model (which is discussed later).

Participants were informed that following completion of the study and the viva, a summary of the findings would be provided to participants by request.

DATA ANALYSIS

Transcription - Semi-structured interviews, field notes and qualitative surveys were transcribed into a word document. These were anonymised and transported to a table format and coded in a process known as initial coding.

Initial coding - Initial coding breaks data into distinct elements of meaning and actions (Charmaz, 2006) which are coded using the gerund i.e. the gerund names the action occurring in the statement. This allows the researcher to focus on actions rather than on description thus aiding the identification of processes. Charmaz (2006) stressed the importance of the gerunds (actions) when coding and writing memos, because in constructionist grounded theory it enhances theoretical sensitivity by focussing on the actions behind what was said. Using the gerund enables the researcher to move beyond static topics toward enacted processes by thinking about actions so the researcher can better see connections and sequences. Charmaz (1995) encourages researchers using this methodology to go beyond the surface of seeking meaning, to search deeper and question these meanings, values, beliefs and ideologies. Researchers are encouraged to immerse themselves in data through coding language in order to keep the participant's life experience to the fore ensuring it remains in the theoretical outcome.

Focused coding - Focused coding generates larger clusters of data into concepts where the most significant codes are the focus with patterns (and even new codes) being identified; during this time tentative hypotheses begin to be constructed (McLeod, 2006). By studying the processes, researchers define and conceptualise relationships between life events and experiences by analysing the sequencing, pacing and transitions. Interviews and transcriptions occur concurrently therefore later interviews may be coded with the constructed theory in mind. Through focused coding the most frequently discussed codes are identified; the focused codes become more selective and conceptual compared to the line-by-line initial coding because they synthesize and explain the larger amounts of data. During this period, decisions are made regarding the initial codes in terms of what makes most ‘sense’ i.e. what is this category suggesting given the data it is constructed from. To enhance this, the researcher returns to previous coded interviews, to compare the data in attempt to enhance meaning. This process allows for exploration of whether categories were singular or could be differentiated into sub-categories (McLeod, 2003) with the use of constant comparison. Through focussed coding Jones, Kriflik and Zanko (2005) suggest that researchers filter data and explore the most pertinent passages of the transcript.

Constant comparison - Initially constant comparison is used to find differences and similarities between data and over time establishes analytic distinctions. Using sequential comparisons and comparing accounts during different stages of the same interview enables the researcher to understand the developing constructs. Meanings and factors are never dismissed by the researcher, especially when the findings do not match pre-conceived beliefs; instead the constant comparison analysis is used to make sense of the material, in light of, and despite of, taken-for-granted understanding, beliefs or views. Constant comparison embodies an approach for understanding situations, with awareness that perspectives represent just one view and the researcher’s goal is to understand how the participant sees and interprets their situation (Charmaz, 2006).

Memos - During this analysis process, memos (notes made throughout the research relating to the developing hypotheses) are documented. Memos provide a valid reference when mapping the grounded theory and add substance to the relationships between categories (Bentan, 2000). Charmaz (2001) advocates that the researcher, as author, should develop memos to keep the participant’s voice and meaning present in the theoretical outcome. Memos were written throughout the research process to aid productivity, reflexivity and to promote analysis and the developing grounded theory, in line with recommendations by Charmaz (2006).

Theoretical Sufficiency - The research continued until ‘theoretical sufficiency’ was achieved, which Dey (1999) suggests is an appropriate time for coding to cease because new data is not extending or modifying the categories. Theoretical sufficiency does not necessarily mean a category is methodically exhausted, rather it implies the category is sufficiently adequate to be included without major adaptations or modifications (Dey, 1999). At this time coding can cease. In this study, it meant that each time a category or sub-category re-emerged, what the participant had described did not provide new insight into the category.

Integrating memos and developing the diagram - Memos were sorted and integrated into the categories relating to the data. Charmaz (2006) notes that ideas and tensions between data can be explored with memos, and contribute to the development of categories which are seen as the researcher’s (as author’s) theoretical interpretation. Within constructionist grounded theory, the style of writing needs to emphasise and maintain the participants’ presence and communicate how participants construct their experiences, processes and worlds (Charmaz, 2001). Throughout this process demonstrative quotes were compiled to illustrate the story to enhance the developing diagrammed concept model. During this phase, researchers should remain reflexive in their approaches as they interpret and guide analysis to minimise any moves away from the actual experiences presented. This is why further sampling is useful i.e. to illuminate categories and aid the researcher to re-explore questions and develop new questions in light of categories to promote understanding and theoretical sufficiency within that category.

Chiovitt and Piran (2003) suggest that the validity and rigour of the developing theory can be ensured in the following ways:

i. Credibility i.e. encourage participants to guide the research through using open questions and to use their own words within the developing theory
ii. Auditability i.e. specifying the researcher’s own assumptions which influence the study and

iii. Fittingness i.e. to link the literature to the generated theory.

Using these guidelines the model was developed to include quotations from the participants, which linked to the categories. To enhance the validity of the diagram model and the constructed interpretation of experiences, the researcher engaged in a process of member checking whereby four participants reviewed and commented on the model via telephone (copies of the model were provided for consideration). All four fed back that the model accurately reflected their experiences. Some suggested that the struggles they experienced were evident but the child's experience was not. For example, one participant commented that the child's voice was not present, outlining the constant focus of the parent upon the child, thus re-enforcing the 'focussing on the needs of the child' sub-category. Participants were specifically supportive of the adjustment to the decision category and how this impacted on them personally; one participant stated that this stage was the hardest part of the decision making process. This feedback guided the development of the model and its flow, reinforcing its validity; critical evaluation of this approach will be reviewed in the discussion section.

REFLEXIVITY

One danger inherent in qualitative research is that the researcher only notices material that supports their hypotheses (Babbie,1999). Glaser (1992) suggests that existing knowledge, which relates to the research area, may guide researcher assumptions and Urquhart, Lehmann and Myers (2010) suggest that researchers should ensure that their prior experience and knowledge does not lead to pre-formulated hypotheses as these can hinder the construction of ideas. I therefore aimed to acknowledge my existing ideas and assumptions in an attempt to 'allow the data to speak for itself' (Hill et al., 1997) whilst being mindful to understand how my knowledge and ideas could impact on the research. I tried to remain open to the themes through an in-depth re-reading of the transcripts, with regular discussions and explorations with the supervisory team, by sticking closely to the grounded theory method and being mindful of the need for reflexivity.

As a reflexive research practitioner, I support Etherington's (2004) view that our identities are constantly changing and developing based on our experiences. By using reflexivity I strove to notice how these experiences and responses impacted on my knowledge and actions. Having this awareness encouraged me to better understand how I interpret my social world, which Etherington (2004) suggests is needed within research practice as researchers' questions are located within themselves. With this in mind, it is important to understand and consider our own objectives, assumptions and biases as these potentially impact on why we chose the specific subject of interest. Understanding this aids awareness of researcher bias and acceptance that previous knowledge and experience will impact on the study (Mykhalousking, 1997). Therefore rather than seeking neutralisation, Etherington (2004) suggests that researchers accept and explore their own knowledge and experiences and embrace these as legitimate sources of knowledge.

Cutcliffe (2003) stresses the importance of researchers sharing their experiences with their readers, so that readers can understand the researcher's perspective; to this end, I will outline my interest in the research question, which was stimulated by seven years of experiences within private and NHS residential settings as an assistant psychologist with adults and children diagnosed with varying degrees of learning disabilities and associated complexities. I have counselled individuals of all ages with learning disabilities (who live with family or in out-of-home care) and also employees working in this area while working as a trainee counselling psychologist. This experience included liaising with families and assessing children before they enter the residential settings where I have worked. From these experiences, I noted the challenges that parents and children faced as they sought support and their fear of the support also. I completed counselling courses to aid my ability to manage these situations personally, and my interest in these led to my doctoral studies.

As part of my doctoral studies (and within my role as a trainee counselling psychologist), I conducted research, in my second year, into the interpersonal dynamics among employees within residential settings. During this research many employees discussed their issues, feelings, concerns and experiences within their work environment which included frequent disagreements with parents. As my experience grew, my research interests transformed into a desire to explore the processes experienced by parents in these circumstances. I currently work within an early interventions team (linked to social services) working with families who have children ‘on the edge of care’ (which means social services have concerns that parents are unable to support their child at home due to possible abuse or neglect). The aim of my team is to support families to manage the care of their child in an attempt to decrease the number of children requiring out-of-home care such as foster care, respite and placements – both voluntary and involuntary. I work with reunification, supporting troubled families and developing interventions to aid family support in line with the social care agenda. These experiences sparked an ongoing interest in families and their troubled dynamics, as I gained first-hand experience of working with individuals who were seeking out-of-home support for disabled (and non-disabled) children and those who were under care orders or child protection plans. From this I became interested in how parents’ individual experiences of caring for a child with disabilities contributes to decision making regarding their care and how this psychologically impacts on the parent, the child and the family. I was motivated to understand the impact this decision (i.e. to continue providing care, or to place their child into out-of-home care) had on parents because I had experienced some who seemed to struggle and others who seems to adjust more easily.

Given my previous knowledge and experience within this field and with an understanding of the troubling dynamics which I have experienced as a result, I recognise that my theoretical constructions will be influenced by my experiences. McGhee, Marlans and Atkinson (2007) suggest that researchers have no control over what is already known to them; however they can control what is added to their knowledge base. With this in mind, it is important to acknowledge my prior assumptions in line with past experiences and viewpoints based on my past knowledge of supporting family members prior to and during their child moving into differing forms of care. This forms part of my reflexivity. At the start of the project, I made note of any expectations that I had and considered my biases. Through this process I acknowledged that I hold a number of biases towards social care which include a belief that social workers lack a focus on the needs of the family and focus solely on the physical needs of a child without always considering the emotional impact on the child. My standpoint towards social workers relates to past experiences within residential care and there is a constant battle to reduce costs i.e. to not always provide the support needed on an individual basis. However I have for the past year worked within a social care team, and my view of social care has softened to understand the constraints they are limited by. However coming from such a standpoint means I hold assumptions that social care is not particularly helpful to families. Furthermore I have met families who have expressed their experiences of this process in both positive and negative terms. I therefore hold a standpoint that experiences of parenting a child with disabilities is challenging and choosing care is utilised to reduce the parental stress. I have to recognise the potential impact of my reactions when parents discuss social care involvement, as my subtle non-verbal responses may indicate my bias. I acknowledge that as the researcher I play a key role in the research process, and my reactions will impact on both my participants and my data analysis. For example, I could miss potentially relevant information which contradicts my assumptions. I discussed these issues with my supervisory team and documented my expectations of the research as part of a reflective journal. I consciously thought through possible biases such as these, before the research began and also during the research phase. A reflective diary was kept, as well as field notes following each interview, survey, phone call, training event, discussion or email to aid the research process. Furthermore to aid validity and reflexivity, participants were encouraged to view and comment on the model.

I also considered how my gender, culture, class and ethnicity potentially impacts on my participants and on my data analysis. Firstly I note that I am a female researcher in her early thirties who is of white British ethnicity. I come from a working-class background and work in a middle-class profession; as such I can sustain myself personally and financially without needing support from others. I do not have any disabilities and I have no dependents. This position means that I have not experienced direct discrimination, and neither have I experienced parenthood. As a researcher these factors potentially influence my topic of interest and the reactions of participants when they talk to me about these experiences they have had, which I have not had personally.

Denscombe (2007) outlined the disadvantages of face to face interviews in regards to the different responses participants may have depending on their view of the researcher which is known as ‘interviewer effect’ for example, gender, age, ethnic origin. This potentially impacts on the amount of information participants are ‘willing’ to share and their honesty. In this study it is impossible to fully explore if these factors affected the data, but it is important to acknowledge their potential impact.

I have had my own experiences of working with families and understand how my position as a trainee counselling psychologist may influence participants and that their previous experience with social services, society, organisations and professionals, may mean they perceive me as being part of the system against which they have experiences and expectations i.e. of how I will react to them or of my expectations of them. They may have had concerns relating to my opinions about out-of-home care and learning disabilities generally. Social constructionists invite researchers to consider their own experiences and meanings and to accept that within qualitative research, analysis links to the co-constituted account (Finlay, 2002). This is why reflexivity is beneficial as it accepts that the researcher shapes the construction of the research. To manage this (and to minimise my impact on the participants), I attempted to give adequate timing to allow participants to share their stories and aimed not to indicate any personal reactions to their stories.

I note that some of my own responses included feeling sad, upset, disempowered, anxious and angry as they shared their struggles and experiences. Hunt (1989) illustrates that when participating in research, some may experience such feelings as well as helplessness and loneliness as they re-live the context being discussed. As a professional who strives to support individuals suffering distress and uncertainty, it was challenging for me to hear their stories of discrimination and professional ignorance. As a trainee counselling psychologist I sometimes felt ashamed of being someone who works within the field. I also noted feeling frustrated when some participants described the abuse which had occurred when their child was in care and surprisingly how some participants seemed to accept that this was par for the course. This upset me because clearly, poor care is not acceptable.

These responses can be explored in the light of the psychodynamic literature which emphasises how unconscious needs and transferences occur within the researcher-participant relationship which Parker (1997) suggests is useful when the researcher reflects on why a participant’s story specifically ‘moved’ them. Overall my strongest response was one of wanting to share their stories and highlight them in my research to ensure the decision-making processes and related elements are appropriate for carers, parents, children, professionals and organisations. This is due to my increasingly conscious awareness of a need to help others, which links to my choosing a role which involves supporting people. During the process of transcription I recorded my feelings and reactions to the experiences being articulated by the participants and shared these with my research supervisors. Finlay (2002) outlines that such reflection should begin once the research is conceived, in an attempt to examine personal relationships which might skew the research in a particular direction. This served to aid reflexivity and the analysis process.

RESULTS

A substantive theory was constructed from the analysed data illuminating a cyclical process whereby participants struggled to cope with threats to their identity evoked by their learning disabled child, their internalised norms about parenting, stigmatisation and the lack of professional support and understanding. To defend against the threats to their identity, participants attempted to create a compensatory 'good parent' identity through focusing selflessly on the needs of the child, becoming an 'expert parent' and advocating. Defensively, difficult feelings towards their child appeared to be minimised; the 'system' became the focus of their anger, rather than the child. Throughout there was a sense that their concerns were not being heard by professionals, especially as they fought for diagnosis; this pushed them into a sense of 'coping not living'. In a desperate attempt to preserve their 'good parent' identity, they told themselves that they could cope. This denial often led to relational and financial difficulties, which, when coupled with a lack of social and professional support led eventually to mental health difficulties and finally, to becoming completely overwhelmed and to 'breaking point'. 'Breaking point' aided admission (to the self) that they could not cope and motivated decision making to place the child into care; this led to further guilt and reinforced the negative parental identity. Parents then needed to re-build self-esteem and were back in the cycle of creating a compensatory identity and 'fighting the system' to convince professionals that they needed the placement. Once the move occurred, participants had to adjust to their decision and the loss of both their child and their parental role, which led to becoming over involved (as the expert parent and clashing with service providers), or being redundant; both caused a dilemma in terms of assessing parenting roles and identities which contributed to stress. This process was on-going as the parent constantly monitored and evaluated the care, linking to the continuous nature of the process.

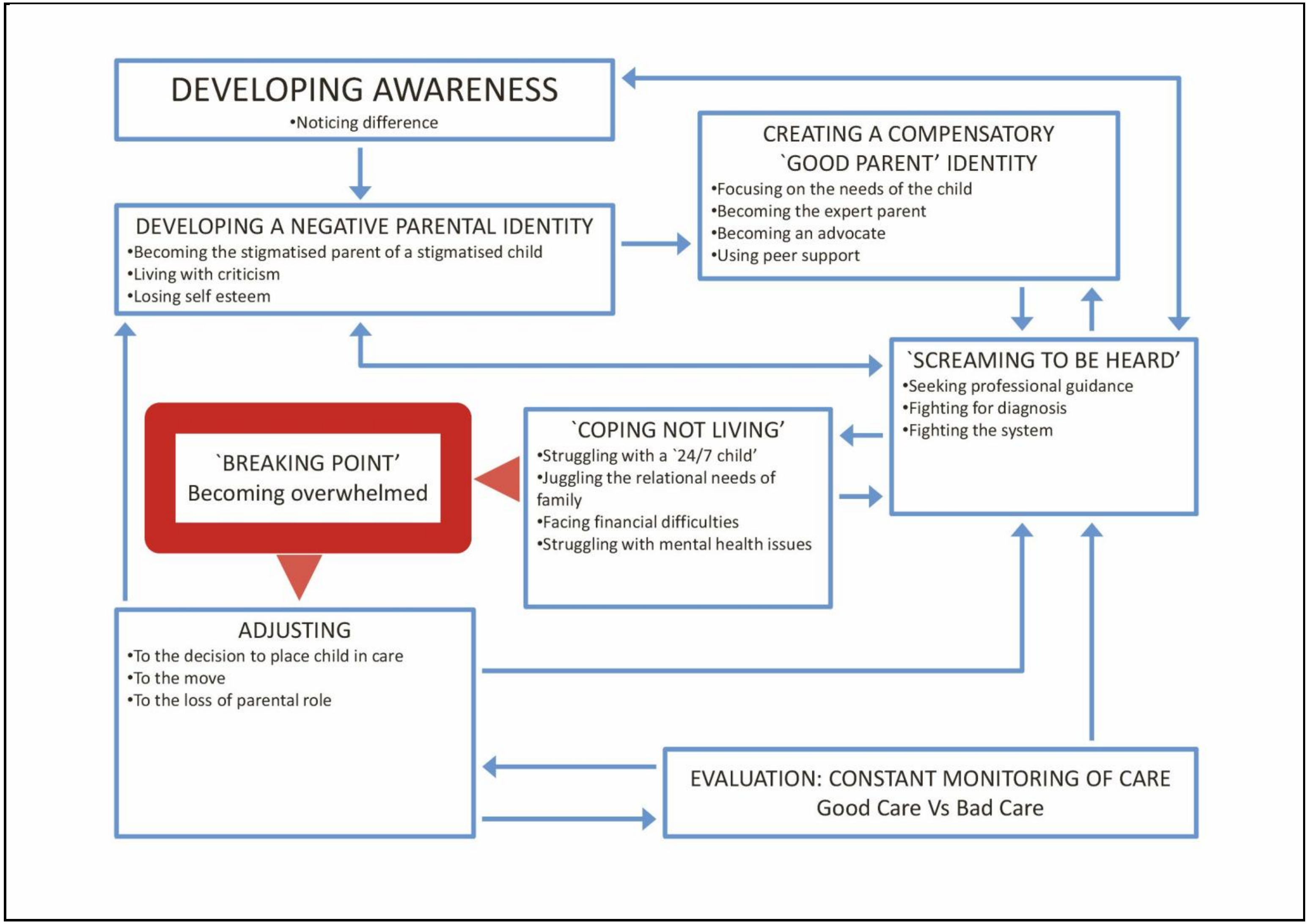

Figure 2 – Psychosocial model: Placing a child with learning disabilities into out-of-home care: Parents' / caregivers' identity, decision making processes & breaking point

DEVELOPING AWARENESS

Noticing difference

The majority of participants described the first step in the process as one of noticing difference. This was based on early subtle differences in their child, linked to delays in developmental milestones such as switching off or showing a lack of interest in their surroundings:

> *"After almost a year he was not progressing normally, he seemed to switch off from time to time for several hours, that is taking no interest in his surroundings, food and making no attempt to move to crawl*" [Participant 9 - Father of son with Down's syndrome, learning disabilities and challenging behaviour, in out-of-home care.]

A significant element within this process was when parents directly compared their child to those of similar ages, which served to enhance their developing awareness of the differences:

> *"I really began to realise he had problems, he just wasn't developing as fast as my friends children who were all about the same age"* [Participant 6 - mother of son with Fragile x syndrome, learning disabilities and aphasia, in out-of-home care.]

These subtle observations caused parental concern at a time when the parent was developing a new relationship with the child and developing their own parental identity. Despite noticing differences, the awareness that there was an actual disability remained unclear and the parent did not understand what the differences indicated:

> *"It was not something that I could define, it was just that he acted very different"* [Participant 17 - Mother of son with ADHD, autism, learning disabilities, challenging behaviour and no verbal communication, in out-of-home care.]

The terminology used by participants during this early stage was filled with subtle but negative connotations with parents using words such as 'problem', 'difference' and 'not progressing normally' to explain their child.

Participants described how concerns about their child's development were exacerbated by social encounters such as attending play group; at this stage parents received feedback from others about differences such as the child not crawling, speaking or interacting with the environment. This served to enhance the parents' awareness that there may be an issue or even a disability, but they remained uncertain.

> *"you've sort of got a group of Mums and babies and people don't really know what to say... they are starting to see that your baby wasn't doing what babies should be doing and that my baby wasn't and there was that awkwardness"* [Participant 10 - Mother of daughter with autism, epilepsy, chromosome disorder, learning disabilities and challenging behaviour, in out-of-home care.]

> *"You know and he just wasn't able to mix and the more…other kids were interacting and playing and doing all the normal things, the more he would be off in a corner"* [Participant 18 - Mother of son with autism, learning disabilities, communication difficulties, considering out-of-home care.]

Participants described how other people often didn't know how to react to the parent or the child (possibly echoing the parents' own reactions to their child).

DEVELOPING A NEGATIVE PARENTAL IDENTITY

These responses then increased the parents' sense that there was something wrong which was internalised as the first steps to seeing themselves as being a 'bad parent'. This negative internalisation appeared to be exacerbated by the parents own struggle to understand their child and to contain their difficult feelings towards their child whom they did not fully understand.

Becoming the stigmatised parent of the stigmatised child

Over time, participants described experiencing social prejudice (segregation, isolation and marginalisation), which contributed to the development of a negative identity. This stigmatisation was generally focussed on the child, but by default overtime experienced and internalised by the parent. Participants outlined examples of ‘enacted’ stigma such as outright discrimination:

> *“I found it was um, sometimes harder coping with other people actually than coping with my daughter, like at village play group for example one of the mums was awful, was absolutely awful to us .... And it was so upsetting that some of the things she was saying”* [Participant 4 - Mother of daughter with autism, mild learning disabilities, in out-of-home care.]

Other participants described ‘felt’ stigma i.e. not direct discrimination, rather members of the public stared or whispered, which was internalised as fear and shame when their child presented atypical behaviours such as hitting others, biting and constantly screaming:

> *“People would just look at you as if to say keep that child under control”* [Participant 15 - Mother of son with learning disabilities, asperger’s syndrome, has been in out-of-home care but currently at family home.]

Participants responded by constructing themselves as ‘bad parents’ for not managing their child, which was further exacerbated because support networks reduced:

> *“We lost a lot of friends and relatives because they didn’t understand um what to do or what to, they would just avoid us. Even the church that I used to go to and I used to take [name of son] to church.... it was like the red sea opening again people would see us and cross the street to walk on the other side of the road”* [Participant 17 - Mother of son with ADHD, autism, learning disabilities, challenging behaviour and no verbal communication, in out-of-home care.]

This sister outlined how she tried to understand the social reactions to her brother’s disability and concluded that society views those with disability and differences as ‘sub-human’, which contributes to the internalisation of stigmatisation:

> *“I think a lot of it is lack of respect for other people, just seeing people with disabilities as other, sub-human other, just in the same way that some people you know have racial prejudices”* [Participant 14 - Sister of a brother with

> learning disabilities, Aspergers syndrome, has been in out-of-home care but currently at family home.]

These experiences occurred when the parent and family were already struggling to manage and understand their child.

Living with criticism

Many of the participants experienced criticism alongside stigmatisation, mainly comments by other people relating to the parents ability. This had long-lasting negative impacts on participant's identity i.e. viewing themselves as 'bad parents'.

> *"She was my first child... I think they could see that [name of daughter] had delayed development, but I think they possibly thought that it was the way I was managing her that was causing the behaviour and I don't think they realised how difficult it was"* [Participant 10 - Mother of daughter with autism, epilepsy, chromosome disorder, learning disabilities and challenging behaviour, in out-of-home care.]
>
> *"I was constantly being told that it was my parenting skills and that I couldn't blame my daughter, that I was exaggerating".* [Participant 6 - mother of son with Fragile-X syndrome, learning disabilities and aphasia, in out-of-home care.]

When the disability was not visually identifiable, such as autism or a learning disability, participants experienced a deepening internalisation of stigmatisation following criticism, especially when their child acted in a perceived 'non socially typical way' such as screaming or hitting themselves. Some participants believed that because their child did not 'appear disabled' or in most cases did not have a diagnosis (thus parents could not understand their child's needs fully) they were 'blamed' for poor parenting. This social reaction further reinforced the parent's sense of identity as deficient, as society implied *they* could do better, and the parent was left feeling criticised as if they were 'doing it wrong':

> *"because he looked normal... when he played up in a shop or other public place, people would make comments like if he was mine, I'd give him a good hiding, they were blaming me"* [Participant 16 - mother of son with Fragile X syndrome, learning disabilities and aphasic, in out-of-home care.]

However some participants acknowledged that even when a disability was 'seen' or more easily noticed by others, such as Down's syndrome, they continued to experience criticism (mainly in the form of 'if he were my child I could do better').

Losing self-esteem

Feeling stigmatised and experiencing external criticism led to participants blaming themselves, which affected their self-esteem. In these situations, participants tended to internalise others' hostile behaviours and comments. This internalisation impacted their self-esteem over time. For example this father outlined how perceived hostility towards his son's challenging behaviours reinforced a negative sense of himself due to his inability to manage and understand his son's needs (at this time prior to actual diagnosis) which contributed to his losing self-esteem and social isolation:

> *"I worry about being judged by other people and this reinforces my feeling of worthlessness"* [Participant 8 - Father of son with moderate learning disabilities, epilepsy, autism, chromosome abnormality and challenging behaviour, in out-of-home care.]

As indicated above, the external reactions of others reinforced self-criticism and poor self-esteem.

> *"I lost a lot of confidence and I felt that I was being seen as this first time mum and I just wasn't a very good parent".* [Participant 10 - Mother of daughter with autism, epilepsy, chromosome disorder, learning disabilities and challenging behaviour, in out-of-home care.]

Participants' experiences did not appear to be recognised as important amongst others, friends, family and professionals; their struggles to manage seemed to be 'ignored', and instead a construction of blame towards the parent for 'doing it wrong' served to reinforce a negative parental identity:

> *“I thought she was being mildly slow and I was kind of blaming myself”*
> [Participant 10 - Mother of daughter with autism, epilepsy, chromosome disorder, learning disabilities and challenging behaviour, in out-of-home care.]

CREATING A COMPENSATORY ‘GOOD PARENT IDENTITY’

In order for parents to defend against the threat to their identity, they appeared to create a *compensatory good parent identity*. To achieve this, participants focused selflessly on the needs of the child, often neglecting their own needs in the process. Defensively, difficult feelings towards their child were minimised through this phase with a focus instead on unconditional love. Participants seemed to find it more tolerable to blame the ‘system’ and professionals rather than the child, possibly defending against the anxiety evoked by these feelings by projecting them onto the external world. Difficult feelings became focused on *fighting the system* rather than on battling with the child, and on not being heard by the system, rather than not being heard by the child. The parents seemed to be convincing themselves they alone could cope; that the difficulties were external rather than internal because external influences (society) to date had been unsatisfactory and damaging.

Focusing on the needs of the child

Participants described caring for their child with limited external support. This isolation maintained the focus on the needs of the child because parental experience so far had generally related to a lack of acceptance and reliance on others, motivating them to cope, by developing their own deep understanding of their child’s complex and individual needs. Focussing on the needs of their child and developing a sense of knowing the child better than others, served to enhance the participants’ self-esteem as they undertook the 24/7 caring role and over time perceiving themselves to be ‘the best carer’ for their child.

> *“we were the only people who knew him...you can’t just hand them to somebody who doesn’t understand them and expect them to cope”*
> [Participant 7 - Mother of son with moderate learning disabilities, epilepsy, autism, chromosome abnormality and challenging behaviour, in out-of-home care.]

However, somewhat paradoxically, the compensatory belief that others cannot be trusted seemed to leave primary carers with the predicament of either caring themselves or receiving support from people they didn't feel able to trust. Participants described how this psychological conflict between wanting to care for their child because they could not trust others, versus the uncertainly of being able to manage forever, caused guilt and anxiety. In some cases what appeared to be a projection of difficult feelings towards the child onto others, exacerbated the sense that others couldn't be trusted, leaving participants with little psychological choice other than to focus selflessly on their child's needs. To manage this, participants appeared to neglect their own needs and appeared reluctant to seek out-of-home care or respite (at this stage) due to a pattern of focussing their needs solely on the child and filling their time:

> *"Filling his time is a major thing for us, and once he gets bored and I think then a degree of frustration sets in and that is when you start to have behaviour problems.... as long as you can keep him occupied um something that he may be interested in although that is quite difficult .... We have to just keep thinking of things"* [Participant 3 - Mother of son with apert syndrome, autism, learning disabilities and challenging behaviours, in out-of-home care]

It was apparent that throughout the interviews parents/carers never spoke of being angry, frustrated or annoyed at their child, even when faced with a child's incredible loudness, as one parent laughed *"he has no volume control"* and another explained with humour that a six foot tall man *"jumping up and down, woof, woofing"* in the lounge was *not easy*. There is potential that the anxiety evoked by these experiences was managed by psychological defences such as humour or displacement which enabled parents to be able to focus on the child's needs even while being overburdened:

> *"it's been a process, a tough process I mean she is absolutely adorable though and I wouldn't change her for anything. You know, she's my daughter and I love her to bits"* [Participant 4 - Mother of daughter with autism, mild learning disabilities, in out-of-home care.]

Becoming the expert parent

The need to become the expert parent seemed to be compensation for their 'bad parent' identity related to participants' negative experiences of society and from being discounted and dismissed by professionals when seeking to gain understanding and guidance (which is discussed in the category 'screaming to be heard'). Participants sought qualifications and experience to ensure they were informed about the (assumed or confirmed) disability. One participant completed a Master's degree in Autism because she suspected her child had autism (which was later diagnosed). Participants described how having time to research what their child's special needs were, assisted their psychological adjustment to their child's differences aiding coping and acceptance of their child. Becoming an expert meant they perceived themselves to know more than the 'experts' which compensated for previously not understanding their own child:

> *"I had read every book in the local library, I went to every course or conference or whatever to do with Autism... I even did a masters in Autism to try to understand him better and learn"* [Participant 13 - Mother of son with autism, severe learning disability, no speech and challenging behaviours, in out-of-home care.]
>
> *"I became a learning disability nurse because I was fed up of fighting on the outside and at meetings we were always treated as if we knew nothing about our children..... So I thought I would get as many qualifications as everybody else because then I could argue my point better. .... So I thought if I became a professional as well therefore they can't fight me quite so easily"* [Participant 17 - Mother of son with ADHD, autism, learning disabilities, challenging behaviour and no verbal communication, in out-of-home care.]

Other participants sought practical experiences which reinforced their expert parent identities, as this mother demonstrates:

> *"I have volunteered for different organisations so that I can keep up to date with information"* [Participant 12 - Mother of son with a heart condition, Down's syndrome, mild learning disability, living with parent.]

Gaining qualifications and experience enabled participants to defend against the negative feelings evoked during previous stages but the category was re-entered following diagnosis as a response to lacking professional support / guidance.

Becoming an advocate

Becoming an advocate allowed participants to support others which enhanced their identities as a competent parent i.e. they symbolically redefined their role as helping others in similar situations, contributing to a positive sense of self. This seemed to follow experiences with professionals i.e. during ‘screaming to be heard’, participants related their need to offer advocacy to others due to the lack of professional guidance over wanting or receiving diagnosis. Some used advocacy to fight discrimination for themselves and some wanted to use it to support others by changing policies:

> *“I think the whole system of support and the attitudes towards people with learning disabilities is um, just so much that’s wrong and needs changing. So I’m kind of not just doing it for [name of daughter], I’m doing it for that as well, for everyone else that’s been treated like she’s been treated”* [Participant 10 - Mother of daughter with autism, epilepsy, chromosome disorder, learning disabilities and challenging behaviour, in out-of-home care.]

By helping others, participants maximised their self-esteem and made positive contributions to peers and saw it as ‘giving something back’. This was achieved by sharing experiences and offering support on forums or in parenting groups which this father outlined was like therapy:

> “*We are more than happy to help as most people don’t realise some of these things you know.... the more I can do to help them you know it helps me in a way, it’s therapy for me”* [Participant 8 - Father of son with moderate learning disabilities, epilepsy, autism, chromosome abnormality and challenging behaviour, in out-of-home care.]

Using Peer Support

In many cases participants were not supported adequately by friends and family, and professional support was lacking. However, participants did benefit from peer support (group sessions) from those with similar experiences to their own. This aided their understanding of their child's needs, enhanced coping and reduced stress and isolation.

> *"It was once a week for two hours or maybe one hour but it felt the best respite I ever had and that was very good. All they did was chase [name of son] I think but for me it was sitting down and having a cup of tea with the other parents"* [Participant 13 - Mother of son with autism, severe learning disability, no speech and challenging behaviours, in out-of-home care.]

Peer support aided learning, awareness, coping and acceptance which promoted psychological adjustment and gave a sense of the unity and acceptance, which had been missing:

> *"I find the support groups are the ones that give you the actual practical support. Um yeah, yeah that is how I get support"* [Participant 18 - Mother of a son with autism, learning disabilities and communication difficulties. Parent considering out-of-home care for the first time.]

The support available varied with some experiencing face-to-face groups and others benefiting from social networking. These allowed participants to develop awareness and construct a view of their child's needs based on other's experiences and gave guidance and confidence to begin seeking a potential diagnosis:

> *"Six years later I am sort of learning more from parents than from anybody else, by going on Facebook and we just compare notes"* [Participant 10 - Mother of daughter with autism, epilepsy, chromosome disorder, learning disabilities and challenging behaviour, in out-of-home care.]

Creating a compensatory 'good parent' identity appeared to assist participants to channel struggles, frustrations and anxieties into positive actions. This coping strategy enabled participants to reconstruct their identities into being 'the best parent they can be' and to evaluate their situation and themselves in a more positive light, even while they were consciously or unconsciously struggling to manage.

The process, at this stage, moved parents towards seeking professional guidance in an attempt to develop needed understanding. By sharing their concerns with professionals they anticipated that they would be guided and receive needed answers about their child.

'SCREAMING TO BE HEARD'

This category was entered at differing times throughout the process. The three subcategories link to different stages and share a theme of participants needs not being recognised or validated by professionals. Initially, participants sought professional guidance and over time (as their awareness of their child's differences grew) they sought diagnosis. Once breaking point was reached, they then 'fought the system' to convince professionals that out-of-home care was needed.

Participants described how they attempted to ascertain a more thorough awareness of their child's needs by seeking professional guidance and support. They also described their distress when they found that responses from professionals included being disbelieved, judged and perceived as 'not good parents'. The impact of the stress and strain was enhanced by the evaluation that professionals did not care, as demonstrated here;

> *"I have horrendous guilt about everything for him and I have been suicidal at times I have thought about driving off a cliff with him... nobody really gives a damn, you know you have all these professionals telling you they care and they don't"* [Participant 17 - Mother of son with ADHD, autism, learning disabilities, challenging behaviour and no verbal communication, in out-of-home care.]

This mother illustrated the longevity of fighting professionals due to not being heard over decades:

> *"I have been fighting professionals for 16 years, longer than that, quite a big statement isn't it really, but yes to get exactly what we need with social services, mental health and education"* [Participant 6 - Adoptive mother of daughter with mild learning disability, autism, disorganised attachment disorder and challenging behaviour, in out-of-home care.]

Seeking professional guidance

Participants outlined anxiety and struggles when speaking to professionals especially when they were noticing differences in their child but had not yet considered or received a diagnosis. Many described how professionals did not take their concerns seriously. One mother outlined how her role and supposed incompetence was used by a professional to justify why her child was challenging (rather than considering there may be a learning disability or neurological issue, which was later confirmed as mild learning disabilities and autism). This impacted significantly on the mother's emotional frailty at a time when she was trying to understand her child and developing as a new parent; her relational expectations of her child were not met as the child responded with constant crying when the mother attempted to attend to her needs. These experiences coupled with the response from professionals, contributed to a sense of herself as 'a bad mother' linking and contributing to the development of a negative parental identity, based on personal responses:

> *"I had very little understanding I was a first time parent .... I kept saying that something is not quite right can't put my finger on it she's quite challenging, to be told that she just needs a mother"* [Participant 6 - Adoptive mother of daughter with mild learning disability, autism, disorganised passionate disorder and challenging behaviour, in out-of-home care.]

Such experiences linked to displeasure and anger towards health care professionals, and remained evident throughout the process, as outlined when parents later sought diagnosis and eventually out-of-home care (i.e. they had constructed a view that professionals would let them down) as such it appeared that the reactions of professionals had long-lasting implications. Struggling with concerns and perceptions of not being taken seriously during the child's early years and beyond, ignited parent / professional conflict.

> *"His behaviour became very unpredictable and increasingly violent. I regularly asked for help from the doctor and psychologist, but since my son only became violent at home they couldn't see what the problem was"* [Participant 16 - mother of son with Fragile x syndrome, learning disabilities and aphasia, in out-of-home care.]

This parent / professional conflict affected the families' welfare and jeopardised future professional input i.e. families may not seek help due to early negative experiences which enhances their mistrust of professional support.

> *"I was extremely frustrated because nobody would believe what [name of son] was like and therefore were not listening to my concerns. I was also exhausted, with my health close to a break down"* [Participant 16 - mother of son with Fragile-X syndrome, learning disabilities and aphasia, in out-of-home care.]

Participants' awareness was not enhanced in a positive way during the process and they remained unclear as to whether their child's differences were based on their own perceptions or due to their parenting abilities. This set a framework of self-blame which fed into the '*developing negative parental identity'* category.

Fighting for diagnosis

Participants described struggling to gain diagnosis which caused stress and in some cases took decades to achieve. Furthermore, many participants described how their search for diagnosis was quashed by professionals dismissing the child's symptoms, especially in the early years. Participants described how they fought the system to have what they saw as their right i.e. to have their child assessed and diagnosed. In all cases, parents assumed there were underlying problems and diagnosis was eventually obtained. Participants were specifically interested in the dual diagnoses i.e. learning disability with additional disabilities such as autism, because they wanted to understand the behaviours which were not necessarily linked to learning disability alone. Challenging behaviour was the most concerning issue for participants and the factor which they mainly sought answers and support for. One participant outlined that diagnosis was significantly reassuring because it aided her understanding:

> *"It is still that feeling of sort of having a medical label of your child makes a huge difference"* [Participant 10 - Mother of daughter with autism, epilepsy, chromosome disorder, learning disabilities and challenging behaviour, in out-of-home care.]

Confirming diagnoses came as a shock in some cases, even though in this example the physical awareness of the disability (Down's syndrome) was evident, yet participants still required clarification in the form of a formal diagnosis:

> *"The diagnosis was a shock to us his parents and of course to other family members, grandparents, etc. as his older sister and brother were perfectly normal"* [Participant 9 - Father of son with Down's syndrome, learning disabilities and challenging behaviour, in out-of-home care.]

A diagnosis was sometimes immediately given i.e. Down's syndrome or fragile X syndrome (usually when there were observable characteristics), but in other cases took decades to achieve:

> *"We had to constantly fight .... We knew something obviously wasn't right and that was incredibly difficult and I remember we wrote lots of constant letters to various people.... we felt we were in need of a diagnosis and they said we don't like labels and we said well tough, we need one"* [Participant 17 - Mother of son with ADHD, autism, learning disabilities, challenging behaviour and no verbal communication, in out-of-home care.]

Formal diagnosis was important to all participants. Firstly they had suspicions that their child had a disability which was supported by knowledge gained through research, and by talking to peers. Secondly, following obstacles with professionals and a 'lack of support', diagnosis served to validate the parents' concerns. This in turn potentially reduced the internalised guilt as parents could move towards blaming the diagnosis for their child's difficulties rather than themselves, or the child. The emotional impact of having or not having a diagnosis influenced participants' interpretations of the child's issues, as either an actual disability or a non-diagnosed yet perceived disability. The diagnosis appeared to be an anchor for many participants in their search for understanding, and aided them in considering future options regarding the care of their child. There also seemed to be a sense of belonging once diagnosis was received as they could sign up to support groups and enhance their knowledge. Fighting the system is a process, within this category, which was entered following 'breaking point' and discussed later.

'COPING NOT LIVING'

Even with a formal diagnosis and assessment of need, it appeared that providing consistent care generally fell to the parent and dominated their lives with emotional and social costs. As participants gained awareness and understanding of their child's disability, they desperately attempted to preserve their 'good parent' identity in the ways previously outlined. In doing so the parents convinced themselves they could cope with their child's care needs. In trying to cope they appeared to neglect their own needs and in many cases, those of their family, which led to family and relationship breakdown in many cases. These stressors accompanied by financial difficulties and coupled with lack of social and professional support led to *'coping not living'* :

> *"We've just been coping we haven't been living to be honest"* [Participant 8 - Father of son with moderate learning disabilities, epilepsy, autism, chromosome abnormality and challenging behaviour, in out-of-home care]

Struggling to cope with the continuous child care was further complicated by the parents' grief for the child they had anticipated, and their attempts to adjust their identity to that of the parent of a disabled child. This mother outlined challenges adjusting to what she terms the 'mental element' of the disability (the learning disability) as she recognised the social implications because medical intervention could not change the situation and the parent knows her child will not change cognitively:

> "*it's amazing what they can do with the physical side of things the surgery and so on it's absolutely amazing, um but the mental stuff, is just something else,*

> *isn't it. It's just difficult to get a grip on and think about how to help them best, especially when it's got all the social implications hasn't it, so um, yeah"* [Participant 3 - Mother of son with apert syndrome, autism, learning disabilities and challenging behaviours, in out-of-home care]

The experience of coping not living was echoed by this mother who identified that day-to-day caring was a challenge but she continued to fulfil a caring role for over eighteen years:

> *"The home situation is getting more difficult because it is increasingly affecting our lives"* [Participant 18 - Mother of son with autism, learning disabilities, communication difficulties, considering out-of-home care.]

Struggling to cope with a '24/7 child'

The severity and type of disability present was influential i.e. the more complex the needs of the child the more stressful the parenting role and the greater the struggle. This participant outlined how professionals could not provide adequate support or respite due to the child's complex needs, yet the mother was assumed to be able to manage with the 24/7 caring role, even though she had additional children to support:

> *"all the professionals are saying they can't cope, but there was me with 3 other children at home supposed to cope where none of the professionals could which was really weird"* [Participant 15 - Mother with a son who has learning disabilities and Aspergers syndrome, has been in out-of-home care but currently at family home.]

The most significant struggle for participants was to manage their child's challenging behaviours. The struggle was exacerbated by growing awareness that the responsibility of care would not reduce as the child aged, as they always require some level of support:

> *"it's just like having a big version of a small child really isn't it, You can't leave them they're not doing their own thing they are always doing whatever you are doing or sorted out for them to do so it's just like having an extension of a young child really I suppose"* [Participant 3 - Mother of a son with apert

> syndrome, autism, learning disabilities and challenging behaviours, in out-of-home care]
>
> *"I tried to cope as much as I could...we didn't have any access to any nursing help, night time or anything, no help around the house, nothing, we just had to cope the best we could, you know, that was extremely, extremely difficult"* [Participant 7 - Mother of son in out-of-home care.]

As time passed the child's needs took an emotional toll on the caregiver due to constant supervision especially as the child aged and grew in size. Many participants outlined that lack of sleep was an issue and they were unable to rely on others for child-minding which came at the expense of all family members and their relationships.

Juggling the relational needs of the family

*S*trained relationships were common, due to parents' focusing on the constant caring needs of their disabled child.

> *"It did get to a crisis point where it wasn't that we didn't care for each other but we just couldn't cope with the situation we were in with the children that we were thinking of separating"* [Participant 6 - Adoptive mother of daughter with mild learning disability, autism, disorganised passionate disorder and challenging behaviour, in out-of-home care.]

Some participants experienced separation due to living stressful and almost separate lives because of the constant caring needs of their child. This had repercussions on the remaining carer's ability to manage because the caring role was focussed on one parent. This participant outlined how her husband left due to having mental health issues:

> *"You know [name of ex-husband] just couldn't cope with it. He really couldn't he got very fragile, he had a breakdown".* [Participant 15 - Mother of son with learning disabilities and aspergers' syndrome, has been in out-of-home care but currently at family home.]

Participants also described the struggle to manage the relationship between themselves and their disabled child.

> *"The whole thing was absolutely horrible and um of course I felt really guilty and um I also felt faint-hearted because you know he was damaging me a lot and it's not very nice when you are frightened of your child"* [Participant 17 - Mother of son with ADHD, autism, learning disabilities, challenging behaviour and no verbal communication, in out-of-home care.]

As a result, the family dynamics between siblings and parents was adapted to compensate for the caring needs, often resulting in isolation between siblings and parents rather than family unity;

> *"If we were going out, trying to do something with the children, one would take one and one would take the other, we just couldn't work as a family anymore"* [Participant 13 - Mother of son with autism, severe learning disability, no speech and challenging behaviours, in out-of-home care.]

To manage relationships, parents seemed to blame themselves and internalised the feelings of guilt relating to the situation. They did not focus anger or blame on the child; this is potentially because externalising feelings towards the disabled child may have been too damaging psychologically as the child is the one in need of parental support and care. This mother explained that she sacrificed her other son due to providing constant care for her disabled son, leading to guilt:

> *"We had sacrificed (name of son without LD) for (name of son who had a LD), and so (name of other son without LD) lost out a lot, and in the end he probably came to hate, he's frightened of (name of son with LD), yes exactly frightened and he's told me that he thinks that if he ever got into a fight with (name of son with LD) he would you know, kick him to death and of course I then feel guilty". [*Participant 17 - Mother of son with ADHD, autism, learning disabilities, challenging behaviour and no verbal communication, in out-of-home care.]

The caring needs and the presence of the disabled child affected parent-child relationships and sibling relationships, and added layers of complexity to already stressful and isolating experiences. Participants seemed to feel obliged to manage the relationship and safety needs of all their children. The relationship between siblings was complex and in this example, the child with the disability was presenting challenging behaviours towards his siblings, which the parent recognised over time and was compelled to manage.

> *"It was apparent his needs were having an adverse impact on the upbringing of his elder brother and sister"* [Participant 9 - Father of son with Down's syndrome, learning disabilities and challenging behaviour, in out-of-home care.]

To ensure the safety of siblings, participants implemented constant vigilance to reduce the risk of harm. This was not always possible and took an emotional toll on the primary carer as they struggled to cope and evaluate their parental identities in relation to their ability to support all their children:

> *"He would focus his stress and frustration on one particular totally innocent person, and um when he was at home, it was his little sister".* [Participant 3 - Mother of son with apert syndrome, autism, learning disabilities and challenging behaviours, in out-of-home care]

> *"I loved him to bits but I didn't understand basically why he was beating the whole family up"* [Participant 14 - Sister of a brother with learning disabilities and Aspergers syndrome, has been in out-of-home care but currently at family home.]

Such examples further demonstrated that the challenging behaviours of the child were significant in relation to maintaining or damaging family relationships.

Facing financial difficulties

Many participants were unable to work due to the full time caring needs of their child which in many cases placed an additional financial strain on the family. Participants' finances did eventually contribute to *'breaking point'* and seeking out-of-home care:

> *"It's partly our finances, you wouldn't want to think you were chucking a kid out because you can't afford it but it is partly for us"* [Participant 18 - Mother of son with autism, learning disabilities, communication difficulties, considering out-of-home care.]

Struggling with mental health issues

Every participant experienced chronic stress at some point leading to breaking point. Mental health deterioration was a common reaction to the enduring stress evident throughout:

> *"I have been on anti-depressants since my daughter was probably 5 or 6 on and off from then, so my mental health has been affected"* [Participant 6 - Adoptive mother of a daughter with mild learning disability, autism, disorganised attachment disorder and challenging behaviour, in out-of-home care.]

> *"It was just too much for me I had a breakdown, in fact I had two breakdowns not long apart... I've kind of been managing depression ever since to a varying degree".* [Participant 8 - Father of son with moderate learning disabilities, epilepsy, autism, chromosome abnormality and challenging behaviour, in out-of-home care.]

> *"I've got general anxiety disorder, whether that's a result of what's happened with (name of daughter) I don't know... It's hard to say, I don't like to blame her for it, because if I say it is because of her it is almost like I am blaming her for it"* [Participant 10 - Mother of daughter with autism, epilepsy, chromosome disorder, learning disabilities and challenging behaviour, in out-of-home care.]

Most participants continued to experience stress and in many cases depression, which further added to their negative parental identities.

BECOMING OVERWHELMED: 'BREAKING POINT'

The compensatory positive parental identity enhanced self-esteem giving temporary solace. However this defensive position relied on the ability to cope alone and to focus solely on the needs of the child. This led to a position of '*coping not living'* and caregiver burden which eventually took its toll when coupled with the challenging behaviour of the child and the strain on family relationships. *'Breaking point'* is the accumulation of this caregiver strain, as participants became psychologically overwhelmed and were forced to admit (to themselves and others), they could no longer cope. In the majority of cases participants were able to manage up until a certain point, which included long durations of *'coping not living'* and cycles of *'screaming to be heard',* and alternating between negative and positive parental identities. Breaking point identifies the psychological crisis stage.

> *"as a family we were at absolute breaking point, really, really bad"* [Participant 6 - Adoptive mother of daughter with mild learning disability, autism, disorganised passionate disorder and challenging behaviour, in out-of-home care.]

Arriving at breaking point forced participants to realise (and accept) that things were not working and motivated decision making about out-of-home care. Without this crisis point decisions about out-of-home care would not progress and things would remain stagnant irrespective of how the family was actually 'coping'. It is as if parents defensively convinced themselves that they could cope until they became overwhelmed by the enduring stress.

> *"we have, reluctantly made the decision that we are no longer able to cope and keep him safe during his violent spells"* [Participant 16 - mother of son with Fragile-x syndrome, learning disabilities and aphasia, in out-of-home care.]

The emotional distress at this stage was immense with little external support, but served to motivate needed change:

> *"When she was un-happy and distressed it was crucifying me and I was just a very un-happy person... we can't live like this, she can't live like this she was in a terrible state"* [Participant 10 - Mother of daughter with autism, epilepsy, chromosome disorder, learning disabilities and challenging behaviour, in out-of-home care.]
>
> "*It was just agony for me particularly, this is my little boy [long pause] Sorry [tearful]*" [Participant 13 - Mother of son with autism, severe learning disability, no speech and challenging behaviours, in out-of-home care.]

ADJUSTING

Adjusting to the decision to place child into care

Having reassured themselves that they alone could manage in order to protect both their child and their 'good parent' identity, participants were then forced to confront the idea that someone else could care for their child, a realisation that seemed to be anxiety provoking.

> *"I think I just spent the entire morning crying..... It was a terrible time. I don't know it just, very, very emotional I felt. That worried me then that maybe I wasn't making a sound judgement because I was so emotional but I calmed down and I looked at places"* [Participant 4 - Mother of daughter with autism, mild learning disabilities, in out-of-home care.]

Due to reaching *'breaking point'* participants were able to admit to an inability to cope, which enabled them to consider out-of-home care.

> *"it was a decision we had to think of very carefully it was a very painful thing, things got difficult my husband suffered from severe depression and my daughter was finding life a little bit difficult, so a decision had to be made"* [Participant 13 - Mother of son with autism, severe learning disability, no speech and challenging behaviours, in out-of-home care.]

Participants moved to adjustment which forced them back into developing negative parental identities as they fought the system to convince professionals of their decision for out-of-home care and to achieve funding.

SCREAMING TO BE HEARD

Fighting the system

This process was entered once parents had made the decision for out-of-home care. This sub-category relates to ‘screaming to be heard’ as participants again returned to fight to convince professionals to support their decision for out-of-home care. The emotional impact of making a decision, then having to fight the services to gain their approval added to the psychological toll:

> *“If I had been allowed just to be a mum supporting and looking after a special needs child, and not had to try and look after a special needs child and fight the system of professionals .... I think the outcome for our family could have been so different.* [Participant 6 - Adoptive mother of daughter with mild learning disability, autism, disorganised passionate disorder and challenging behaviour, in out-of-home care.]

Parents had to convince professionals that out-of-home care was required and should be funded. In some cases, they believed out-of-home care was needed, but social services were not always convinced therefore they fought to overcome these challenges (which sometimes took years). Throughout this process participants were forced into managing prolonged periods of ‘*coping and not living’* again, which enhanced stress on the parent, child and family system. As a result, participants were obliged to utilise legal avenues to fight the system and gain out-of-home care, which many suggested was anxiety-producing and an avenue they would have preferred not to have needed to engage with. Participants gained the psychological and emotional strength for ‘*fighting the system’* through reassuring themselves that the choice for out-of-home care was the ‘best thing they could do for their child’. Fighting for care occupied the participants and gave hope that change would eventually occur.

This participant illustrated how she was reliant on professionals' services to support her desire for out-of-home care and in this case social services pulled out their support at the last moment:

> *"Social Services were in support that she did need a residential supported school…you need two different sets of professionals to back you to have any say with the panel to get a chance of getting a residential placement. Four days before (name of Daughter) went to panel, Social services pulled out on us"*. [Participant 6 - Adoptive mother of daughter with mild learning disability, autism, disorganised passionate disorder and challenging behaviour, in out-of-home care.]

Such experiences undoubtedly added to the stress and strain of the situations participants faced**.**

Once funding for out-of-home care was agreed and professionals were in support, participants began looking for the right placement for their child. It was as though the decision for out-of-home care was an assault on the self i.e. enhancing ongoing experiences of stigmatisation, so they sought to regain self-esteem through ensuring they chose the best possible care.

> *"If we can find somewhere that caters for his needs and doesn't try to squeeze him into a box that they will fit around him rather than the other way round then I think we can actually find something… we would have to feel you know that we weren't chucking him into a horrible or even stressful situation"* [Participant 18 - Mother of son with autism, learning disabilities, communication difficulties, considering out-of-home care.]

The location of the out-of-home care was significant with many wanting care close to home which was not always possible. The environment and availability of out-of-home care proved more significant to the decision; for example participants were content to travel long distances as long as they believed the out-of-home care was the best available.

> *“The more places you look at the better...it just felt like a nice environment. It’s quite small … it’s just got quite a nice feel to it.* [Participant 4 - Mother of daughter with autism, mild learning disabilities, in out-of-home care.]

It appeared that even with a lack of choice, participants implemented strategies (possibly unconsciously) to reassure themselves that it was actually the ‘best care’; many participants accepted the first establishment which looked remotely suitable and then reassured themselves that the care ‘was the best’ whilst actually in some cases it was the only care available.

> *“In this neck of the woods there are only two special schools....the school we were offered was the best and virtually the only, you know we were fortunate to be honest”* [Participant 8 - Father of son with moderate learning disabilities, epilepsy, autism, chromosome abnormality and challenging behaviour, in out-of-home care.]

> *“We just looked at that one setting, it was recommended to us, I went to visit it um and it was at the right location”* [Participant 5 - Guardian of cousin with Down’s syndrome and mild learning disabilities, in supported living.]

ADJUSTING

Adjusting to the move

The adjustment process following the move to out-of-home care was one which some participants remained in for a long time, whilst others progressed through more quickly. The immediate reaction to the move for the majority of participants was psychologically challenging and in most cases the emotional response was unexpected:

> *“it was absolutely heartbreaking leaving him and he would cry and scream a bit and it would break our hearts um and we felt guilty”* [Participant 17 - Mother of son with ADHD, autism, learning disabilities, challenging behaviour and no verbal communication, in out-of-home care.]

> *"For the first six weeks of his absence, I felt physically sick wondering if he was being treated properly."* [Participant 16 - mother of son with Fragile X Syndrome, learning disabilities and aphasia, in out-of-home care.]

> *"Although it is really hard for a parent I think it is very important to let your children go and particularly also those with learning difficulties and I know it's really hard .... It's very difficult for a parent to let go um, and make that step, you have to be very brave really"* [Participant 2 - Mother of son with Down's syndrome and moderate learning disabilities, in residential college.]

The mix of emotional responses illustrated why adjustment time was required as participants managed their immediate reactions and internally evaluated their decision. Guilt however remained:

> *"I feel guilty that I had to send him away. I knew it was the right thing to do, it was right for me but I didn't have children so that I could send them to boarding school and a huge amount of guilt I lost a lot... we lost the family"* [Participant 17 - Mother of son with ADHD, autism, learning disabilities, challenging behaviour and no verbal communication, in out-of-home care.]

Over time the adjustment encouraged a sense of relief in the participants as they began to accept the decision and reassure themselves it was the right choice, as this mother illustrated:

> *"I guess my main feeling once he was settled was one of relief"* [Participant 16 - mother a son with Fragile X syndrome, learning disabilities and aphasia, in out-of-home care.]

This led to a process of adjusting to the new experiences within the dynamic of a loss of role and loss of child.

Adjusting to the loss of parental role

Participants described a loss of role once the child moved into out-of-home care. At this time, participants appeared to engage in grieving the loss of role and evaluating themselves as parents. Many participants, such as this father, found managing the loss psychologically devastating, and the guilt evoked added to a negative parental identity:

> "*Not many people know how mentally challenging it is sending your helpless child away..... I am empty, my spirit crushed and heartbroken and as a result feel that I am undeserving of my life because I have let my son down so badly by not being able to provide a future at home for him. I hate myself as I feel that I have thrown my son to the wolves. How can I call myself a parent, doing this to my own vulnerable son?...If I ever start crying I will never stop, This has ruined my life* " [Participant 8 - Father of son with moderate learning disabilities, epilepsy, autism, chromosome abnormality and challenging behaviour, in out-of-home care.]

During this adjustment process and loss of role, it appeared that the conscious reasoning (reason for the decision) came into conflict with the reaction from acting on the decision. This caused internalised conflict and self-doubt i.e. have I made the right decision? At this stage, participants reported high levels of stress based on powerlessness, frustration and fear in the light of their lost caring role:

> *"it's hard letting somebody else take control of, your child's life you know and deciding what's best for them"* [Participant 4 - Mother of daughter with autism, mild learning disabilities, in out-of-home care.]

Analysis suggested that during this phase participants felt redundant as they adjusted to the changes relating to their loss of role, which was explained by this mother and impacted on her sense of self:

> *"I find my roles dropped away somewhat um... they do say that they, value my views and things like that but I'm very wary of how much to tell them and how much information to give them. Because I don't know how much they want to know, I feel like um, I feel a bit of a nuisance I feel as if I'm maybe not wanted"*

> [Participant 4 - Mother of daughter with autism, mild learning disabilities, in out-of-home care.]

The participants began to question their identity and did not want to feel like a nuisance to the child or service providers. They believed their role had diminished, which affected their day-to-day life and motivation which again impacted on their parental identity. This finding signified the importance of parental identity / involvement and the meaning it had to the caregivers' wellbeing and ability to cope following decision making.

> *"I would be happy to die tomorrow if it were not for my caring responsibilities and my desire to look after [name of child's] wellbeing albeit from a distance. There is nothing else left for me"* [Participant 8 - Father of son with moderate learning disabilities, epilepsy, autism, chromosome abnormality and challenging behaviour, in out-of-home care.]

Over time, adjustment occurred as long as the participant saw their child was safe. However, in order to assess this and to hold on to the parental role they engaged in the category *'constant monitoring of care'*.

EVALUATING: CONSTANT MONITORING OF CARE

Participants had been (and continued) in a process of adjustment. Most of the participants described feelings of loss of role which linked to a desire to remain involved in their child's care. This is achieved through evaluating the care received in a continuous process, although the levels of what was evaluated as good enough or bad enough were individual. Bad care was generally characterised by a lack of safety such as when safeguarding concerns were raised i.e. the child being hit or harmed by others. The evaluation of care was not as simple as good care equalling happy or satisfied parents, and bad care equalling unhappy or dissatisfied parents; this process appeared far more complex:

Good care

When ‘good’ care was evaluated by the participant i.e. they saw their child as happy, safe and developing in the out-of-home setting, it was evaluated in terms of the quality of services.

> *“I think it comes down to the quality of the services that are available and the staff that you know and just the care that people have, that’s it. I mean care and respect for other people”* [Participant 15 - Mother of son with learning disabilities and Aspergers syndrome, has been in out-of-home care but currently at family home.]

The findings suggested that when participants evaluated the quality of care as ‘good’, they felt satisfied. This enhanced their ‘good parent identity’ as they internalised the outcome as directly due to their decision i.e. they chose the best care for their child. This process aided adjustment to the loss of parental role, which enhanced self-esteem and linked into creating a compensatory ‘good parent’ identity:

> *“No doubt in my mind that it’s the right thing to do and he’s blossoming”* [Participant 2 - Mother of son with Down’s syndrome and moderate learning disabilities, in residential college.]

They then continued to monitor the care to reinforce this message to themselves.

In contrast to the above, the findings also suggested that some responded to the evaluation of ‘good care’ by expressing a lack of satisfaction. For example some seemed to perceive good care as a direct reflection of their inability to cope i.e. others can cope and keep the child happy, but I (as their parent) was unable to. This impacted on their self-esteem and reinforced a ‘negative parental identity’.

> *“I don’t feel I can enjoy anything anymore because our lovely son is not here with us to enjoy things with us. I feel very guilty even though he is enjoying his life in a different way”* [Participant 8 - Father of son with moderate learning disabilities, epilepsy, autism, chromosome abnormality and challenging behaviour, in out-of-home care.]

This response resulted in feelings of inadequacy and a disenfranchised role as they saw others managing the child in ways that they could not. This new ‘lack of control’ over the child’s care and subsequent lack of satisfaction with the care placement illustrated the complex nature of the evaluation. Other examples showed that participants may evaluate the overall care as good, but the staff as bad:

> *“I find it incredible you know they, they don’t know me, they don’t know (name of daughter) and it’s surprising over the years how many people say… oh well I know (name of daughter) and I’m thinking hang on you’ve only met her twice, how can you say you know her?”* [Participant 4 - Mother of daughter with autism, mild learning disabilities, in out-of-home care.]

Even though the care was evaluated as good, some parents felt powerless and uninvolved in the child’s care. This impacted on their identity linking back to the cycle of adjustment to the loss of parental role:

> *“obviously they’re lovely [the staff] and they try to do all the right things but perhaps sometimes not quite sensitive to things ...they’re basically, cared for by strangers, it’s caring strangers but never-the-less they don’t know them , it’s a situation that is out of your control and you have to be just trust that they are doing the best that they can and that I suppose keep an eye on things”* [Participant 3 - Mother of son with apert syndrome, autism, learning disabilities and challenging behaviours, in out-of-home care]

> *“None of us felt that we were listened to there by staff. I suppose from their point of view they are the experts, they know better”* [Participant 11 - Mother of son with Down’s syndrome, learning disability, in out-of-home care.]

Bad care

When the child’s care was evaluated by the parents as ‘bad’ i.e. the child was not happy or was not being cared for adequately, they internalise themselves as being at fault for choosing the placement. This resulted in guilt and a loss of self-esteem:

> *“I still feel guilty and I have horrendous guilt about it… he’s had 5 safeguarding in about 3 years, he’s been abused by carers”* [Participant 17 -

> Mother of son with ADHD, autism, learning disabilities, challenging behaviour and no verbal communication, in out-of-home care.]
>
> *“My biggest thing, though, was that none of the staff supporting him seem to care or how can I put it, love him, because it was just like he has come from a family that really love him they couldn’t give a shit really....you know this is my brother you’re there to look after him and provide him with a warm home and you are not doing that at all”* [Participant 14 - Sister of a brother with learning disabilities and Aspergers syndrome, has been in out-of-home care but currently at family home.]

However, in some instances, the evaluation of ‘bad care’ enhanced participants’ roles because they needed to remain involved for the sake of their child. They now must ‘*fight the system’* again to ensure the best care for their child, or move to being the expert parent by guiding the care staff, which reinforced the ‘good parent identity’:

> *“He can be on a short fuse and can become frighteningly violent, almost like a crazed frightened wild animal. On each occasion the catalyst can be traced back to circumstances that could have been avoided by conscientious and trained carer. You need to remind the staff as too few carers have the ability, training or presence of mind to do this.”* [Participant 9 - Father of son with Down’s syndrome, learning disabilities and challenging behaviour, in out-of-home care.]

Participants noted that out-of-home care providers needed to ensure adequate training of all staff and retention of good quality staff. Furthermore, parents wanted to feel welcomed into the environment, which sadly was often not the case. This forced them to return to needing to create a compensatory ‘good parent’ identity and progress to ‘*screaming to be heard’* i.e. when they were concerned about poor care and wanted their child moved again. These processes were continuous and cyclical; the role of the parent and desire for ‘best care’ was never eliminated. This parent outlined how she was contacted by a member of the care team who suggested bad care was taking place and despite contact to social services, the concerns were not taken seriously adding to stress and anxiety.

> *"At one time one of the staff came to me and said can I talk to you and he told me about the horrendous things that were going on"* [Participant 15 - Mother of son with learning disabilities and Aspergers syndrome, has been in out-of-home care but currently at family home.]

In contrast, there were examples whereby participants evaluated 'bad care' but did not act to change the setting and instead seemed to reassure themselves that 'these things happen'. This potentially related to the psychological impact that going back through the decision making process cycle may have on them psychologically, so they reassured themselves the care was adequate. There seemed to be a tendency for some participants to see care in a positive light, potentially distorting their perceptions and monitoring levels of bad care because the parent couldn't tolerate 'fighting the system' again:

> "*So it is always important to bear in mind that things are going to happen and they will continue to happen but to see the big picture and see what is important"*[Participant 13 - Mother of son with autism, severe learning disability, no speech and challenging behaviours, in out-of-home care.]

The differing responses to the evaluation of care motivated participants to examine the next course of action and whether to make a decision for change. For example, some participants sought to move their child to different settings, others chose to return their child home and some kept the child where they were. Participants remained in a state of constant monitoring of care.

The model shows an interrelated process where parents / carers can become stagnated at any one point or can move around the model continuously. There is no end point as the cycle continues throughout the life stages, and with changes in funding, legislation and family needs, this further guides the movement between each stage of the model.

DISCUSSION

A grounded theory was constructed from the data which outlines the basic psychosocial processes involved when caring for a child with learning disabilities and how stressors, both internal and external lead to breaking point and to the decision to place the child in out-of-home care. The core-category in this process relates to parental identity as the parent struggles to protect their own identity whilst facing intolerable demands. Initially the process starts with parents developing awareness of their child's disability which contributes to the development of a negative parental identity as does the experience of stigmatisation at a time when they are struggling to cope and understand and contend with difficult feelings towards their child. To defend against these threats, participants appear to create a compensatory 'good parent' identity which involves focusing solely on the child's needs, and becoming 'expert parents' and advocates. In a desperate attempt to preserve their parental identity parents try to convince themselves that they can cope, which increases stress and causes relationship breakdowns, financial difficulties and mental health difficulties. In addition, parents face additional stressors when they attempt to gain professional guidance and support. The combination of these stressors finally leads to 'breaking point'. This critical juncture, whereby the parent becomes completely overwhelmed by the pressures they are facing, both internal and external, aids parental acceptance that they need to seek change in light of conscious realisation that they cannot cope. However the subsequent decision to place the child into care further reinforces the negative parental identity so the cycle of creating a compensatory identity enfolds as well as fighting the system to convince professionals of their need for care. Once the move occurs, adjustment to both the decision and the loss of role is required, which can link back into parents becoming over involved i.e. as the expert parent, resulting in clashes with service providers, or in a role of redundant parent. Both outcomes cause stress and link to constant monitoring and evaluation of the care provided, which illustrates the circular and ongoing nature of the process.

DEVELOPING AWARENESS

Curry et al. (1997) suggest that parents of learning disabled children generally realise something is different or wrong before professionals do, a claim which is supported by the findings of this study and marks the first steps within the process. Participants described how their awareness of their child's disability developed due to recognising subtle differences in their child's developmental milestones. The grounded theory presented here also identifies that when parents begin to develop this awareness they often feel confused and uncertain which supports Davis' (1993) finding that this is a common reaction to disability. Kearney and Griffin (2001) suggest that when parents become aware that something is wrong with their child, they may also experience shock, numbness, sorrow and denial. Interestingly, denial of their child's disability or difference did not appear to be a factor for the participants in this study; once participants believed there was something wrong, they sought to find reasons for their beliefs to aid understanding of their child, rather than denying their suspicions. Denial seemed to be more evident when parents attempted to minimise their own difficulties later in the process.

DEVELOPING A NEGATIVE PARENTAL IDENTITY

The role and identity of parents is commonly defined by their caring role (Crocker and Quinn, 2004), therefore when parents experience criticisms (both internal and external), this affects their self-esteem and confidence as a parent. This study found that all participants experienced threats to their parental identity over a period of time which contributed to their decision making processes when seeking out-of-home care. Participants described how experiences of stigmatisation contributed to the development of a negative sense of self which seemed to be a significant factor within the process model. This supports Beresford's (1994) claim that stigmatisation enhances stress because it occurs at a time when there is already uncertainty and fear. Gray (2002) describes the difference between 'enacted' and 'felt' stigma; both forms of stigmatisation were experienced by participants in this study. Stern et al. (2000) studied stigmatisation towards disabled children and suggest that the social awareness and stereotypical beliefs about the disability contribute to people adapted their behaviours and stigmatisation.

Many of the participants experienced external criticism which impacted on their sense of self and contributed to their construction of themselves as ‘bad’ caregivers. Darbyshire and Whitaker (1999) suggest that social reactions to disability and parenting are dependent on the environment and individuals in that society. Similarly Scarnier et al. (2009) suggest that such social criticisms add to the pressure experienced by parents when caring for a child both within and outside of the home. This was evident in this study as parents described their fears about public reactions to their child (external criticism), an experience which linked to internalised stress and lowered self-esteem. Lickel et al. (2005) suggest that parents blame themselves for their lack of control over the situation, which can contribute to a sense of helplessness. Participants in the present study outlined how they internalised public criticism and hostility which contributed to isolation and a reduction in self-esteem, which link well to existing literature. For example Apple and Golden (1997) suggest that individual behaviours and experiences are guided by the society in which that individual lives. As such, the criticisms experienced related to social norms about parenting roles and social expectations.

The loss of self-esteem relating to this part of the process links to literature on the social construction of disabilities noted by Dudley-Marling (2004) who acknowledged that disability is seen as relating to the ‘child being wrong’ rather than acknowledging that the system in which they are living or learning may be flawed. Participants in the present study appeared to internalise blame against themselves, for their child’s disability rather than criticising the construction of disability. This internalisation contributed to a loss of self-esteem and feelings of guilt and helplessness, at a time when parents were unclear about what the child’s differences were due to the lack of a formal diagnosis and knowledge.

Belsky`s (1984) model of parenting involves cognitive constructs such as self-esteem, which influence parental behaviours; losing self-esteem negatively impacts on the parent-child relationship and parenting styles by decreasing information exchange, which then impacts on the child’s learning. Belsky suggests that for parents to achieve enhanced self-esteem in this area, they need to manage their levels of stress.   . Abidin’s (1992) parenting stress model suggests parenting stress actually results in negative parenting due to cycles of low self-esteem, helplessness and guilt which further enhance stress. With enhanced stress, parental capacity to parent actually reduces, which impacts on the relational elements i.e. bonding between parent and child. Mash and Johnston's (1990) research focussed on the parent-to-child relationship and linked parental stress to parent-child conflict. Their research suggests that negative parent-child interactions increase parenting stress, for example, when the child presents challenging behaviours or lack of speech, the parent may internalise this as their (the parents') fault or externalise it as the child's fault. As a result this can leave the parents feeling helpless, as blaming difficulties either on the child or the self contributes to lowering self-esteem and increases guilt and hopelessness, which reinforces the parents' development of a negative identity.

The findings of the current study support and add to these findings; the grounded theory presented above suggests that participants seemed to move from *developing a negative parental identity* towards *creating a compensatory good parent identity* to manage stress and to enhance their fragile self-esteem. Overall, the parents sought to develop and maintain a role in which they were integral to their child's life, which they could achieve as long as they were able to defend against negative experiences and enhance their self-esteem through creating a compensatory good parent identity, which was a complex and ongoing process. Milliken, Herbert and Northcott (2003) supports this stating that changes in parental identity are not linear and are influenced by fluctuations in the child's behaviours, their medical needs, and society.

CREATING A COMPENSATORY GOOD PARENT IDENTITY

In order for parents to defend against the threat to their identity, it appeared that they attempted to create a *compensatory good parent identity;* participants appeared keen to stress that they would not change their child and expressed unconditional love. Hanline (1991) suggests that parents may focus all their attention onto a disabled child to compensate for their feelings of grief about the child's disability. Lavin (2001) suggests that parents often avoid dealing with concerns such as fear, uncertainty or marital issues by focussing their attention on the needs of their disabled child and other children. This was evident in this study whereby parents seemed to focus entirely on the needs of their children and by doing so they often neglected their own needs and those of other family members.

There is limited research into this process, with primary attention paid to the needs of elderly carers rather than across the age range. Bowley and McGlaughlin (2007) surveyed parents aged over 70 and concluded that many still were not ready to discuss the future needs of their offspring, with one significant reason being that they had no confidence in existing service provisions, instead believing (or perhaps reassuring themselves) that they could cope. A study by Cains, Tolson, Darbyshire and Brown (2012) explored the needs of older parents caring for offspring with learning disabilities. Their study suggests that parents reassured themselves that they could manage due to the lack of professional support and information and that this resulted in isolation; even when faced with deterioration in their own health or mental well-being they continued to provide constant care and attention for the child believing that they had no other choice. In the present study parents were only able to consider alternative sources of support once they had reached ‘breaking point’,

Another compensatory strategy within the model was to seek qualifications and experience in the area of learning disability or additional disabilities. Becoming an expert meant that participants could then share their knowledge and in some cases, felt reassured when they seemed to know more than the ‘experts’, which served to enhanced their self-esteem and views of themselves as competent parents This supports the findings of Beresford, Rabiee and Sloper (2007) who found that parents wanted to feel skilled, and that this was critical to their sense of themselves as a competent parent. Becoming involved in advocacy, which formed part of the process for many participants, performed a similar function. Advocating, according to Karp and Bradley (1991) is crucial to parents for a number of reasons; it ensures that they receive and share information about services and best care ideas; the findings of the present study is that advocacy also enhances the ‘good parent’ identity.

Milliken, Herbert and Northcot (2003) explored the experiences of caregivers of adult-children with schizophrenia and suggested that parents' identities adapt and change due to the erratic nature of their child's mental illness. Eventually the parents' roles become 're-enfranchised', meaning the parent feels they can 'take on the system' by trying to improve services, for example doing voluntary work, raising public awareness and reducing stigma. This also links to Milliken, Herbert and Northcot (2003) stage of 'embracing the collective' whereby parents realise that anything they do for the cause may help their child symbolically. Although these findings are based on the experiences of parents supporting children with mental health conditions, it adds validity to the findings presented in this study relating to 'developing a good parent identity'. Via advocacy parents enhance their lives and share their experiences for the benefit of others in similar circumstances (and symbolically also for themselves). To expand on this process, self-esteem and positive identity relates to the way individuals think and evaluate themselves, and in general terms occurs on a continuum of self reported positive or negative attitudes. Positive or high self-esteem suggests that individuals see themselves as worthy, whereas negative or low self-esteem links to dissatisfaction with the self. Deci and Ryan (1995) suggest that the higher the self-esteem the better the person is at psychological adjustment. Crocker et al's*.* (2003) theory of contingent self-esteem links self-esteem to levels of performance in areas such as family or academia. Crocker and Knight (2005) note that individuals generally strive (sometimes unconsciously) for success and satisfaction in these areas (family or academia), with the perceived outcome significantly impacting their self-worth. Participants in the present study seemed to enhance their own self-esteem by becoming an expert parent and this process appears to support Crocker et al's. theorising. Satisfaction with life and the self is also an indicator of psychological well-being. Pavot and Diener (1993, 2008) spoke of the construct of satisfaction as process-laden with social criteria to which one judges oneself; when individuals construct their satisfaction levels relating to their life and parenting abilities, this impacts self-esteem and emotional well-being, for example in this study some felt satisfied because they perceived they knew more than the professional and some felt satisfied because they were able to focus solely on their child, which enhances well-being and identities.

Parents' ability to create a compensatory identity was aided by external support groups and peers, but not generally by professionals. Bromley and Blacher suggest that the availability of social networks and extended family or friends contributes to a reduction in parental stress (Bromley and Blacher, 1989; Bruns, 2000) and overall satisfaction and confidence to manage stressful situations, indicating the significance of the grounded theory presented above with regards to understanding the processes involved when caring for a child.

'SCREAMING TO BE HEARD'

Participants found the process of attempting to gain professional support to be challenging, dissatisfying and stressful, which is supported extensively within the literature. Davis and Rushton (1991) also linked parental dissatisfaction to failures within professional services, suggesting services do not view childrens' needs within the holistic role of the family i.e. not considering the dynamics of the entire family. This is then associated with parents' perception of poor professional interaction and communication, with a result of difficult engagement between families and professionals. Davis and Meltzer (2007) suggest the Family Partnership Model to address such parent / professional issues. Their model recommends guidance for practitioners in order to enable them to support and interact productively with parents, for example by guiding professionals to be explicit about what each person is trying to achieve. This can be achieved through working collaboratively to help parents (and professional) understand what is happening and find better ways to cope rather than the professional dictating recommendations. Their model instead argues that empowering parents through psychological and social adaption enhanced parents' independence and problem solving skills in the context of their individual social and community lives. These elements seemed significant to participants in the current study and potentially would go some way to address their 'screaming to be heard' perception.

Taarilia et al. (2002) suggest that professional support is a major factor in terms of parents' ability to cope. Research suggests that over 50% of mothers are dissatisfied with the professional communication and support relating to disability (Pearson, 1999). Many participants in the present study described how their search for answers was frequently quashed by professionals and their concerns about their child’s symptoms dismissed. Participants expressed a desire for respect and empathy from professionals, but this was lacking as was general guidance and information. These findings support theories and research by Beresford et al. (2007) who suggest that many parents experience inappropriate or inadequate support from professionals and family, which exacerbates their anxiety and isolation. They conclude that the most positive avenues of support came from professional counselling which served to enhance emotional well-being and enhance self-esteem, but also note that many parents refused counselling due to previous unsatisfactory interactions with professionals.

For the participants in the present study, diagnosis seemed to be a main focus and one they fought passionately for, sometimes for decades. The literature in this area explains how late diagnosis impacts families. For example Graungard and Skov (2007) suggest that late or uncertain diagnosis negatively affects parents as they have long held a belief that there is something wrong, which was often the case in this study. The findings of the present study are in contrast to existing research in the field which suggests that receiving a diagnosis of intellectual disability causes parental reactions including fear, denial, anger, frustration, guilt, grief and mourning. Landsman (1998) describes such reactions as the ‘trauma of dashed expectations' and the beginning of relentless stress. The present study found that participants were generally reassured by receiving a diagnosis and experienced relief because it confirmed their hypotheses about their child and potentially protected their parental identity i.e. ‘I didn’t cause the disability’, ‘it’s not my fault’.

Even after parents had reached breaking point and have made a decision to place their child in out-of-home care the fight continued as parents sought to convince professionals that they required this support. Throughout this process, participants’ concerns continued not to be heard or validated, which is supported by literature; Doig et al. (2008) concluded that parental experience of seeking respite services was negative and stressful. McGill et al. (2006) supports this view with similar research into families seeking residential schools as parents experienced stress due to limited services. Similarly Martin and Colbert (1997) suggest that accessing the necessary services is a very confusing and frustrating process whereby individuals face bureaucratic red tape and conflicting professional recommendations.

It is of some concern that when parents are exhausted and 'burn out', they fear that they may harm their children (Oakley, 1992). Burns (2009) found that 64% of children with learning disabilities within residential settings are on Care Orders, meaning the child has been removed from the parents' care via the courts system due to social services deeming the child to be at risk of significant harm. Beresford et al's. (2007) research indicates that parents of disabled children want services and professionals to help them achieve outcomes, increase their knowledge base about the disability and to increase care-givers physical and emotional well-being. Participants in the present study consistently found this support to be lacking and resorted to 'screaming to be heard' instead, which further reinforced their negative parental identity. The impact of these early experiences, and the impact of these on the formation of a negative parental identity, seems like a new finding within the field. Furthermore findings link to the research question of decision making and parental experiences of those caring for children with learning disabilities.

'COPING NOT LIVING'

In a desperate attempt to preserve their 'good parent' identity participants in the present study attempted to convince themselves that they could cope, despite all evidence to the contrary. While literature suggests that not all parents experience significant struggles when rearing their child who has disabilities (Summers et al., 1989), the findings of this study suggest that participants struggled to cope in the face of significant stress, and that their child's challenging behaviours were a major factor associated with this. Research supports this finding as challenging behaviours have been found to contribute to higher levels of parental hopelessness (Padencheri and Russell; 2002) and lowered optimism (Baker, Blacher and Olsson, 2005). Challenging behaviour is more consistent and enduring in those with developmental disabilities (Matson et al., 1991) indicating why it was identified as an important factor in this study. Mansell and Wilson (2010) also identified that challenging behaviours increase the risk of parental stress and burnout.

While parents found juggling the needs of all of their children challenging, the focus generally moved to the needs of the disabled child over siblings. Family therapy literature suggests that siblings of disabled children may experience similar reactions to their parent (Batshaw, 1991) and may either over compensate by caring for their sibling above their own needs or withdraw completely. Participants described how the disabled child often took precedence over other children, especially when challenging behaviours were present, resulting in the parent responding immediately to protect the children.

In many cases the child’s disability was instrumental in parental separation. Research suggests that relationship difficulties are exacerbated by stress as many take their frustrations out on each other or those around them including their children (Redmond et al., 2002), which can lead to marital problems, difficulties with parent-child or sibling relationships, sibling rivalry and child abuse. Conversely, Keating (1997) found that many parents with a learning disabled child experience a strengthening of their relationship; however this was not supported by the present study. Beresford et al. (2007) suggest parents attempt to manage the needs of their family, but often have limited resources to assist them, resulting in isolation and a forced responsibility to maintain the family often at the cost of their own needs. In addition, many of the participants interviewed faced financial difficulties which added to family strain and is supported by the literature. For example Gordon et al. (2000) noted that income impacts on family stress and is a main source of anxiety and furthermore, that families of disabled children often have lower incomes, yet require extra finance for services or resources which are not covered fully by disability benefits. Beresford et al. (2007) found that parents of disabled children felt ‘lost’ in terms of their personal identity, with the parent and care-giving role dominating their lives. Some wanted to gain identities outside of the family such as in work or other interests, but due to the caring needs of their child felt unable to do so, which again impacted on their sense of self, as well as their financial situation.

Every participant experienced chronic stress at some point which led them to breaking point. Chronic stress has health implications which can affect physical health, and negatively impacts on psychological well-being (Seltzer et al., 2009).

McGrother et al. *(*1996) found that parents of disabled adults reported 40% more limiting health disorders than the general population, and depression was four times more common among female carers. The present study supports these findings as many participants experienced depression and helplessness at some point in the process. Research suggests that 56% of mothers of children with learning disabilities experience significant difficulties in resolving loss and trauma related to their child's condition (Fletcher, 2004). Singer (2006) suggests that such findings emphasise why parents are at an increased risk of mental health problems, especially depression. In addition, Lecavalier et al. (2006) suggest that psychological distress in parents correlates with the level of behavioural problems of children with learning disabilities i.e. higher levels of challenging behaviours are associated with decreased parent-child emotional reciprocity and increased parental stress.

‘BREAKING POINT’: BECOMING OVERWHELMED

A new and unexpected finding presented in the current study, is that participants appeared unable to consider out-of-home care *prior* to becoming overwhelmed and reaching breaking point. ‘Breaking point’ is the significant moment whereby participants acknowledge consciously that they can no longer manage caring for their child and this acknowledgement initiates the decision making process. The concept is new within the learning disability field. In this presented study the child's diagnosis and behavioural characteristic were significant contributors to the parents' stress and thus contributed to breaking point.

ADJUSTING

Participants in the present study initially wished to keep their child at home, perceiving parental care as the ‘best care’, potentially suggesting why 59% of adults with learning disabilities live with their family (Beadle-Brown et al., 2006). However, once parents made a conscious decision for out-of-home care (following breaking point) they then had the challenging task of convincing social services that they require out-of-home care.

For the participants in the present study admitting to not coping and deciding to place their child into care seemed to lead to further guilt and reinforced the negative parental identity. ‘Good parenting' appeared to be constructed as being affectionate, having control, showing warmth and being involved. These are elements that have been grouped into three areas: control, structure and support (Koblinsky, Morgan, and Anderson, 1997; Maccoby and Martin, 1983). The grounded theory presented in this study outlines how parents strive to manage and adjust to the anxiety associated with their decision about out-of-home care by ensuring the care they choose is the ‘best’ (control), remaining involved with the child (structure), and reassuring themselves that the placement will provide warmth and affection to their child (support). These elements appeared to serve as a coping strategy which aided parental adjustment to the decision for out-of-home care, enabling them to reduce anxiety and to maintain a ‘good parent’ identity.

Decision making is a cognitive process which has moral factors and is motivated by both rational and irrational perspectives (Reason, 1990). The decision making processes at times of stress or exhaustion may differ when compared to times of less stress. For example, Mencap’s (2001) survey found that children usually enter the care system when parents decide they can no longer cope with the burden of caring and it may seem like the only option due to the ongoing high levels of parental stress. For the participants in the present study the sense of parental responsibility for their child remained despite the emotional costs (choosing for them to be cared for by others). In an attempt to protect both their sense of a ‘good parent identity’ and their parental role, parents attempted to convince themselves that they made the right choice as this belief reinforced their self-esteem. Furthermore through evaluating care the parent could remain involved and monitor the child, which enhanced their parental role. The grounded theory regarding this adjustment offers new insights into the processes involved within the learning disability field. It also adds to the current literature regarding adjustment to the decision, studies outlined that difficult feelings are expressed such as grief, anticipated loss and anger (Schofield et al., 2000; Doka, 1989). These feelings were expressed as parents considered separation from their child whether through choice of through the court system (Schofield et al., 2000). Managing these feelings and reaching a resolution is challenging in the light of the parents redefining their parental identity, which is emotionally draining (Schofield et al., 2011) and one which was identified in this study as parents faced the anxiety of acting on the decision.

The findings of the present study illustrate the challenges caused by the loss of the parental role. Doka (1989) suggests that parents grieve both the loss of their child and their parental role which links to reactions of grief. Doka (1989) described this as ‘disenfranchised grief’ i.e. grief that is not acknowledged or supported socially. Schofield et al. (2011) carried out a similar study exploring parents’ reactions when their child entered foster care. They suggest that parents managed the threat to their identity by accepting that their status as parent had profoundly changed. Their study suggested that most experienced parental isolation, and although they did not experience social condemnation (because their child did not live with them) the parents feared this external criticism and judgement, resulting in a choice not to discuss their child’s care with others including family and professionals. This parallels the findings of the present study: many participants assumed that their decision to place their child in care would be criticised, an assumption that appeared to be based partly on their own experiences of being criticised as a parent and partly on their social constructions around good parenting.

This present study also adds insight and a new perspective to the literature on adjustment to loss (relating to out-of-home care) by exploring the responses to parents who are managing the perceived loss of their child and loss of parental role, a loss which is not recognised socially. This links to theories of disenfranchised parental roles (Milliken, Herbert and Northcott, 2003). This study found that parents strive to ensure their child is safe but are met with obstacles and feel their role has diminished; in some cases, parents were relieved to see their child happy, while others remained concerned that their child was actually unhappy.

Ho¨ jer (2007) and Schofield et al. (2010) suggest that parents can face diversely challenging reactions to loss especially when they feel relieved to see their child is being cared for, but uncertainty because someone else is proving the care. Kielty (2007) explored the changing identities for divorced and separated parents and suggests that mothers aim to come to terms with the loss of their child (and their care-giving role) by sustaining a personal and public ‘good parent’ identity in order to cope with their loss. However, identity resolution and self-esteem were affected because the mother remained separated from the child. Managing separation and threat to the self was enhanced when the parent accepted that the separation was due to their decision. This finding is supported by the present study as parents seemed to focus on the decision being ‘their own’ and one which was required for the ‘good of their child’. Nonetheless, feelings of guilt were commonly expressed as the parents struggled to adjust and accept that the child was being cared for by others. There was a sense that the child would never return to the parents’ care, leading to turmoil in the light of the loss of the previous 24/7 caring parental role. This led to feelings of worthlessness and a profound sense of loss as parents embarked on a new life without their child, which forced them into ‘negative parental identity’. This was an unexpected finding and a factor not initially envisaged within the research parameters and research questions; however a finding that proved to be a significant part of the process. To manage these feelings some developed new roles and identities focussed on the needs of their child by evaluating and monitoring care to maintain a level of involvement and reduce the loss of role, thereby potentially enhancing self-esteem.

EVALUATION: CONSTANT MONITORING OF CARE

Essex et al. (1997) reported that 80% of informal carers (parents / guardians) of adult children with cognitive disabilities were satisfied with current residential services. Of the 20% who were not satisfied, there was a pattern that these did not seek support over their lack of satisfactions due to anxiety regarding the future care for their child i.e. would the child be moved or returned home. Fear of the future and the assumption that care would be poor (at some point) seemed an element within the evaluation process.

This study offers new insight into parents’ continuous need to evaluate and assess the appropriateness of the care offered to their child. This process of evaluation appears to enable the parent to retain some sense of a parental role and to remain engaged, but an additional factor was the fear that their child might be harmed.

To understand these fears, the literature on availability bias is useful. Availability bias is a cognitive process which contributes to individuals overestimating the probability of events because the events are associated with memorable occurrences (Kenji and Shadlen, 2012). For example, the Winterbourne View abuse scandal in 2012 which was aired on TV's Panorama programme, showed care staff abusing individuals with learning disabilities in an out-of-home setting. Due to this event being significant and memorable and graphically displayed by the media, the bias (that out-of-home care staff will abuse those with learning disabilities) is compounded on the societal level. To manage their assumptions and fears, parents sought to reassure themselves that they made the right decision by evaluating care and in some cases choosing to move their child to new placements, or even returning them home, if they perceived abuse to be occurring.

Parents seemed to struggle with their loss of roles and had contradictory ideas about the child's care, for example switching between seeing the care as good or bad, or in some cases as both good and bad. Such contradictory stories are supported by the literature and occur when parents' identity is under threat such as when they experience a loss of child or the child enters care because the parental role changes (Schofield et al., 2011), which creates stress and dissonance. To manage the associated stress parents are forced to modify their behaviours, beliefs and attitudes to create a more consistent experience in order to protect themselves and their identity. Aronsa (1969) argues that contradictory cognitions and tensions are hard to resolve because the concepts impact parental self-esteem but parents constantly change perspectives depending on new information and emotions. Kielty (2008) spoke of narratives which parents use to manage these changing and threatened identities to fill the gap between their sense of self as perceived by others (mostly experienced through stigmatisation) and seeing themselves as good parents (which maintained the good parent identity). Participants seemed to use narratives to enhance their identities such as telling themselves and others 'I am a good parent because I chose the best care for my child', 'I am a good parent because my child is being well cared for' or 'I am a good parent because I am challenging poor care'. It is argued that parents need these strategies and narratives to sustain a positive identity even though there remain contradictions between narratives i.e. what they experiences and express, suggesting why parents can evaluate care as both good and bad. With this in mind, the ‘redundant’ parents can deny or deliberately push memories aside to ensure psychological survival which demonstrates the complexities and personal evaluations involved when assessing care and how parental roles seem to play a significant part.

Schofield et al. (2011) suggest that professionals play a key role in parents’ abilities to maintain a good parent identity, especially following a sense of loss. Parents need to be treated with respect, gain information and remain involved in the child’s life. Participants in the present study felt that care home staff did not seem to recognise that their constant monitoring of the care related to their desire to remain involved in their children’s care and lives. The lack of support from the care home staff enhanced parents’ feelings of redundancy. Therefore the parent and care home seemed to drift apart causing a lack of communication and respect for each other with emotions running high and potential for relationship breakdown. In some cases, the lack of confidence in care homes and the inability to adjust to the loss of role potentially contributed to why some parents chose to return their child home or move them to another care home. Millikan, Herbeert and Northcott (2003) suggest that parents expect to maintain a relationship with their child, however, this may reduce as the parent eventually withdraws their control over the child regarding decision making. They suggest that at this stage, parents can anticipate enjoying their life with more independence. However the findings of the present study suggests that parents remain involved in a cycle of evaluation and re-evaluation and that parents refused (or felt unable) to relinquish their parental responsibility for their aging child, The model illustrates a continuous process relating to parental identity which never ceases, as the parent continues to maintain the parental role for their child (of any age) due to fears over the appropriateness and quality of care provided and their reaction to the decisions they make and have made about their child’s needs, care and future.

RELEVANCE TO COUNSELLING PSYCHOLOGY

The findings of the present study are highly relevant to counselling psychology as the processes in place may influence immediate and long-term psychological wellbeing and health for parents, the child and the family system. This study aims to inform those working to support parents about these processes and may enable them to address the issues identified thus reducing stress and anxiety, and potentially enabling parents to provide better care for their child (at home if they want).

The basic social psychological processes outlined above contribute to an increasing understanding of the experience of parents of children with learning disabilities and. These processes can involve threats to parental identity, the development of a compensatory parental identity and a struggle to manage both the threats and the stresses attendant on parenting a child with learning disabilities. This can lead to ultimate psychological breakdown and motivates decision making around appropriate care, and impacts adjustment to decisions.

It is hoped that these findings will benefit counselling psychologists working within the field of learning disabilities and could be useful in the domains of psychological therapy by bringing these issues and processes to the fore. The entwined elements of enduring stress, which is evident throughout the process, is specifically relevant to counselling psychology as stress affects health and psychological well being (Seltzer et.al., 2009). Many participants in this study experienced severe psychological distress and some considered suicide due to the stress and strain experienced. This was exacerbated by participants experiencing a lack of social and family support with professional empathy, tolerance and understanding being less than satisfactory. The insights provided by this study should aid professionals, working to support parents of children who have learning needs by enhancing awareness of the processes involved in parenting from birth and beyond. This may encourage the implementation of guidance and strategies to reduce (and to encourage understanding about) the stress and anxiety experienced by parents, which potentially impacts on their caring abilities.

Finally this grounded theory should aid understanding about why ‘good care’ is so important (not just ethically but emotionally) and why parents’ roles continue to focus on care and why this can result in parental hostility towards professionals.

RECOMMENDATIONS FOR PRACTICE

Counselling psychology emphasises the subjective experience of individuals through collaborative relationships by seeking to understand inner worlds and constructions of reality (Strawbridge and Woolfe 2003). It is argued that counselling psychologists are well placed to advocate for families and individuals with learning disabilities through training, supervision and direct practice. For example by providing guidelines, implementing appropriate training and development programmes for professionals working within the field of learning disabilities to include organisations, social care, health visitors, schools and general practitioners. These professionals were identified by participants as the initial contacts for support, but were not necessarily empathic to the participants’’ needs, resulting in feelings of isolation and ‘not being heard’. By encouraging and sharing parental experiences and how this impacts on family stress, interventions may be beneficial for parent and professional relationships.

Recommendations are that counselling could be utilised to support parents to manage and understand these experiences at any point within the process, although it needs to be stressed that a stage model is not being advocated here, but rather a grounded theory of the processes involved, which is a more fluid process. This could be achieved through individual, family and couples therapy, to reduce distress and improve coping, potentially minimising the number of families reaching breaking point and the number of family breakdowns and separations. A comprehensive study by Contact-a-Family (2003) indicated that families suggested that counselling should be offered soon after the diagnosis or birth of the child because parents typically face many questions, worries and uncertainties and struggle to adjust, a finding which is supported by this study. In line with this, counselling psychologists could contribute to parent training programmes thereby promoting understanding of parental stress specifically when caring for children with disabilities. The focus on parental stress and psychological factors appears to be under-emphasised in parent training programmes (Gilick and Zigler, 1995).

Further recommendations for practice relate specifically to the support offered to parents and families. For example psychologists could develop a structure of support and intervention to help parents and families access, understand and express their feelings and reaction to diagnosis, which was a significant barrier for parents. This may aid the psychological adjustment following diagnosis and is significant because parents' experiences during this early stage seemed to set a precedent for how they relate to professionals later in the process i.e. unsatisfactory interactions with professionals in the early stages suggest that parents may be reluctant to trust professionals in later stages and they may not seek professional support at a later date. This could be achieved through providing training to parents and families (as well as to professionals and through peer reviews / training).

Signposting to support services is a further recommendation for practice, as many parents expressed a lack of knowledge about where to gain support and information. Although there is some evidence that this is available online for example by using search engines, the data suggests that participants generally completed significant research independently in search for answers and information which often left them facing further uncertainly. To address this, specific information could be provided by professionals in conjunction with parents and be available in leaflet form and online. This information could identify links to support groups, agencies and advocacy services; participants found these the most beneficial avenues of support available to them, but complained that they were difficult to access. Such information could be accessed online as well as available at GP surgeries, hospitals and children's' centres to allow for easier access.

A further recommendation, links to supporting parents through decision making and choosing out-of-home care. This was an area where parents experienced significant stress. The data suggested that parents were often reliant on 'word of mouth' rather than being able to consider and compare services. It is recommended that organisations and social care agencies develop an online data base which contains out-of-home care information such as Ofsted and Care Quality Commissions reports and evaluations, so that parents can search by location and ratings to assist them in finding suitable support. This would be an inexpensive and easy approach to aid choice and decision making. Such ‘publication’ of data should help drive up quality and care standards over time as ‘failing’ organisations would be motivated to improve their ratings as they know families can read the outcomes and over time this may help them strive to achieve outstanding care. Parents may also wish to offer reviews on specific services and organisations to aid other parent’s choices of care.

A significant recommendation is for care-home staff to be more aware of the stress and difficulties experienced by some parents prior to them placing their child in the care home. The grounded theory presented in the present study suggests that participants often felt isolated and left out of the decision making process once their child entered the care system, which caused ongoing stress. This could be achieved through parental support groups run in collaboration with out-of-home care establishments and through providing training and supervision to organisations and their staff. This may help reduce the anxiety parents and families experience through improved communication and understanding. Additionally organisations could be encouraged to consider developing parents’ evenings and parent / teacher meetings, which seem to be lacking in out-of-home care environments, but are useful in mainstream schools.

DIRECTIONS FOR FURTHER RESEARCH

The elements identified within the grounded theory process outlined above indicate a continuous cycle and contribute to the literature on parental roles and responsibilities. Because the study identified that all participants were parents or family members of children who had learning disabilities as well as additional diagnoses, it is suggested that further research could focus on exploring the similarities and differences of need depending on diagnosis as this study and previously cited literature suggests that it is the challenging behaviour rather than other diagnosis which contributes most to stress and strain. Exploring this further would offer more insight into where support can be focussed.

The study focussed on the experiences of participants who chose to place their child in out-of-home care rather than those who were required to do so due to interim or full Care Orders. Under the Children Act (2004), Interim or Full Care Orders are acquired through the Court system to remove a child from the parents' care due to neglect or harm. An area for further research would be to explore the processes involved in these circumstances; this would also allow for an exploration of how parents adjust following out-of-home care placements in these circumstances.

On reflection, it appears that participants rarely expressed intolerance, anger or frustration in response to their child although this was expressed by others around them. It would be beneficial to explore this further as it is suggested that at some point all parents and family members experience frustration of their child's behaviours. The lack of reported intolerance could be due to parental defences or due to retrospective accounts. Participants could be supported to understand that their reactions are normal. Exploring these potential defences more thoroughly could aid clinical interventions, through either counselling, groups or skills workshops to help parents manage stress and acceptance of their feelings towards their child.

Exploring the impact on the person with the learning disabilities when the parent is making decisions regarding out-of-home care seems like a valuable next step for research given the limited literature currently available. The aim of this would be to understand their experiences and feelings during this decision making process and how they adjust to their new environment. This would enable comparisons to be made with the parents' experiences and would give a more thorough understanding of the needs of families, siblings, extended family and individuals.

LIMITATIONS OF RESEARCH

Although the sample captured a range of contexts and circumstances, there were a higher percentage of female participants compared to males despite recruitment requesting both genders. All participants, with the exception of one, were Caucasian so a sample did not represent culturally diverse experiences. Furthermore, those individuals who declined to take part in the study may have experienced more negative or positive experiences which could not be voiced. There were very few positive comments about the decision for out-of-home care. This may reflect the difficulties families face or could be related to those who experienced struggles wishing to share their views due to their lack of satisfaction. It is a possibility that others with more positive experiences did not have the motivation to participate and therefore did not come forward.

Reflexivity - Given my past experiences of supporting individuals with learning disabilities and complex behaviours and their families, I had anticipated uncovering a smooth process for parents choosing out-of-home care, as a tool to relieve their stress. However, it emerged that participants' primary focus was to seek out-of-home care in part due to their stress but in the main to ensure the best care for their child (which they perceived they could no longer provide at home). Additionally the stress they experienced never subsided even when care was achieved i.e. there was a continuous cycle evident. Therefore with the fundamental philosophy of grounded theory in mind, it was important to maintain objective distance and limit my effects on the data set (Kennedy and Ligard, 2006).

It is also acknowledged that the grounded theory in this study is based on my own constructions; reflexivity is beneficial throughout these stages of construction as it accepts that the researcher shapes the research. To manage this (and to minimise any impact on the participants), I attempted to give adequate timing to allow participants to share their stories during interviews and aimed not to indicate any personal reactions to their stories. Seale and Silverman (1997) suggest one way to aid validity and objectivity when constructing qualitative methodologies is to record data and then reproduce the detail in the transcription as this aids accuracy when analysing. This was the chosen method for this study. Although this does not solve the problems of reliability and validity, it does mean that the data recorded is accurate in terms of the wording. It's important to note that the focus of qualitative research is more about ensuring rigour rather than reliability and validity (Seale and Silverman, 1997). For example by acknowledging researchers responses aids reflexivity and rigour; I note that some of my own responses included feeling sad, upset, disempowered, anxious and angry as participants shared their struggles and experiences. Seale and Silverman (1997) suggest that researcher's must be mindful that all knowledge and feelings do not hold equal weight and value, thus I acknowledge that the data is my construction of what has been expressed and shared. In such circumstances, the need for reflexivity and objectivity is vital to allow the data to speak for itself. Elliotte and Lazenbatt (2004) outlined that the quality of research is implicit when considering the validity of any study. One error which needs consideration relates to the misinterpretation of data which links to inaccuracies in the construction of theory. To aid this, researchers can seek to validate by checking for accuracy through the transcript with the participants (Seale, 1999). To aid accuracy, I did share one transcript with a participant who requested a copy. This participant did not want changes and agreed the data reflected her viewpoints. Secondly, I methodically checked each recording against the transcribed document to confirm the record was accurate.

During analysis the data was also explored and discussed with the research supervisory team to aid reflexivity and analysis. Furthermore, a selective sampling method was used initially and then a theoretical sample was targeted in attempt to refine and develop categories (Charmaz, 1990). In my study, a participant who was not seeking out of home care was contacted as a comparison. Overall, I do believe the reflexivity utilised during the study, how well the concepts produced are grounded in the data and how the model works and fits with the literature, all combined with participants' feedback establish rigour.

The developing model was also discussed with four participants to aid analysis. It is acknowledged that this is not necessary in grounded theory (Elliott and Lazenbatt, 2004), due to the progressive nature of the theoretical sampling and constant comparison. However my primary purpose was to aid validation and to attempt to counter researcher bias, but it does not mean that validation is necessarily absolute (Murphy et al., 1998). Elliott and Lazenbatt (2004) suggest that grounded theory can target subjectivity by memoing, which is important in controlling the distortion of analysis as well as aiding the researcher's reflexivity relating to bias.

Grounded theory, as a methodology, has been widely adopted by qualitative researchers and is said to aid explanation of what is actually happening rather than suggesting what should be going on. As such it encourages concepts and meanings to be shared through the research process. Grounded theory is argued to be valid because it uses patterns found in empirical data and utilises constant comparison to confirm the theoretical constructs in the data (Glaser, 1978, 1992; Strauss and Corbin, 1998). With these methods non-expected findings cannot be ignored; therefore in this study, whatever the reason for unexpected findings, it was fundamental not to ignore data because it did not fit with perceived notions (McGhee et al., 2007).

To ensure validity, notes on potential impacts on the data were kept and formed part of the constant comparative analysis. Additionally, memo-writing assisted awareness of this potential effect on data as recommended by Charmaz (2000). I also have to bear in mind how I as the researcher may have impacted on the participants. Given the need for the compensatory 'good parent' identity it is possible that participants may not have felt comfortable identifying that they had relieved their stress through their decision (relating to parental identity and stigmatisation), and sharing this with an 'outsider'. Denscombe (2007) outlined the disadvantages of face to face interviews regarding the different responses participants may have depending on their view of the researcher. This is known as 'interviewer effect', for example gender, age, ethnic origin and potentially impacts on the amount of information participants are 'willing' to share and on their honesty. In this study it is impossible to fully explore if these factors affected the data, but it is important to acknowledge their potential impact. By having as large a sample as possible and then comparing the findings to the literature, the validity of the study is enhanced because parallels and distinctions can be made and discussed as relating to experiences of potential participant or researcher bias.

CONCLUSIONS

This study offers an original insight into the complex processes relating to parenting children with learning disabilities particularly regarding how participants respond to perceived social stigma, develop coping strategies, seek diagnosis and eventually reach breaking point and for some the decision to opt for out-of-home care for their child. Exploring parental identity is important because it identifies the ongoing struggles and psychological distress experienced based on social constructions and responses, and suggests decision making for out-of-home care is never a first or easy choice for the parent / family. Examining and linking together the factors leading to the 'breaking point', which is a new finding within the field, demonstrates how the cycle of *coping and not living* can occur for decades as parents convince themselves they can cope within limited external support and chronic stress. The child consumes the parents' life and role and this is never diminished, even when the child eventually leaves home and is cared for by others. This unexpected finding, unanticipated at the outset of the research, suggests that the decision making process is a continual one and that shifting parental roles and adjustment is ongoing. The decision for out-of-home care does not necessarily reduce the chronic stress the parent experiences, despite an assumption by the parents (and possibly indicated by the literature) that decision making has an endpoint that will reduce stress and anxiety.

The processes involved when adjusting to the decision for out-of-home care and the actual move is one which can be psychologically damaging and stressful for the parent as they come to terms with their decision. In addition this study hints at the conflict which can arise between care homes and families as the parents may fight to remain involved in their child's care, albeit from afar. The process outlines why parents can have conflicts with care homes as they evaluate care and strive to remain involved.

Participant's experiences suggest that many faced difficulties in the processes of securing funding for out-of-home care and dealing with professionals with most finding their own way through the bureaucracy. Participants suggested that parental ferocity often determines the level of support received which should be provided on a needs basis rather than based on ‘who shouts the loudest’. Advocates and lead professionals could help parents and families to receive the correct support and guidance. It is argued that services should be providing a systemic focus to support individuals with learning disabilities as it is usually the families who support them yet these families are frequently criticised and isolated. Furthermore, future research could be to explore attitudes of professionals towards these parents.

The findings of this research add to the literature by bringing to the fore the complexities of decision making and how evaluation of decisions in this area is continuous.

Participants’ experiences indicate that decision making for out-of-home care is not an easy choice for families and is often a result of being unable to manage the stresses and strains and the psychological result is *‘breaking point’*. This diverts parents from their prime role of caring for their child as they are forced to focus on evaluating the decision continually in the hope of providing their child with the best care in a safe, trusted and inspiring environment.

I would like to conclude that from my own perspective I have gained an insight into the continuous struggles parents / caregivers face within the often limited options available to them. The psychological impacts that bring them to breaking point have given me an avenue of particular professional interest that I can hopefully explore in the future.

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Placing a child with learning disabilities into out-of-home care: Threats to parental identity and how this impacts the decision making: a grounded theory exploration.

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***Accessible* summary**

- The paper used interviews and a survey to explore parents' decision making processes when choosing out-of-home care for their child with learning disabilities; it emerged that parental identity was a key factor within this process
- The aim was to understand how parenting experiences and stress influence care-giving, roles, relationships, coping and decision making for out-of-home care.
- The findings reveal parental isolation, stress and difficulties in adjustment, creating negative parental identities which had to be defended against in order for the parent to cope with the caring needs of the child and decisions about their child's care.

Summary

The article adopted a social constructionist grounded theory methodology; fourteen participants were interviewed and three completed a qualitative survey. The objectives were to gain in-depth understanding of the processes and experiences when raising a child with learning disabilities and how these experiences contribute to decision making for out-of-home care. The aim was to provide a conceptual framework grounded in the parents' experiences.

The analysis outlined a cyclical process relating to the challenges faced by the parents, which led to 'breaking point' and the decision for out-of-home care; parents developed awareness of their child's disability combined with social prejudice, which contributed to the development of a *negative parental identity*. To defend against this, parents created a *compensatory good parent identity* and in doing so convinced themselves that they could cope with *the 24/7 child*. This increased stress caused relationship breakdowns, financial difficulties and mental health problems. In addition parents faced additional stressors when *screaming to be heard* by professionals as they sought guidance, diagnosis and support. Eventually *breaking point* was experienced as they became overwhelmed. This initiated the decision making about out-of-home care. Once the move occurred, a process of *adjusting* and managing the *loss of role* was entered, linking to *evaluation and constant monitoring of care*. In

this sense parental responsibility was never relinquished and parental roles were redefined. The findings outline a lack of support, information and guidance for parents and families based on their experiences of prejudice and dismissal of concerns by society, professionals and on occasion's family and friends.

Keywords - *Parental identity, parental roles, care, decision-making, grounded theory, learning disability.*

INTRODUCTION

It is estimated that 1,191,000 people in England have a learning disability, of these 21% are known to learning disability services (*Emerson et al.,* 2011). Davis (1993) suggests that when a child has a learning disability, the rate of disturbance in families rises to 30-35% as opposed to 10-15% in families with no disability; a survey by Mencap (2013) indicates that 50% of adults with learning disabilities live with families, with 29,000 living with parents aged 70 or over who may not be able to manage their caring roles. Research indicates that parents of disabled children are particularly vulnerable to stress (Warfield, 2005; McLennon & Urictiuk, 2008). Challenging behaviour is more consistent and enduring in those with developmental disabilities and contributes to stress and lower levels of wellbeing (Matson *et al.*, 1991); challenging behaviours impact the parent-child relationship affecting the parents' sense of self by decreasing parental self-confidence and increasing stress. Moran et al. (1992) outline the irony that those children most in need of sensitive care challenge the parents' ability to provide it.

Caring for someone with a learning disability has moved away from hospitals to the community; Beadle-Brown et al. (2006) suggested 41% of people with learning disabilities are supported by local authorities (which may include out-of-home care). Out-of-home care is any supported environment where the person lives and requires some level of continuous support. A survey by Mencap (2001) suggests that children usually enter the care system when parents can no longer cope and it seems the only option due chronic stress. Parents experience practical and moral dilemmas when making decisions (Milliken et al, 2003). However the decision making process regarding out-of-home care is complex and not well understood. Studies into the parental experiences of loss of a child, such as when a child enters foster care, outline the challenges and difficulties faced in light of such moral decisions; outcomes include loss of self-esteem, grief, loss of role identity, regret and anger (Ho¨ jer, 2007). Managing these feelings or reaching a resolution is challenging, as to do so the parents have to redefine their identities due to the loss of the child, which is emotionally draining (Schofield et al. 2000). Doka (1989) suggests that despite this loss, parents' reactions and grief following relinquishment of a child is not acknowledged or supported socially, enhancing isolation. There is currently no literature exploring the experiences of parents who place a learning disabled child into out-of-home care which this study attempts to address; it is not unreasonable to suggest that similar reactions could be present because role and identity is commonly defined by parents' caring responsibilities (Crocker & Quinn, 2004). Thus the way parents define themselves is constructed by experiences and they are therefore vulnerable to criticisms and stigmatisation which threatens identity and decision making. A study by Cairns, Tolson, Darbyshire and Brown (2012) explored the future needs of older parents caring for offspring with learning disabilities; their key findings outline that in the early years the parent began to acknowledge the unforeseen impact the child's disability would have on the family for example the parent would need to continue to care for the child which would not relinquish with age. Furthermore the study outlined that professionals tended to have low expectations of the person with learning disabilities in regards to their progression and future. This echoed the realisation that parents were facing constant care for their child with no end in sight as they faced a reality that the care fell to them. This emphasised the isolation and 'going it alone' processes which parents reported as they believed there was no alternative because the external care was unsatisfactory. This showed parallels to the professional guidance and support which parents noted was also lacking and unsatisfactory. The findings outlined that better support was needed for families and suggested parents were ignored by health and social care professionals and forced to continue caring roles despite deterioration in their own health and wellbeing. Eventually the parents reached a decision regarding their child's future with some deciding to keep their child at home despite being dissatisfied with their lives, the challenges when bonding with their child, and their overall inability to manage. Others questioned their ability to manage, outlining it as unrealistic due to their age and health deteriorations, and they decided to seek care support. In summary Cairns et al. (2012) outlined that parents lack professional support and information regarding their child's needs often resulting in isolation and a struggle to manage the caring needs of their child. Parents remained concerned about the child's future but were reluctant to plan in light of poor expectations of care available. Parents continued in a caring role, believing there was no other choice due to low expectation of external care. This article builds on these findings with a focus on decision making for out-of-home care and how stress and parental identity influences this.

METHODOLOGY

The purpose of this study was to explore 'breaking point' in the parents and caregivers of learning disabled children and how this impacts on the decision to place the child in out-of-home care. The research aims to inform those working to support parents and children, to enable clearer interventions to address these processes, reduce stress and anxiety, and enable parents to provide better care for their child.

Design

This is a qualitative study adopting a social constructionist grounded theory methodology (Charmaz, 2006). Data collection was via semi-structured interviews and a qualitative survey. Epistemologically, grounded theory methodology acknowledges the interrelationships between researcher and participant whilst acknowledging the subjective nature of this dynamic (Pidgeon & Henwood, 2007). Charmaz' (2006) methodology is viewed as a flexible set of principles and practices aimed at construction rather than interpretation.

Sampling strategy

A purposive sampling strategy was adopted with the inclusion criteria that participants had at least one child (of any age) with some degree of learning disability who was living in out-of-home care or for whom out-of-home care was being considered. As the analysis developed a theoretical sampling strategy was adopted. In line with Charmaz (2010) a pilot study was not required to support the development of interview questions because the questions were developing through an iterative process as the research progressed.

Participants

The sample comprised seventeen participants; two birth fathers, twelve birth mothers, one adoptive mother, one sibling and one guardian. Fourteen participants were interviewed and three completed a specifically designed qualitative survey.

Participant number	Gender / Relationship	Person discussed	Diagnosis of child / summary	Where does the person being discussed live	Age child first moved to out-of-home-care
1 Interview	Birth mother	Son	Autism, learning disabilities & communication difficulties	With parent who is considering out-of-home care	None - Never been away from home
2 Interview	Birth mother	Son	Down's syndrome & moderate learning disabilities	Residential college	Age 17 1 move to date
3 Interview	Birth mother	Son	Apert syndrome, Autism, severe learning disabilities & challenging behaviours	Residential home	Age 18 1 move to date
4 Interview	Birth mother	Daughter	Autism, mild learning disabilities	Residential home	Age 18 3 moves to date
5 Interview	Guardian (cousin)	Cousin	Down's syndrome, mild learning disabilities	Supported living	49 1 move to date
6 Interview	Adoptive mother	Daughter	Mild learning disability, Autism, disorganised passionate disorder, autism & challenging behaviour	Residential college	Age 11 3 moves to date
7 Interview	Birth mother	Son	Moderate learning disabilities, epilepsy, autism, chromosome abnormality	Residential home	Age 23 1 move to date
8 Interview	Birth father	Son	Moderate learning disabilities, epilepsy, autism, chromosome abnormality & challenging behaviour	Residential home	Age 23 1 move to date
9 Survey	Father	Son	Down's syndrome, mild learning disabilities & challenging behaviour	Supported living	Age 8 9 moves to date
10 Interview	Birth mother	Daughter	Autism, Epilepsy, chromosome disorder, moderate learning disabilities & challenging behaviour	Treatment / assessment hospital	Age 14 3 moves to date
11 Survey	Birth mother	Son	Down's syndrome associated with learning disability	Supported living	Age 20 1 move to date
12 Interview	Birth mother	Son	Life threatening heart condition, Down's syndrome associated with mild learning disability.	With mother Not considering out-of-home care	NA
13 Interview	Birth mother	Son	Autism, Severe Learning disability, No speech & challenging behaviour	Supported living	Age 12 2 moves to date
14 Interview	daughter / sister	Son	Learning disability & Asperger's syndrome	With family (left out-of-home care)	Age 13 6 moves to date
15 Interview	Birth mother	Brother	Learning disability & Asperger's syndrome	With family (left out-of-home care)	Age 13 6 moves to date
16 Survey	Birth mother	Son	Fragile X which caused Learning Disability & Aphasia	Residential home	Age 6 3 moves to date
17 Interview	Birth mother	Son	ADHD, Autism, learning disabilities, challenging behaviour & no verbal communication	Residential home	Age 11 6 moves to date

Figure 1 - Table of participant information table

Procedure

Ethical approval was gained from the University of the West of England's research committee. The approaches to recruitment were; direct contact to out-of-home organisations and support services, via word of mouth / networking, and a specifically designed website (www.learningdisabilityresearch.co.uk). Research posters were distributed to all services and organisation that consented to take part or aid recruitment.

Analysis

Surveys and interviews were transcribed and coded. Coding reduces the data into elements of meaning (open coding) then into larger concepts (focussed coding). The relationships between the concepts are explored to establish analytic distinctions looking at similarities and differences in data (constant comparison) resulting in the development of a grounded theoretical model which is a constructive story of the process. The model was modified following discussion with participants. Memos (notes made throughout the research, relating to the developing hypotheses) were written to aid productivity, reflexivity and promote data analysis and the developing grounded theory in line with Charmaz (2006). Sampling continued until 'theoretical sufficiency' was achieved Dey (1999).

Reflexivity

Cutcliffe (2003) stresses the importance of researchers sharing experiences with their readers; my interest in the research question is based on my experience of working with families, children and adults with learning disabilities within home and organisational settings as a trainee counselling psychologist and in roles within social care settings. I acknowledge that these experiences are likely to impact my assumptions and biases.

RESULTS

The grounded theory outlines a continuous cyclical process with a core-category relating to parental identity. Experiences relating to parenting such as criticisms and stigmatisation led to the development of a *negative parental identity* at a time when the parents were already struggling to cope and understand their child and contain difficult feelings towards them. To counter this threat to identity, parents created *a compensatory good parent identity* by focusing selflessly on the needs of the child, and sought to become the *expert parent* through gaining qualifications and by becoming involved in *advocacy*, which aided self-esteem and coping. In a desperate attempt to preserve their ‘good parent’ identity parents reassured themselves that they could cope without support, however in doing so they neglected their own needs and in many cases those of their family, leading to relationship breakdown. These stressors were often accompanied by mental health and financial difficulties, which, when coupled with desperate attempts to obtain professional help, led to becoming overwhelmed and *breaking point*. Breaking point allowed a more conscious awareness of the difficulty in coping and enabled participants to consider the prospect of out-of-home care. The decision to obtain out-of-home care led to further guilt and reinforcement of the *negative parental identity*. In addition once the move occurred parents faced both the loss of their child and the loss of the parental role; they sought to adjust to both by striving to maintain a relationship with their child through constant monitoring of care.

Parental identity

Parental identity was identified as the core category within the process; participants oscillated between 1) *developing a negative parental identity* and 2) *creating a compensatory good parental identity.*

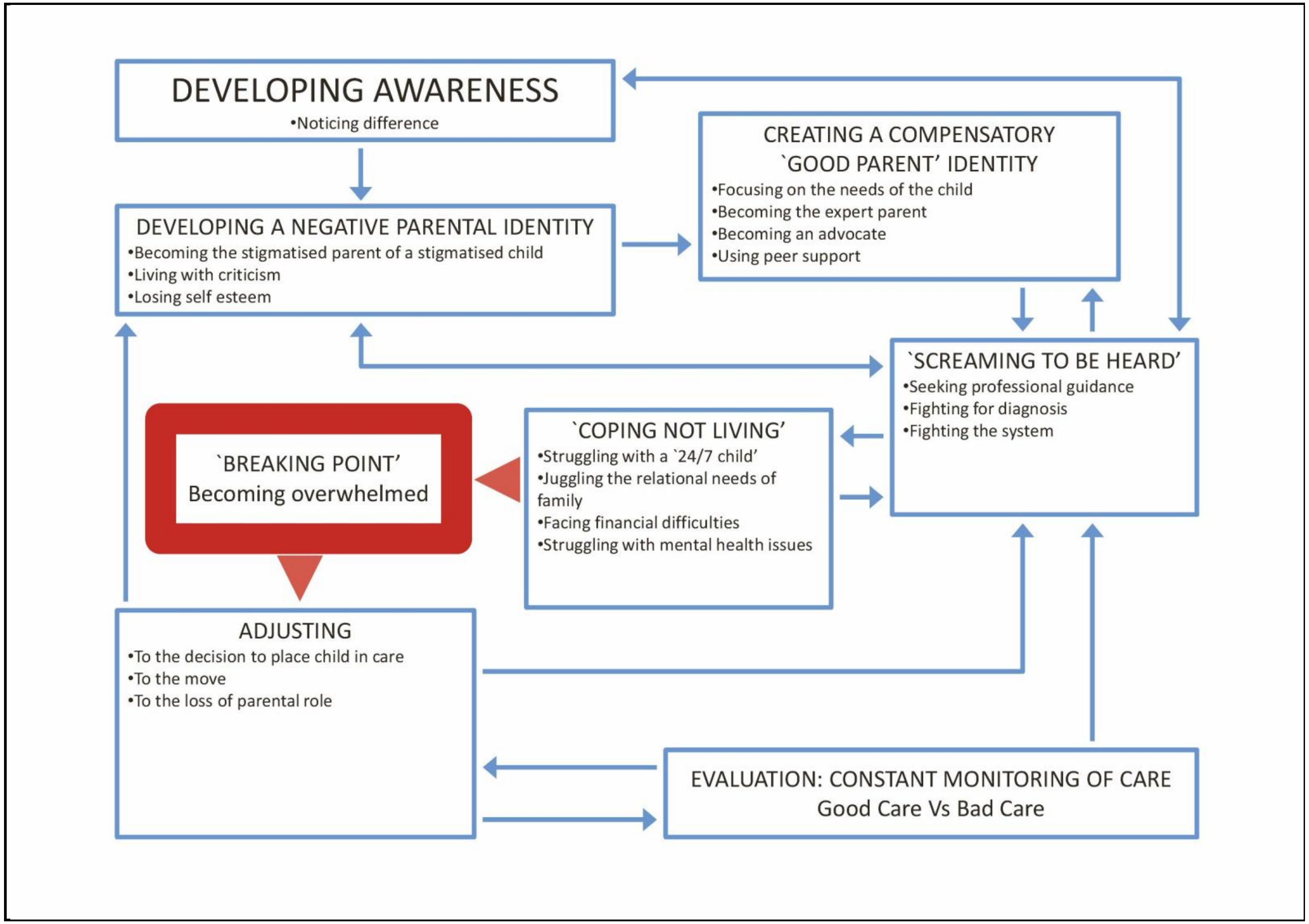

Figure 2 –Psychosocial model: Placing a child with learning disabilities into out-of-home care: threats to parental identity and how this impacts decision making processes and breaking point

Developing a negative parental identity

The majority of participants described the first step in the process as one of *noticing difference*; their own perceptions were confirmed through receiving negative feedback from others; this led to the development of a negative parental identity; Stigmatisation was focussed on the child, but by default, experienced and internalised by the parent:

> *"People would just look at you as if to say keep that child under control"* [Participant 15]
>
> *"I worry about being judged by other people and this reinforces my feeling of worthlessness"* [Participant 8]

Rather than the child's behaviours being linked to a disability, parents felt 'blamed' for poor parenting. This social reaction further reinforced the parents' sense of identity as deficient because society implied others could do better, and the parents then interpreted that they were doing it wrong:

> *"because he looked normal... when he played up in a shop or other public place, people would make comments like if he was mine, I'd give him a good hiding"* [Participant 16]

This negative internalisation appeared to be exacerbated by the parents' own struggle to understand their child and to contain their difficult feelings towards them, contributing to reduced self-esteem:

> "*I lost a lot of confidence, I felt I was being seen as this first time mum and I just wasn't a very good parent... I think they possibly thought that it was the way I was managing her that was causing the behaviour and I don't think they realised how difficult it was"* [Participant 10]

Participants' experiences did not appear to be recognised as important by friends, family and professionals; their struggles to manage seemed to be 'ignored', and instead a construction of blame towards them for 'doing it wrong' served to reinforce a negative parental identity:

> *"We lost a lot of friends and relatives because they didn't understand, they would just avoid us" [*Participant 17]

Creating a compensatory 'good' parent identity

In order for parents to defend against this threat to their identity, they appeared to create a *compensatory good parent identity by* focusing selflessly on the needs of the child, often neglecting their own needs in the process. Defensively, difficult feelings towards their child appeared to be minimised with a focus instead on unconditional love. It was apparent that participants never spoke of being angry, frustrated or annoyed at their child. Participants seemed to find it more tolerable to blame the 'system' and professionals rather than the child, possibly defending against the anxiety evoked by these feelings by projecting them onto the external world. Difficult feelings become focused on *fighting the system* rather than on battling with the child, and on not being heard by the system, rather than not being heard by the child. The parents seemed to convince themselves they alone could cope; that the difficulties were external rather than internal because their contact with others was frequently unsatisfactory and damaging. Focussing on the needs of their child, served to enhance self-esteem as they undertook the 24/7 caring role and over time perceived themselves to be 'the best carer' for their child:

> *"We were the only people who knew him"* [Participant 7]

Somewhat paradoxically, the compensatory belief that others did not / could not know or support the child left primary carers with the predicament of either caring themselves or receiving support from people they didn't trust. It is possible that the anxiety evoked by these experiences was managed by psychological defences such as humour or displacement which enabled parents to focus on the child's needs even while being overburdened, which reinforced their sense of self as 'good parents':

> *"It's been a process, a tough process I mean she is absolutely adorable though and I wouldn't change her for anything I love her to bits"* [Participant 4]

The role of *expert parent* appeared to compensate for the negative parental role exacerbated by negative experiences from society and from being discounted and dismissed by professionals, as well as their own struggles with their child, which undermined self-esteem. Participants sought qualifications and experience to ensure they were informed about the (assumed or confirmed) disability which meant they perceived themselves to know more than the ‘experts’

> *“I even did a Masters in Autism to try understand him better”* [Participant 13]

> *“I became a learning disability nurse because I was fed up of fighting on the outside and at meetings we were always treated as if we knew nothing about our children”* [Participant 17]

Becoming an advocate also allowed participants to support others which further enhanced their identities as competent parents.

> “*The more I can do to help them you know it helps me in a way, it’s therapy for me”* [Participant 8]

In many cases participants were not supported adequately by friends and family, and professional support was lacking. However, participants did benefit from peer support (group sessions) from those with similar experiences to their own. These methods assisted participants to channel struggles, frustrations and anxieties into positive actions, enabling participants to reconstruct their identities into being ‘the best parent they can be’ and to evaluate their situation and themselves in a more positive light, even while they were struggling to manage.

As time passed the child’s needs took an emotional toll due to constant supervision especially as the child aged and grew in size. Participants manoeuvred through a psychological maze as they struggled to establish their role and relationship with a child who required constant vigilance both at home and in public.

> *“I loved him to bits but I didn’t understand basically why he was beating the whole family up”* [Participant 14]

This eventually became unmanageable, resulting in *breaking point* and forcing participants to realise (and accept) that things were not working:

> *“I reluctantly made the decision that we are no longer able to cope and keep him safe during his violent spells”* [Participant 16]

This realisation motivated decision making for out-of-home care. Without this crisis, decisions would not progress and things would remain stagnant irrespective of how the family was actually ‘coping’. It was as if parents defensively convinced themselves that they could cope until they became overwhelmed by the enduring stress:

> *“As a family we were at absolute breaking point”* [Participant 6].
>
> *“it was a very painful thing, things got difficult my husband suffered from severe depression and my daughter was finding life a little bit difficult, so a decision had to be made”* [Participant 13]

Breaking point reactivated the *negative parental identity*, which was framed with self-blame and guilt i.e. they had provided constant care and now had decided they would allow others to care for their chid.

Adjusting to the loss of parental role

Having reassured themselves that they alone could manage in order to protect both their child and their ‘good parent’ identity, participants were forced to confront the idea that someone else would now care for their child, a realisation that provoked great anxiety. The immediate reaction to the move for the majority of participants was psychologically challenging. In most cases the emotional impact was unexpected due to the sudden loss of the child and the need to immediately evaluate if they had made the right decision:

> *“We all found it very hard and sad because he was our son and it was empty”.* [Participant 13].

Immediately the parents were faced with a loss of role as they were no longer the primary 24/7 carer and they experienced grief as they questioned their decision. Many found managing the loss psychologically devastating, and the guilt they felt added to a negative parental identity now that the parental role was redundant:

> *“Not many people know how mentally challenging it is sending your helpless child away... I am empty, my spirit crushed and heartbroken... I am undeserving of my life because I have let my son down so badly by not being*

> *able to provide a future at home for him.... How can I call myself a parent, doing this to my own vulnerable son, I don't feel I can enjoy anything anymore because our lovely son is not here with us to*" [Participant 8].

During this adjustment to the loss of role, self-doubt emerged i.e. have I made the right decision? At this stage participants reported high levels of stress based on powerlessness, frustration and fear, returning them to *developing a negative parental identity.* The participants began to question their identity and felt at a loss and somewhat redundant; their role had diminished, and this affected their day-to-day life and motivation. This finding highlights the importance of parental identity and the significance of the caring role. These processes are continuous and cyclical; the role of the parent and desire for 'best care' is never eliminated.

DISCUSSION

The identity of parents is commonly defined by their caring roles (Crocker & Quinn, 2004); the way parents define this role is socially constructed and such social constructs can threaten the identity of the parent of the learning disabled child. This research found that certain experiences negatively impacted the parents' sense of self, which they defended against by redefining how they viewed themselves as parents in order to ensure they could care for their child. This research suggests that participants develop early awareness of their child's disability based on *noticing differences* through subtle observations This finding is supported by Curry et al. (1997) who suggests parents generally realise something is wrong before professionals. This is the first step to seeing themselves as being bad parents' as they struggle to contain their difficult feelings towards the '24/7 child' who they do not fully understand.

Developing a negative parental identity - Stigmatisation forges a parental identity entwined with self-blame and criticism; this links to 'enacted' and 'felt' stigma (Gray, 2002) which enhances parental stress. Scarnier et al. (2009) suggests that social criticisms add pressure on parents when caring for a disabled child both within and outside of the home. This research adds to those findings, identifying that this was particularly the case when the child also presented challenging behaviours, which were perceived by the parents as a threat to their self-image. This is supported by Lickel et al*.* (2005) who suggested that when managing social prejudice, individuals experience feelings of shame, which threatens their identity and confidence. This is occurring at a time when the parent is already internalising and defining their parenting roles in a negative way as their child is not necessarily responding as expected. Such parental responses link to the literature on parental stress models. Abidin's (1992) model suggests parenting stress results in negative parenting due to cycles of helplessness and guilt, which enhances stress and lowers parental capacity, impacting on relational elements i.e. bonding between parent and child. Milliken and Rodney's (2003) study into children with mental illness outlines endless turmoil with shame, guilt, depression and frustration reported as common experiences as parents attempt to care for their child independently.

***Creating a compensatory 'good parent identity* -** In order for parents to defend against the threat to their identity, they create a compensatory good parent identity. This is supported by the literature, as developing coping strategies to manage stress, serves to enhance self-esteem (White & Hastings, 2004). Hanline (1991) suggests that parents may focus all their attention on the child to compensate for their 'actual' grief of the child's disability, which can come at the expense of other relationships. This was evident in this study whereby parents focused entirely on the needs of their child. A compensatory strategy was to seek qualifications and experience in the area of learning disability or additional disabilities; becoming an expert meant that participants could share their knowledge and in some cases felt reassured when they seemed to know more than the 'experts', which enhanced self-esteem and views of themselves as competent parents. This is supported by Beresford, Rabiee and Sloper (2007) who found that parents wanted to feel skilled as this was critical to their sense of themselves as competent. Becoming involved in advocacy performed a similar function; advocating, according to Karp and Bradley (1991) is crucial to parents as it ensures they receive and share information about services and best care ideas which enhances their identities as 'good parents'.

Deci and Ryan (1995) suggest that the higher the self-esteem the better the person is at psychological adjustment. Crocker and Knight (2005) note that individuals generally strive (sometimes unconsciously), for success and satisfaction in areas such as family or academia, with the perceived outcome significantly impacting self-worth. It is suggested that participants in the research sought to enhance their self-esteem by becoming the expert parent due to this. Parents' ability to create a compensatory identity was aided by external support groups and peers, but not generally professionals. Bromley and Blacher suggest that the availability of social networks and extended family or friends contributes to a reduction in parental stress (Bromley & Blacher, 1989; Bruns, 2000) and overall satisfaction and confidence to manage stressful situations.

Not all parents experience significant 'struggles' when rearing their disabled child (Summers et al., 1989), however participants in this research all described struggling to cope with the '24/7 child'. Every participant experienced chronic stress at some point which influenced their coping strategies, impacted on their parental identities, and eventually led to *breaking point*. This research constructs the concept of *'breaking point'* as the accumulation of caregiver strain; parents become psychologically overwhelmed and are forced to admit (to themselves) they cannot cope. They progress to decision making once their fragile defences have crumbled, leading to an ongoing need to strengthen the 'good parent' identity in light of the decision they make i.e. I can no longer manage, I will seek the best out-of-home care. A similar study by *Annerstedt* et al. (2000) into *'breaking point'* of caregiver burden for patients suffering from Alzheimer-type dementia found caregiver burden correlated with the patients' diagnoses, abilities, and symptoms. This shows similarities to this research as the child's diagnosis and behavioural characteristic was a significant contributor to the parents' stress and thus contributed to breaking point.

Adjusting to the loss of parental role - The decision about out-of-home care related to parental stress and could be assumed to relieve stress; the findings instead indicate that placing a child in out-of-home care enhanced stress requiring significant adjustment to both the loss of the child and loss of parental role.

Participants sought to reassure themselves that it was the right decision in order to manage this process. Studies outline the different feelings of grief, loss and anger that are expressed when parents are separated from their children whether through choice or through the court system (Schofield et al., 2000 and Hojer, 2007). Managing these feelings and reaching a resolution is challenging; parents need to redefine their parental identity which is an emotionally draining task (Schofield et al., 2011). Participants in this research expressed hopelessness and self-criticism following role. Doka (1989) suggests that parents grieve both the loss of their child and their parental role described as ‘disenfranchised grief’ i.e. grief that is not acknowledged or supported socially. Schofiled et al. (2011) carried out a similar study exploring parents’ reactions when their child entered foster care; they suggest that parents managed the threat to their identity by accepting their status (as parent) had profoundly changed; their study suggested most experienced parental isolation. In some cases parents were relieved to see their child happy however others remained concerned that their child was unhappy. Schofield et al. (2000) suggests parents face such diversely challenging reactions to loss, even when they are relieved to see that their child is being cared for by others. This research suggests that if parents evaluate out-of-home care as better able to provide care than they were, their parental identity is compromised resulting in feelings of inadequacy and a disenfranchised role. However if the out-of-home care is perceived to be bad then the parent is still needed (to change / improve the situation for their child), but becomes anxious as they blame themselves for choosing inappropriate care.

The ‘emancipated parent’ is described Millikan and Northcott (2003) suggesting that parents generally expect to maintain a relationship with their child but reduce or withdraw their control over as the child ages. This research identified that only a low proportion of parents ended at this stage; instead re-evaluation continued and the participants stayed in a cycle of disenfranchised grief and loss of role which they struggled to manage and re-define as they see themselves as parents without a child (and thus no specific role) sometimes resulting in the aging child being returned home.

IMPLICATIONS AND RECOMMENDATIONS FOR PRACTICE

It is hoped that the process outlined in the study will help organisations and individuals working with parents of disabled children, to better understand the challenges and how these affect roles and identities, which influence stress contributing to the struggles faced by parents. The findings may encourage the implementation of guidance and strategies to reduce (and simply understand) the stress and anxiety experienced and how this impacts on caring abilities and parental identity, and to help parents and families understand their changing identities. Recommendations for practice include designing and implementing training and development to increase professional empathy and understanding; it is suggested that organisations and agencies need to understand the impact that inadequate care has on parents and services to ensure they support employees to understand parents' reactions and needs, with the aim of maximising relationships, improving child care and reducing 'care burden' due to dissatisfied parents continually moving their child. Out-of-home care establishments should strive to support the parent and child when managing transition; psychological support focussing on adjustment is lacking which is detrimental to parents' wellbeing. Additionally, therapeutic support could be utilised to reduce stress and improve coping, minimising the number of families reaching breaking point, family breakdowns and separations whilst acknowledging how these impact parents' wellbeing and identities.

DIRECTIONS FOR FURTHER RESEARCH

Because participants rarely expressed intolerance, anger or frustration towards their child an area for further exploration is to examine the reasons / function of this, as it is suggested that at some point all parents experience frustration due to their children's behaviour. Also an inevitable next step is to explore these same processes by interviewing individuals with learning disabilities regarding stress, decision making and reactions to out-of-home care in attempt to expand knowledge of the learning disabled person's experience.

LIMITATIONS

Although the sample captured a range of contexts and circumstances, there were a higher percentage of female participants than males. All participants, with the exception of one, were Caucasian, thus the sample did not represent culturally diverse experiences and could be viewed as a limitation.

CONCLUSIONS

This study offers an original insight into the complex processes relating to parenting and caring for children with learning disabilities. Exploring parental identity is important because it identifies the ongoing struggles and psychological distress experienced, based on social constructions and responses, and suggests decision making for out-of-home care is never a first or easy choice for the parent / family. Examining why parents feel obliged to spend decades *coping and not living* demonstrates the cycle and how parents convince themselves they can cope with limited external support because they have lost faith in external support. The child consumes the parents’ life and role and this is never diminished, even when the child eventually leaves home and is cared for by others. The impact of decision making and stress is generally overlooked and there is limited support and understanding available. The adjustment to the move is also an under-researched area and one which is psychologically damaging for the parent as they come to terms with their decision, changes in parental role and hints at the conflict which then arises between care homes and families as the parents fight to remain involved in their child’s care, albeit from afar. The lack of understanding from society, professionals and care homes throughout this process is identified is alarming as these factors are integral to parents sense of self and coping. The study suggests it is usually the family that supports the disabled person, yet families are frequently criticised and isolated. The findings add to the literature by bringing to the fore the complexities of decision making and how adjustment and evaluation of decisions is continuous and based around parental roles and identities with parental responsibility never being relinquished.

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APPENDIX A

Ethical approval certificate

University of the West of England, Bristol
Faculty of Health & Life Sciences
Research Governance
Project Certificate

Project Details Overall approval status for HLS10-1862 is ***APPROVED***

Project Title:	Placing a learning disabled child in residential care: parents' decision making processes. A grounded theory exploration.	
Project Area/Level:	Psychology / Doctorate	
Proposed Start/End Dates:	01-12-2011 / 01-05-2013	
Chief Investigator:	Ms Rebecca Andrews	
Supervisor/Manager:	Ms Andrea Halewood Review Complete	☑ <-Approval Lock should be checked
Section Status:	Approved	

Ethics Ethics Not Required? ☐ or Previous Approval? ☐

Supervisor/Manager Status/Approval:	Review Complete	☑
Ethics Scrutineer Status/Approval:	Not Reviewed	☑
Ethics Chair Status/Approval:	Not Reviewed	☐
UWE Ethics Comm Status/Approval:	Not Reviewed	☐
Ethics Section Status:	Approved	

Health & Safety Low Risk? ☐ or Previous Approval? ☐

Supervisor/Manager Status/Approval:	Review Complete	☑
H+S Scrutineer Status/Approval:	Review Complete	☑
H+S Chair Status/Approval:	Not Reviewed	☐
H+S Section Status:	Approved	

Genetic Modification No use of GM Organisms?: ☑

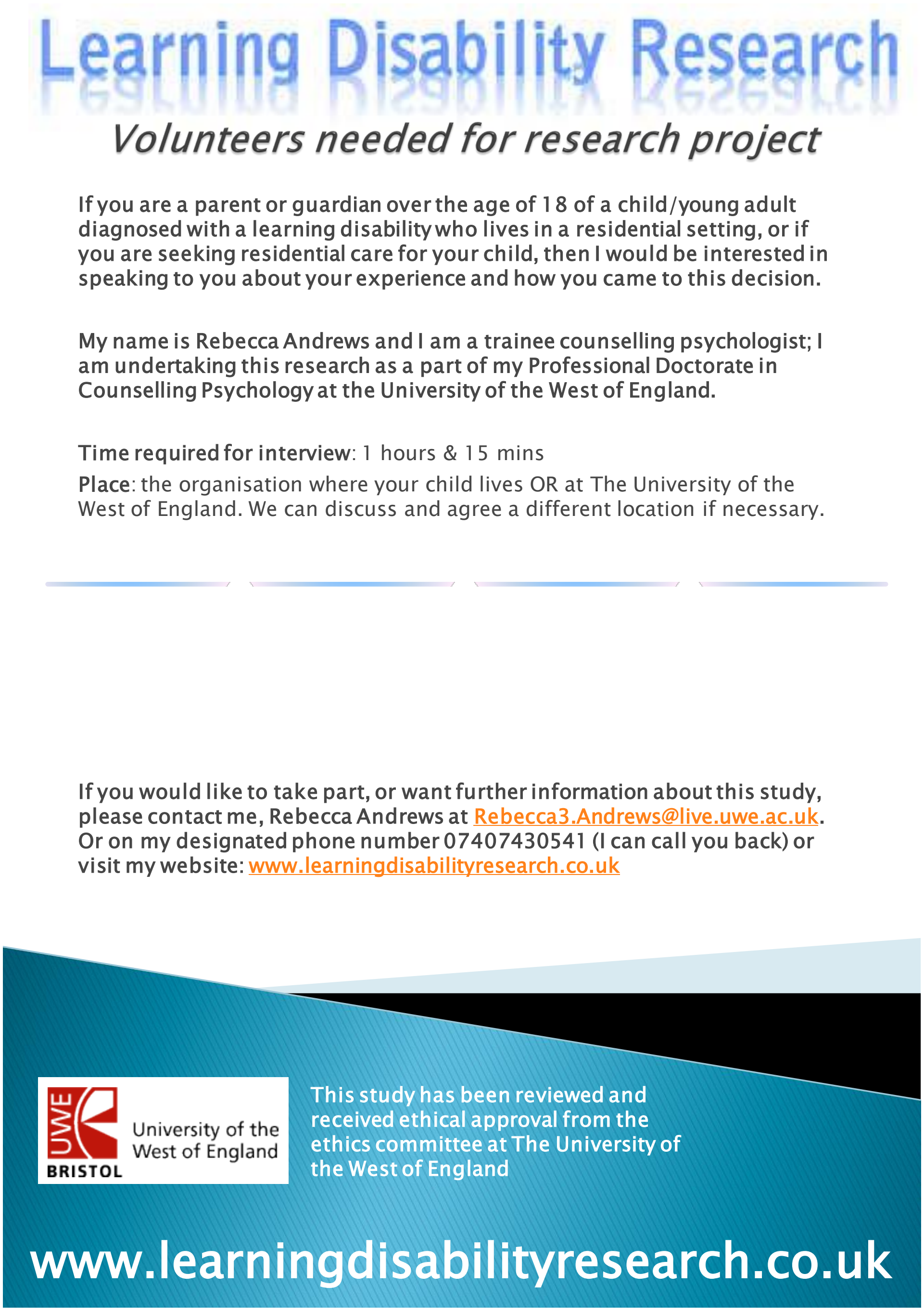
Supervisor/Manager Status/Approval:	Review Complete	☑
GM RA Lead Worker Status/Approval:	Not Reviewed	☐
GM Chair Status/Approval:	Not Reviewed	☐
GM Section Status:	Approved	

Animal Care & Husbandry No Involvement of Animals?: ☑

Supervisor/Manager Status/Approval:	Review Complete	☑
Animal Care Chair Status/Approval:	Not Reviewed	☐
Animal Care Section Status:	Approved	

APPENDIX B1

Recruitment Poster *(produced in A4 and A5 sizes)*



Learning Disability Research

Volunteers needed for research project

If you are a parent or guardian over the age of 18 of a child/young adult diagnosed with a learning disability who lives in a residential setting, or if you are seeking residential care for your child, then I would be interested in speaking to you about your experience and how you came to this decision.

My name is Rebecca Andrews and I am a trainee counselling psychologist; I am undertaking this research as a part of my Professional Doctorate in Counselling Psychology at the University of the West of England.

Time required for interview: 1 hours & 15 mins

Place: the organisation where your child lives OR at The University of the West of England. We can discuss and agree a different location if necessary.

If you would like to take part, or want further information about this study, please contact me, Rebecca Andrews at Rebecca3.Andrews@live.uwe.ac.uk. Or on my designated phone number 07407430541 (I can call you back) or visit my website: www.learningdisabilityresearch.co.uk

UWE BRISTOL University of the West of England

This study has been reviewed and received ethical approval from the ethics committee at The University of the West of England

www.learningdisabilityresearch.co.uk

APPENDIX B2

University of the West of England
BRISTOL

ID no.

Participant Information Sheet

Placing a learning disabled child in residential care: parents' decision making processes: a grounded theory exploration.

Please take the time to read the following information carefully; if there is anything that is not clear or that you would like more information about then please do ask.

What is the purpose of the research?

The aim of this study is to interview parents and guardians of children who are in residential care to explore the decision making processes which led to placing their child in residential care. By exploring parents / guardians views and decision making experiences, I hope to promote psychological understanding of this process to improve the support offered by practitioners such as nurses, GP, psychologists, social workers, care staff. By identifying the processes leading up to this decision, the research aims to enable better support structures for parents / guardians This would potentially reduce stress and anxiety, and potentially speed up referrals for residential care or home care. Psychological support could assist parents through this process prior to, during and following a child moving into a residential setting

Who is carrying out the research?

My name is Becky Andrews and I am a trainee counselling psychologist in my 5th and final year of training; I am undertaking this research as a part of my Professional Doctorate in Counselling Psychology. My project is being supervised by Andrea Halewood, a Senior Lecturer in Counselling Psychology at UWE.I have worked with adults, children and families within the field of learning disabilities since 2004. From October 2012, will be working within a Children and Families Intensive Support Team.

Why have you been invited to take part?

You have been invited to take part because you a parent / guardian of child who is currently living in a residential setting or seeking residential care. I am interested in hearing about your experiences in this area.

What will happen if you decide to take part?

Interview

If you decide to take part in the study by being interviewed, you will be asked to confirm that you have read this information sheet and to sign a consent form. You will then be interviewed at a time that is suitable for you; either at the organisation where your child lives or the University of the West of England. We can agree on a different location if this is necessary. The interview will last approx. 1 hour and our discussions will be recorded using a Dictaphone voice recorder. I will ask you 5 broad questions which I will give you prior to our meeting. I can meet with individuals and couples.

Qualitative Survey

A qualitative survey asks for participants to write an account in response to 5 broad questions. You can complete the survey online using my website (www.learningdisabilityresearch.co.uk) and submit it online or you can complete the survey and email to me (Rebecca3.Andrews@live.uwe.ac.uk). Or it can be returned by post on the address below. If you decide to complete the survey you will be asked to complete some details and will be given a unique ID number. The survey can be saved and completed at your convenience.

What happens if you decide at any point that you do not want to carry on with the study?

You may withdraw from the study at any time without giving a reason and any data collected from you will be destroyed.

What are the benefits/risks of taking part?

Although there are no immediate benefits for you in taking part, you may find the opportunity to talk about and reflect on your experiences to be helpful. Additionally, the results of this study results have the potential to contribute to our understanding of the issues involved in placing a child into residential care, which is currently an under-researched area.

However, it is possible that talking about your experiences may evoke some distress as you will be recalling material which you may have found difficult at the time. If this is the case you can stop the interview at any time without giving a reason. I will also provide you with the contact details of sources of support should you require them.

Will my participation in the study be kept confidential?

All information collected for the study will remain confidential; data stored on paper will be held in locked filing cabinets and data stored on my computer will be password protected. All potentially identifying information will be removed at the point of transcription or return of the survey and only anonymised data will be shared with study supervisors or written up.

What happens at the end of the research study?

All data will be analysed and the findings will be written-up and submitted as part of my Doctoral research. Papers for publication in academic journals may also be written based upon the findings in which case all identifying features will be removed in order to maintain anonymity.

What participants need to do if they wish to take part:

If you do wish to take part you can contact me on e-mail: Rebecca3.Andrews@live.uwe.ac.uk or on my designated mobile (I can call you back) 07407430541. You can also visit my website www.learningdisabilityresearch.co.uk

What if there is a problem?

If you have concerns about any aspect of the study you can contact me by e-mail: Rebecca3.Andrews@live.uwe.ac.uk. or ring my mobile designated phone number 07407430541. or write to me on the address below.

You can also contact my supervisor Mrs Andrea Halewood:
Tel: 0117 32 83889
Email: Andrea.Halewood@uwe.ac.uk or

Contact Address:
School of Social Science
University of the West of England
Frenchay Campus
Coldharbour Lane
Bristol
BS16 1QY
United Kingdom

APPENDIX B3

University of the
West of England
BRISTOL

ID no.

Participant Consent Form

1. I confirm that I have read and understood the Information Sheet for the study entitled ***Placing a learning disabled child in residential care: parents' decision making processes: a grounded theory exploration***
Please tick to indicate yes [ ]

2. I have had the opportunity to consider the information, ask questions if I so wish and have had them answered satisfactorily.
Please tick to indicate yes [ ]

3. I also understand that I am free to withdraw from the study at any time without giving a reason.
Please tick to indicate yes [ ]

4. I agree to have anonymised quotations from my interview used in any published material'.
Please tick to indicate yes [ ]

5. I consent to take part in this study.
Please tick to indicate yes [ ]

6. By signing below you are indicating that you consent to take part in the study.

Participant:

Print name ______________________________ Signature: ________________________ date ____

Researcher:

Print name ______________________________ Signature: ________________________ date ____

APPENDIX B4

Debrief sheet

University of the West of England
BRISTOL

Placing a learning disabled child in residential care: parents' decision making processes: a grounded theory exploration.

Thank you for taking part in this study, your participation is most appreciated.
If you have any questions about the study then do feel free to ask me now or contact at any time.

Please remember that you have the right to withdraw the information collected about you at any time during or after the study. All you have to do is tell me verbally or email me with your ID number (which can be found at the top of your Participant Information Sheet) and your data will be removed from the study. .

It is possible that you may have experienced some distress as a result of talking about your experiences. If this is the case, then the following people may be able to offer support:

- The Samaritans who provides confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide.

Phone: 08457 90 90 90 **Email:** jo@samaritans.org or **write** Chris, P.O. Box 9090 Stirling, FK8 2SA

- Relate offers advice, relationship counselling, workshops, mediation, consultations and support face-to-face, by phone and through website. **Call** 0300 100 1234 or **visit** http://www.relate.org.uk/home/index.html

- The following links may be useful:
  http://www.mencap.org.uk/ (Mencap)
  http://www.parentinguk.org/ (parenting UK)
  http://www.bild.org.uk/ (British instate of learning disibailities)
  www.familycarers.org.uk (National Family Carer Network) or call 07747 460727

If you have any comments or concerns about the study, please email me:
Rebecca3.Andrews@live.uwe.ac.uk or ring my mobile DESIGNATED 07407430541

You can also contact my supervisor Mrs Andrea Halewood:
Tel: 0117 32 83889 Email: Andrea.Halewood@uwe.ac.uk or
Address:School of Social Science, University of the West of England, Frenchay Campus
Coldharbour Lane, Bristol, BS16 1QY, United Kingdom

Thank you once again.

APPENDIX B5

Survey consent form & Survey

University of the
West of England
BRISTOL

ID no.

Available to view online at: http://www.learningdisabilityresearch.co.uk/documents.asp

Placing a learning disabled child in residential care: decision making processes: a grounded theory exploration.

Please take the time to read the following information carefully; if there is anything that is not clear or that you would like more information about then please do ask.

Before completing the survey the following questions must be answered:

1. I confirm that I have read and understood the Information Sheet for the study entitled

Placing learning disabled child in residential care: decision making processes: a grounded theory exploration

2. I have had the opportunity to consider the information, ask questions if I so wish and have had them answered satisfactorily.

3. I also understand that I am free to withdraw from the study at any time without giving a reason.

4. I agree to have anonymised quotations from this survey used in any published material'.

5. I consent to take part in this study.

6. By returning this survey you are indicating that you consent to take part in the study.

Please agree using the drop down menu that you have read and agree to the points above 1-6, and consent to take part it this research:

You have agreed to write an account of your experiences. Please use the questions below to prompt your response. Use as much space for each question a you require.

1. Information about you. Please use the space below to give a brief summary *for example birth parent, step parent, adoptive parent, guardian, relative, your relationship status, geographical location and approximate age.*
   Click here to enter text.

2. Information about your child / the person who you are discussing? *For example their age, how long have you known this person, do they have a diagnosis / what is their diagnosis?*

Click here to enter text.

3. Can you tell me some information about your situation and child / relative *for example is your child currently in residential care, are you looking for residential care, are you changing their living arrangements?*

Click here to enter text.

4. Can you tell me something about your experience of parenting a child or supporting the person who has a learning disability?

Click here to enter text.

5. Can you tell me something about the decision making process during this time, leading to your son / daughter moving to residential care OR you considering residential care?

Click here to enter text.

6. Can you say something about your emotional well being prior to this decision?

Click here to enter text.

7. Can you say describe the quality of support offered, available or utilised?

Click here to enter text.

8. Is there anything else that you would like to add about the factors that led to this decision?

Click here to enter text.

Thank you for your comments and for supporting this research. Once you complete the questions, please return to me on my email address: Rebecca3.Andrews@live.uwe.ac.uk

Please read and keep the de-brief sheet.

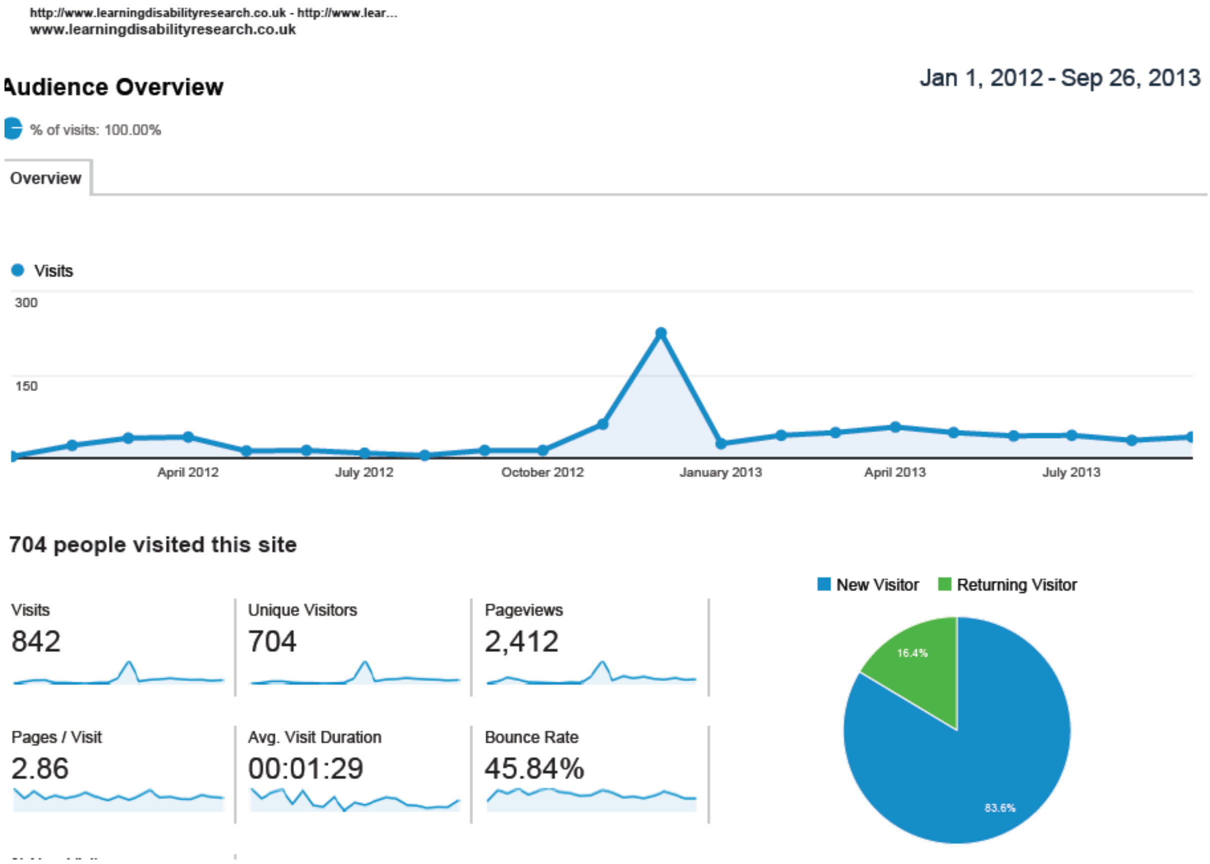
If you need to contact me to discuss the form (prior to or following submission) please do so.

END

APPENDIX B6

Research site statistics for www.learningdisabilityresearch.co.uk

Showing visits to website 1st January 2012 to 26th September 2013.



http://www.learningdisabilityresearch.co.uk - http://www.lear...
www.learningdisabilityresearch.co.uk

Audience Overview

Jan 1, 2012 - Sep 26, 2013

% of visits: 100.00%

704 people visited this site

Visits: 842
Unique Visitors: 704
Pageviews: 2,412
Pages / Visit: 2.86
Avg. Visit Duration: 00:01:29
Bounce Rate: 45.84%

APPENDIX C

Demographic information table

Participant ID	Gender / Relationship	Person discussed	Diagnosis of child / summary	Where does the person being discussed live	Age child first moved to out-of-home-care
002 Interview	Female: Birth mother	Son Age 18	Down’s syndrome & moderate learning disabilities	Residential college	Age 17 1 move to date
003 Interview	Female: Birth mother	Son Age 22	Apert syndrome, Autism, severe learning disabilities & challenging behaviours	Residential home	Age 18 1 move to date
004 Interview	Female: Birth mother	Daughter Age 20	Autism, mild learning disabilities	Residential home	Age 18 3 moves to date
005 Interview	Female: Guardian following aunts death	Cousin Age 50	Down’s syndrome contributing to mild learning disabilities	Supported living	49 1 move to date
006 Interview	Female: Adoptive mother	Daughter Age 24	Mild learning disability, Autism, disorganised passionate disorder, autism & challenging behaviour	Residential college	Age 11 3 moves to date
007 & 008 Joint Interview	Female: birth mother Male: birth father	Son Age 24	Moderate learning disabilities, epilepsy, autism, rare chromosome abnormality & challenging behaviour	Residential home	Age 23 1 move to date
009 Survey	Male: Birth Father	Son Age 47	Down’s syndrome contributing to mild learning disabilities & challenging behaviour	Supported living	Age 8 9 moves to date
010 Interview	Female: Birth mother	Daughter Age 28	Autism, Epilepsy, rare chromosome disorder called associated with moderate learning disabilities & challenging behaviour	Treatment / assessment hospital	Age 14 3 moves to date
011 Survey	Female: Birth mother	Son Age 25	Down’s syndrome associated with learning disability	Supported living	Age 20 1 move to date
012 Interview	Female: Birth mother	Son Age 25	Life threatening heart condition, Down’s syndrome associated with mild learning disability.	With mother Not considering out-of-home care	NA
013 Interview	Birth mother	Son Age 22	Autism, Severe Learning disability, No speech & challenging behaviour	Supported living	Age 12 2 moves to date
014 & 015 Joint Interview	Female: Birth mother Female: daughter / sister	Son / brother Age 38	Learning disability & Asperger's syndrome	With family intermittent support by personal assistants & family	Age 13 6 moves to date
016 Survey	Female: Birth mother	Son Age 41	Fragile X which caused Learning Disability & Aphasia	Residential home	Age 6 3 moves to date
017 Interview	Female: Birth mother	Son Age 24	ADHD, Autism, learning disabilities, challenging behaviour & no verbal communication	Residential home	Age 11 6 moves to date
018 Interview	Female: Birth mother	Son age 18	Autism, learning disabilities & communication difficulties	With parent who’s considering out-of-home care	None - Never been away from home

APPENDIX D

Guidance on journal article publication

Name of proposed journal:
Journal article to be submitted to British Journal of Learning Disabilities.

Information of proposed journal:
The *British Journal of Learning Disabilities* is an international peer-reviewed journal published by the British Institute of Learning Disabilities. It aims to be the leading inter-disciplinary journal in the learning disability field. It covers debates and developments in research, policy and practice. It publishes original refereed papers, regular special issues giving comprehensive coverage to specific subject areas, and specially commissioned keynote reviews on major topics. In addition there are reviews of books and training materials and a letters section. The focus of the journal is on practical issues, with current debates and research reports. Topics covered include:

- current trends in residential and day-care services;
- integration, rehabilitation and quality of life;
- education and training;
- employment and occupation;
- recreation and leisure;
- advocacy and rights;
- family and carers;
- adoption and fostering;
- causes and management of specific syndromes;
- Staff training; new technology in practice.

Journal publication guidelines:
adapted from source - http://onlinelibrary.wiley.com/journal/10.1111/%28ISSN%291468-3156/homepage/ForAuthors.html

- Articles should be no more than 5,000 words in length including references.
- There must be a title page *with* full names of all the authors; the name(s) and address(es) of the institution(s) at which the work was carried out. The title should be not more than 50 characters, including spaces; and up to six key words to aid indexing.
- Authors must include an *accessible* summary of their papers by bullet pointing no more than 4 bullet points and demonstrate why the research matters to people with learning disabilities.
- Include a 150 word comprehensive summary of the contents of the study
- Include *keywords section* with the words which have relevance to the type of paper being submitted, this is for reviewing and citing purposes. Use up to 6 keywords
- All symbols and abbreviations should be clearly explained. Also use the preferred term “people with learning disabilities” wherever possible, not “learning disabled people”.
- The Journal follows the Harvard reference style (using EndNote or Reference Manager)
- Tables should only be used to clarify important points and should be self-explanatory and numbered consecutively with Arabic numerals
- All figures (graphs or pictures) should be numbered in sequence with Arabic numerals. Each figure should have a legend and all legends should be typed together on a separate page at the end of the manuscript and numbered correspondingly. All symbols and abbreviations should be clearly explained.

Reasons for proposed journal: This journal was chosen to submit to because it is likely to be read by the target audience of professionals supporting families of and people with learning disabilities as well as most likely to be read by families.

APPENDIX E

- Two transcribed and coded interviews -

Transcript of participant 4	Open Codes	Focussed codes
R. I’m gonna put the recorder in kind of in the middle. Hopefully we can both be heard in it. Um to begin with how about you telling me a little bit about you and your daughter and your family a quick background.		
C. Um, my daughter (name of daughter) born in **** she’s just turned **, um, my first husband her dad was Spanish. Um, he unfortunately got cancer and died when she was um a just fifteen months old when he died, she went through her development checks and was fine and then which is common to Autism which is what she’s been diagnosed with and then just before age three she was diagnosed as Autistic and she’s had input from what from then really. Do you want to know what school background she’s had.	Discussing age of diagnosis Acknowledging input came following diagnosis	
R. Yeah that would be really helpful, C. I was only discussing this the other day with somebody, she did actually, I probably give too much to her because she had, made it too difficult for her because when she was little she went to the village play group twice a week which was just mornings, then I got a place at a nursery which I thought would be good for her but they refused to take her without support so managed to obtain support for her that was just one morning a week, and then the other two mornings she went to the child	Wondering if she made the situation worse – (possibly spoiling her, allowing her to get away with things she shouldn’t have)? Reminiscing ?? Explaining difficulties of early support, nursery. Fought to get extra support to get her into nursery Trying to do the best for daughter, play group, nursery, wanting her child to mix with	Focussing on child’s needs (socialisation?)

development centre in (name of local city)	others.	
C. So there was a lot of moving around a lot of different places to get used to with hindsight, I think it was probably too much, really but um at the time I was just grasping at straws and I would of done anything to try and kind of improve things for her.	Reflecting on hindsight it was "too much" -emotional expression of parent doing her best "grasping at straws" Explaining how she wanted to help her child, give her the best she could.	Focussing on the importance of child having stability – (focussing on child's needs)
R. OK.		
C. Then she went to primary school, age five she went to (name of primary school), which is a main stream but had a special needs unit. Um, She went there upon until the age of eleven, but I felt that she was ready to leave there before that. I wanted something else for her but the authorities wouldn't let me move her. So we looked at several schools and we decided on (name of residential school) which is in (names location) which was a special school for Autism. She went there for five years I think or more and then unfortunately they closed it down, and um,	Describing primary school and benefit of special needs unit. Comparing views of what was best "authorities won" Surrendering to authority view.	
R. Yeah.		
C. So we were left then with situation, because she was still under age and she wasn't an adult. We had to find another school for her and we had less than six months, well less than that to do it in to settle ..... So the we looked at loads and loads of places that was when we made a decision that she would live away from home. Well she didn't to begin with she got a place at (name of residential school) in names location, and that's for Autistic. She went there, and she, she stayed there during the week, and came over every weekend, but soon we realised that the journey was getting too much for her.	Complexities of age (child/adult) Pressured by time to find a school. Reminiscing on school visits. Deciding she'd leave home. Describing school Outlining the problems with travel (for daughter)	

Even once a week it was all motorway and too much stimulation. So we decided to leave her there for a bit longer but that was really tough for me and um, and then um from then on we then moved on into adult services from there.	Acknowledging it was her decision which was tough.	
R. Hmm hmm, ok		
C. And she is now at (names current residential setting for adult) which is at (location), which is just 20minutes away from me.	Describing current residential setting and duration from home	
R. Oh lovely		
C. So it's, it's wonderful, we've had our little problems there, um but um, but she's been there a year now, but she likes it there and that's important to me. There has been things going on but hopefully they're being sorted.	Pleasure of close location Acknowledging issues but the importance that daughter is happy Un-happy about the problems	Evaluating decision?
R. Ok, I wonder when you went to look at (names current residential setting for adult) did you get a feel for she liked it or, did or didn't like it?		Choosing care
C. Yeah, I did, I did because I've look at so many places now, particularly schools and things, that you do, I think the more places you see, somebody told me that once, that the more places you look at the better the idea, what you don't want. The ... if you see what I mean and I think that is true, I it just felt like a nice environment. It's quite small and um, yeah it did, it's nice it's just got quite a nice feel to it, and it's fairly local which was a plus.	Comparing different schools Identifying what she is looking for Identifying the setting, feels nice/ Importance of community services	Not enthusing too much about the school
R. Yeah,		
C. And they do activities for her so she's busy.		

R. Hmm mm		
C. and they are concentrated on building her independence skills, which to me is the most important thing really.	Acknowledging what is important	
R. And when you were looking, what kind of input did you have from other people, from I don't know from, help with funding help with finding it or did you do a lot of the leg work?		
C. Um, we did a lot of the leg work, but it all started with looking for places when (residential school) closed down. The teaching staff there have I become friends with, Um (name of daughter) teacher in particular was really, really helpful and the head of education, they came with us to visit various places, and actually has it turned out her teacher, because she was losing her job. She lived over towards (location) so she actually got a job at (Residential school) became (name of daughter) teacher again. So (name of daughter) at least had that sort of element of continuity so um I was particularly pleased about that, it was important to me, I know it sounds awful it sounds, almost selfish but, I was trying to think what, what... and I always had this kind of feeling that what makes me happy makes (name of daughter) happy and vis-versa, you know so um. We always kind of had this bond.	Reminiscing that she did the leg work Acknowledging who had assisted and importance of this. Trusting in staff she already knows Reflecting on mother daughter relationship The close bond	Stability Bond/attachment?
R. Yeah.		
C. So um it was important to me at the time, as soon as she got there, it didn't seem quite so important. She did ad, and she does adapt to other people, but yeah, they gave us help and subsequently from (name of reidential school). (name of		

previous residential school) I have to say are brilliant at transition, really good they were so good and um you know I couldn't have done it without them.	Giving positive feedback about transition. Praising/relying on their support	Reviewing the good transition = a good school
R. Great, yeah, I know of them you here some great things, how great they are how up-to-date they are with everything. They are quite um.		
C. (current residential setting) it's part of (Names the service) Charity.		
R. Oh right I have In fact they are helping me with recruitment too. I have heard of the group, Yeah, well great ok. So how do you feel about, you know about moving on then, to work through 1 to 5. Try to give a little bit more detail. How are we doing for time we have up to an hour.		
C. Ok		
R. So if we can talk a little bit more, about your experience of parenting a child who has a disability?		
C. Yeah		
R. How you found that when you said your partner had died.		
C. Yeah, it was very hard, um looking back, I mean you just do it, but um looking back, um I was discussing this with my husband that, um that when (name of daughter) was little there was lots of behaviour problems, in just a lot of it was just typical children growing up and being you know, being a pest sometimes, but with her there was a lot frustration because she couldn't make sense of the world. As she's got older it's got easier and that's much easier but as a child, I, I think as well, I mean after my partner died	Reminiscing that you "just do it" Illustrating behaviour problems. Comparing typical children to her child. Suggesting as daughter got older, it got easier	(expressing that her child is different to others? – trying to explain why her child is different i.e. the diagnoses)

I did get quite depressed and I struggled really, because it was just the two of us and I got frustrated at times and I'd get angry and I shout. Um but it was um, I found it was um, sometimes harder coping with other people actually than coping with my daughter, like at village play group for example one of the mums was awful, was absolutely awful to us and um I just told the lady that was running it that I was going to pull (name of daughter) out cos I said I don't, we don't need this and it was so upsetting that some of the things she was saying. Anyway they sorted it and we carried on and it was much better we'd cleared the air. But sometime people can be incredibly cruel, you know other people the parents, even children so it was difficult and of course things like childrens parties you know, I use to fall into all that when (name of daughter) was little but I realised after a while it just wasn't worth going along with and the gap widened when the children got older. When they were little they would you know accept (name of daughter) as she was but as the gap widened, as they got older the gap between them widened, you know they would go on and do their thing and Name of daughter still you know as she was really. So I quickly realised that to you know not force issues and just go with the flow really, but it took a long time, well a long time really to do that. I feel comfortable with it. R. And were you living here at the time? C. Yeah, yeah always lived here. R. And do you have family nearby now?	Acknowledging difficulties without partner (frustration) Sharing challenges with other mothers/community. Lack of understanding of daughter condition from other people. Reminiscing that people are cruel Describing difficulties with child's peer group as children grew up. Lack of acceptance Reflecting on her need to change her expectations.	Judgement /prejudice from others Lack of others understanding Ignorance of Autism by others (different is more significant as child ages?) or more challenging to manage? Finding a way to manage the stress & challenges (coping strategies = to go with the flow)

C. No, well I do now, I mean I met my husband my present husband he lives just down the road here. So he's very near his parents live down here, and um we met I been on my own for about four years when we met and um we got a son together now he's thirteen, (name of daughter) just 20. They get on really well together really, I think they are really very caring of each other.	Describing sibling relationship (positive)	
Um so yeah, other than that at the time I had no family at all nearby. My dad use to come down and visit, help frequently, whenever he could but he lives like 100, 150 miles away and he died a few years ago. So that was it and I got my sister and my brother but they got their own things going on so um.	Discussing family support (lack of)	
R. Alright great, ok do you want to move onto number 2 ?... We are talking more about now the decision making process during this time, leading to your daughter moving to residential care, Are you able to talk through your emotional well being prior to this decision, what led to that and what it felt like and that kind of thing?		
C. Well when she was at (location or school) we'd envisage her becoming residential at some point there.		
R. Right	Expectation she would be in care eventually	Expectation she would be in care eventually (parents joint expectation)
C. and of course that decision and that choice was taken away from us when the school closed.	Lack of choice – school closed.	Parent seeking 'control' and choice of care
So then um, I did look at a couple of local schools where she could travel each day.	Describing schools they considered.	
I, I think perhaps looking at it maybe it was me being selfish but I wanted her close at hand, I always wanted her, I don't want her to be at the other side of the country or anything like that I	Importance of location/close to parent.	Parent internalising her desires into a negative

wanted, I want her near. But obviously so long as it’s the right place, so I did look at a couple of local schools where she could have gone as a day pupil but the one I really liked was full, that was in the (name a local special school). R. Oh yeah. C. I loved it as soon as I saw it I loved it and I thought oh I could see her there but they were full and they were absolutely adamant they couldn’t find another place. Um I asked (name of the school in local city) again because I had looked at that previously before she went to (name of residential setting) but I um It’s, it’s just too many people and I think it would have really frustrated her being there. Um and then I just thought um, yeah when she when I um, when I chose (name of residential setting she stayed in) I realised she would have to bored there, Um I can’t I looking back I think it was just, it was really difficult, I kept looking at it and thinking, oh I don’t like that aspect or I don’t like that and then at some point it just I looked at other places and then I came back to that and thought yeah of them all, I like this the best. Even though it, and oh they told us that a new school was being built so that was an added factor so I thought well at least they won’t have these little places like before where they had these little buildings that were their schools. Um but looking back um in actual fact (name of daughter) struggled at one point and she ended up being taught one to one, in one of those little rabbit warrens rather than in the big school so that shows how much I knew but I um I just, I warmed to them, I definitely warmed to them and I met a lady who	But out weight for the right place. Describing her love and her need to be with her daughter and the need to be involved in her life. Reminiscing on visit to the right school. Sadness it was full. Weighing up the options of schools/settings. Wanting what she felt was the very best for her daughter. Acknowledging the service wasn’t perfect/right but no other options. Weighing up the options Don’t like the setting but warmed	i.e. ‘being selfish) Parent wants to remain involved in child’s care i.e. wants to remain her mum Choosing care Weighing up decisions about the right care – trying to reassure herself? Love/bonding Weighing up decisions about the right care – trying to reassure herself? Wants the best. Hypothesising that good

manages Family Services and she said something to me that I'll never forget and she said "You're trusting us with your most precious um possession if you like and we know that, and we will honour that, that sort of thing"...... and that was such a lovely thing to hear.	to the staff. Importance of staff attitude/communication.	staffing = good care?
R. Yeah.		
C. Nobody else had said that anywhere and that sort of clinched it for me I think really.		
R. And um regarding keeping you informed again not evaluating the work they do but how important do you find it or do did you find it then to be informed regularly that sort of thing...		
C. Very important I still feel it now where (name of daughter) is a (name of current residential setting) and it's different now she is in adult services it's totally different but I don't see why it should be and 'm sort of I ... without being a nuisance I want I do want to hear what she's doing. I don't care how big or small I mean I don't want them to ring me every day with update and things like that. Um but just to think about things or people to think about what that parent at home might be feeling, you know and um and the child as well the person the young person is, it is important I think to keep that family connection going definitely. I just didn't hear about achievements. It's just wonderful for me.	Outlining the importance of communication/liaison. Acknowledging differences in adult and children services. Expressing her needs Expressing importance of services sharing with parents. Let down.	Changes in services Wanting to remain involved as the parent – but fearful of being a nuisance (loss of roll?)
R. Yeah		
C. And no matter how big or how little they are it's important, very important yeah because I can see my son every day and I know his achievements and things he's worried about and it matters to me	Expressing importance of services communicating.	Wanting to remain involved as the parent – but fearful of being a

and so it matters to me even though she is away very much so.	Sharing differences of parenting a child at home V in-care.	nuisance (loss of roll?) - As if the child at home keeps a mum but the child away doesn't ?
R. hmm mm ok great, ok can we move onto number 3 kind of all about your emotional well being, leading up to it. Currently you know if you are alright with that.		Sharing with parents.
C. Yeah, um well prior to it, because the school had closed I was um phew, well I shock myself sometimes but when school closed (name of special school) that is um, I was just devastated as were staff. All the other parents we've sort of I've seen several contact with other parents at the time because of this parent group we formed and of course it was difficult because they were spread far and wide in the country. But a couple of people especially, um I was quite close to and we discussed it a lot to where we were all devastated. Suddenly all these children had to sort of be found places. It was traumatic to say the least really traumatic and everybody was feeling it and the tension was palpable you know it was really, really tense and it um affected the kids it affected the parents it affected the staff it was it was awful. As a result places I went to I just want, I just remember going to see the head at (residential setting) I think I just spent the entire morning crying, I was just so upset that suddenly finding ourselves in this position of having to find somewhere else. Um it was it was a terrible time. I don't know it just, very, very emotional I felt. That worried me then that maybe I wasn't making a sound judgement because I was so emotional but I calmed down and I looked at places and unfortunately the places I liked best were full and that was	Changes in own limits Discussing parenting group. Describing parent's devastation and anxiety and stress. Feeling responsible for finding places. Empathising of difficult times. Emotional impact/pressures/stress. Concerned her emotions affected judgements.	Parent 'getting a voice'; fighting for child (child's needs = motivation) Importance of peer support Responsibility remains on eth parent to find care (anxiety) (anxiety – lack of external support?)

really, really, hard to cope with and um as I said I tried first that I found somewhere to make sure Name of daughter could come home as frequently as possible. I really wasn't ready to let her go although people kept telling me best let her go, you must let her go. R. Who were the people telling you that, if you don't mind. C. Um, staff at (names residential school setting), even, you know the ones that had helped us were saying that you must you know you must let her develop and that she needs her independence, everybody spouts that. R. Hmm mm C. Even my boss at work you know says, there's about, cos I had an issue recently and I said well if she doesn't like where she is I'll pull her out and find somewhere else. R. Mmm mm C. and he said you must not have her at home, he said whatever you do don't have her at home. I think where he was coming from he was thinking more the authorities once you're at home that's it you know, you find it really, really hard to find a placement again because they will say well she's just been provided for I think that's what he meant. But other professionals have said things like you know, oh yes you know you must find somewhere else and I find it incredible you know they, they I don't know they don't know me they don't know (name of daughter) and it's surprising over the years how many people say, I've heard people say oh well I know (name of daughter)	Limited places at desired locations. Important her child to be able to come home. Desperate to remain in daughter's life. Reminiscing that she was told to let go; for good of child. Expressing how others felt she was holding her daughter back unable to let go. Pressurised by boss. Reminiscing on once they come home you won't get help. Identifying challenges of finding a placement. Explaining views of professionals. Not feeling understood by professionals. Dismay that people/professionals think they know.	Choosing care – limited satisfactory environments Reminiscing that she was told to let go for good of child. - Responsibility onto others rather than self? Reminiscing that she was told to let go for good of child. - Responsibility onto others rather than self? / feeling pressured? (feeling like the bad parent for holding her child back?) 'blaming the system' – removing own responsibility for choices? Experiences of conflict with professionals (not feeling understood)

and I'm thinking hang on you've only met her twice, how can you say you know her?		Others perception – she seemed to accept friends and her bosses views of needing care but not professionals (WHY?)
R. Yeah		
C. It's absolutely crazy the way some people speak and I think that that is something that's bothered me over the years.		Anger/frustration projection onto others? Rather than on the child?
R. Yeah		
C. people sort of taking the upper hand and saying well you know this is best for her or that's best for her and they don't know her.		
R. Mmm yeah. Now I have heard that a lot through interviewing different people that, that can often be quite a difficult thing		
C. I admit by my own admission I am very sensitive and especially surrounding my children, I'm extremely sensitive but I mean I don't know a mother that isn't really, but I can be over sensitive I admit that but as the same token I have got my head screwed on, I got my feet on the ground and I know what I am looking for and what's what and I don't you know some people attitudes it's incredible really I mean don't get me wrong there's been some marvellous people over the years as well, fabulous people, but they move on and that's hard to take sometimes 'cos you	Acknowledging her personality. Comparing good professionals and bad professionals (attitudes). Explaining the dismay and despair at losing a good professional.	
find somebody brilliant and they move on, they're head-hunted or whatever. We had a wonderful, wonderful I thing she was a speech and language therapist , she was amazing and she was so tuned into us, immediately tuned in to us, but she left and I cried when she left, because I just thought it is so amazing to find somebody that really knows you, or feels that they	Describing good staff. Acknowledging good staff Changes in staff	A deep desire to be

know you and helps you in the right way, you know, you just,.. you do I think particularly when children are young, you need so much support and especially if you've no partner or sometimes even if you've got a partner, some partners are not, you know, overly supportive sometimes, I've heard, R. Umm,.. you made a point earlier on about a parent group that you were involved with, are you able to tell me anything about that?	Describing the importance of feeling supported/understood.	supported/understood.
C. well that one it's,.. it didn't really, .. it wasn't easy because as I said, the parents were spread far and wide so much of it was by e-mail which was very impersonal, um, but I,.. prior to that, when (name of daughter) was at primary school, I was in an,.. um, a group there that was,.. it was a charity actually, they had a charity and I joined it, but we were all parents as well, so I had lots of input there um, and that was,.. I found that really interesting, really interesting and supportive, and I joined a group, um within (name city) um,.. but it, it folded um due to really,... I mean it's pressure, you know the lady who was running it, um she was really, really good at it, but she had pressures, well she had a child with Autism. So it, it it's really hard to maintain something like that and it was a shame because other groups have kept on but ours folded and, um you know I remember setting up some kind of like a little,... my,.. my part in all this was	Discussing parent support group.	Support is valuable
setting up a like a library service, so that any new parents coming through would have some material, some literature to look at,.... support that way, ... so it,.. we	Describing role of sharing information/supporting others.	

could have been really good but it was just,.. we were all,. You know we were besides looking after children we were all working as well so something's got to give in that situation,.. we just couldn't maintain it, and as I say then, back to (name of residential setting), the um, the parent group there was spread very similarly, so it was hard to, to keep that going in the way that it should have been done. But I did,..I as I say, I made friends with a couple and we sort of, we still in touch with each other which is nice, not,.. not frequently, but you know we do keep up with each other's children	Challenges of parenting, working and being able to support others. Making links with parents.	Challenges of trying to manage work and child Support is valuable
R. yeah, ok, um,... what came to mind then, when you were looking um locally for where your daughter could move to. How, how did you find anywhere you know, did people recommend or go and have a look. You talked about the one lady highlighted to you about (names current residential setting for adult) I think one of them?		
C. Um how did I hear about (names current residential setting for adult) I, I can't remember how I found out about that infact. I'd heard of it through somebody and my old boss he's retired now, um he knew of them because when he set up the trust where I worked they set up a a similar time so he knew the man who was running it, and he said yeah, yes it's a very good organisation. So I kind of looked at their website and i was a little bit put off because it kind of put a lot of emphasis on land based activities and I thought oh, I can't imagine (name of daughter) trudging around in the mud feeding sheep and things like that. Um but when I went to meet them they, you know they reassured	Unable to recall how she knew about setting (word of mouth) Reassuring self it is a good organisation. Wondering is it the right place.	Choosing care. Reputation of setting

me that they do lots of other things as well. She didn't have to go and feed the sheep if she didn't want to, um so um yeah, it was quite nice.	Reassured by care staff/organisation	
R. You may have heard that one through word of mouth but you looked on line before you went there.		
C. Yeah, I did yeah..		
R. Ah when you were thinking of any more that you may have looked at can you remember how you found out about them?		
C. Oh, um there was a place I looked at in (city name) Um an how did I hear about it? Again I think that was word of mouth, that was through one of the parents, cos she was looking at it for her son, and I went to look at it and it was brand new sort of um provision, oh no that, sorry you are talking adult provision now aren't you?	Explaining the Importance of word of mouth and reputation.	
R. Either, or either		Justifying distance
C. Oh right this is when i was actually still at school sorry, and that would have been residential, could have been residential. She could of come home daily but that was a bit of a trek. Um that was brand new apparently some millionaire had invested all his money in this which was fabulous and I was swayed I think by the glamour, for a little while but then I realised that behind it they didn't have an awful lot behind it as yet, I mean it will improve in time, but at the time they had had Ofstead and for a brand new school that was pretty worrying. Um, but everything else was superb and I must admit I was very tempted I went back there I think it was three times in all to have a look. And then	Extending travel/distance. Justifying her choice Feeling able to choose.	Can cope as long as it's 'the Best school'? (reassuring self)

in the end I decided against it and that's when I went to (names residential school setting) and um decided on that. Because then I think I put the fact that (names residential school setting) had years and years and years of experience and they had a really good Ofstead so I thought that,	Justifying choice Years of experience, good Ofstead.	
C. that's the place to look for.		
R. Yeah weighing that up		
C: I mean I don't, I mean in certain areas people they say oh don't take too much on Ofstead and things but to me it's just a its an extra, you know and if it's a decision between one that has and hasn't I would go for the one that has.		
R. Mm Yeah.		
C. Um		
R. and did it feel like your decision ? if you get what I mean, your call.		
C. Is this with the schools now?		
R. Yeah, yeah		
C. Well I did try battling, like with (names residential school setting) I really, really, pushed and pushed there but it was no good and another school I found was at um oh gosh, um, oh I forgotten the name of it now it's um, it's in the (location), the beginning of the (location) , um I can't remember now, um it's amazing isn't it considering I liked it um sorry its just because I'm aware of it recording. (laughter) um yeah and I liked that too and I pushed for that. They had a residential place but this was bazaar, they had a residential place available but not a place in the school.	Managing without first choice. Residential place V residential schools.	Making do with care (lack of choices).

R. Ah right		
C. and I thought well no can’t do that (laughter) um so um but yeah when I sort of hit on places I thought right really go for this and then it’s awful, it’s disappointing when you can’t get in it’s so disappointing cos you kind of throw everything at it to no avail.	Outlining the choice and disappointment when it can’t happen.	Making do with care (lack of choices).
R. but it appeared then that it related more that they didn’t have the room rather than not getting the funding or anything like that.		
C. (interrupts) oh no, to be honest I hoped that the funding would be there. I just hoped and I think actually in view of the fact that (name of residential setting) closed I think that put us in a good position for funding. I think it was fairly guaranteed because of the fact that they knew that they had to pace (name of daughter) somewhere. So I think that wasn’t a massive issue whereas it might have been under normal circumstances. So I felt that the pressure was off in that area and I could just concentrate on just finding a good place.	Funding Concentrating on finding a good place.	Funding issues
R. and when it came to moving into adult then did, can you recall if they altered funding or if funding became a problem then. They hand over to another team don’t they?		
C. They do		
R. To be honest I don’t really understand the process even now it just happened and um I just went along with it to be honest	Acknowledging lack of understanding on funding.	Funding

and I really don't understand the process very well. I still don't um, it can be hugely complicated I think. Um I think when (name of daughter) at (names residential school setting) I was led to believe that you know funding could be a big, big problem. The sooner you found a place the better um, in fact we did start the process off early and we moved her earlier than, she was due to leave school in the um, when I say earlier she was due, when does people leave school? She was probably June, June wasn't it? Yeah well we actually moved, we did move her in June but she was um, we moved her before she would of had that long summer holiday. If you see what I mean.	Acknowledging the Complexities of funding. Influenced by other view points. Early preparation	Why so much early preparation ? (defence / need for change?)
R. yeah, yeah.		
C. So we didn't have that worry of her settling in at home and not wanting to go anywhere. So we moved her straight from (names residential school setting) straight into (names current residential adult setting)		Acknowledging the worry and reassuring the self
R. Mm ok		
C. Which I think was the right thing to do.		
R. Yeah ok	Reassuring self it was the right thing to do.	
C. To yeah, yeah relieve any sort of stress on (name of daughter) really.	Justifying choice.	Focussing on relieving stress of child (what about acknowledging the need to relieve stress on the self?)
R. they are looking at the moment um to transition around eighteen, nineteen right but the authorities are now planning on the same teams working on transition between fifteen to twenty-five, so they continue to be the team start to finish rather than handing over to a seperate adult only team	Transition	Transition = ongoing cycle or future care to consider
C. Oh and I do that sounds great.		

R. and service users will only deal with the one lot of transition people who they know a bit more they've been involved fro the start and you don't have that hand over		
C. (interrupts) that's So good.		
R. So I hope that will come off.		
C. So do I.		
R. Ok, how we doing for time, yeah one half hour another		
C. C. Sorry I did that		
R. Yeah, no problem		
C. that was um (names residential setting) , because again the head of education who was at (name of residential setting) she left of course, well she had no job and she went to be um head of education at (names residential setting) but I loved that, I loved just loved something about it and I really wanted (name of daughter) to go there and then I found out of course that it is only until she's twenty one I think, and it wasn't in the holiday she'd have to come home.	Importance of same Staff. Gut reaction, loved it. Still; wanting stability in her daughter's life. This time someone she knew.	The right care – 'Just something about it'.
R. (interrupts) So that didn't quite fit	Going from what she needed most ie: her daughter with her as much as possible, to putting what she thought was best for her daughter.	Wanting security.
C. No, it didn't quite fit but I liked that.		Wants V what is best.
R. With (names current residential adult setting) then um, would your view be for her to remain living at (names current residential adult setting) .		
C. Yes, yes I think so		
R. Yeah		
C. Yeah we, were just going to just iron out a few creases quite important ones actually. I probably shouldn't go into it	Safeguarding concerns.	

here but there was an issue.		
R. Ok		
C. and um, it was quite serious and again that really upset me and um just, but she seems to have coped (name of daughter) seems to have coped and so I'm, I'm going with her and um, you know were sorting it out. Were sorting things out.	Reassuring self about sorting it out.	Emotional- evaluating the care (although unhappy reassures self it will be sorted out)
R. ok		
C. but yeah I'm on the whole pleased the staff is very nice they are all very approachable um, and she's doing things she's busy and um she has made progress which is great.	Praising staff/setting. Trying to convince herself that it is all ok.	Child making progress (convincing self)
R. Mmm, great, great		
C. Yeah.		
R. and your involvement I mean do you feel that you are integral to that like do you think oh, it would be great maybe for her to learn and develop in other areas, do you feel you can feed that back to the staff or not?		
C. Um, yeah, I, it is different when they become adults and I find, I find my roles dropped away somewhat um. I mean that they do say that they, that you know they value my views and things like that but I. I'm very wary of how much to tell them and how much information to give them. Because I don't know how much they want to know.	Parental role reducing. Concerned not to tell too much to be a nuisance. Not fully trusting staff?	Redundant. Parent role reducing. Sharing experiences of staff / feeling like a nuisance
R. Ok		
C. I feel like um, I feel a bit of a nuisance um I mean I've been told that I'm not but the thing is the majority of people at (names current residential setting) are		

quite a lot holder than (name of daughter) she’s the youngest there by quite a way. That’s fine because she has always related better to older people anyway than herself but that’s not an issue because they, they’re nice people the residents there and everything they seem really, really nice. But um I find it hard because a lot of the parents are quite a lot older as well as a result and so some have, probably some don’t have an awful lot of input. I find that where I work as well when you’ve got elderly parents they got their own issues probably later in life and lots of maybe ill health things like that. Um, but I’m still in school mode, you know when (name of daughter) was still at school and I’m still, I want to know, I want to do and I want to be part of it. And I feel as if I’m maybe not wanted, and maybe I need to discuss that with them really and explain myself a bit better, but it’s difficult. Managers seem to be absolutely fine about it (name of daughter) key worker not so sure.	Reassuring self that daughter relates better to older people. Reassuring self that people are nice. Perception that older parents won’t have a lot of input. Feeling not wanted by carers. Not one hundred percent happy with situation.	Need to reassure self that daughter is fine Analysing level of input (reassuring self) Feeling redundant. Perception that residential environment doesn’t welcome parents / wanting to talk to care staff about this
R. and regarding key worker, again do you feel involved that, I don’t know, did you get to pick the key worker?		
C. No, no I didn’t, um she was chosen, cos (name of daughter) got a key worker and a co key worker and now the key worker was chosen probably because of, I think she has some experience with Autism, but Autism in younger children um which at the time I thought was very good and she, she’s very sensible person. She seem very level headed, um and mature and um the co-key-worker I, he was sort of vaguely known to me anyway, cos he use to work where I work now as a care worker, and I’ve got a lot of time for him too, he seems very nice too but even though they are key	Explaining key worker role.	Importance of knowing staff.(trusting care staff?)

workers they don't spend a huge amount of time with (name of daughter) name of daughter again got to be used to working with other people to which she is and she was at (names previous residential school setting) because even though she had a key worker the whole point was they had to get use to working with other people, which is sensible.		
R. Yeah		
C. yeah, yeah exactly you can't pin it to one person, but I use to think that. I use to want one person to be regularly in (name of daughter) life, to be solid, but I realised that that can't happen. It shouldn't happen it's not right. Um, but yeah um, I have a little bit of input there but I want more.	Wanting specifically one staff member. Wanting more input/say.	Problematic due to multiple carers. Dissatisfied with level of input.
R. ok		
C. I don't want to be there on the, you know every day and I want my time to now with my family but I'm learning to back off a bit, on the one hand in that allowing time for myself and to my son and my husband, and that I've been entirely focussed on (name of daughter) all her life. So it's kind of a learning process for me too, is to sort of you know, learn to back off a bit, but, but I want to know what she's doing, I'm interested. I can't help that, so um	Focussing on daughter V rest of family.	Backing off, allowing time for rest of family.(justifying i.e. she says she wants more input but can't do it due to blaming staff then reassures self she can care for other son instead)
R. (interrupting) yeah well your her mum		
C. I have to find a way around that, and I don't see why when suddenly magically they become adults. Then all that changes and I don't see why that should because (name of daughter) not long out of school really. Only a year ago she left school and um I just think that um you should have that continuity and I feel as though it is		Always considering the future - Transition to adult hood.

important for parents to be seen around anyway. Because I think that the people living there that they need to know that their parents are part of their lives there. You know they don't just belong in their home and then they go back to (names current residential setting) I feel it should be a, I think I've said it before and I feel we should be working as a team. I believe we are a team and we are all there to help (name of daughter) R. Yeah C. You know become, whatever she is going to become. R. Mmmm and thinking like do you feel you can drop in at any time, like if you wanted to go right now would you feel you had to ring to let them know you're coming or do you feel you could go C. Um I do go some evenings I just pop over. R. Yeah, C. I mean in the day time it is different because the managers are around in the day time and I suppose if I wanted to see him I would ring and make an arrangement to see him. Cos he's got lots and lots of commitments. It is different in the day time and I probably would ring up because you know she you know(name of daughter) may be going out. But yeah I do, I feel fairly comfortable in just popping out there and they make me welcome when I go. R. Mmm ok, great, alright then let's have a look. We may have covered number 4 and number 5. Alright what's going on here, try and think what went on around	Out lining needs (hers and daughters) Discussing visiting daughter.	I'm still her mum : (importance of parental role). Disenfranchised roles

the time you mae the decision we may have covered it but can you think of anymore to add		
C.Well yeah, (interrupting) again people kept saying you know, that she's got to get her independence, got to get her independence in order to do that you've got to kind of let her go a bit and so by being residential would help because then she would then have 24 hour um experience rather than just you know the hours of school.	Unable to let go of her daughter. Being persuaded by others to let her go. Explaining other's views. Wanting to care for her daughter herself.	Outsiders giving suggestions.
And I could see that I could understand all that but I, for a long time I couldn't let her go and even when um, we knew we would have a fight on our hands at (name of residential setting) to get her to go residential because she'd been going as a day pupil for a few years.	Describing making the decision. Preparing for a fight.	Complexities of making the decision (the desire to care at home V acceptance you can't) A belief that fighting for care was the only way
While I think we had a massive case to put forward um to get her a placement, we decided in the end before we knew they were closing that we would try and get (name of daughter) a place a residential place there for her final year so it got her use to living away from home and I'll be absolutely honest with you know my heart was not in it at all.	Not wanting her daughter to leave.	
But I went along with it everybody was telling me it was for the best and I went a long with it and then it was all taken out of my hands when the school closed.	Acknowledging her heart was not in it. Pressures of other's views.	Complexities of decision making relating to head and heart Going along with other's views – blaming others ?
But obviously we then we realised that because we couldn't get local places that she would have to go residential it was very hard, hard coming to terms with it but my hand was forced	Realisation of no local places.	
and time was you know tight um it was hard it was really, really hard I went to places I got depressed at places. I saw some awful places really awful but I wouldn't leave my cat there you know just, I don't know really, quite made you down, made you feel really down.	Explaining bad visits, awful places. Depressing for mother. Describing environments.	Choosing care Geographic pressures/locality.

Through probably no fault of people there I am sure the people running it were very well meaning but it was just something about the environment that really sort of got you down. Um so it was hard.	Outlining emotional impact.	Lack of choice, lack of time, lack of places. Emotional toll.
R. A lot of the time you had kind of did you have an immediate feeling of ohh,........ yes or definitely not		
C. (interrupted) oh Yes I walked into one place and I could, I would have walked straight out again but I stuck with it we looked around into the classrooms the residential part and oh it just made me feel the worse. I mean don't get me wrong it was in the most beautiful setting it was amazing but you got in there and I just wanted to get out. And it was really, really awful. And yet and I'll tell you what, what drew me out to (names previous residential school setting) and it sounds really stupid this but we were sat in the cafe that was nothing special in the restaurant and um the sun sort of came in through the window and it just changed the whole perspective and I thought this is, this is alright. I thought this is alright this will do and people were they're lovely up there they're so friendly. So, so, friendly, I thought yeah this I'll be alright.	Describing immediate response to placements. Reminiscing why she chose residential setting (importance of friendly staff)	The right place aids adjustment and acceptance of the decision (the right care = the right choice)
R. It'll be alright		
C. I mean we had our ups and downs there and we had two aspects of (daughters name) behaviour deteriorated it did .... the first time in (name of residential setting) just before it closed and I still maintain she got wind of it somehow, that something was going on and her behaviour just went way off the scale and we couldn't cope it was awful. Oh and we had to resort to medication for the first		

time ever. Um and she s still on medication now but she’s much, much better and then when she went to (names previous residential school setting) she did it again we had an episode there. But again you know, and I think my decision just backed briefly when I finally came to the decision about (names current residential setting) was there were people there with varying disabilities all um, um all fairly able actually in many ways but very vulnerable um there’s um but what I decided was I think (name of daughter) had I felt she’d had enough of an Autistic environment. R. Right, right yeah, C. I felt that she needed to be with people who were more able and who could perhaps bring her along a bit you know that she could talk to. I mean she tends to talk at you she’s very repetitive by nature of the disability but I felt that I and that she’s actually very friendly and that there’s one man who lives in her flat and they are quite close friends. They, they seem to gel together and they talk to each other and I think he’s got some autism too. But it’s nice apparently they do have a good rapport. R. Great. C. So that to me was really important and it’s so calm, it’s so calm compared to a autistic environment which can be incredibly noisy and stressful and I think that’s made a difference. R. Mm mm yeah, yeah. Mm often can’t it, you can pick the environment but maybe you can’t pick the people who are going to be living in that environment.	Describing challenging behaviours. Resulting to medication. Finding reasons for her daughter’s behaviour. Explaining needs of others in setting. Joyful at daughter’s friend relationship. Describing environment.	Knowing they couldn’t cope anymore ;reached their limit Transition Not blaming child ; blaming diagnosis Importance of other residents more able to bring her on. Importance of child’s peer development (aids parental acceptance of care)

C. Exactly that's right R. and um C. It is difficult, and um the manager at (names current residential setting) he chose carefully the right flat for (daughters name) I think and um she seems to get on well with the people in there which is good. R. Great, great ok, How do you feel, do you feel comfortable talking a little bit about her behaviour? C. What when she displayed really um, R. Yeah, um what happened C. Um the first time she developed I guess it was a phobia about her hands she started coming home and she started looking at her hands. Turning them over and looking at them all the time and then she started saying her hands were dirty. And I said no they're not dirty they're clean and she just, it just escalated from there and she was convinced and she was looking at the lines in her hands and saying they were dirty and I just couldn't calm her and it just escalated and escalated to the point where she ended up screaming. And she and I was trying to get to the bottom of it she went once a week from (name of residential setting) she went to this horticultural college and um they were doing lots of out door work you know cutting bracken and things like that. My husband had this theory whether it was right or not um that she had to wear gloves to do the gardening and things and so we wondered whether somebody had said right put the gloves on to keep your hands clean and then when she took her hands, her gloves off they would then tell her to	Describing behaviours. Looking or finding a reason for her behaviour.	

wash her hands because they're dirty and it got her confused, but I, I mean I don't know, I really don't know. There was of course this thing about the school closing as well happening and her behaviour it just escalated and escalated and it got to the stage where, when she sort of goes into melt down as it is often described she doesn't see you, she doesn't hear you, she's just completely oblivious to everything except what she's focussing on. R. Yeah, yeah C. and I couldn't get through to her at all, not at all not at all we've been extremely lucky in that she's never been really physical, she's pushed me, um but that's about it, she never hits out, she never lashes out. She might up-turn a chair, or something like that, but she never um, has been really physically aggressive. But it's the shouting and the screaming that just wears you down and um I just couldn't, I couldn't get to the bottom of it at all and that in the end we had to result to medication. Um to R. To bring her level down help her calm C. Yeah, I think that can be the hard thing when you can't get to the bottom of it and you can't make it ok. C. No R. You no um, C. (interrupts) at that time I think we'd let it go I think but I think actually at (name of residential setting) she'd came round eventually. I think it was when she went to (names previous residential school setting)	Autism. Outlining challenging behaviours.	

That we actually,.. when she had a second episode and the staff seemed to recognise it,.. as it happened it was about the same time of year, it was just after Christmas, sort of that lull between Christmas and Spring, you know that time,.. um, whether it was all the excitement of Christmas and suddenly, you know, things went with a slump, I don't know, I just don't know, we still don't know what caused it and then as I say, at (name of residential setting) she, a,... at (names previous residential school setting) , she she went like that again and that is when she was on medication.	Explaining what she feels is reasons for her daughter's behaviour.	Justifying/understanding child's behaviours.
R. um,.. and again, how did you feel,.. did you come in and talk to the doctors..		
C. it was so stressful, because the doc... the psychiatrist went to visit her at school and then he came to see me and I remember, he got out of his car and he came across the road and he had a prescription pad in his hand and I thought that's a bit presumptuous and he was talking to us about it and um, he said, well I suggest she has this, this and this or whatever, and I said how can you make that decision in just meeting her in half an hour and he convinced me that you know, he knows his job and he just felt that it was, it was right for her at this moment in time. He said obviously you don't have to and I let it go for a couple of weeks and it just got worse and worse and worse and in the end I said right, she just going to have it now,.. I wanted to keep her off it see, as much as possible, then I realised it was hurting her by not being on something, and, um, looking back, he was right, it was just I wasn't ready for him and his ways	Outlining stress when you can't understand behaviour. Presumption of psychiatrist (reassured by status).	Significance of stress when you can't understand behaviour. Stress

but he's actually,.. I've really grown to respect him immensely,... he knows what he is talking about . But it, it's hard, it's hard letting somebody else take control of,.. of,.. of your child's life you know and deciding what's best for them, even though he's an expert at it, you know, I just felt at the time it, it got too much you know that suddenly there,.. I just felt, I felt like they were just going to try to quieten her down and you know, and that was it but he was thinking of her long term health. But at the time, I felt that it was,.. you know 'cos I was,.. I tell you why I thought that, because the first episode we had um, my husband rang up Social Services 'cos she was absolutely going mad one day and I was beside myself and he rang up social services and the duty social worker said, well you just have to get her sedated. And that's when that thought process came from,.. when I met the psychiatrist I thought all he wants to do is shut her up you know and move on. And it is very, very hard to trust people when you get attitudes like that along the way so um,.. it is it's um,. A real um,.. it's been a process, a tough process I mean she is absolutely adorable though and I wouldn't change her for anything. You know, she's my daughter and I love her to bits, R. yeah, yeah,.. well I've only heard a little bit about it, like I only feel I know her a tiny little bit, um, yeah, OK, . um,.. have you got any more that you want to add, ... we're really up to the end, but we've covered quite a lot,... anything that you think you wanted to add, or make a comment about that, ... pause.. C. ... I'm not sure, I, I think I'm trying,..	Want to keep child safe. Her need to care to be in charge of her daughter. Reliance on others/experts. Fearful of just quieting her down. Reminiscing of past experiences/attitudes. Reflection of it's been tough.	Relinquishing parental control of child Importance of developing a relationship with child . Social Services contact ; fearful of their views . Hard to be Trusting of professionals.

thinking along the lines of people in these professions you know people we've met,.. I've said to you, people, some people we've met going back along the way have been fantastic but there have been a few 'iffy' ones as well, R. when you think of the more 'iffy' people, can you think of anything in particular that they have done that could be improved upon,., C. yeah, like for instance when (name of daughter),.. with um,.. my memory is hopeless at the best of times, but I can remember certain instances when, when she was at primary school, she had um, she had a statement of special needs and we'd have our review and the um person who came along to the review she would have been the, um,.. oh gosh, I don't know what her position was, but she came along to the review and as I entered the classroom she and the head teacher were talking, and they carried on talking when we sat down, and they were chatting about just day-to-day things, you know, and having a laugh about something, and I felt that that was inappropriate really, because I was ready to start the meeting and they were still chatting about just anything really, you know , just their personal lives, really and I just felt that was really, really inappropriate . Um,.. So I think sometimes you know professionalism needs a bit to be desired in these situations. Yeah,.. it, it's a difficult job though, I appreciate, some of the jobs are difficult I think, um, but as I say we've had some good people and some not so good people,..... but people tend to do a lot of report writing,.. I tell you what's bugged me over the years is that you tell	Feeling that the needs of her daughter were the most important thing. Experiences at review/ Iffy people professionals. Importance of professionalism.	Review: evaluating carers behaviours and how this impacts on their view of care . Staff attitudes – parents evaluation of care .

somebody something then somebody else comes along and you've got to tell them all over again and then you tell somebody else all over again, and that when you get changes in social workers, you've got to start your story all over again and you think why can't people just pass this information on at least the bare bones and then, you know, take it from there,.. and I just found myself repeating myself all the time and I feel that sometimes there are too many people involved. You know I always think back to way back when maybe you have a district nurse, or somebody like that who deal with so many different aspects, but now it's like it just bounces off here, there and everywhere,... it's not that, you have to go to there, if you want that you go there, and each time you have to repeat your story and that annoys me and there's a thought that (name of daughter)'s personal information is lying on somebody's desk,.. potentially, and it does happen, I know it does, but it,.. it,.. that annoys me really.... need more,.. I don't know. R. yeah, I get, I get that though, thinking about the number of people who are involved, and they, I don't know, they might all have their own paperwork, their own file, own info, yeah... C. there's such a lot of cross-over of information now , and rather than one person focussing on something, it's.. it just bounces here, there and everywhere,.. and um, um actually, it doesn't always come together, so it fails sometimes you know, because they haven't got all the information because one of the persons got something that's relevant and nobody else has, do you know what I mean, and	Disappointment of having to reiterate facts. Suggesting too many people involved. Angry with the system, lack of an efficient system. Experiences of information being shared/people involved. Explaining how in-experience in the system causes problems.	Repetitive nature of informing new staff or professional (staff changes are constant) Repeating the story. Disappointed - Paperwork lying around. Information sharing is poor (unsatisfied with professionals and staff).

that, that's annoying I think.		
R. OK, um,.. regarding you, do you think anything could have helped you through it,.. I mean you've talked that from time to time you got quite stressed particularly looking at (name of residential setting) and that kind of pulled the rug out from under you really and that you had to get her moved on, do you think anything or anyone helped you with that,..		
C. maybe,.., yeah, just somebody to sit down and talk.		
yeah and listen, listen to the problems some sort of mediator, then, if you like, somebody um,.. that they were all out on a limb as well, all the teaching staff, and actually to be fair, they helped us tremendously, the couple I'm thinking of particularly, they were incredibly helpful considering that their own jobs were on the line. You know they took time out to help us and I won't forget that. That was very important. Um,.. so yeah, it.. it's,.. I think we've been lucky, we've been lucky in lots of ways but we've been unlucky in others. I don't know really, if I think of anything else, I'll let you know.	Recommending a mediator. Expressing the importance of having help from someone. Grateful to those who supported them.	Advocate – needing support
R. Yeah, fine,.. and looking ahead, within, I don't know a ten year period, what do you see for your and your daughter?		
C. I daren't (laughs...) um,.. now I see (name of daughter) as being fairly settled where she is and hopefully that will continue and she will continue to progress, um,.. yeah but I don't, I try not to think too much of the future, it frightens me too much 'cos I always worry about what's		

going to happen to her when I'm gone and I just,.. if I stop and think about that, it just,.. it's too much. R. OK, .. right,.. anything else to add or clarify? C. I don't think so, R. I think we've covered the questions. I'm going to turn the recorder off then.	Terrified/frightened of the future	Future fear is constant

Transcript – participant 10	Open codes	Focussed codes
General chat at introduction agreeing on interview. R asks for details of background to the case. I. (name of daughter) is AGE she has moderate to severe learning difficulties and she functions like a two to three year old. She has Epilepsy quite complex epilepsy she has a very rare chromosome disorder called 1Q12.1 or something. R. Not heard of that. I. Not many people have its characterised by a lot of behaviour issues and Autism she has Autism. She wasn't diagnosed with this until she was 22. That was thanks to a research project she had been under Great Ormond St as a child and we put her forward for a research project when she was about 16. I think it didn't show up anything but they kept her DNA and her parents DNA mine and her Dad's and they retested and they were supposed to let us know but they didn't, but that's	Explaining rare chromosome disorder Explaining late diagnosis / new test available – which parents didn't ask for but was done Recalling lack of information from professionals:	Explaining diagnosis process (lateness of it all) as a way to describe child

not,.. it doesn't bother me, they retested for other research projects and I got this letter out of the blue when she was 22 saying that they found this chromosome disorder, they had used new genetic testing technology called CJH micro-array. It just gives more detailed knowledge, gives them more detailed insight of what's going on with the chromosome like a magnifying glass I presume. Compared to previous test she had which showed nothing. It was a very new sort of chromosome disorder nothing much was known about but since then 10 years on about 2006, 6 years sorry, six years later I am sort of learning more from parents than from anybody else by going on face book and we just compare notes about our kids and that,......They don't think it is ever going to have a syndrome name because they are all so different, they have all got learning difficulties, some people are silent carriers don't even know they have got it until their child is diagnosed with it. Um so it has all been a bit of a mystery really, um, yeah a lot of different effects but what the kids all seem to have in common is failure to thrive as babies 3.10. Um and eating, severe eating problems, some of them are tube-fed and um developmental problems or delays seem to vary, some have none and some have,...more like (name of daughter) did, glue ear,... like (name of daughter) had, epilepsy that seems to be very common, a lot of them seem to be affected by autism,.. (name of daughter) wasn't diagnosed with Autism until she was 22 either, that was diagnosed very late so throughout all those years, up to her age 22, we didn't know what was her problems. I think we got an idea when she was referred to great Ormond street, I can't remember what age she would have been I think she was about 10 I guess I think we realised that there was probably a genetic disorder but they just couldn't find it they couldn't pin point it and that was a great source of anxt really to me not to know what was wrong. Especially in the early years I felt very out on a limb, um I belonged to groups you know of other parents that we would meet up with, everyone	Suggesting she learned more from other parents than professionals Comparing individual differences of diagnosis Lateness of Autism diagnosis	Feeling unsupported by professionals Diagnosis is important Importance of diagnosis to explain problems Angst about lack of diagnosis Angst about other

seemed to know what was wrong with their child and I didn't and I felt like a bit of a fraud I got a bit of stick when (name of daughter) got a blue badge and someone else's child had a known disorder didn't get a badge you know and yet (name of daughter) got far more severe in mobility and all sorts of issues that she had then and now you know than that other child but because she didn't have a known cause it was almost like a fraud somehow going around to groups so yes it was sort of a strange experience so I am revisiting that now I belong to a group of parents that have children with a rare chromosome disorder in my local area and even though they all have different chromosome disorders I just feel far more like I belong because we know what's wrong but even then we don't know much about how it affects our children and much about their chromosome disorders in general it is still that feeling of sort of having a medical label of your child makes a huge difference.	Reminiscing about difficulties of 'fitting' into a group without a diagnosis : after diagnosis 'fitted' in better Feeling of 'belonging' due to diagnosis	parents understanding but not me Support for her disability (blue badge) feeling like a fraud as other child didn't get one Justifying needs based on diagnosis Importance of diagnosis
R. So you found a medical diagnosis or label quite helpful for you and your family?		
I. Yes, very much so, I don't know..., I mean now with Facebook and everything, there's groups,.. like a group called SWAN,... that's Syndromes without a name, and people connect on there, and it's known that there are a lot of people out there that have a syndrome without a name, a genetic disorder where they can't find the cause even now, even with new genetic testing technology, there's still a lot of parents out there where they can't find a cause, but because of the internet, I think that it's made them feel less alone and they know there are help for parents that don't have a diagnosis, they don't have a name for the disorder, and so possibly if I'd had (name of daughter) now that side of things wouldn't be so difficult,.. I think that's how things were then,.. not knowing, not having the internet, not really feeling like I was connecting with anyone else, I was kind of alone, and of course, going to Ormond street	Belief that medical diagnosis was beneficial Explaining the importance of the internet – helps with research but only when likely cause is identified	Supporting others through own experience

where 30 to 50 percent of Children they see in the genetic clinic have no known cause,.. they know it's genetic but they can't find a cause. And that astonished me, I had no idea, it was a surprise. But that's kind of the background really.... I think one of the biggest challenges was her behaviour, it's so easily misunderstood,.. you've got a child where when she was little, she looked fairly normal, she was fairly silly for her age and she was having these huge behavioural problems and screaming bouts, and of course everyone then puts their pennyworth in and says have you tried this and have you tried that and leave her with me for 10 minutes and then they come out all distraught and you realise that you can't get (name of daughter) sort of out of these outburst things when she goes into them,.. it was a bad time,.. she was my first child and you know I lost a lot of confidence and I felt that I was being seen as this first time mum and I just wasn't a very good parent, you know. So there was a lot of issues about not knowing what's wrong, having all these behaviours, the complexity of how (name of daughter) presented, possibly if she had had more medical problems rather than physical things, you know, I don't know if that would have made a difference as well, but it was all, it all seemed more subtle back then, but now it's all far more obvious, more documented, you know... R. are you able to elaborate on her behaviour back then. I. she was a very placid baby, but what was really strange, it was like Jekyl and Hyde, she would even as a tiny baby, she would have these, just these long screaming episodes and um I remember leaving her with her Dad's parents while we went to someone's wedding and they rang us up, or I rang them to see how she was and they said she was inconsolable and they didn't know why, and she would get these episodes where she would just be inconsolable and scream and scream as if she was in a lot of pain, um and yet in those	Identifying biggest challenges of child's behaviour Explaining that disability which is not visible impacts society's impression: child looking *normal* to the world = less understanding and more judgement? Judged by others who think they can do better Challenges of it being first child? Not knowing what to expect/ is this normal? 'I just wasn't a very good parent' Comparing then to now : physical V medical problems Reminiscing on early sign: Jekyl and Hyde - as a baby he screamed in pain	Judgement Physical appearance – she looked normal Identifying biggest challenges of child's behaviour Social perceptions / prejudice (others making suggestions) Types of disability impacts perceptions? Reliving the early experiences of parenting (ups and downs)

periods she was the loveliest, most sunny-natured baby, you know always smiling, sociable absolutely wonderful and we just couldn't work it out but I wonder now if she had reflux because a lot of these kids have reflux but no doctors picked up on it, even though she would arch back like that and we knew it wasn't Colic because you would bring your knees up with colic. So um nobody suggested anything else and whether she got use to that and it became entrenched but as she got older these screaming episodes moved into	Reliance on GP? - GP not picking it up	Feeling let down / blaming GP for not picking it up?
something like tantrums really severe ones and older still they have just been a feature of her life ever since, just sort of long melt down things where she would self harm. They could be triggered by certain things like um she had a lot of ear operations because she had a glue ear so they use to put tubes in the ear then and grommets and things but I don't think they do that so much now. Every time they did that she had to have a general anaesthetic and when she came round from one of these anaesthetics she would come		Reliving the early experiences of parenting (ups and downs)
round in one of these melt downs. It was really strange and certain medications seem to set these off as well. It was like an allergic reaction in the brain I don't know how else to describe it but it could also be triggered by we don't know what just randomly and we were always trying to find out what was her blood sugar so we could give her a little yoghurt in the afternoon or we wondered if it was to do with being tired so she needed an afternoon nap but nothing we did seemed to pin point it and still to this day we still don't know why.	Describing melt-down – still not understood by professionals. No answers	Anxiety due to lack of understanding of the problem / what the disability was
But she could go periods without having these episodes. She would have seizures these epileptic seizures and it seemed like these episodes were like they wouldn't be happening but she would either have the epileptic seizures or she would have this screaming things but has she got older that sort of changed but then she has been put onto medication for seizures and different medication for behaviour so the picture has been clouded by medications.	Describing teh severity of seizures (medical issues)	
But now she has had a three year stay in a settlement and	Recalling how medication	Medication = less

treatment unit and they have adjusted medications and she is not having the screaming out bursts now, touch wood as they seem to have the right balance with her medication now, she's just not having them and her seizures are under control as well but it has taken them a long time to get that balance. So she still has challenging behaviour but it is not of that intensity and it is a different type of challenge and it is much ear to deal with. Now it is more that she um, she can be very loud and frightening because she doesn't have a volume control on her voice at the moment this seems to be due to some anti-epileptic medicine that she is on at the moment which is really bizarre it seems to of affected her voice volume. So she is very loud and she talks non-stop so it is different picture but you know she's happy and that's the main thing. It's more challenging to deal with than anything else she is quite happy being like that and she's still sleeping at night at the moment, but it's like there is lots of different (name of daughter)'s that we have seen over the years and this is another (name of daughter). So it's like she can't sort of shut herself up, it's like ADD or Turrets or something, but kind of not,.. because you know she is sleeping OK, but yeah there have been times when she swore a lot in these sort of narrative periods but that seems to have passed thankfully and yeah we never know what (name of daughter) we are going to see next, she's sort of multi-dimensional, but this seems to have been the pattern for the last few weeks you know that she's been sort of non stop talking and loud.	stabled her child. Coping with loudness & accepting child was happier (reassured) Accepting child is full on but accepts this.	challenging behaviour (saw this as a positive) Focussing on the child being happier Parental instinct – thinks child is doing ok in herself
R. are you able to elaborate on the help you had from family or the community		
I. um in the early years, it was awkward all round really with family and community. I don't think,... Mum, Mum was going through a difficult time because my dad had early onset Alzheimer's so she was caring for him um and I don't think I had much understanding from family then of what was	Negative reaction / support from extended family	Implications of no support (justifying why others didn't; support her)

really going on. I think they could see that (name of daughter) had delayed development, but I think they possibly thought that it was the way I was managing her that was causing the behaviour and I don't think they realised how difficult it was and you know I had quite a few,.. it was things were quite frosty between me and my sister, she was quite judgemental about things which she often is until she experiences them herself, but she did sometimes have (name of daughter) and her brother to stay and then they'd keep her up all night and then she'd kind of realise and then she'd get some idea, and I think over time they gradually realised exactly what it was that I was dealing with and now they are very sympathetic, and they do understand but it took them time, I think you have to kind of live with it to really see the full extent. So that was difficult, and the community,.. I think back then I probably bored friends, you know you've sort of got a group of Mum and babies and people don't really know what to say,.. they are starting to see that your baby wasn't doing what babies should be doing and that my baby wasn't and there was that awkwardness so again if I had a diagnosis you could sort of explain you know and it was a strange creepy feeling for everybody really and I don't think anybody there knew how to deal with it and so it was, you know I just felt very unsupported, very alone in the early years it was very difficult and my marriage wasn't going well either. My first marriage that did actually end in 1990 so (name of daughter) would have been about 6 when that marriage ended. That wasn't because of (name of daughter) there was other issues going on with my husband as well, (name of daughter)'s dad and um, it was just a very, very hard time really those first sort of seven years of (name of daughter)'s life and now I am with the partner I met the partner I am with now and he is very supportive and um completely different and um obviously understanding with what was being gained with the nature of (name of daughter)s problems and it was all a very gradual and the support that was coming in you know I was getting	Explaining possibility that family thought she was managing WRONGLY and causing the behaviour issues Explaining judgement from sister Believing friends get bored and don't know what to say (isolation growing) Recalling the awkwardness and importance of being able to explain a diagnosis to others (it's not my fault?) Parent lost without diagnosis? Feeling s of isolation Impact on marriage? not necessarily due to child Outlining positive relationship with new partner	Experiencing stigmatisation from others (family) and feeling blamed Struggling to Cope - no support (isolation growing – from family to friends) Experiencing prejudice and wanting to justify with a diagnosis (which she didn't have) maybe to defend against judgement / being blamed? Struggling to cope / lack of support Impact on relationship Reminding self how bad it was back then

respite and (name of daughter) was at a special school and they kind of understood what was going on they could see what was happening and (name of daughter) was getting more and more help and support and I was as a family we were getting that but it was a bit too little too late really it felt like at the time. But it was there, it was there at the time and it did come.		Impact of late support – too late
R. and I talking about what is being looked at through the report being compiled by these interviews.		
I yeah I mean support services are sort of mobilized when my marriage broke up and I lost my home and so the 3 of us well we were about to lose our home it was about to get repossessed it was sort of the 80's crash that you get you know we have the credit crunch now but people were losing their homes then at that time and we were sort of involved in that and everything really sort of fell apart, then that was when we started getting respite and (name of daughter) was getting, they were supplying a taxi to get (name of daughter) to school and things like that cos I had 2 younger children to look after, and I kind of felt guilty that I had these other 2 children but I hadn't really realised then how severe (name of daughter)'s difficulties were, I thought she was being mildly slow and I was kind of blaming myself for the behaviour and I thought she'd kind of grow out of stuff you know. I really was completely I don't know, in the dark, I didn't know what I was facing to be honest. If I could see into the future I think I'd have been terrified, so you know perhaps if I had buried my head in the sand or I was just clueless, you know I just didn't know what lay ahead, but yeah the support services came then, and um again I guess they just increased over the years as (name of daughter)'s problems have become more marked, or over the years she's got bigger as happens with a lot of people with chromosome disorders or learning disabilities or autism, you know often these things become more marked as they get older and that's what happened with (name of daughter) and so	Suggesting social services mobilised when needed : introduced respite care (school taxi) Realising impact on younger children Lack of understanding on child's cognitive functioning and what she was facing 'TERRIFIED' if I could have seen the future Identifying social services support increased over the years due to child ageing	Internalising the guilt as struggling to manage 3 children alone Indicating the terror of the journey A need for ongoing professional support

when she was 14 um they were trying different drugs to try and manage behaviour and epilepsy and we were having these really, really bad screaming outbursts they introduced her to anti-psychotics and she had reactions to them and they made her worse rather than better and we ended up just taking her down to the local children's ward and saying you have got to admit her you got to try and sort this out we can't live like this, she can't live like this she was in a terrible state she was. The nurse that was actually looking after her said that's not learning disabilities, that's psychosis she was naked covered in scratches in this off the main children's ward they were trying to figure out what to do with her and um and in the end they bought in this school doctor who is now the child paediatrician, sort of local community paediatrician. I don't know if she was then or if she was just the school doctor but she came in and she managed to orchestrate various specialists to look at (name of daughter) and to figure out what to do and they tried, um they introduced some new medications, they tried lots of medication while she was on the ward she had some really bad effects from some but within 2 weeks they managed to find some medication regime that calmed her completely down and she had the next 7 years where she was really stable much more stable than she had been you know for the earlier part of her life. And um we got her into this fantastic school, um which was um for people like (name of daughter), I remember when we first went to the school all the children were different and probably looking back they probably had rare chromosome disorders. Well but she tried there as well that was a term only boarding school so she would come home at weekends and school holidays and she would be away in the week, that was a huge wrench but actually I wish we had found it sooner it was brilliant for her and a lot of people she was with were slightly more able than her which seemed to bring her on as well and she had some really good teachers and I think the best was brought out of her from the age of about the age 10 on in the sense of schooling because she, around the age of about	Describing medication changes to stabilise behaviours Pleading for help: we can't live like this. She can't live like this. Recalling how medication helped calm child, child went to boarding school Acknowledging it was a wrench but the best choice for their child – helped her develop Recognising importance of good schooling	Far of the future? Taking action for change – fighting or the support when she accepted she could not cope Breaking point! – the child was suffering and parent cannot cope (parent took action) Relying on medication The move: accepting

8, 9 or 10 I think it was she moved to a severe learning disability school from a moderate learning disability school so that helped, they were very good but because her behaviour was so difficult um they were struggling, so by the time she was 14, we took her to the children's		that child was difficult and that care home would struggle
ward and the school was struggling as well, so that's when she went on to the term time boarding school.	Recognising that the school was eventually struggling with issues of behaviour	
And so things were pretty stable then, um and then she was about 19 and she moved into adult services and	Seeking help from professionals	
again we were very lucky, we,.. at the same time that she moved into adult services we moved to ***** with my husband's job and we found a very good residential service that kind of kept up the good work that had been done at the school.	seeing self as lucky -	See's our-of-home care as a relief and they are lucky to have it
But then it all went horribly wrong, um her platelets dropped very, very low and she was rushed into hospital and they um figured out that it may have been the medication she was on, the long term effects of the medication she was on helping her to stay calm was actually having effects on her blood, her blood count, so they had to take her off it straight away,	long term medication caused health failure	Outlining that change occurs quickly and child's health deteriorated
and her platelets bounced back up so obviously they were right, it was the medication but the problem is we were left with (name of daughter) in the ward again, unmediated apart from seizure meds, and she was just immediately even on the ward having these awful screaming out bursts again and I remember driving her up the M3 to come home, she was trying to open the car door when it was.... these were just behaviours we	Parenting role – what is the role here?	
hadn't seen for years. And it was really scary and horrible and how the hell are we going to get her back settled and what are we going to	Recalling difficulties keeping child safe in car	Childs safety ?
do and around that time she had been moved into a smaller council home by the same residential service that she'd moved into, when she moved into adult services in ******. The idea was that they would start them off in this sort of big home and it was a new service and it was just pristine with loads of careers it was like Southfork this house it was just huge, she had so much attention. Um then she was moved into this smaller home and it had one sort of on area for the residents to sit in there was just one lounge and then their bedrooms		Significance of continuous moves when things deteriorate

and um (name of daughter) was obviously presenting with this behaviour and the other parents were starting to see it when they came to visit or came to take their kids home and they were complaining. So the impact on the other residents was massive and she got evicted from the care home. During all that time we were back to where we were when she was aged from 10 to 14 so saying to the doctors medication look she needs medication so they were back to giving her anti-psychotics again so she was getting worse and worse and worse. And so from the time they changed her meds to the time when she was admitted to hospital in 2010 there was just this deterioration in (name of daughter), and the screaming's were regularly a lot of self harm she was stripping off several times a day just in complete distress and losing her cognitive abilities and we just kept being told by her learning disability team that she needed to be in the right environment that it was to do with the residential homes that they weren't geared up for looking after her that she needed somewhere where they were geared up for looking after someone with Autism, a,.. whenever we tried to find anywhere that was geared up for dealing with Autism, they didn't have any spaces or they did, they only had males there and of course (name of daughter) with her stripping behaviours couldn't be with males, adult males and so we just weren't getting anywhere so in the end, we knew that she needed meds changed again, we knew the only chance she had was to go into hospital and for them to assess and treat her basically as before, and there was a funding dispute between the county council that was funding her which was **** authority where we previously lived and the PCT where we are now ***** PCT because ***** PCT were saying it wasn't a medical problem, they didn't want her to be eligible for continuing health care, you see, so they're are saying it's not medical it's environmental and it's the residential care homes fault. County council is saying of course its medical she needs to be in hospital. So they were in agreement with us but they would be because they didn't want to	Adult services, promises failed Noticing deterioration of behaviour, blamed on environment/care home Outlining lack of relevant care places available Explaining funding disputes	Significance of continuous moves when things deteriorate or fail (impact on parent and child?) Anxiety – unable to find the right environment (indicates the complexities of the child) Care home evaluation(continuous) Good places = lack of spaces Having to face beaurocricy to get care Fighting for support / funding

pay anymore. So this huge funding dispute, two placement breakdowns, (name of daughter) just getting worse and worse and worse. We took legal action got her into hospital ***** agreed to fund without prejudice. Um and now she is coming to the end of her assessment and treatment she is stable again and um, we are now fighting more battles really to get her moved on to appropriate accommodation. Everyone's accepted now that she needs boarded living on her own with 24 hour care because you know the risk obviously of her deteriorating again and we can't risk her being evicted again because of moods, we are not saying that the environment doesn't affect her, it does but so did the medication and they were just focussing on the environment, so what we don't want is another placement breakdown for (name of daughter) so residential isn't going to work you know it's not going to be sustainable for her. So we are trying to get homes close to us in the village as possible, but it's been a constant fight really to get (name of daughter)s needs met since she was born um and it's like a,.. never ending. Um so that is where we are now but the good news is (name of daughter) is happy, she's settled she is herself again. She has got her cognitive skills back she's got all her quirks and her.,, you know she's just engaging in things going on around, you know she's interested and she complies most of the times. She's not having these horrible outbursts and her epilepsy is under control so the fact she is in an institutionalized environment wasn't you know, suitable.... as accommodations go. We found to us it's kind of,... so what, you know it's not the biggest issue, it's an environment she's, um,.. people know her in,... and she's happy in..., if they're not going to be able to find her somewhere suitable, I'd rather she stayed there frankly. But there's just so much rhetoric and policies about this, that and the other and causes problems really when you look at the individual but you know, they are not, they're not looking at the individual, that's the problem, and every time you try and meet somebody's individual needs they are complex	Explaining funding placement breakdown adding stress; legal action was taken by parent. Choosing appropriate care/fighting battles Explaining ongoing battles to get child help (trying desperately to have child close by) No individual care to assist with child development	Resulting in legal action to get things done Fighting to support/care Funding arguments Funding Taking time to make sure the care is right / suitable for child (parent is making the decision once funding is agreed)

like (name of daughter) you are blocked. You know housing benefit caps mean that rents aren't affordable um and we would have to top up as her parents we would have to top up her rent which we don't want to do for the rest of our lives why should we really commit to topping up rent for (name of daughter) to live in the community. So we are just kind of dealing with that as well and trying to find appropriate housing near us. Um so it looks like there will be another legal battle as you rang this morning I have been busy writing a letter to ***** PCT basically saying why we think she needs to live in our community near her family and our reasons for doing that and if they don't respond in so many working days the solicitor is going to get involved and try and get her what she needs. They are suggesting we look at social housing for her and social housing we've seen is just wholly unsuited to (name of daughter) you know the noise around she could end up getting evicted again she's going to impact on neighbours you know they are all overlooked and very close together most of them don't have gardens or they have communal gardens most of the two bed roomed properties she is eligible for and you know it's just not meeting (name of daughter)'s needs at all that kind of community I don't see how she could ever put down roots at all, the building is going to have 24 hour care and probably be ostracised because of the noise she makes how is she going to integrate into a community so the average, well any social housing we've seen they, they on their site they suggested we look at every week is in that confined area with flats and things like that and because of what I have told you so far about (name of daughter) stripping off screaming and thrashing about the level of limitations with her communications and things like that, how would somebody like that integrate into a community and this is the whole support ethos of unsupported living is that people with learning difficulties aren't meant to segregated in institutions they are meant to be out in the community and I am saying well actually she is better off in a so called institution, the community of that	Explaining financial burden to support child Explaining placement battles to get child closer to home being offered (unsuitable alternative). Fighting for child's individual living needs to be met.	Outlining the complex needs of children verses the generic support / care a viable Care/environment is the key choosing care Location is important (wanting family to remain a significant part of her life) Choosing care Parents know the Child's needs, V policies (that drive service providers).

institution limited though it is than they are out in the kind of community that they are offering her here. So that's where we are at the moment. It's bitter-sweet, you know we're really happy that (name of daughter) is stable again, but what we've had to do to get her there, the distress, um the years of distress that she's had to suffer because nobody would listen to us about her history um we've just got to kind of think to lengths galore towards the PCT and the BCT that let us,.. the County Council you know that were war-ing back to the funding um so it's all sort of um that's sort of going on and gone out and being addressed and then were go.. we're stuck going on with no future. But we just know we've got to get it right now, now we've got her stable again through this 3 years in hospital we know that we, we're not going to get chance after chance, you know to try and make things right for (name of daughter), they've got to be right now, um so that's,. We're not going to allow her to leave hospital whatever we have to do until they've got something that's going to meet her needs fully, everything's got to be in place. I don't think the hospital would be happy with her leaving them until that's in place either. I was talking to the CEO and he said that some of their patients and (name of daughter)'s a prime example of just so complex that they just need a very expensive support package but obviously they don't want to provide it, um and that's just how the current system is set up, and I do kind of sympathise with some of these local authorities and the PCT and how it's set up that they get these people that are really complicated, maybe there should be a central funding for them, you know Government funding for somebody that is that complex, where it comes from a central pot, though that's not,.. I can't do anything about that, we've just got to fight for what (name of daughter), to keep her stable, we can't have her going back to suffering the way she was for prolonged periods again, so we'll do everything in our power fighting for what she needs now, you know you've got to focus on that and her....	Being dismissed Historical reflection indicates a life battle, still ongoing for medical intervention and living care that requires an individual approach rather than standard care. Explaining loop holes in funding for children. Some require extra help so needs can be met as individual and complex cases.	Not feeling listened to as parents Funding restricting places. Future Funding Fighting to keep daughter stable Acceptance that her

R. you talk about fighting,.. are you that character,.. a fighter, or did you have to become a fighter? Is it part of your personality? I. That’s an interesting question,.. Because I don’t know,.. my Mum said this to me, um not so much put in those terms she actually said to me how do you,.. how would your life have been if you hadn’t had (name of daughter), you know what sort of an adult do you think you would have turned into if you hadn’t had (name of daughter), and it’s hard to say ‘cos I’m a great one for taking up the cause and anything to do with learning disability, that’s kind of why I’m always taking up causes involving that. So I guess I am probably one of these people that is a bit of a fighter anyway, I’ve had quite a very strict Dad, he’s been in the Army and everything and what he’s said,.. he ruled the household with a rod of iron and what he said went. Mum never argued with him and she was very, very,.. Mum was extremely subservient, um she’s a bit like that with us now um her own children, she wouldn’t say boo to a goose and I sort of took on the role of being the family sort of person that kicked back against my Dad, my brother had quite a lot of ill health, he had... he was quite fragile, he was the oldest but he had heart operations and things like that, so Dad sort of bullied him a bit. That sounds horrible, not ‘cos he had heart operations but my brother was a bit odd,.. probably now he may have been diagnosed with Autism or something, he was very bright at school, but crap at sports and always getting bullied at school and um I don’t think he was the boy that my Dad kind of,.. you know he wanted a proper boy if you know what I mean. And my sister, was 4 years younger, she was the baby of the family, and I kind of took on the role of standing up against my Dad, and I think um I was a very wild rebelling teenager um, so when I had (name of daughter), I guess that my personality was already formed as being a fighter, and I dread to think what happens to parents that kind of aren’t of that makeup, you know, they probably would sink. Yeah, I don’t know. I	Learning to fight battles from childhood experiences so carried the torch of rights forward.	role is to fight for her daughter forever (to ensure daughter is happy) Personality Assertive parent (is this learnt due to need or inherent?)

really do feel for them, and I kind of feel ... (interrupted briefly by mobile ringing). Yeah, so I do kind of think that in raising um the issues that happened in the past with (name of daughter), and not sort of walking away and what happened and concentrating on the future I do feel that we are highlighting issues that are going to affect other people that don't have someone to fight for them. Not necessarily even those with mums that aren't very assertive, but those that don't have parents around at all, or advocates, or.. because advocates are quite limited in what they can do, so I kind of feel we are not just fighting for (name of daughter), I think the whole system of support and the attitudes towards people with learning disabilities is um just so much that's wrong and needs changing. So I'm kind of not just doing it for (name of daughter), I'm doing it for that as well, for everyone else that's been, a,.. treated like she's been treated, 'cos I think somebody said to me once, what do you think would have happened to (name of daughter) around the time she went into hospital, what do you think would have happened to her if you hadn't sort of fought for this, and I think that she would have carried on, she would have been chemically coshed, constantly, she was being chemically coshed anyway but she would have had even more chemically coshing and she'd have probably been imprisoned in a high security type unit, but um and very, very, just, her life would be a basket case, she would have been a complete,.. no quality of life at all. So you've got to then think well actually are there people in that situation then, who haven't had anyone to fight for them who are in that situation and shouldn't be because nobody has looked at their medication, or thought outside the box about what could be driving their challenging behaviour,.. too busy blaming,.. you know passing the buck and blaming,.. nobody taking responsibility and just damping down the behaviour with restraints, chemical restraints as well as physical restraints and you know I just find it all quite horrific really because just seeing how (name of daughter), the change in (name of daughter) now to what	Speaking out for families against lack of professional help and funding Suggesting changes are needed/attitudes are wrong Reflecting on what daughters life could have been without her mum Professionals may have treated child incorrectly without parental input and willingness to fight in child's corner throughout.	Support Sees self as the fighter Social stigma / prejudice against disabilities Using advocating to repair the stigma? Medication (chemically coshed) Fear of what others experience/or what could have been? Parent role has been redefined as a fighter ?

she was sort of 3 years ago when she was admitted to hospital, people come in who haven’t seen her,... there was somebody from some outside inspection that saw her last year and they came in and saw her again last week and they just couldn’t believe the transformation. We’ve seen it gradually,.. and my mother-in-law,.. we took her up to my mother-in-law’s, she lives up in um about an hour drive away, and we haven’t been able to take (name of daughter) up there for you know years because of her misbehaviour, and she just couldn’t believe the change in her either. You know it’s people who haven’t seen her for a while and um they just can’t believe how different she is, and a, yeah I think she said I thought we had lost her, not lost her as in died, but thought we’d lost (name of daughter) as in she was just so,.. I can only say a basket case I guess, that’s the only way I can,.. you know she was in such a state, there was just no quality of life there so it would have been a case of just managing,.. Suppressing, rather than looking at what could be the root cause of what was manifesting in her. So yeah, I mean I appreciate (name of daughter)’s quite a complex case but there must be other people that you know have similar situations and not been listened to and things like that and ended up in a really bad situation, but,.. yep... R. can you tell me about your emotional wellbeing during these times and specifically relating to *** moving I. my wellbeing?,.. a,... there have been times where I have been affected, um the (name of daughter) before she went into hospital was a really difficult time. That’s just before we took the legal action, I was up half the night writing e-mails and things like that, trying to get things sorted and I was um, couldn’t eat, um I think I was really heading for,.. I mean I don’t know, I mean I’d got general anxiety disorder, whether that’s a result of what’s happened with (name of daughter) I don’t know,.. I don’t take any medication for it and just something the doctor has diagnosed but I said I	Identifying results from quality care. Concerns re improper care of child in needs Expressing concerns as a Parent unable to get correct care for child. Explaining anxiety (sleep deprivation)	Fear that child would be lost in her challenging behaviours (fighting to preserve her quality of life) Questioning the system - not being listened to Parental stress, sleep issues

didn’t want to take medication that I would rather manage it in other ways. It’s hard to say, you don’t know how you would be otherwise do you, you just don’t know and I don’t like to blame (name of daughter) for it, because if I say it is because of (name of daughter) it is almost like I am blaming her for it and you just don’t know if it is all down to (name of daughter) So I have an auto-immune thing as well, a syndrome just that the bodies mucus glands attack the body and I end up with sort of flare ups where everything is just aching, eye joints are very sore and I don’t know if that was brought on by the stress or whether I would have that anyway it doesn’t run in the family but you don’t know I am 52 now and you get these things, you are going to get..., you know all I can tell you is that when (name of daughter) was suffering I was often breaking into tears and I was a very angry person. But I think now she is not suffering and I am not fighting the PCT we are getting certain things sorted I feel more..., I don’t feel sort of emotionally crippled by it, because (name of daughter) is ok I think if (name of daughter) wasn’t ok and she was un-happy and was distressed it was crucifying me and I was just a very un happy person. So I guess when she’s well I am well as well as I can be in that sense.	(Mothers stress) Explaining what is ‘ok’ Empathy for child	Stress Emotional toll of the experiences Fighting for change = feeling better The child’s emotions impact the parent
R. Now have you got anything to add		
I. can’t think of anything but if you think of anything else you can always ring me or email me etc.		
Well one more thing to add on that, improving things is to um more joint working really. I think this whole division between PCT and county councils. Is it mainly adults, parents of adults you are speaking to or children as well?	Identifying a need for professionals to work together	Identifying a need for professionals to work together; as they are not doing so
R. Yeah,		
I. I mean I don’t know children’s services may well of changed but from parents I have met there is a lot of disjointed working going on and there		

always has been and there still is in children and adult services and you get the situation then instead of actually focussing on helping the person the PCT is wasting their time and resources arguing with county council about funding as I said it just doesn't make sense that's probably my final point. There is all these people arguing about who should be taking the responsibility and that person just becomes invisible then, they forget that there is a person here who is not having a life, their life is on hold while they are arguing and I know they will say it should affect the persons care but even if that's,... I don't agree with the argument anyway because it does, but even, even forgetting that it is wasting their time because their time is better spent on other things rather than you know arguing with each other about who should be taking responsibility for funding and care management. I just find it un-believable and ludicrous. R. A number of people I have interviewed have identified funding being a big problem too many people arguing and nothing being acted on. I. Yeah, I second that 13th that.	Frustrated that gaining funding for out-of-home care is complex and deviates for the actual care of the child	Professionals shifting responsibility and time is wasted arguing about funding possibly at the expense of families and children?