The Stories of Parents who have an Adult Child with High-Functioning Autism or Aspergers Syndrome- A Narrative Study

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1. ABSTRACT

Background and Aims

Although existing research has begun to explore the experiences of parents who have an adult child with Autism, there are limited studies available that explore how a parent makes sense of this experience over time and how they story that experience. In line with the gaps in the research, the aim of the present study is to hear what stories the parents who have an adult child with HFA (High-Functioning Autism) or AS (Aspergers Syndrome) tell and further understand how these stories may reflect changing parental roles over time. The parents constructions of their role within that experience are considered as well as the wider and social contexts of those stories told. This is considered an important area of research, to enable a rich exploration of this area with parents who have adult children with a diagnosis of HFA/AS.

Methodology

This study utilises a qualitative approach. A total of seven participants were included, all of which were parents who have an adult child with a diagnosis of HFA/AS. All parents were interviewed with a semi-structured interview guide to elicit storied experiences over time. Six individual stories and one joint story are included in the analysis. A Narrative analysis approach is utilised within this study to transcribe, analyse and interpret the findings.

Analysis and Findings

Global impressions of each interview are presented initially with reference to both performance and structure of each storied experience. The performances of the narratives are varied and include performances aimed to deliver understanding and awareness to a wider social audience and some that aim to connect emotionally. Individual stories are analysed for content, identifying storylines. Collective storylines are then presented as a result of shared storylines emerging through the data. The strongest narratives are identified by three main plots which include the first plot of ‘Losing, Questioning and

Ultimately Attempting to Strengthen One’s Sense of Self’ which captures the negotiation of the parent role, questions of self-blame and the loss of an alternative life. The second plot of ‘The Making, Breaking, yet Ongoing and Painstaking Relationships with Services’ identifies the on-going challenging relationships with a variety of service provisions, including educational, health and social care, with an overwhelming parental sense of having to advocate on behalf of their child. The final main plot of ‘Nurturing a Past, Present and Future Relationship with My Son’ is also storied, encompassing narratives related to identifying positive attributes within their son over time, the changing nature of their relationship and the future for their adult child.

The context and broader narratives of gender, ‘normal’ family-functioning, role of the parent and independent living were also present in the parent’s stories. These findings are discussed with reference to the strengths and limitations of the methodology, clinical implications and directions for future research.

2. INTRODUCTION

'Narratives do not mirror, they refract the past. Imagination and strategic interests influence how storytellers choose to connect events and make them meaningful for others.' (Riessman 2005)

Within this chapter, I have initially identified my position as a researcher considering both personal and professional experiences that have informed this. The theoretical underpinnings of the study are then highlighted with the aim of enabling the reader to understand the lens by which the topic has been approached from. I have presented a literature review, identifying gaps within the literature and highlighted the clinical relevance of the present study. The research aims and questions are presented in the final part of this chapter.

2.1 My Research Position

Qualitative research is generally understood to be considered a subjective methodology whereby the researcher may approach the research from a certain personal 'stand point'. Bannister, Burman, Parker, Taylor & Tindall (1994) highlight that a researcher brings their own meaning and values to a piece of work and subsequently I aim to consider both the impact of my background and position and the context in which the research takes place. Riessman (1993) also highlights that the mark of the person creating that work is always evident in the construction of that piece of work. The acknowledgement that all writing can be seen as a reflection of one's particular historical and cultural context, situated in a specific place and time (Richardson 1994), encourages a transparent stand-point in the early stages.

As a researcher, I identify myself as a white British female from a working class background. My upbringing and background has undoubtedly installed and nurtured strong values regarding supporting each other within family units. As a clinician therefore I have always had an active interest in understanding family support systems and the ways in which a family may 'pull together' in the face of adversity. This interest was further fuelled when I began working within the Autism community and began observing the challenges that families experience, particularly parents, in order to be able to offer on-going support to their child with an Autism Spectrum Disorder (ASD). As my professional background has involved working with both children *and* adults, whom have a diagnosis of an ASD, I have been able to see the level of support that parents may provide, to meet their child needs, not just in childhood but through to adulthood. In particular I have observed the struggles and frustrations that can occur for parents, once their child turns 18 and is considered an adult in the wider society, therefore needing to access adult services and encouraged to transition into 'adulthood'.

My interest in the area developed further as I became more aware of some wider social views that have suggested a level of 'over-protectiveness' within these parents, particularly as an individual's High-Functioning Autism (HFA) or Asperger Syndrome (AS), can be less obvious, due to their intellectual levels being of average or above[1]. In addition, the somewhat 'invisible' nature of an ASD condition to those with little understanding of the condition may further compound a parents sense of frustration, as the impact of an ASD on their child's day to day functioning may not be overtly recognised. My research has further been borne out of the additional frustrations of the restraints of clinical practice in being able to 'hear the stories' of the parents, feeling that within adult services, parents are massively undervalued as a source of informing health care services of what is needed.

Through working with individuals and families with ASD, I am aware that my views and experiences cannot be simply 'put aside' for the purposes of research, but that I arrive at this research with the acknowledgement that such experiences will inform my portrayal and interpretations. Thus I have aimed to highlight my position with clarity to frame the context of the research. In addition, I have presented the research in the first-person which aims to demonstrate my awareness and acknowledgement of the interpretive positioning I have as the researcher (Wells 2011 p.121). I aim to bring a

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[1] Full diagnostic definitions and classifications presented in section 2.3.

‘personal voice’ to the research highlighting the presence and influence I may also have brought to the stories told (Gergen 1999).

2.2 Theoretical Stance

The current thesis position is underpinned by a narrative theoretical approach. Gergen (1998) highlights that the application and understanding of narrative is informed by social constructionism and postmodernist thinking. In line with these theoretical assumptions that underpin the study, it is understood that research is done “with” rather than “on” the participants (Gergen 1999). This approach considers that meaning can be communicated and constructed via narrative stories. The cultural context whereby stories are shared and exchanged can impact on ones construction of their individual identity as certain values or beliefs are nurtured within both stories and communities (Mitchell & Egudo 2003). Knowledge is therefore understood, from a social constructionist perspective, to be developed and understood within the context of social interaction.

By adopting a social constructionist stance and acknowledging the crucial role of context in the development of reality and knowledge (Mitchell & Egudo 2003), I hope to story the experiences of parents that may challenge and further inform dominant narratives about the role of a parent of an adult child with HFA/AS and the impact on the parental role as the child becomes an adult. Through the process of storying their experiences, the understanding is that the accounts of parents can highlight aspects of their role and identity as a parent, and can be further explored within the context of current service provisions.

Darwent (2000) describes the processes of knowledge transfer, highlighting that through stories, meaning can be communicated and constructed, thus imparting knowledge. It is through hearing the stories of parents whom have an adult child with HFA/AS that a better understanding of how parents make sense of this experience and their role can be understood. Through examining the stories and structural properties of these stories, it will be understood this does not reflect a truth or a reality that is ‘out there’ but instead an interpretive, rhetorical and constructed narrative (Riessman 1993).

In line with the theoretical underpinnings of the research therefore, it is important that I consider the words and language used within the study, acknowledging the multiple meanings they may have when used in different contexts. Thus the definition of ASD and additional terminology utilised within the study is addressed.

2.3 Autism Spectrum Disorders (ASD)

Autism is a pervasive developmental disorder (PDD) characterised by impairments in social communication, imagination and interaction with restrictive and repetitive set of interests and behaviour (American Psychiatric Association [DSM-IV-TR], 2000). Individuals with Autism have a set of identified difficulties that often result in receiving a large amount of support from childhood through to adulthood, due to the lifelong nature of an ASD (Matson, Hess, Neal, Mahan & Folsted 2010). The difficulties in cognitive, emotional and social functioning can present as a complex combination of needs.

Previous Diagnostic and Statistic Manual (DSM) editions have considered both HFA and AS as separate diagnoses with both being recognised and understood to include an IQ of 70 or above and considered to be part of the Autism Spectrum, being classified as ASD’s under the DSM-IV (American Psychiatric Association 2000). However, the diagnostic labels have recently been re-classified under one umbrella term; “Autism Spectrum Disorders” (American Psychiatric Association [DSM-V], 2013) and I essentially have done the same with regard to purposive sampling. Although I will use both terms, as it was previous definitions that informed the respondent’s stories, the terms HFA and AS will be used interchangeably within this piece of research as although there is some research suggesting differences between the two diagnoses (Klin, Jones, Shultz, Volk-mar, & Cohen, 2001), many dispute whether there is in fact any difference between the diagnoses (Attwood 2003).

Furthermore, the controversial DSM-V (2013) has combined both diagnoses under an ‘Autism Spectrum Disorder’.

Although defining and utilising such labels does not fit comfortably with me within a social constructionism framework[2], I acknowledge the usefulness in utilising them for descriptive purposes. In addition, I am aware of the importance placed upon a diagnosis for parents who may view it as a helpful way of accessing needed specialist services and thus it feels helpful to mention this, for the purpose of the research study.

2.4 Autism as a ‘Disability’- Considering Terminology

Previous research has focused on the impact of a diagnosis of Autism along with other conditions that are identified as a ‘disability’ (Greenberg, Seltzer Krauss, Chou & Hong 2004). However, Lawson (2003) highlights that some individuals with Autism advocate that rather than the condition being seen as a disability, they argue that it should be seen as a ‘difference in ability’. For the purposes of this research project, ASD will be identified as a condition within my reflections, however within the literature search and in line with the majority of the existing research, the term disability will be utilised if referred to in this way by another author.

I will also be utilising a ‘person-first’ language within the study which refers to an approach to seek the person first and the disability/identified condition second (Blaska 1993). By utilising this approach the aim is to identify the person as an individual made up of many attributes, rather than as an individual defined by a condition (Hanft 1989). This is considered the more respectful way of referring to an individual with a diagnosis and has also been utilised as an acknowledgement of the power of language and communication within society. Blaska (1993) highlights that language is a reflection of how society may view the ‘other’ and that the elimination of stereotyped words or phrases helps foster a more inclusive environment. The ‘person-first’

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[2] A social constructionist perspective questions the use and helpfulness of ‘labels’, raising concerns as to whether they are attempts to place definitions that are restrictive in shaping our understanding of the world (Burr 2000).

philosophy is also in line with the narrative stance of this study as different stories may reflect different aspects of an individual. Within this study therefore I will be utilising the term 'individual with HFA/AS' or 'individual with an ASD'.

2.5 Literature Review

A literature search regarding the impact on parents who have a child/adult child with ASD was carried out over a 12 month period, utilising key terms to locate relevant research (Appendix A outlines all details and terms included in the literature search). A focused literature review has been organized by presenting the contextual narratives of ASD then moving onto narratives about family and parenting to inform the reader of the current context. Current research and understanding of the impact of parents both in childhood and adulthood is then explored. Although the current study is focused on parents who have an adult child with HFA/AS, the narrative approach utilised is concerned with the parents experience over time and thus literature regarding the impact both as a child and adult is explored. This is in order to capture how current literature may represent the impact in the differing life stages and is relevant in identifying any changes in perceived impact over time.

In order to further understand and explore the stories of parents who have an adult child with HFA/AS, the cultural and contextual background of the stories is considered. I have therefore chosen to focus on the context of the understanding of an ASD within a 'Western' culture, focusing on the understanding of 'parenthood' and 'normal family functioning' implicit in societal narratives.

2.5.1 Narratives about ASD (Existing and Past)

As both AS and HFA are recognised as ASD conditions, it is important to consider how ASD as the 'umbrella' term has been understood by society. Through the decades there has been a history of dominant metaphors that have been identified in attempts to conceptualise ASD with prominent cultural narratives existing that ultimately influence policies and interventions (Broderick & Ne'eman 2008).

A 'cultural narrative' can be defined as a meta-narrative within society that has broad or deep cultural influence, with 'narrative' referring to the stories that people live amongst (Gordon & Paci 1997). Both past and existing narratives of ASD are important when considering the way cultures, individuals with ASD and parents have attempted to make sense of their experiences with the condition. It is within the dominant cultural and contextual narratives that parents are raising their child, and this will influence the co-constructed narrative of social and cultural understanding around ASD. Broderick and Ne'eman (2008) discuss the cultural purposes of Autism metaphors that have existed over time and state that a metaphor may serve to create a 'common-sensical' narrative between aetiology, causes and culturally dominant notions about appropriate responses to the condition. Broderick & Ne'eman (2008) make reference to the metaphors such as 'Autism as a foreign space' and an individual with ASD 'arriving from another planet', highlighting that the metaphors shift in line with how Autism is understood at a particular time. For example, Broderick & Ne'eman (2008) refer to changes regarding moving away from the 'alien metaphor' in favour of a more 'civil rights' approach whereby individuals with ASD themselves actively reject such metaphors, in favour of a more positive minority group metaphor.

Bettelheim (1967) wrote about the notion of individuals with Autism appearing to 'retreat' from the rest of the world, which in turn led to queries about what it was these individuals were retreating from. The understanding that inadequate parenting was responsible for an active withdrawal (as opposed to a withdrawal initiated by the child), contributed to a dominant cultural belief and subsequently a culture of blame towards parents ensued, with focus shifting to the parents of children with an ASD. Conclusions were made that implicitly blamed the closest person for motivating a child to such a withdrawal and therefore Broderick and Ne'eman (2008) highlight that for many years there was an unjustifiable blame put on the mother for somehow 'causing' their child's Autism as a result of being a 'refrigerator mother'. Popular past explanations for the aetiology of Autism regarding psychodynamic explanations of child/parent interaction during infancy contributed to additional burden and stress being placed on families of those with Autism (Gray 2001).

Holmer Nadesan (2005) explores the construction of Autism and notes that the psychoanalytical understanding of Autism lost favour both in the social sciences and within popular culture in the 1970's. She highlights that new understandings of the constructions of Autism began to form, following both cognitive psychology and organic psychiatry influences, impacting on how Autism was perceived and understood. However, Holmer Nadesan (2005) criticises positivistic biases that have since dominated and attempts to address the social and historical context that has enabled Autism to be identified and labelled in the way it is today. She concludes that there is no universal "truth" of how Autism should be understood, but that whilst noting biological components, suggests that Autism is a process of identifying, interpreting, remediating, and performing embodied differences that are cultural and historically specific. Nevertheless, Holmer Nadesan's (2005) position regarding the cultural understanding of Autism could be heavily criticised as failing to acknowledge or value the experiences of those who feel their lives are impacted by an ASD. Suggesting that ASD are the consequence of society's reactions to such a presentation may perhaps serve to undermine such experiences.

Although there is not the scope within the current research study to provide a more detailed summary of the history of the construction of Autism, such understandings are important not only to further understand the individuals directly impacted by ASD, but to consider how ones ideas of normality and difference are influenced by social institutions such as health and social care. Although the understanding of 'causes' of Autism has developed with earlier psychoanalytic views being dis-credited, cultural narratives may still linger and can occasionally re-surface in literature on Autism (Gray 2001). For the parents who now have adult children with HFA/AS, it may be that these cultural accounts have lingered, particularly as those children have now turned into adults with additional cultural narratives perhaps existing, regarding the desired role of the parent, as a child transitions into adulthood aiming to lead an 'adult life'. Steyaert & De La Marche (2008) comment that although Autism is currently understood to be a neurodevelopment disorder, there is an absence of a theory that thoroughly explains the neurobiological mechanisms at work. Gray (1995) suggests that subsequently Autism may be susceptible to parents own constructions of its aetiology and causes.

2.5.2 Narratives about 'Normal' Family Life

A further dominant narrative that is important to consider is the construction and understanding of 'normal' family life that families are operating in. Gray (1997) highlights that considering the impact of parents and families of those with an ASD has historically been considered in the context of how it may actually differ, when compared to the 'normal' family life (DeMayer 1979). However as Gray (1997) suggests, the construction of 'normal family life' is a complex and ambiguous notion in itself, as what may be one family's reality may not be another's. The idea that a family is constructed by its participants as a social reality (Holstein & Gubrium 1994) and therefore exists as a 'collective representation', rather than a given reality, is important when considering the notion of a 'normal' parent-child relationship within a family unit.

DeMayer (1979) suggested that individuals whom have HFA are more likely to have a 'normal' life with more successful psycho-social development (when compared to individuals classified as having 'lower-functioning' Autism. However, such claims can potentially have unhelpful implications as families may feel compelled to achieve this 'normal' life despite difficulties in doing so. Gray (1997) highlights that such assumptions can mean that the unique problems associated with HFA may be ignored. Parents may therefore have contrasting opinions to professionals, who have their own 'taken-for granted' assumptions regarding how well a family is operating, in relation to their own construction of what a family is and how it should function (Gubrium & Holstein 1993). This could result in parents feeling they need to justify or clarify how much they may feel their experience differs from that of a ‘normal family’.

Gray (2001) identifies that behaviours such as ‘self-control’ are strongly valued in western culture with society focusing on the ‘functioning’ ability of an individual. This fits with the embedded normalising ideologies in Western culture whereby the aim is to live up to a ‘normal’ standard of functioning. Any deviation from this - or a condition such as ASD - can be considered a ‘disability’, in that it may threaten the ability of an individual to deal with the routine tasks of daily life competently (Becker 1997). Hyden (1995) reflects that a narrative reconstruction is likely to follow, whereby parents may need to shift their understanding to make sense of the ‘disability’. Becker (1997) suggests that cultural categories such as ‘family’ or ‘personhood’ may be drawn upon in an attempt to cope successfully with the ‘disability’ and in an attempt to lead a ‘normal’ family life under difficult circumstances.

Gray (2001) presented three narratives of Autism considering how parents with young children with ASD attempted to make sense of their experiences. The paper concluded that the experience of difference (e.g. illness or a disability) is countered against strongly embedded cultural values of normality which contributed to three parent narratives identified as accommodation, resistance and transcendence. Gray (2001) also highlighted that the narrative re-constructions of the parents in the study drew upon master narratives of science, politics and faith, to try and make sense of their experiences, noting narrative reconstruction of moral aspects. Such research suggests that parent’s central values will affect how their experience of Autism is understood in the context of their life (Hyden 1995).

Contrasting narratives may be problematic for a parent themselves as they find themselves struggling against a dominant narrative of what a ‘normal family life’ should be or co-constructing with service providers and professionals regarding ideals of how ‘normal life’ is to be achieved. A parallel process can also occur whereby a parent may attempt to adhere to dominant cultural beliefs about a child ‘growing up’ and becoming more ‘independent’, with possible feelings of guilt or frustration being evoked, if they are not able to mould with this narrative of their role expectation. Becker (1997) highlights that despite inherent difficulties that parents may experience; they can still attempt to live up to society’s expectations.

2.5.3 Narratives of Parenthood

Existing and powerful cultural and historical views, regarding the role of a parent and what being a parent ‘means’, in the western world impacts on how individuals attempt to parent and how they make sense of this experience. Such powerful discourses can be particularly problematic if the dominant view or understanding of knowledge about parenthood is contradicted or challenged in any way. Hayley (1976) identifies the strong western cultural narrative of the parental ‘task’ of nurturing a child’s independence and the perception that ideas of ‘growing up’ should be encouraged and developed by the parent. Independence and separation are dominant Anglo-American ideals regarding a child and parent relationship (Gower & Dowling 2008). Master narratives such as these form the cultural and historical context whereby parents may understand their role. In addition Gray’s (2001) explorations regarding parental conceptions of their child’s Autism conclude that in some cases the parents role can threaten culturally sanctioned ideas about family, ‘normality’ and their role as a parent for their child.

There are many implicit assumptions about the role of the parent that shape an individual’s experience of parenthood such as the notion of ‘unconditional love’. The parental role of being able to offer ‘unconditional love’ is explored by Kall (2009) whereby it is suggested that the notion of indestructible and unquestionable love is the definition of motherhood rather than it being just a quality of motherhood. Such dominant ideas exist that place the mother in a position whereby her role is to ‘always be there’ emotionally if not physically, as a moral imperative and to love unconditionally with any contrary to this involving a risk of being labelled as a ‘bad mother’ (Kall 2009). Other marginalised ideas of parenting or alternative constructions of parenthood may therefore be overshadowed or not be able to be heard as dominant cultural discourses prevail. This raises questions however regarding what the consequences are for parents who do have additional challenges placed on their experience as a parent, such as a child’s challenging behaviours, life-long disabilities, mental illness, or even criminality with a dominant discourse of normalising ideologies being problematic.

In addition, gender differences regarding the potentially differing roles of mothers and fathers within parenting exist that contribute to ones identity within this role. Wille (1995) explored the differing roles identified between mothers and fathers, highlighting that historically ideas of the mother as the primary caregiver-nurturer and the father as the material provider or ‘rule-maker’ have been dominant. Although such ideas have adapted somewhat, with social changes such as more mothers returning to work (Gray 2003) impacting on such narratives, expectations and interactional styles between genders still exist (Stephens 2009).

2.5.4 Impact on Parents with Children with ASD

There is a range of evidence that explores the impact on parents whom care for a child with Autism (Hastings & Brown 2002, Midence & O’Neill 2009, Dunn, Burbine, Bowers & Tantleff-Dunn 2001, Rodrigue, Morgan & Geffken 1990). Factors such as locus of control, coping styles, perceived self-efficacy and social support have been explored in relation to negative outcomes such as stress levels and depression (Dunn, Burbine, Bowers & Tantleff Dunn 2001). Previous research has focused on the psychological well-being of individuals whom are the primary caregiver of a child with Autism and has shown that there is a higher risk of psychological difficulties in parents of children with ASD compared to parents of non-disabled children (Bromley, Hare, Davison & Emerson 2004). Autism research suggests that various level of social support can impact on the parent's psychological wellbeing and that more support results in less depressive symptoms (Benson & Karloff 2009) and lower levels of negative impact (Bishop, Richler, Cain & Lord 2007). A higher level of positive mood was also reported for parents who experience a high level of social support (Pottie, Cohen & Ingram 2009). However, what is not made explicit or explored further within these studies is what components of social support are most notably helpful and *what it is* about social support that makes such a positive and significant difference to their experience. For example, it is important to consider whether social support is an implicit indication of acceptance or whether it is a sense of feeling not blamed, indicated by others actions, which lead to such positive assumptions. It may be that being able to talk about their experiences within social support networks impact on a parents own sense-making of their experience as a parent.

Additional research has shown differences in perceived impact of caring for a child with HFA/AS, dependent on the gender of the parent. Gray (2003) found that although fathers reported an impact on the family as a whole, they often did not identify any personal impact on them. If levels of distress were reported by fathers, it was due to the level of stress that their wife was experiencing. Mothers were more likely to claim that their child's Autism had affected their emotional well-being, with many mothers distress high enough to require medication or psychotherapy. However, although the study emphasises the existing literature and assumptions about gender and coping strategies, Gray's (2003) research could be criticised for only including parents whom were viewed as holding more 'traditional' gender roles within the family units as no 'non-traditional' couples were included in the sample. The allocation of gender roles in terms of employment and domestic responsibilities was consistently traditional among all other couples in the study thus, if couples who utilised a more egalitarian approach to domestic responsibilities were included in the study, the results may have further informed understanding. This is important to acknowledge as dominant narratives about gender will impact on a parents experience despite gender roles and coping activities being constructed within the context of the family.

A further exploratory study was completed by Fleischmann (2004), who explored narratives that were published on the internet of parents with a child with Autism. Using a textural analysis method of narrative analysis, the research explored the stories told with a particular focus on the adjustment process for the parents. Fleischmann (2004) showed that important storylines emerged for parents regarding their growing sense of self-empowerment and acceptance. However, although this study contributes further to the understanding of a parents sense-making and identity as a parent, the sample utilised may be representative of stories told specifically by individuals who choose to share their story on an internet forum, thus reflecting a particular ‘type’ or ‘style’ of parent approach.

2.5.5 Impact of Parents with Adult Children with ASD

Although the literature base regarding the impact on parents with children with an ASD has been heavily researched there is a limited amount of research that explores the parental impact of caring for a child with this diagnosis when they reach adolescent and adulthood (Hare, Pratt, Burton, Bromley & Emerson 2004). Seltzer, Krauss, Orsmond, & Vestal (2001) reviewed adult studies stating that there was a large amount of ‘unchartered territory’ regarding the impact of parenting adults with an ASD. They highlight the need to understand this impact further, given the dynamic and evolving role of the parent and the variability of stressors that can present themselves over time. Seltzer et al (2001) also suggest that it may be that the core deficits remain in adulthood, but suggest that symptoms of Autism may abate in some individuals over time. If this is the case, it would make sense that a parent’s perceptions or understanding of their role may also change over time.

However, parents who have a child with Autism face lifelong care giving responsibilities and although in other families, adolescence is a time for promoting independence and autonomy, this particular time can present challenges for those with Autism (Howlin, Alcock & Burkin 2005). Gray (2003) highlights the importance of considering this specifically within HFA/AS, as individuals with HFA are likely to eventually have to work, live independently and otherwise enact a typical adult role, which may be in contrast to an ASD with accompanying intellectual disability.

Taylor & Seltzer (2010) explored changes in the mother-child relationship during transition to adulthood, identifying the need to understand parental well-being, during the transition years. They found that parents were more at risk at this time of experiencing stress, particularly if their child did not have an additional learning disability (LD), as the process of entering adult services with limited resources is increasingly challenging. Potential contributing factors such as comorbid LD, gender of child, unmet service needs and family income were investigated in the study, with conclusions that the impact is different for those without LD. Those without an additional LD were less likely to have occupational/educational activities after leaving school and parents reported a decrease in parental warmth. They suggest that the lack of opportunities and day activities may result in frustrations for family members, consequently impacting on parental warmth.

Hare et al (2004) investigated the health and social needs of family carers supporting adults with HFA/AS and highlighted the association between parental emotional distress and unmet needs, particularly regarding service provisions for their adult child. They utilised a semi-structured interview and a variety of scales aimed at exploring the level of social support, awareness of support services and challenging behaviours present. The scores and responses were collated with themes identified such as worries about the future, parents having restricted lives and experiences of services. This research did not find a link between levels of distress and abilities and behaviour of the child. Interestingly, they suggest that this may be due to parents finding ‘ways’ of coping and accommodating their considerable needs. However the implications of that conclusion are that parents are still providing a key role but that their management, understanding or acceptance of that role may have changed perhaps by finding a way to make sense of their experience and adjust accordingly. The limitations of the methodology fail to capture a more detailed understanding regarding potential adjustment or changes that occur over time, as the quantitative data was most heavily referred to, in an attempt to find correlations.

Overall the existing limited research related to parents experiences are not able to capture how the parent makes sense of this experience and thus whether their responses or attitudes are linked to their perceptions of their adult child in a particular point in time and how the experience may impact on their role and identity as a parent. Seltzer et al (2001) also highlight that even in the small amount of research that has been completed, there has been a failure to consider or highlight gratifications of the parent-child relationship, in addition to difficulties that may characterise the relationship.

2.5.6 Understanding Parent's Sense-Making

The research that has been completed in this area has been helpful in exposing emerging themes regarding parental needs. For example, Hare et al's (2004) research did demonstrate that parents reported that more Autism-specific interventions were needed and also more support for adults with ASD. However, what appears to be missing within the research is a more in depth understanding of how the parent makes sense of their experience across time and the meaning they attach to their role and identity as a parent. Many studies have utilised structured interview schedules but with a focus on standardised measures aiming to measure elements such as positive affect and marital satisfaction (Bromley, Hare, Davison & Emerson 2004, Hare et al 2004, Smith, Greenberg & Seltzer 2012, Hartley, Barker, Seltzer, Greenberg & Floyd 2011) - which, although is helpful in considering associations, it fails to capture a richer exploration of the experiences of these parents.

The way an individual may share their experience with another and talk about their 'story' is an area that requires more understanding, particularly as the parent continues to contribute and play a key role in the adult child's life. In particular, it is those parents of children who do not have an additional learning disability that may experience significant changes, as research suggests differences in services and support available following this distinction (Smith et al 2012). For example, Seltzer et al (2001) found that the challenges of being a parent with an adult child with ASD changes, compared to when they were a child with ASD, unless there was an accompanied LD.

Krauss & Seltzer (1999) suggest that it may be that the parenting experience is stressful in a different way as their child’s needs may change as an adult. They also suggest that the parents coping strategies may have changed as they have become older and that behaviours can reduce over time, as parents become ‘used to’ the role of caring. In addition, Hare et al (2004) highlight that when the child with Autism is an adult, the parents may actually become ‘resigned’ to the limitations of services and therefore what appears in research studies as parents reporting ‘contentment’ or appropriate adjustment, is actually just a reflection of their reduced expectations.

Understanding the experience of a parent who cares for an adult child with Autism is integral, considering the vital support role that they fulfil within their lives. In an individualistic society, whereby independence and autonomy is encouraged, challenges are created for the parent when there are in a position whereby withdrawing support could be detrimental to their child’s quality of life. Distinctive difficulties within the diagnosis of Autism include the fact that the individual’s impairments are not always overt and subsequently the level of support that is required is not always fully understood (Hartley et al 2011). Individuals may appear much more able than they are and therefore the significance of support roles such as parents is not always identified.

2.5.7 Emphasis on Coping

Although some studies have attempted to capture a richer and more in-depth understanding of how parents make sense of these experiences (Krauss and Seltzer 1999, Hines, Balandin & Togher 2012), there appears to be an emphasis on coping and how parent’s beliefs may influence their coping style

(Gray 2001). In addition, most of the more in-depth exploratory research has been explored with parents whom have *children* with Autism (Gray 2001, Gray 2003). More recently research has begun to explore older parents (aged 60 and above) experiences with adult children with Autism. For example, Hines et al (2012) completed a narrative analysis that explored how beliefs and perceptions of older parents regarding their child's Autism inform their coping strategies. In particular, the focus on older parents was understood to be helpful in exploring whether parents of Autism have a different sense of their experience, when compared to parents of those with an intellectual disability. The narrative approach within this study enabled those experiences to be considered within a context of their entire life history. Their research found that parents coping abilities and positive perceptions of their son or daughter with Autism are influenced by their beliefs about the aetiology of Autism. For example, they found that parents were more likely to preserve positive perceptions of their adult child if they were able to 'blame' the objectified Autism and separate it from their offspring's 'true' self.

The emphasis on coping strategies may be helpful when considering parents' management of stress. According to Antonovsky (1987), how an individual makes sense of the world and applies coherence to their experiences, is linked to whether successful coping strategies can be utilised. Lazarus & Folkman (1984) developed the cognitive model of stress and coping and highlighted that caregivers may handle stress and solve problems, dependent on their specific coping style and strategies. However, Stern, Doolan, Staples, Szmukler & Eisler (1999) explored the disruption and reconstruction of narratives of family members caring for relatives diagnosed with a serious mental health illness and noted the struggle that human beings are engaged in, to try and make sense of their experiences and relationships. Although coping styles are important when considering the repercussions that they may have on aspects of their care-giving, capturing the lived experience is also important and understanding how one struggle's to make sense of a difficult life experience is key. Walsh (1996) highlights that meaning making and the search for coherence appears to be significant, when considering care-givers resilience.

2.6 Clinical Relevance

This research is considered to be clinically relevant, due to the potential implications of under-utilising and under-valuing the role of the parents who have adult children with AS/HFA. In contrast to some of the literature presented above, the unique difficulties that can be faced with these parents is that due to their adult child's intact intellectual abilities, they may not hold the role of the official 'caregiver' in such an explicit way, as may be apparent with an individual with intellectual difficulties. Holding an un-official but potentially integral role has additional complications, as parents may therefore find it difficult to define their position to services (Hare et al 2004). The stories of the parents, whom are often key people in these individuals' lives, are shared in a context whereby existing dominant discourses regarding both the condition of ASD and their role as a parent can result in barriers of being able to 'tell their story'. Opportunities given to parents of service-users to share their understanding of their perceptions generally can be limited as Bloch, Szmukler, Herrman, Benson & Colussa (1995) acknowledged, in regards to their work with caregivers of individuals with Schizophrenia. They describe the keenness for family members to discuss "the saga of caring for the ill relative", albeit acknowledging limitations in opportunities.

Further understanding of the 'system' that the individual operates in and the key people in their lives will be beneficial for future clinical practice and will aim to encourage systemic ways of working. The unique and varied ways that individuals with an ASD can be impacted (Wallace, Parr & Hardy 2013) is also significant when considering the unique insight that a parent may be able to bring, particularly as they could at times be considered an 'expert' in their own child's condition.

Hyden (2008) explores narratives in illness and highlights that telling stories are not only able to be considered as representations of events but can be considered as ‘social action’ stating that through stories, social states can be changed, established and negotiated. Therefore social change within health and social care settings can occur and is fundamentally embedded in conversations that are had with not only service-users themselves but key people in those individuals lives, whether they be in adult or children services. It is therefore an aim of this research to enable stories to be heard and further explored to gain a richer and more in depth understanding of the parents lived experience.

2.7 Area for Further Exploration

Although existing research has begun to explore the experiences of parents whom have an adult child with Autism, there are limited studies available that explore how a parent makes sense of this experience over time and how they story that experience.

The purpose of this narrative study is to explore the experiences of parents whom have an adult child with HFA/AS and understand how they create and construct their experiences and relate them to others. The aim is to understand the potential impact of key changes over time such as life stages (the child moves from childhood to adulthood) and how the parent makes sense of these changes, which in turn forms and contributes to their own role as a parent. I also aim to consider the wider social context of the stories being told.

2.8 Research Questions

- What stories do parents tell, who have an adult child with HFA/AS?
- How do they tell these stories?
- How do these stories reflect changing parental roles over time?
- How might these stories be shaped and constrained by implicit wider cultural narratives around parenthood?

3. METHODOLOGY

Within this section I aim to provide a transparent account of the methodology utilised within the study. The epistemological position adopted and the rationale for locating the study within a qualitative framework, specifically within narrative inquiry, is discussed. In addition, the research design and process of analysis is presented with the ethical considerations of the study detailed. Aspects related to the quality and credibility of the study is also included to enable the rigour and trustworthiness to be considered by the reader.

3.1 Locating the Study in Qualitative Research

The research questions within this study were considered as most appropriately addressed within a qualitative piece of research. The philosophical assumptions within qualitative research, particularly regarding the stance towards 'reality' are particularly significant within this study, given the understanding that each participant will bring their own 'story' and interpretation of reality; of their experience. Embracing the notion of multiple realities (Denzin & Lincoln 2005) is in line with the ontological position of this research. Qualitative research allows meaning and experience to be explored, to gain a richer idiographic understanding of individual experiences (Chamberlain, Stephens & Lyons 1997).

In addition, the epistemological position of qualitative methods within a postmodernist paradigm is suitable for the present study as I aim to consider the *relationship* between myself as the researcher and the stories of the parents, appreciating the role that I might have in shaping the telling of these stories. This is in contrast to a quantitative methodology that would consider the researcher as an 'objective outsider' to the topic within a more traditional, positivist approach to research. Thus, a qualitative approach embraces the subjective interpretations that may follow, albeit these will be evaluated with qualitative rigour (Meyrick, 2006). Thus, by utilising a purely qualitative approach I acknowledge that the stories of the parents and the findings will be shaped by my experience as a researcher in collecting and analysing the data and will be (at least in part) inductive and emerging (Cresswell 2007 p19).

There have been a limited number of studies that explore the experiences of parents with *adult* children with HFA/AS in a way that enables a rich exploration of individual's storied experiences. The majority of past research in this area focuses on the experiences of parents whom have *children* with HFA/AS and has involved the use of various rating scales, in an attempt to 'measure' the potential impact (Dunn et al 2001). However, there is a uniqueness to how an ASD may manifest and present itself, due to the degree and intensity of features identified within ASD varying between individuals (DeVaan, Vervloed, Knoors & Verhoeven 2013). Subsequently, qualitative research is better suited at being able to consider a more detailed exploration of individual narratives, in an attempt to capture how a parent stories their experiences of having an adult child with HFA/AS.

3.2 Epistemological Position

Denzin and Lincoln (2005) highlight that individual researchers bring different worldviews to qualitative research. They discuss how a set of beliefs guide the actions of the researcher emphasising that one's worldview will inform the practice of research. In considering how a parent with an adult child with HFA/AS makes sense of their experience I have been inspired by constructionist ideas as it was understood that this approach could accommodate my desire to understand both personal accounts and to investigate storylines and the wider societal narratives that inform them. A social constructionist perspective regards the understanding of 'knowing' and 'truth' as a subjective and constructed concept, whereby meaning is constructed through social interaction and within a context (Mitchell & Egudo 2003).

The epistemological stance of this research is compatible with the type of qualitative methodology that was chosen; i.e. Narrative analysis. Narrative analysis enables multiple truths to be explored, acknowledging that an individual builds and communicates their understanding of themselves and the world through stories (Frost, Nolas, Brooks-Gordan, Esin, Holt, Mehdizadeh, & Shinebourne 2010). A narrative approach to inquiry also views individual's storied experiences using language as not simply reflecting a stable and singular meaning, but as a 'constitutive of reality' (Riessman 1993).

3.3 Using Narrative Inquiry

Riessman (2005) highlights that research studies aiming to explore a small number of persons more detailed experiences can benefit from a narrative approach. A narrative approach enables a more in-depth and detailed analysis of how an individual makes sense and stories their experience over time. It also allows a way of systematically studying personal narratives of experience (Squire 2008). In addition the idea of participants' responses being a picture of 'true reality' can be challenged, enabling the analysis to focus on the 'co-construction' of the story between teller and listener/researcher (Holstein & Gubrium 2004).

For this study, narrative can be usefully applied as I aim to hear the stories of the individual's lives and also to understand how they story their interactions with others, particularly health care professions or in the context of a health or social care setting. Kirkman (2002) states that narrative theory, which underpins narrative research approaches, enables the exploration of both the complexity of individual's lives and the multiple interactions within cultures and individuals. As this research is interested in how participants make sense of their role as a parent of an adult child with HFA/AS, narrative inquiry lends itself to capturing the way they communicate their story of particular experiences.

Bruner (1986) identifies two ways of knowing. One is understood to be a 'paradigmatic' way of knowing which suggests there is an objective truth based on logical proof and empirical evidence. However, Bruner also suggests a 'narrative knowing', understood to be created and constructed through the meaning making of persons stories of lived experiences. In line with the research aims of the study, narrative enquiry shows that local knowledge is valued as constructed between people who actively engage in its creation.

The research question *'What stories do parents tell, who have an adult child with HFA/AS?'* is helpfully understood by narrative inquiry, which aims to be a collaborative piece of research enabling parents - whom may have hitherto lacked the opportunity - to story their experiences. It is also suitable as a research study that may serve to challenge the dominant paradigmatic assumptions of the 'researcher as the expert' and consider the participants to be the experts of their own narrative, which is then shared and collaboratively developed with the researcher. The way the parents tell their stories and how they make sense of their experiences within a narrative approach, may enable us to construct meaning about that individual's sense of self. Riessman (1993) highlights that individual's claim identities and construct lives by process of a personal narrative of past events and actions, acknowledging that stories are context dependent and are constructed between people.

3.4 Alternative Qualitative Methods

Although consideration was given to alternative qualitative methods, it was felt that narrative would be most helpful in exploring the individual lives of the parents, with regards to how they have storied their experiences of their adult children with HFA/AS over time. Narrative analysis enables the opportunities to gain layers of understanding of a person and their culture (Etherington 2009). In addition, in line with narrative analysis the study explored performative, structural and content aspects of the individual stories and thus there was an additional interest in *how* the story was told and 'laid out'.

Alternative qualitative methods such as discourse analysis focuses on the analysis of the language used (Hodges, Kuper & Reeves 2008) and would not enable satisfactory exploration of the wider context of the parent's experiences. A grounded theory approach would also not be appropriate, as the aims are not to develop a theory that explains process, action or interaction, as would be the aim of a grounded theory study (Strauss & Corbin 1990). In addition, as Riessman (1990a) highlights, the grounded theory method may in fact ‘fracture’ the data as it is not concerned with the interviewees portrayal of the story and thus the researcher may be unable to portray a participants experience in its ‘fullness’ In addition, a phenomenological approach which focuses on understanding the essence an experience or lived phenomenon would not be appropriate as the performance aspect of each person’s experience would not be considered, given the focus would be more on the universal essence of a human experience (Creswell 2007 p.58). Furthermore, in contrast to analysing isolated experiences, narrative analysis would enable the opportunity to see how the parents make sense of their experience in the context of their whole life (Smith & Sparks 2009).

3.5 Design

This is a qualitative study with a narrative approach. The sample was collected using a non-probability sampling technique, following a purposive sampling approach (Patton 2002), as participants were selected as parents of an adult child with a diagnosis of HFA or AS. This approach was used because the study aimed to target this population to explore their storying of experiences around having an adult child with HFA/AS.

3.5.1 Inclusion Criteria

All participants were required to have an adult child (over the age of 18) with a diagnosis of HFA/AS. Both mothers and fathers were invited to participate in the research although the focus was on eliciting parent’s individual narratives. I wanted to pursue fathers in addition to mothers, given that father’s narrative voices have been relatively under-researched (Williams 2006). The focus was on obtaining *a* parental family representative for the parent story, however in one case a couple volunteered. I aimed to be inclusive and to capture potential alternative narratives recognising that narratives and stories of individuals are the product of culture, relationships and social roles, including gender (Gergen 1994).

The only exclusion criteria imposed for this study was if the parent's adult child's diagnosis was accompanied by a diagnosis of a Learning Disability, understood as an individual with an IQ within the Learning Disability range, i.e. of below a score of '70' (admittedly using positivist criteria). Additional cognitive deficits would bring additional and potentially different types of experiences for parents and thus were not included.

Therefore parents that had adult children with HFA or AS would be eligible to participate. Parents who had adult children with co-morbid mental health difficulties were also included in the study. Research suggests that co-morbid affective disorders in those with AS are the rule rather than the exception (Attwood 2003b). Such research may not present as entirely surprising, when one considers the stress that may be experienced by those with AS, due to the nature of their illness. Hare et al (2004) suggests that life experiences may be an important factor in the development of psychological distress. For example, those with AS may experience chronic levels of stress, due to their continual attempts at social inclusion, their difficulties with social reasoning, empathy and verbal communication (Attwood 2003b). Therefore, the stress of coping with their diagnosis may manifest itself in co morbid affective disorders. It was therefore felt that excluding people on this basis would mean that significant aspects of the stories of parents, whom have adult children with these diagnoses or functional difficulties, would be missed.

3.5.2 Participants

The sample size was seven participants. This reflected recommendations that within narrative research the sample size should be a small number to allow for detailed analysis, a minimum number suggested for complex analyses being five (Wells 2011, p.20). The small sample size reflects the attentive analysis that is needed requiring the attention to consider multiple factors such as nuances of speech, the relationship between the interviewer and interviewee and historical and social contexts possibly shaping stories (Riessman 2005). Each participant was recruited from two voluntary support groups, which cover a specific geographical area in the UK. The two groups were chosen as both were equally suitable groups to recruit participants from and it was considered that targeting both would increase the chances of successful recruitment. Both are monthly support groups held by parents of individuals with HFA/AS, aiming to support parents or carers of adults, whom have a diagnosis of HFA/AS. Contact was made with the group facilitator via e-mail requesting a visit to the group, to initially facilitate a focus group[3] in line with the design process and also to initiate recruitment. The final recruitment and participants included in the study are presented in Table 1.

Participant:	Mother (Eileen[4])	Mother (Barbara)	Mother (Jackie)	Mother (Tanya)	Mother (Angela)	Mother and Father (Carol and Bill)
Age:	57	67	62	52	58	56 and 60
Adult Child's Gender:	Son (Max)	Son (Joe)	Son (Chris)	Son (Luke)	Son's (John and Jim)	Son (Liam)
Son's age:	25	27	31	27	32 and 21	25
Diagnosis	AS	HFA	AS	AS	AS	AS
Interview Location:	Home	Home	Home	Home	Community Venue	Home

Table 1: A table displaying the participant's relationship to their adult child with their gender, age, diagnosis and location of interview.

I requested to interview Carol and Bill separately, however they chose to share their stories together. After considering whether including a joint story would be appropriate given it is an anomaly amongst a set of individual interviews, I decided to include their co-constructed story. The was based on

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[3] Full details of the focus group are located in section 3.7.

[4] All names have been changed to pseudonyms to protect anonymity.

my feeling that a joint narrative was relevant in informing the research particularly considering that predominantly two parents are involved in raising and parenting a child. Thus it enabled me to capture and interpret how the experience may be storied jointly, as it reflects an eventuality that may be more fitting with the ‘real’ world. However, in all other cases only individuals volunteered and it was felt that utilising individual stories initially would be important.[5]

3.6 Ethical Considerations

Ethical approval from the University of Hertfordshire ethics committee was gained prior to the commencement of the study (Appendix B). As the participant recruitment was sourced from voluntary organisations, NHS Ethical approval was not needed and therefore NHS ethical approval was not sought. This is because if participants do not enter the study through NHS routes then NHS REC review is not required (National Research Ethics Committee 2009).

3.6.1 Consent

Each participant with provided with a consent form (Appendix C) which they were asked to sign to ascertain agreement in their participation in the research study. Participants were encouraged to ask any questions they may have regarding the study, prior to completing the interview. This was to ensure a transparent process regarding participants understanding of what they were consenting to and to ensure clarity. Participants agreed that they had been told the purpose of the study and stated that they would be willing to participate. All details of the study were provided in the information sheet (Appendix D) outlining the aims and participation requirements, prior to requesting consent. The consent given also included consenting to the writing up and submission of the research study to be submitted to University of

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[5] Communication for the centre of narrative research at UEL has suggested that joint and familial narratives are *only now* being considered given the complicated nature of how to approach and analyse, hence why the focus for the present study has been on individual stories with focus on justifying the inclusion of the one joint narrative.

Hertfordshire as part of a formal submission for the Doctorate in Clinical Psychology qualification.

3.6.2 Confidentiality

Participants were each informed that the information collected from the interviews would be anonymous and confidential. This information was provided both verbally and within the information sheet. Any names, ages or places identified within the interviews were anonymised or omitted. Following the interviews the data was coded (e.g. 1, 2, and 3) and saved in password protected documents that could be accessed only by me. Hard copies of interview notes and consent forms were stored in a locked cabinet, to further ensure confidentiality.

3.6.3 Withdrawal

The information sheet clearly stated that participants were able to choose if they wanted to participate in the study. They were also informed that they could withdraw from the study at any time without needing to provide any form of explanation and without any repercussions. It was also stated that if following the interview they decided to withdraw their data, they could make contact to arrange this.

3.6.4 De-Briefing

Each participant was de-briefed after the interview process with the purpose and aims of the research summarised verbally and the de-brief form (Appendix E) provided. Each participant was asked how they felt following completion of the study and encouraged to ask any questions or raise any queries they may have regarding their participation in the research and were invited to provide any feedback on the interview process. They were also encouraged to utilise the contact details provided on the de-brief form, if they felt that following the interview they had additional questions. Details were provided of an independent charity that they could contact if they chose to. Sammut-Scerri, Abela & Vetere (2012) note the importance of the de-brief procedure for all participants, considering that sensitive and difficult emotions can arise from discussing personal information.

3.6.5 Risk Management and Avoidance of Harm

As I was meeting with participants in their home, a risk management plan was put into place regarding managing my own personal safety. The plan included providing a colleague with details of scheduled interview times and locations and phoning on arrival and departure at each location. The lone worker policy issued by the University of Hertfordshire (CRIPACC) was referred to in considering this process.

The emotional impact of sensitive interviews on both the researcher and the participants is a concern that has been increasingly recognised within qualitative research (McCosker, Barnard, & Gerber, 2001). I therefore managed my own emotional responses to the research process, by having a support network inclusive of my research supervisor and colleagues that were contactable should the need arise. As the interviews could potentially cause distress to parents as they are re-telling their experiences which may have been difficult for them, each participant was reassured that they would be able to terminate or pause the interview at any stage if desired. Signs of distress were monitored by me and I utilised my clinical skills to attend and respond to any demonstration of upset identified within the participants.

3.7 Service-User Involvement: Focus Group

Following ethical approval I attended one of the voluntary support groups to hold a focus group. It was advertised in the group newsletter that I would be present and group members were invited to attend. The focus group was held for 1 hour and the aim of the group was to elicit areas that individuals felt would be helpful to share in storying their experiences, in order to refine the research approach.

I aimed to obtain service user led questions. It was explained to the group that their responses would be used to guide the questions for the semi-structured interview, to enable the interview to capture and allow opportunities for participants to share their story without feeling that key questions were missed. This decision was informed by the Guidance for Good Practice: service-user involvement in the UK Mental Health Research Network (Faulkner 2005) that recognises the benefits of involving service users in research as a collaborative process. This design feature was utilised as I did not want to impose ‘expert’ outsider questions on the participants, but wanted to be led by what group participants felt were important areas to tap into for stories.

There were 25 people at the focus group, including males and females, parents and siblings and the overall aims of the research were explained to the group.

Participants were asked to discuss as a group what areas they may want to share, if they were storying their experiences as a parent or carer. I then asked them the following questions:

- What questions would be important to ask a participant taking part in this research about their experience?
- What could be the benefits of this piece of research?

3.7.1 Reflections of the Focus Group

Following the focus group, a basic thematic analysis was completed in order to inform the semi-structured questionnaire. Common themes were identified within the group discussions. These included questions regarding experiences of support that has been offered by family/friends and professionals, as individuals felt that support at the different levels could be key to each person’s story. It was also identified that transition periods and diagnoses would be important areas to ask about.

Kitzinger (1995) highlights that focus groups enable group discussion, which can encourage participants to use their own choice of vocabulary to communicate issues of importance, fundamentally generating their own questions as they pursue their own priorities. As a narrative study this was important, as even at the pre-interview stage individuals' stories influenced the types of questions that were included. The focus group also provided the benefit of having some contributions of narratives by individuals who would not necessarily choose to participate in one to one interviews. Yet as a group they participated in revealing some of the dominant narratives that were felt within the group, such as feeling 'judged' or 'criticised' in their role, as a parent or carer of an adult with an ASD[6]. They noted the opportunity to discuss those would be a helpful within the interview which shaped the questions in the interview regarding identifying sources of helpful or unhelpful support.

Following the focus group, participants were given information sheets and it was explained that an e-mail with my contact details would be circulated by the group facilitator, with further information about how to participate in the research study.

3.8 Development of the Semi-Structured Interview

The semi-structured Interview (Appendix F) had a total of 13 questions, which were divided into four sections. The questions were regarding the parent's role, the relationships in their life, current and past support and finally thoughts about the future. These were selected following on from the focus group and as acknowledgement that different topics and probes for each can be helpful in eliciting narratives from individuals (Riessman 1993). A semi-structured interview method was chosen as it was considered an effective way to potentially scaffold the emergence of difficult stories, which is consistent with co-constructing stories. It was chosen over alternative methods including an unstructured interview as it was felt that the stories could become impoverished or lack detail, if participants were discussing difficulties and had

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[6] The findings of the focus group have been included within the methodology section as opposed to the results section. This is as they are used to inform the methodological approach of the semi-structured interview, rather than to be used as findings in response to the research questions.

difficulty sharing without the aid of guided questions or prompts (Corbin & Morse 2003).

Although utilising an unstructured interview was considered, Corbin & Morse (2003) highlight that such an interview can come with the risk of a participant divulging information they are not necessarily wanting to share. As parents are being asked to share their story, which may involve sharing personal, intimate aspects of their lives, it was felt that it was important this was promoted in a contained and safe manner, with some structure being placed on the process. It is also noted that in the comfortable atmosphere of their home, information that individuals may usually be more wary about sharing, may be given (Larossa, Bennett & Gelles 1981). Also, it was understood that a semi-structured format would enable the opportunity to include possible follow up questions, as a way of inviting the interviewee to expand on the story being told (Kvale 2007). This is also in line with the positioning of the narrative approach highlighted within this study, which considers narrative as a co-construction between interviewer and interviewee and therefore a more active interviewing style with additional questions is reflected (Squire 2008). This is in contrast to alternative considerations of narrative that may identify the narrative as being completely within the individual and thus would aim to ask very few questions (Mishler 1986).

3.9 Procedure

3.9.1 Pre-Interview Phase:

Following ethical approval, the focus group was carried out and I contacted the group facilitators from the voluntary support groups, requesting they disseminate information about how to become involved in the study. They forwarded an email to the group mailing list, inviting them to make contact with me if they were interested in participating. An information sheet was provided as an email attachment, providing details of the study with my contact information. Nine participants made contact with me. Participants were asked to confirm that they were a parent of an adult child with an HFA/AS and that their adult child did not have an additional diagnosis of a Learning Disability. Two individuals did not meet the inclusion criteria and therefore seven participants made up the sample. Six of the participants were mothers and one participant was a father (with one mother and one father being parents of the same adult child, whom chose to be interviewed together).

All participants were contacted individually and were given the option to either meet at their home or to conduct the interview at university facilities. They were each given the choice of location, because as Wells (2011) highlights, storytelling is responsive to the social locations of the story and that researchers work hard to empower individuals to have control of the stories they tell. Allowing participants to choose the location of their interview was important to enable and support narrative production.

3.9.2 Interview:

Each participant was given an information sheet at the beginning of the interview and asked to sign a consent form. Each interview lasted from one hour (60 minutes) to two hours (120 minutes) and was carried out at the participant's homes with the exception of one mother whom requested we meet at a local community venue, whereby there was a private area appropriate for the interview to be carried out. She explained this was due to feeling that her home would be too noisy and that there would be too many distractions.

3.9.3 Post-Interview

Following the interviews, all participants were de-briefed and a debrief form was given. This is in line with the British Psychological Society's code of ethics (2009) that emphasises the need to ensure that any emotional distress that may have arisen during the interview has decreased.

3.10 Reflective Journal

Etherington (2004) discusses reflexivity within a narrative approach and highlights the active constructing of interpretation that occurs between researchers and participants. A reflective journal was kept by me throughout the data collection. Gilbert (2001) emphasises the use of a fieldwork journal as a way of enabling reflexivity noting that the process encourages a researcher to keep track of theoretical perspectives and of their own assumptions in addition to monitoring emotional reactions. This was utilised to record and capture immediate thoughts and feelings both prior and following completion of each interview[7] based on the understanding that it was important for me to capture my immediate sense of a participant's story. I also documented reflections following the transcription process.

3.11 Accessing Research Findings

The participants were advised that the findings would be written up, depicting the main findings and would be available to view if they chose to. All participants stated that they would like to have access to the findings and were informed that an e-mail would be circulated following the completion of the research, with details regarding how to access them.

Although the summary of findings would be available to participants following completion of the study, the findings during the analysis and interpretation stage were not given to the participants to review. This decision is based on the studies epistemological position that regards the result not as a representation of 'truth', but based on my understanding as the researcher and as a representation of a co-constructed story. In addition, Wells (2001) notes that potentially there are risks when sharing the interpretations with participants whom may feel 'objectified' or 'pathologized' in the process of the re-representation of their story. Riessman (1993) also highlights that as stories are not static, meaning can shift and change as the story is shared and therefore it may not be possible to have a participant affirm the researcher's

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[7] Examples of reflexivity journal are located in Appendix G.

interpretation. Therefore I have taken responsibility of presenting the final analysis acknowledging that it is my perspective of the ‘truth’. However, to avoid any misguided leaps in the analysis process, the results and interpretations were reviewed between me and the research supervisor to corroborate the findings as meaningful and credible.

3.12 Data analysis

3.12.1 Transcription

Each interview was transcribed in line with qualitative research whereby data is transcribed to subsequently be coded and analysed (Poland 1995). Riessman (1993) highlights that in Narrative analysis, it is absolutely essential to tape and transcribe the data, acknowledging however that it is an interpretive practice. The researcher’s views and conceptions will impact on the representation of that transcript. As part of the analysis of the data included considering performative elements, it was felt appropriate to include pauses, ‘umms’ and any other signs of listener participation in the speech, to provide a sense of how the story was being told (Riessman 1993).

In addition, I kept a reflective account of observations made, regarding how the story was told to note any additional nuances, facial expressions that may not be captured on the audio that would further inform that analysis process. Mishler (1991) identified that the complexity or transcribing oral transcriptions can impact significantly on interpretations. Pauses and non-verbal communications present should be monitored and preserved, acknowledging the affect and impact on the interpretation. I transcribed three out of six audio tapes and the remaining three audios were sent to a professional transcription service for a verbatim transcription. The transcription service signed an anonymity agreement prior to the service being utilised (Appendix H).

3.12.2 The Analysis Process

Gehart, Tarragona and Bava (2007) highlight that analysis within narrative research is not an activity that is carried out as a separate activity after data collection. Instead it is a process that occurs throughout the research process. It can be seen as emphasising the co-construction of meaning between researcher and participant. Etherington (2007) suggests that through the process of listening to a participant's story and reading conversations, a researcher is using their personal understanding to take what is said and compare and inquire how the stories can make sense together. Therefore the stories are re-presented in the analysis process, with the researcher's acknowledgement of shaping the dialogue and narrative co-construction. Peller (1987) also suggests that a neutral and objective representation of the world is not possible and that interpretation is continually practiced and is on-going. Therefore the analysis within this research is not seen as a separate entity completed after data collection but instead as a layer of the representation of the research process (Riessman 1993), acknowledging that I as the researcher will tell what the narrative signifies, by editing and reshaping what was told (Behar 1993).

In considering the analysis of the interviews I have drawn upon methods discussed with various researchers (Riessman 1993, 2003, 2005, 2008, Lieblich, Tuval-Mashiach, and Zilber 1998 and Bamberg 2011, Emerson and Frosh 2004). Each transcription was analysed in the same way to allow them to be analysed in equal depth. Initially I listened to each audio twice, whilst reading through the transcript with the aim of completing a quality check and to immerse myself in each interview, re-familiarising myself with the focus and 'feel' of the interview. An example of the complete analysis process for one participant has been included (Appendix I) to assist transparency, along with the participants' transcript[8] (Appendix J).

- *Levels of Analysis*

Each transcript was then read through a total of four times. Mishler, (1991) states that transcriptions of 'the same stretch of talk' can have meaning

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[8] Within the transcription, the voices of the interviewee and interviewer have been placed on separate lines to highlight he co-construction of the narrative and to acknowledge both parts within the interview.

constituted in very different ways. Therefore each reading focused on a different element of the analysis, with the initial reading focusing on obtaining both a global impression and the thematic content of the stories. The second reading focused on the performance of the story, considering how each story was told, with a third reading focusing on the structure and organization of the story. The fourth reading was focused on considering the cultural and social contexts of the stories told and any explicit or implicit references made.

Through the analysis process I looked at integrating an understanding of these aspects of storied telling and although the analysis is presented in a linear format, I moved between stories to identify and group collective storylines.

- *Data Analysed for Content*

Each story was analysed to obtain an overall impression of the narrative as guided by Lieblich et al's (1998) holistic content analysis. This was to inform the research question regarding 'What stories do parents with an adult child with HFA/AS tell?' by getting a feel 'for the life' and allowing the meaning of the text to 'speak' to me as the reader (Lieblich et al 2008). Narrative thematic analysis focuses on themes played out over time and emphasises the content of a story and focusing on 'what' was said. The content of what is said is analysed, based on the understanding that language can provide a route to meaning (Riessman 1993). As I am interested in the meaning making within each parents story, and how they story their role, the content analysis was completed by initially identifying the storylines and themes that are embedded in each individual narrative, as opposed to the chronological sequence of the story. This is because clear chronological accounts were not necessarily given by participants and considering the content as themed storylines, also more helpfully reflects the complexity of the storied lives as fluid representations of their lived experience.

- *Data Analysed for Performance*

Riessman (2005) highlights that storytelling involves a performative component as well. That is, the story-teller is telling a story to an audience and thus attention needs to be paid to *how* that story is told and communicated. Thus, use of language and gesture may act to 'move' an audience and therefore questions that I felt needed to be considered when considering how the parents told their stories included:

How do parents tell their story?

Why did they tell it in that way?

The performance aspect was an important part of the analysis that was chosen to assist in answering the research questions, as part of the analysis is considering the 'story-telling' considering Para-linguistic as well as linguistic means. Bamberg (2011) explains that performative analysis is suited to research that is asking questions about one's identity. As this piece of research enquires as to the stories told by parent and their role which may include their identity as a parent, it was felt that the performative aspects of their storytelling, such as gaze and pauses would be appropriate to consider. Riessman (2003) also notes that performance of a narrative can be viewed as a presentation of 'self', noting how a narrator can involve the listener in 'doing' their identities, as part of their identity construction (Riessman 2005).

- *Data Analysed for Structure*

The data was analysed for the structure, considering the ordering of individuals stories as well as how well it 'hung together', i.e. the narrative coherence observed (Habermas & Bluck 2000). Riessman (1993) recommends beginning with the structure of the narrative, when undertaking the analysis procedure, noting that it avoids any tendency to read a story simply for its content. My understanding is that Riessman does not want researchers to get absorbed within the analysis of content at the expense of other interpretive elements of a narrative, such as performance and context.

However, the natural order for analysis for me personally has been to attend to the content initially, although I have ensured I have moved on to additional areas for analysis including structure.

The analysis for structure involves considering how the narrative is organized. I utilised Leiblich et al's (1998) holistic analysis of form structural approach to consider the structure of the stories. Although some elements of Labov et al's (1982) approach is considered in terms of talking about 'exit' and 'entrance' talks, it was felt that overall Leiblich et al's (1998) holistic approach was more suited to the experience based narratives that were the focus of this study. Labov's (1982) approach was therefore considered less relevant, as mainly focused on an event based structural approach. Leiblich et al (1998) highlight that the identity, perceptions and values of a storyteller can be expressed as much through the structure as the content, noting that the personal construction of the storytellers life experience can be revealed.

- *Data Analysed in Context*

Each narrative was analysed with attention being focused on the social or cultural references made, whether implicitly or explicitly. This level of analysis aimed to explore the research question *'How might stories be shaped and constrained by implicit wider cultural narratives?'* Thus the context is important in considering the setting by which the narrator is operating within and within which their story needs to be interpreted (Riessman 1993). The analysis for context was also informed by Emerson and Frosh's (2004) approach to analysing context, by examining the context in which the stories were created and the social discourses that may be informing the storytelling.

- *Group Level Content and Contextual Analysis*

Etherington (2007) highlights that stories can be analysed across several texts, in addition to being analysed within an individual text. As each individual story was analysed, I was able to consider the stories in relation to each other. Common themes or group stories emerged within the content -

therefore the narratives were pooled together to identify the collective storylines, with both plots and sub-plots being identified collectively.

Polkinghorne (1995) highlighted the benefits of viewing narratives as a collection of stories, acknowledging that it enables differences and similarities of the storied experiences to be noted by the reader. Seidman (1991) also noted that deeper insight and understanding can be gained when viewing stories as a collection rather than as individual stories.

Collective stories were also identified in the analysis of context and therefore the implicit and explicit social and cultural storylines were grouped. This decision was made as it felt fitting to consider and highlight the collective dominant discourses that were integrated into each individual story. Banyard and Milner (1998) also highlight that from a community psychology perspective, focusing on collectives as opposed to individuals, enables the needs of a community to be identified. This is important within the current study as it may helpfully inform what the needs of parents with an adult child with HFA/AS are and how these can be heard and understood.

3.13 Rigour of the Study- Credibility and Validity

Meyrick (2006) highlights that good quality research always ensures that the epistemological position and the theoretical stance is clearly stated in the study. Therefore I have aimed to be transparent with the positioning of this study from a constructionist standpoint. This means that the focus is not on obtaining ‘true’ and ‘correct’ data, but instead considers the validation of data by exploring the *‘trustworthiness’* of the interpretation as opposed to the ‘truth’ (Riessman 1993). To consider trustworthiness, Hammersley (1992) offers a framework in which this can be considered, emphasising that the researchers relationship with ‘truth’ needs to be made explicit, with an additional focus on *relevance* and the contribution of the findings of a study. I have ensured that attention has been given to both areas within the present study.

Polkinghorne (1988) emphasises that narrative research contrasts to the positive paradigm when considering research credibility, as it does not limit itself to formal systems or particular types of rigour, but instead focuses on the linguistic reality of human existence. The '*reliability*' of the study within narrative research is therefore considered in terms of the dependability of the data. This can be measured more helpfully by exploring the *plausibility* of the analysis by use of *reflexivity*[9], which has been considered within this study as an important aspect of attaining transparency. Riessman (2003) highlights that transparency can also be achieved by weaving quotes into interpretations which is demonstrated in the presentation of the results.

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[9] See Appendix G for examples of reflexivity as aided by use of a reflective journal.

4. RESULTS OF NARRATIVE ANALYSIS

4.1 Presentation of the Results

The interviews analysed were predominantly guided by strategies applied by Riessman (1993, 2003, 2005) identified as suited to the analysis of oral narratives of personal experiences. Due to the complexity of the narratives and to deepen understanding of the data, additional adapted strategies were also used (Lieblich et al 1998, Labov 1982 and Emerson & Frosh 2004) as multiple methods allow for a more layered and in-depth appreciation (Smith & Sparkes 2009, Wells, 2011). In addition, Balamoutsou & McLeod (2001) promote the idea of a researcher being able to combine strategies to create a data analysis method that most suits the area of study. Subsequently, I have incorporated a number of levels of analysis from different narrative procedures and sources. This has been done to form a coherent and integrated approach to the analysis. Diagram 1 below illustrates the sequential levels and the sources drawn upon for the narrative analysis (as detailed within the method, section 3.12).

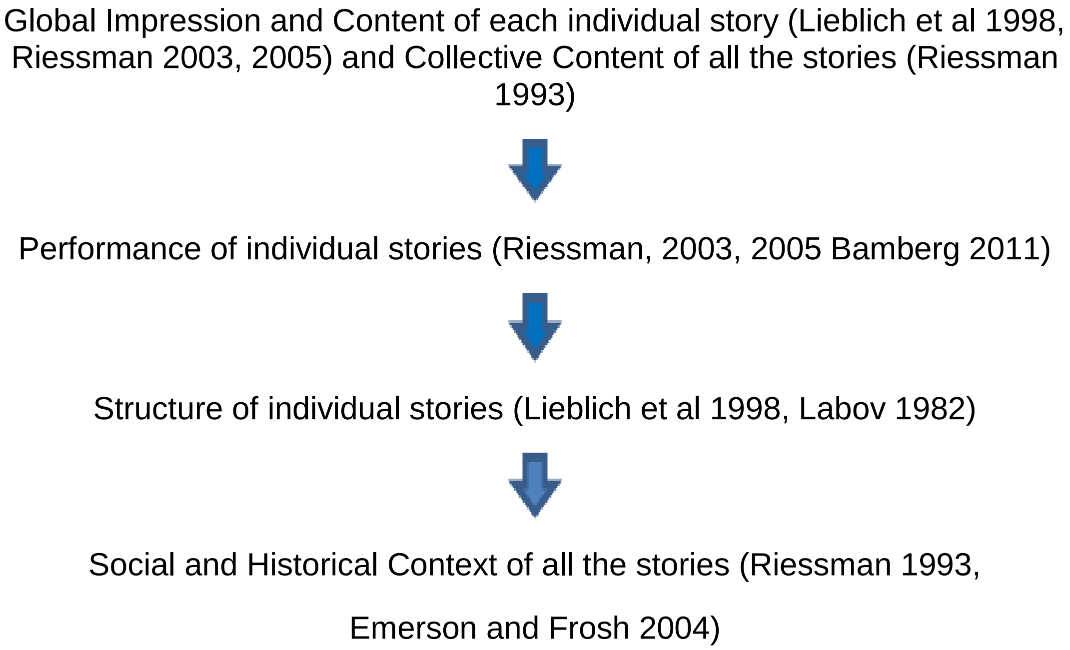

Diagram 1: A flow chart illustrating the levels of narrative analysis conducted and the referenced sources for each level of analysis.

4.2 Considering 'Form'

Both the data analysis and discussions sections have been presented together with an integrative approach. This was considered appropriate as it reflects the narrative position of the research and creates a coherent story for the reader, minimising the possibility of repetition from results across to discussion. The artificial distinction between the results and discussion sections is also in contrast to the study's epistemological position regarding there not being an 'objective' truth that can first be analysed and then discussed. Instead the interpretation of the data is an integrated subjective process that develops through the analysis and is done within a social and cultural context, represented by further linkages to wider discussion points (Wells 2011). Clandinin and Conelly (2000) also make reference to being cautious about prescribing to a specific writing structure within narrative. Thus the integrated and entwined manner by which I have aimed to embed the findings with my understanding of relevant literature and policies, reflects the on-going reflexivity that is present through the process. All participants have been given pseudonyms to ensure anonymity and any identifiable information has been altered throughout.

4.3 Subjectivity

Although the story is understood to be a process of co-construction (Reissman 1993) it does not mean that both the teller and the listener will share the same view (Capps and Ochs 1995). Kvale (2007), highlight that the production of the story is responsive to individual's perspectives and thus the analysis presented does not claim to reflect an absolute truth but instead to consider a 'narrative truth'. Riessman (1993) describes the notion of narrative truth emphasising that truth within a narrative is not about revealing the past, exactly as it was, in an attempt to grasp objectivity. Instead it is viewed as an interpretation which considers the context that has shaped the narrative in addition to the world view that has informed it. In addition Riessman (1993) notes that subjectivity should be considered as an asset within narrative models rather than as a drawback emphasising that it privileges subjectivity and positionality.

4.4 Navigating Through the Stories

The analysis is organized into three parts:

Part 1: The Stories I heard: Initially the interviews are analysed as individual narratives. Six stories are presented; the five individual stories and the sixth joint couple story. Initial global impressions are given for each story as guided by Lieblich et al's (1998) approach reflecting the evolving story as a snap-shot that conveys a sense of how each individual identifies themselves within the story-telling. This presentation of results has been chosen as although there are common themes, each story has differences when considering the structure[10] and performance reflecting the unique story of each participant. Holistic observations have been provided for both the structure and performance elements of the narratives in contrast to utilising more formal techniques to analyse these aspects. This is as although these elements are important, more focus will be given to the collective Plots and Sub-Plots of the narratives later in the analysis.

Part 2: This includes the collective storylines which are presented as 'Plots' with associated 'Sub-Plots'. The group level analysis identified some common experiences and storylines as presented. Additional contrasts from the majority of the other narratives have also been identified, as Creswell (2007) notes the benefits of this when considering a multifaceted interpretation of the meaning of the interview.

Part 3: The Social and Cultural Context of the narratives told are presented in the final part, which considers plotlines that have emerged that highlight the cultural and historical context of the narratives told. Riessman (1993)

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[10] Although the process of 're-storying' (Creswell 2001) was considered, the structure of the participants stories have been analysed in their original form as a holistic structural analysis was used (as guided by Lieblich et al 1998). Thus, as the focus was on the whole story, as presented by the participant, re-structuring the story would not have been appropriate.

highlights that narratives should not be viewed as discrete units with clear structures that are detachable from their surroundings and autonomous from their context. Instead the larger social context needs to form part of the understanding.

4.5 Part 1: The Stories I heard

4.5.1 Story 1 - Eileen[11]

Global Impression

The main experiences that Eileen highlights through her story are examples of feeling blamed or judged by others about her son and her management of her son and subsequent feelings of self-doubt. This included judgement from extended family members, services and her current husband. She describes quite an isolative experience of trying to help her son navigate his way through life with little positivity in her perceptions of trying to access support with few helpful experiences identified. She presents herself as an individual whom is struggling with the demands of her current role and states, *"It's very very difficult. It's like I'm treading on eggshells the whole time"*[12] and explains, *"Yes I am just mentally worn out by him".* Eileen tells the story of feeling quite fragile over the years and describes her struggles in feeling able to cope both historically and more recently. She explains, *"I really feel that I desperately need advice. But I don't know who to turn to for it".* When reflecting on the past she says, *"I think I was really on, on the brink of losing it a bit really"* adding *"And I used to walk around with my arms all folded about and things like that and I [pause*[13]*] I suppose sort of hugging myself really".* Eileen's narrative had a storyline of someone who is fearful of the future as she talks about the future being *"scary"* and stated, *"I wake up in the night worrying about it all".* She presented as an individual who is quite despondent about what potential help others could offer, having described a series of events whereby she has felt

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[11] All results are presented in the 3rd person to clearly demonstrate them as the researcher's interpretations.

[12] Text in quotation marks depicts direct quotes taken from the original transcripts.

[13] Brackets are used to indicate a performance observation and not a spoken word.

re-buffed stating, *“Because we have been rebuffed by social services in the past. I don’t hold out any hopes [pause] I mean [pause] I haven’t even asked them”.*

Performance and Structure of Eileen’s Story

Eileen’s narrative is delivered tentatively. Through her narrative I asked additional prompt questions[14], as there were many pauses and she appeared nervous at times with uncertainty about how much or how little detail to go into. She also describes feeling hot and pauses the interview to open the window, appearing a little anxious. There was the presence of a nervous giggle throughout the narrative, which was often out of keeping with the content; for example, when talking about a difficulty or concern such as, *“Maybe he had a hearing problem [giggles]” and “I might die tomorrow [giggles]”.* Her tone is soft and her delivery of the story is gentle, almost delivered in an apologetic manner. The sense is that she wants to get something personal from the interview, perhaps use the interview as an emotional outlet and she openly explained, *“I’d love someone to talk to”* but the tentativeness may be lack of opportunity to do just that and thus the experience for Eileen appears both novel and anxiety inducing. Eileen’s performance is in contrast to the other narratives in that it felt she was trying less to make communications to a wider audience and that the storytelling for her was about her own personal processing of the experience of being a parent with an adult child with an ASD and appeared unrehearsed.

The structure of Eileen’s story and the course of the development is a rather ‘stable’ narrative with a notable absence of many ‘peaks’ in the story. (A ‘stable’ narrative according to Lieblich et al 1998 is an observed steady plot with no noticeable progression or decline.) She does use some examples to demonstrate reflections of epiphanies early in the narrative and explains, *‘”his behaviour was very different to the other children’s”* and describes a turning point regarding diagnosis stating, *“It was like bling! Light bulb moment…so I*

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[14] See Appendix G (Extract 1) for reflective journal extract related to my role as the researcher in Eileen’s performance.

went to my GP…and I said can you refer me to this place which was Leafy Lodge to have Max diagnosed." However, although she describes feeling *"relief"* the narrative does not go on to progress to 'triumph' whereby the story is perceived as progressing in a positive direction. In fact, several difficult points are then scattered through the narrative for example when she talks about how Max's father committed suicide and also when discussing the uncertainty of the present situation.

Although a clear 'decline' or deterioration in Eileen's experiences is not demonstrated through the structure of the narrative, neither is there a sense of progress, hence the overall 'steady' structure. Lieblich et al (1998) highlights that the structural analysis can be enhanced by the sensitivity of the researcher's perceptions. Thus, as the listener, my evaluative impressions were that there was a steady sense of the storyteller's sadness throughout the narrative. Thus I experienced this story as Eileen communicating that overall she felt that not much had changed significantly for her over time.

4.5.2 Story 2 - Barbara

Global Impression

Throughout her account Barbara portrayed her role as that of a full-time carer. To tell her story, she spoke a lot about the *'battles'* that she has experienced in trying to get her son's needs met and spoke about many active strategies that she utilises to both get things done and to cope on a personal level. Her narrative is purposeful and is explicit in her aims of sharing her story stating, *"I want to turn my negative, the negative impact on my life into something positive, I suppose I'm on a bit of a crusade and a mission, rather arrogantly thinking that I can make a difference so that other people don't have to go through what I go through".* She presents herself as someone who is dutifully trying to communicate her experiences in quite a personally exposing way, talking openly about how her own experiences did not fit with her initial expectations of being a parent and expressing the sadness that comes with that.

Her reports of participating in numerous carers meetings are consistent with her identity of being someone *“on a bit of a crusade”*. I experienced Barbara as very ‘open’ and warm, as she made attempts to connect with me as the researcher[15] and revealed vulnerabilities to her audience. Her narrative also aims to make it clear that these experiences have *changed* her as a person, describing being *“a young woman who travelled the world, went on Concorde, went to Brazil”* to becoming *“totally travel phobic”* and explaining that “*I know that over the years, the impact of my son’s behaviour and needs has actually transposed onto me”*.

Her identity within the story is of someone who is consumed by her son’s needs, explaining, *“And that’s been the story of my life all the way through to try and dig deep, to be resourceful to enable my son to do things for himself.”* The sense is that she is not only talking to myself as the researcher but that she wants to tell the world something about her role and motives, explaining, *‘the reason I think I plough so much, invest so much into what I do with Joe, and with other people, if you like, even with people like yourself, is because I want to try to set, the base on which people will understand what help my son will need throughout his life”.* The implicit message within this may be that she would like other carers to ‘take over’ that role, possibly, so that she is able to ‘let go’ somewhat.

Minister (1991) describes the notion of ‘ghostly stories’ whereby the narrator may be story-telling to not only the listener who is present in the room but also to a wider social audience. It seemed that such ghostly stories were present in Barbara’s story as she delivered her story in a serious and determined manner, perhaps telling her story to potential carers or services that may assist with her son’s needs. Her positioning within her story moves from a position of being an assertive and determined individual to a more vulnerable and sensitive individual, although she feels purposeful in wanting to present

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[15] See Appendix G (Extract 2) for example in reflective journal related to Barbara’s positioning in her narrative.

her varied experiences, in a manner which appears to be somewhat rehearsed and self-confident.

Performance and Structure of Barbara's Story

Barbara uses my name at different points when trying to emphasise aspects of her story, utilising pauses and bringing herself forward to myself as the interviewer when emphasising elements of her story. Riessman (2001) states that much of a person's story can be performed in gesture and action and Barbara delivers her story with moments of intensity perhaps reflecting the emotion attached. Her performative style is 'open', saying *"And I'll tell you some things in a minute that I don't mind you knowing about because I've spoken to my doctor about this and it's an eye-opener for him as well",* perhaps with the intention of really wanting to be heard. She is willing to share personal details of her story in order to communicate the intensity of her experiences and reduces the physical proximity between her and I to bring me further into the story.

As the researcher I demonstrated the positioning of being brought into the story by finishing a sentence of a phrase often heard within the Autism community. As Barbara says, *"People who really know….when you've worked with one person with Autism….*", at which I pre-empted the end of the sentence with …..*"You've worked with one person with Autism!".* This demonstrates my co-construction of the story as the meaning is developed together as I have involved myself in her story. Kelly and Howie (2007) describe the way a story-teller brings the listener on a journey, using the metaphorical concept of a researcher being a 'companion' on that journey. By completing the sentence demonstrates me aligning with Barbara in that journey and responding to Barbara's powerful engagement style in bringing me alongside her. It may be that such engagement tools have been developed as a response to Barbara needing to communicate and persuade others of her sons needs. May (2008) also identifies how people may use narratives to accomplish certain ends in attempts to persuade the listener or audience in some way. Barbara’s performance of her story appears purposeful in attempting to persuade me as the listener of the importance and saliency of her experience. My overt involvement in her story, I felt was prompted by my desire to communicate a sense of understanding, perhaps even reassurance that she is being heard, recognising that this is linked to my own feelings of helplessness when hearing such stories in clinical settings.

The structure of Barbara’s story is that of quite a focused delivery where she responds to questions asked, although is in control of the direction of the narrative. This is in keeping with her identifying that she is familiar with talking to professionals and therefore she demonstrates awareness of wanting to stay on point and explicitly marking going back to aspects of her story if she has deviated, stating, “*but going back to the dependency”* and *“so going back to your questions about professionals”.* She also presents mini-stories when she is attempting to demonstrate a clear example of something and says, *“I can give you a really really hot example’* and “*For example”* … before progressing into a small story[16] clearly wanting to illustrate examples through the narrative. The structure as a whole is one of ‘progression’ with several apparently ‘triumphant’ experiences and ‘victories’ described through the narrative. Progressive narrative trajectory is noted by Lieblich et al (1998) to be one which advances steadily possibly moving from decline to triumph, a structure which Barbara appears to convey. Barbara shifts easily and consistently through topics, although she is clear at which points she wants to emphasise and clarify as salient points, performing with a competence seemingly honed by previous narrative performances in this area.

4.5.3 Story 3 - Jackie

Global Impression

Jackie’s narrative portrayed an impression of someone whom identifies herself as an active and assertive individual in negotiating her experience as a parent.

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[16] Georgakopoulou (2006b) defines small stories as an umbrella-term for ‘snippets’ of talk or ‘telling’s’ that are small in comparison to a ‘grand narrative’ that may feature in a transcript.

Her preferred position appeared to be of someone who is robust and motivated, reporting *"I'm not one to sit and worry, If I need something to be done, I'll battle till I get* it" referring to being in "*battle"* at several points in her story. She makes several references through her narrative regarding her background in the military and being a fundraiser, school-governor, carer-trainer for the county. Riessman (2001) suggests that narrators can position themselves as agentic beings who assume control over events, initiating and causing action. Jackie portrays herself in this way, selecting multiple mini stories to demonstrate this. Her story does not seem to be aimed at evoking sympathy, but rather wanting to be informative and helpful. Her long and lengthy descriptive anecdotes also meant that the emphasis in her narrative was mainly regarding past and historical experiences, with much less descriptive accounts of the present.

She is very keen for me to get a sense of her son and describes him in a positive way, giving the sense that his presentation was never the problem but that it was others responses to it. She wants to communicate his qualities and states *"So he knew virtually all the match results for all the games of the world cup"* and *"well the brightest child in the class, because he never went on to a reading book scheme 'cos he was reading library books way above his age at five".* The general sense of her story is that despite the battles, she was confident in her choices with only very brief moments of vulnerability shown during her narrative when she reflects, *"I'd obviously been very hard on him all these years at school because I just said I'm sorry, you've got to go back*[17]*, there's no two ways about it. Um, and to the point, I mean I have to feel guilty now."*

Performance and Structure of Jackie's Story

Jackie's delivery of the story is in quite a 'matter-of-fact' way, appearing to have somehow distanced herself from the emotional content. She also chose not to have the interview at her home, instead opting for a venue in the

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[17] Jackie is referring to her son "going back" to school.

community, perhaps reflecting an additional attempt to distance herself from the story she is telling or to be able to share her story on ‘neutral-ground’ (Wells 2011). She gives detailed stories of exchanges and interactions she has had with others over time giving great detail in these mini-stories, at times in a seemingly unnecessary way. There is a discrepancy in the manner of the story told whereby the delivery is quite light-hearted with frequent giggles and smiling, despite emotive content. She says *“And he was in a right old state by then, I felt he was suicidal cos he quite often said oh what’s the point, I think I’ll throw myself on the railway line, you know, we had talk”* and this is introduced in the same tone and manner as she discusses other elements of the story. The humour is perhaps integrated with a sense of not wanting to deliver a ‘woe is me’ story, but feeling people are more likely to pay attention, if the story is interesting or entertaining. As the listener however, I felt the style distanced me from the story too, feeling unable to connect with her story, which was perhaps reflected in my limited use of prompt questions, possibly indicating an implicit withdrawal.

Jackie constructs her story in a sequential manner utilising a variety of anecdotes and mini-stories to explain various points of her journey. She is keen to start right from the beginning of the story and begins with *“Right, well Chris was born in 1982”* and *“I knew from almost day one he was not on my planet”.* My first question of the interview regarding her current level of contact with her son is not really acknowledged, perhaps feeling it is more relevant for her to start at a point she feels is relevant[18]. Riessman (1993) points out that a story-teller can experience a fundamental problem as they try to convince a listener who was not there that they feel something important has happened. Therefore, Jackie may choose how to most effectively

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[18] By looking over the transcript, I later became aware that I had fallen into a pattern of responding to Jackie’s chronological narrative by asking “And then what happened?” which felt in line with Jackie’s narrative flow. Riessman (2001) highlights the western pre-occupation with time marching forward and asking “And then what happened?” stating that the temporal ordering of a plot is most familiar in response to this. Therefore, as I listened to Jackie’s story, it may be that I slipped into this pattern of responding.

communicate this by starting at a point she feels will best demonstrate this and her strong metaphorical opener reflects that.

She presents a sequence of further small stories with many appearing to demonstrate the various attempts and battles that she has made as a parent to communicate to others what support her son may need saying, "*I'd been pushing all along…..I kept going to our doctor"* and *"I pushed every limit at school"* and *"well that was our next hurdle really".* Jackie also presents her story with an element of humour at various points with giggles and smiles as she recalls events in a reminiscent way. This is carried throughout her story explaining, *"and she roared with laughter"*, whilst discussing one of her attempts to communicate with the secretary about her son's assessment. She also cites at the end "*True entertainment, our household"* positioning herself as an individual who brings a 'light-hearted' attitude to her circumstances.

Labov (1997) discusses the evaluation element of the structure and explains that a storyteller may make a comparison of what happened and what may have happened. Using Labov's terminology therefore, it appeared that Jackie adopted an external evaluation as through her story she would stop the action and step outside it in order to evaluate it. For example, talking about her son's mood she says *"we'd got to that point, very tearful, wouldn't go out, didn't want to know people. So I always felt that there was, you know, he was heading that way rather fast"* and then evaluates it with *"well I couldn't do much about it, I just, you just have to gee him along".* She appears to make meaning within this evaluation about perhaps feeling powerless despite her active stance.

4.5.4 Story 4 - Tanya

Global Impression

Tanya's narrative was delivered with a real sense of wanting to share the changes that have occurred in her experiences over time. Initially she begins talking about difficult experiences and very briefly attempts to communicate this with quite emotively charged words stating *"It was quite horrendous"* and *“intense really”.* Although the tone is generally that of an optimistic person, she tells her story with a sense of vulnerability perhaps wanting to be clear about the investment that she has in her son’s life. She talks only about herself in relation to her son rather than giving any sense of her own identity separate from that, except when specifically asked. Through her narrative Tanya was clear regarding what aspects she felt had helped and which had not, noting particular key relationships such as her other son and a current social worker.

Tanya presented herself as quite an independent person whom wanted to communicate a level of satisfaction at where she currently is, in terms of her experiences. She appears to be confident in knowing what may be ‘best’ for her son and identified herself as a key agent in orchestrating the current satisfactory position, acknowledging that her ideas had been in great contrast to others initially which she had to overcome.

Performance and Structure of Tanya’s Story

The performative aspects within Tanya’s story were sometimes in contrast to the content of what she was saying. For example, she spoke with some hesitation and tentativeness, despite conveying certainty with strong statements in her story, particularly when she talks about her feelings for her children, stating *“I, I adore my children so much, I’ll do anything to make them happy and to, to give them a good life, do you know what I mean? I’d do anything”.* She is also very clear in identifying herself as a carer stating *“I don’t know, I think I’ve always been a, I think there’s two people in this world, so carers or cared for. And I’ve always been kind of the carer role”*. The performance aspects noted may be suggestive of her wanting to reassure herself that that *is* who she is, despite perhaps having questioned herself at times. She pauses and uses ‘Umm’ frequently, making me wonder if she is considering how to communicate each aspect of her story, perhaps wanting to be clear and articulate rather than ‘rush in’. However, as a listener, I experienced the pauses and utterance as possible underlying self-doubt.

Tanya presented her story initially in almost a bullet point format, perhaps reflecting that she was unclear where to start explaining, *"yeah, I mean it's a very long story, been through horrendous thing"*. She presents some of the experiences as if she is providing 'headlines', in order to give a brief sense of some of the experiences - but does not go into much detail, perhaps as it may be too painful. Jefferson (1979) refers to 'entrance' and 'exit' talks used by participants that may serve to indicate a person's story boundaries, whilst Riessman (1993) highlights that the shape and meaning of a narrative can be altered, dependent on where one may choose to begin and end a narrative. Tanya demonstrated such exit strategies throughout her narrative and appeared more hesitant in going into lengthy stories. For example, when explaining some of her experiences with her son she says, *'And um, he threw bleach in his brother's eyes and all sorts, it was horrendous'* but then swiftly moves on through the narrative saying *"Anyway they then, he was then placed in to supported living complex"*. This could be understood as hesitancy in accessing painful memories and as a way of maintaining a sense of control and independence within her story.

4.5.5 Story 5 - Angela

Global Impression

Angela spoke about her relationship with both of her sons as both have a diagnosis of AS. Her story was a reflective one, whereby she made several references to how she had made sense of her son's difficulties over time, stating *"I think we quickly came to the conclusion that they are just different and difference is not a bad thing"* and *"I wouldn't ask for them to be cured because their Autism defines who they are".* There was a real sense that she had reached a stage of acceptance with her situation and spoke candidly about feeling *"It's almost a bereavement process to start, you know. Once you, you know, you know, your aspirations for that child have disappeared, long* gone". As she was talking about two sons, there were some contradictions within her narrative as there was the weaving together of stories and experiences in relation to them both. At times she would talk about progress as slowing down as she says *“He grew this real good social life with lots of people in it, and that’s gradually whittled down and whittled down and whittled down, he’s not been able to sustain those’* and *“I don’t think he’s as fixed as he used to be”* when talking about her son John but then later spoke about feeling progress and pride saying “*actually as the years have gone by he’s developed some skills where he is quite able”.*

Her story was scattered with ‘messages’ that she felt were important for others to know, particularly in relation to services, whereby she spoke about being unhelpfully rejected as a parent because her son was an adult, explaining, *“I just thought this is really difficult when you won’t speak to me as a parent’* and *“You know, coz I was trying to say look, you know, I can help you if you tell me, you know”.* Her identity through the story is firmly as one of a carer explaining, *“I’ve been a carer so long I don’t know what the real world looks like”.* She identifies herself in this role at various points explaining, “*As parents we sometimes don’t realise we’re carers”* highlighting the enmeshed shift from the narrative identity[19] of a parent to a carer-parent.

Performance and Structure of Angela’s Story

Angela becomes tearful when she talks about her other son’s life stating, *“He’s got his own family now, he’s married, he’s got a daughter, um, he shouldn’t need to pick up the responsibility for his brothers”.* The tearfulness emerges when she is reflecting on the impact on her relationship with her son without ASD. The tears communicated sorrow and sadness and an overall sense of loss, which is present throughout the narrative. Although she communicates a sense of acceptance, her story is delivered with scattered smiles towards me, almost feeling that she aims to reassure me that she is

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[19] Narrative Identity can be defined as how an individual forms an identity by developing an evolving story of the self which integrates their life experiences. This identity may then serve to provide an individual with a sense of purpose in life. (McAdams 2001).

'okay'[20]. She also addresses me directly, and although she chose to sit slightly away from me on a different sofa she uses eye contact purposefully to bring me into her story.

Angela's story mostly involved narrating the present and the future, as well as more general reflective and evaluative comments through her story. She begins her narrative in the present and the structure may reflect the acceptance that she has regarding the past struggles, communicating the impression that she is investing her energy into the present and future, making reference to this by saying *"I want my boys to be happy"* and shares the most 'up to date information'. This structure perhaps reflects her desire to think ahead rather than in the past although clearly she has spent some time reflecting on past events stating, *"I suppose if I dwelled on it I would feel guilty and, but I know that the situation at the time was what it was".*

4.5.6 Story 6 - Carol and Bill

Global Impression

Carol and Bill chose to share their narrative together. Although perhaps intending to present a unified story, Carol and Bill's narratives were dissenting. However, as I have adopted a co-constructionist stance throughout the analysis, I am aware that within their joint interview I will have focused on particular aspects of the analysis, given my own construing. This is recognised in line with my epistemological view that all narratives are co-constructed. Bill's identity was most prominent in the narrative, identifying and making strong statements about his role as a parent stating *"I've been very protective"* and stating, *"I had to push very hard; I'm an aggressive sort of person".* He offers examples of his role in regards to meetings with various professionals and his approach stating, *"I'm all puffed up, here we go again*

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[20] Bamberg (2004) highlights that analysing narratives in interaction involves considering how expressions are put to use, as opposed to speculating about the mental process that the interaction may reflect. Therefore careful consideration has been given to noting interactions and how they felt to me they were being used, rather than assuming an interpretation. See Appendix G (Extract 3) for an example in my reflective journal related to negotiating this process.

but 'cause I felt you have to….All I am, that's me". He also presents himself as having control over various aspects of his sons care over time and states, *"No, he had to be sectioned, I sectioned him"* and when talking about his son's care co-ordinator he explains; *"The latest one, he's been replaced, 'cause I've replaced him. Cause I've replaced him, instrumental, believe it"* identifying having a sense of agency in his sons care.

Bill mentions many individuals by name that he has had contact with in relation to his son, which further reflects his level of involvement in his care. Bill identifies himself as an active and very assertive father whom has a direct approach and explains *"But that's alright, just makes you work harder, makes you more aggressive"* in relation to his feelings of being brushed off by services. When I asked whether he feels he will always have a very active role in his son's future he responds saying *"As long as we breathe"* portraying the level of commitment he feels towards his son and wanting to communicate this to me by leaving no element of doubt. Overall, Bill asserts an on-going unchanging attitude across time; keen to communicate that he continues to be completely focused and committed about getting his sons needs met.

Carol's identity is presented with less clarity in a more fluid and changing way as she appears more reflective regarding her parenting role. She talks about various attempts and struggles with services which are scattered throughout the narrative but says *"I did feel as if I'd stepped back and in some ways I shouldn't have done"*" when talking about her involvement in her son's care but then later reports *"I was quite glad to step back a bit, quite honestly. I just couldn't do it anymore"*. She explains her role as changing over time, with her story shaped as more of a narrative arc, which is in contrast to her husband's positioning, where he appears fixed in his position. She reflects on the changing role stating, *"You get to the point where you just can't, you can't do it anymore, you just can't, you know, you've spent all these years, like so many mothers, dragging your son around to various things, saying, look, look, he's ill, you know, do something."* Despite different narratives, the sense is that each parent is working to their strengths and that they support one another.

Performance and Structure of Carol and Bill's Story

Bill is clear in wanting to communicate his assertive and dominant manner and his delivery of the story seems to communicate a 'no nonsense' approach. Bill's performance of his story includes gestures such as banging on the table and pointing on the table often - when he is attempting to accentuate a point. He is clear about his preferred interactional style explaining *"Don't give me no bullshit"* regarding professional meetings. As a listener I could hear his frustrations, although was aware that my own experiences of being that professional in the room evoked some defensiveness in me, feeling that at times you are not able to give a family answers that they want to hear. I was mindful however of not overtly allowing my defensiveness to enter the co-construction of the story, avoiding a verbal response. Carol's performance was more gentle and hesitant with a lot of 'um's' and 'errs', although she chose to begin the joint story with Bill often finishing sentences for her. She delivers the narrative as though contemplating some of her decisions, often looking up at the ceiling in a 'wondering' manner.

As there were two stories intertwined the overall narrative at times was quite disjointed with Bill predominantly vying to position his story as the dominant received narrative. However, Carol appeared to still persevere with her story which resulted in the narrative being difficult to follow at times as they over-lap speech. Both attempted to deliver their experience in a chronological manner, although they would also hesitate and break the narrative flow as they attempt to recall names and dates. Bill attempts to navigate the direction of the story, clearly explaining to his wife if he feels the story is going in a direction he does not want, instructing her to *"Get to the point when he had to be schooled"* and *"you've missed a big bit Carol".* Bill also demonstrated attempts to fore-close storylines, ending them before they developed. For example, when Carol is talking about the impact of their son's behaviour on his brother, Bill says, "*Just. Just stick to Liam".* The structure is being dictated by Bill in this instance as he attempts to move away from difficult discussion regarding his other son's suicide.

Lieblich et al (1998) note that differences may be present in the way men and women construct narratives, suggesting that more clearly defined plots are devised by men, who conform to a ‘good story’. Bruner (1991) defines a ‘good story’ as one with an on-going plot, clear objective and sequence and causality to events. In contrast, Gergen (1992) suggests that women may deviate from the norm, constructing the story along multiple dimensions. Such differences were observed within these parents joint narrative. Bill’s construction appeared more deliberate and focused, with Carol deviating as the narrative progressed as she questioned and reflected on aspects of her story, in the moment.

4.6 Powerful use of Performance

There was variation in each participant’s performances that enabled the stories to be shared in different ways and indicated each participant’s positioning within their story *and* their relationship with their story. This was despite the similarities in content across each person’s narrative. Barbara used the performance of the story to engage with emphasis and drama. Her relationship with her story appeared more ‘certain’, as if she had told and delivered the story many times. Although her gestures, tone and intense delivery still meant that the story was delivered with passion despite repeated delivery. Eileen in contrast delivered a much gentler performance, using pauses and giggles. Her performance conveyed uncertainty and her relationship with her story appeared more ‘raw’ and vulnerable. However, both participants actually described several similar experiences, particularly regarding feeling blamed by others highlighting the significance in understanding the purpose of each person’s storytelling.

The differences in performances despite similarities in the content, may be due to each person’s performative rationale. Eileen’s performance appeared designed to expose how fragile she may feel, perhaps as a response to the battles that she has been exposed to over time. Her performance aimed to connect on an individual level and having a single person understand her story appeared to be enough of a purpose. In contrast, Angela’s delivery was powerful in appearing to deliver social messages to a wider audience other than just me as the listener. However Angela’s narrative was still delivered with some emotional fragility which served to emphasise and strengthen those social messages.

4.6 Collective Storylines (Plots and Sub-Plots)

Despite individual variations in narratives, collective storylines were present. The main storylines that were identified through the group level analysis have been presented below. Through each narrative, key times such as diagnosis, transition and the future have been integrated into the storylines and thus are reflected within the identified Plots. I have demonstrated the over-lapping nature of the Sub-Plots with the main Plot and also the links between Sub-Plots in diagrammatic form[21]. Braun and Clarke (2006) recommend the use of visual diagrams to produce a ‘thematic map’ enabling the drawing together of themes. Although they refer to this within the context of Thematic Analysis, it was felt that utilising a visual form of the Plots and Sub-Plots would aid the reader and demonstrate the overlapping and fluid nature and relationship between Sub-Plots. Diagram 2 below demonstrates the three main plots identified with the analysis, each with three additional Sub-Plots. The diagram below lays out all the Plots and Sub-Plots to allow for them to be viewed in their entirety, as an overview. Each plot will be discussed individually.

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[21] Arrows have been used to indicate movement between sub-plots as some of the sub-plots were linked to each other and not stand alone, thus representing the fluidity within narratives.

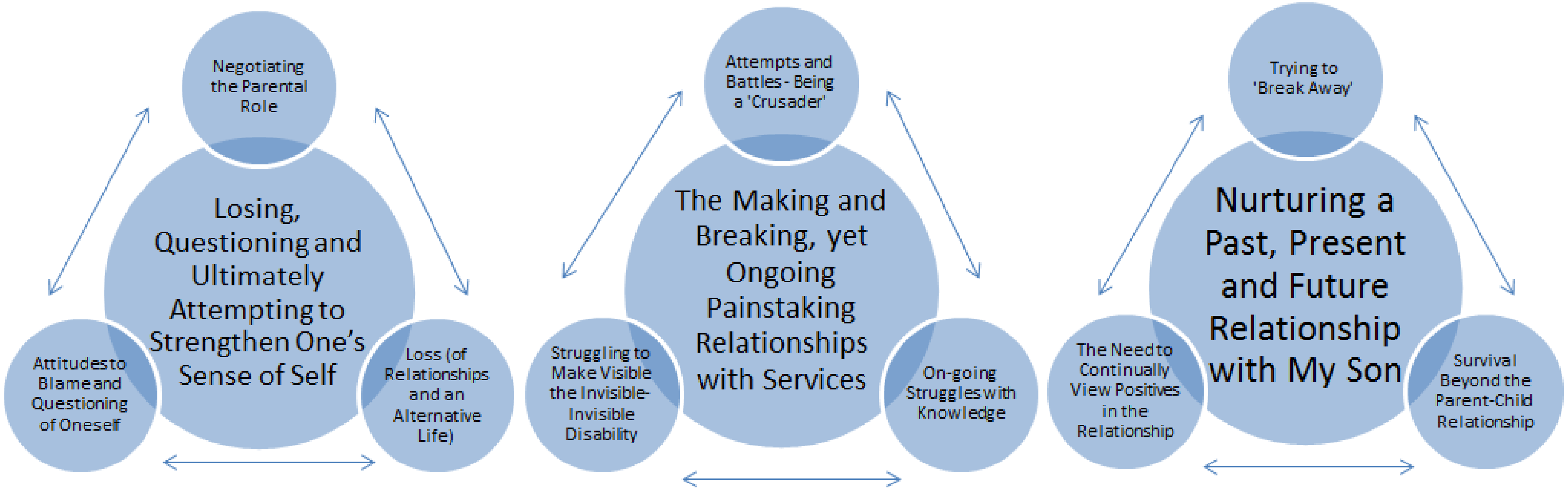

Diagram 2: The three Plots and associated Sub-Plots identified within the narratives of parents who have an adult child with HFA/AS

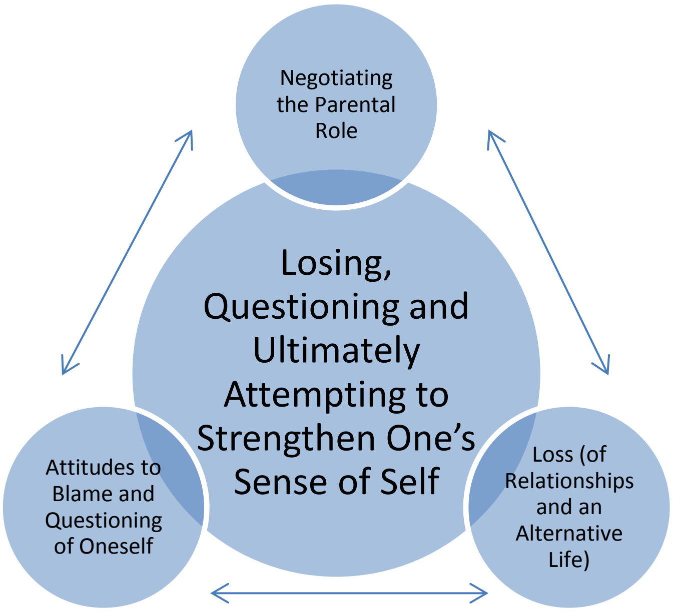

Diagram 3: The Plot of 'Losing, Questioning and Ultimately Attempting to Strengthen One's Sense of Self' with recognised Sub-Plots within the narratives.

4.6.1 Plot 1- 'Losing, Questioning and Ultimately Attempting to Strengthen One's Sense of Self'

Sub-Plot 1: Negotiating the Parental Role

The role of the parent for an individual who has an adult child with ASD can differ significantly when compared to those with a child without ASD. Seltzer et al (2001) highlight the impact on families as they struggle to maintain positive family relationships, experience social isolation and make attempts to manage their child with ASD. Within the narratives all of the participants spoke about their sons' ASD impacting on them as a person and on their parental role. Angela, Tanya and Barbara all explicitly defined and identified themselves as carers. Angela makes several references through her story about the transition of changing from a parent to a carer for her son stating, *"As parents we sometimes don't realise we're carers"* later adding *"I've been a carer so long I don't know what the real world looks like"*. She also reports

"Um I think we become carers without realising it", which highlights the additional responsibilities that go above and beyond the role that may be expected when a child becomes an adult. This highlights a change in the identified role within the parent over time albeit it may occur in a subtle way.

Taylor & Seltzer (2010) report that when a child leaves education the role of the mother with a child with ASD continues, as they are the main source of support with increasing responsibility for service coordination, in addition to the normative challenges of parenting a child through the transition to adulthood. Tanya, Jackie and Angela spoke about the transition phase and support as being *"non-existent"* and *"awful"*. Fussel and Furstenburg (2005) highlight that for typically developing adolescents events such as leaving the family home, finding a job, getting married and having children may be aims in the transition to adulthood. However, the results of the current research suggest that the parental role involves alternative challenges when compared to a parent of a typically developing child as natural progressive steps for example, transferring to college or increasing independent social activities for an individual with ASD can be problematic (Howlin, Goode, Hutton & Rutter, 2004). The contrasting tension in storylines can be seen in both Angela and Tanya's stories who both have independent sons as well as a son with AS.

Both Barbara and Jackie utilised metaphors within their narratives to describe their role. Barbara uses several metaphors explaining *"I am the background hub of his computer. Do you know what I mean, it's like you know, like when you press the button to search on google"*. She also explained, "*If you like, I'm the stage hands in the wings so that he can be front of stage in his own life. That's how I see my role I, I am…..sounds a bit naff but I am like the wind beneath his wings so that he can fly".* Broderick & Ne'eman (2008) state that metaphorical representations are important in claiming control over a narrative and notes that within discussions about individuals with ASD they can generally be seen as off-stage characters referred to with great passion but not fit to offer any lines. Interestingly, Barbara places her son at centre stage within her narrative although the use of the metaphor is still used as a powerful representation as she portrays her identity as subsumed within her son's ASD.

Carol, Angela, Jackie, Barbara and Tanya all identified changes in their role over time. Five of the narratives suggested that the role had changed in a more helpful way as they moved towards helping their son's become more independent. Tanya explained, *"I feel that, you know, we still have a crisis, a crisis probably once a month, big crisis, but then I know I can deal with it"*. Barbara also stated, *'There is a really big difference because that (my role[22]) has evolved over time. That for me has been the step back from his total dependence upon me. We have moved through the total dependence".* Angela reported, *"It's much easier now they're adult's really*" and says *"I think, I think it's changed in the last two years.[23] Um and the reason I say that is that's when the outreach workers have become involved".* Seltzer et al (2001) highlight that parenting an adult with ASD brings different parental challenges than those faced when their son or daughter was a child or adolescent with an ASD. They identify differences in early concerns that may be more focused on managing the overwhelming needs of their child with later parental concerns focused more on securing services and community acceptance issues. There is also some evidence that symptoms of ASD to some extent, may perhaps abate somewhat over time (Seltzer, Krauss, Shattuck, Orsmond, Swe & Lord, 2003), which may inform why the role may change for parents. However, the role change may also reflect the development of additional support systems as Jackie highlights, *"Well I feel even now I'm not doing as much as I did, coz I don't have to battle for services because there are more services out there".* Tanya also acknowledged her role had recently adjusted since she shares the main care duties with her other adult son and stated *"So I'm starting to live, but it's only in the last two years that I've felt I'm starting to live again."*

Nevertheless, it is important to note that Eileen's narrative contrasted somewhat to this as she explained, *"He really relies on me being there".*

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[22] Word inserted to enable sentence to be understood.
[23] Angela is referring to her role within this quotation.

However, Eileen's son is the only adult child in the study whom is not currently receiving any additional support or services from anyone other than Eileen and therefore her narrative is likely to reflect this position. Such a contrast highlights the need to hear stories of parents whom have *'battled'* to get support but not had such successes and may feel unable to make wanted changes to their role as a parent as their children become older. This is clinically relevant in terms of identifying families that are in communities that services are not reaching and how can they be more accessible to people. It is also important to acknowledge that the narratives that had reported positive changes may reflect that the services being offered are improving, in line with recent government and social policies that have aimed to improve service provisions.

Sub-Plot 2: Loss (of Relationships and an Alternative Life)

Tanya spoke about a change in relationships with others and explained *"We had many rifts, we didn't… we became quite an isolated family. We were very isolated".* The Sub-Plot of the change in sociality through Tanya's narrative was about feeling a sense of loss as she explained *"I miss the social side of work [pause] I'm disappointed that I'm not able to work".* Hare et al (2004) completed research looking at the needs of family members supporting adults with an ASD. The findings noted the restricted lives that the parents reported, referencing the impact on their relationships with others and on their own activities. Barbara spoke overtly about minimising contact and states:

"*This is one of the fall outs of being a carer. It's part of limiting yourself, making excuses as to why you can't do something. I'm so good at trying to make ways for Joe to do stuff and I'm not very good at making excuses for myself not to do stuff. Perhaps it's because I haven't got the emotional energy to do both."*

This demonstrated a link between Sub-Plots whereby the parental role being merged as a 'carer role' has extended onwards to loss and changes in sociality[24]. The sense of loss observed in Tanya's and Barbara's narratives was also displayed within Angela's as when asked about her relationship with others she stated; *"Well the friends bit…long gone".* Eileen also noted the forfeiting of social activities and loss of other roles as a consequence of her son's ASD explaining, *"Me and my husband are both keen folk dancers. So there have been times when I've thought we might have gone along to folk weekends but then it was really too difficult to think about with Max".* Research that has focused and explored stress levels and coping strategies of parents with an adult child with ASD (Smith et al 2012) highlight that parents' being able to access social support is an important aspect of their own mental well-being. Smith et al's (2012) study focused on the social support and well-being linkages later in the life course identifying that as the individuals with ASD become adults, there are relatively few formal services that continue to be available for families.

The limitations on the parents' lives and relationships is a persistent storyline that arose in the storied experiences of these parents. In addition, the impact on their relationship with other children, suggested a sense of loss whereby Angela, Tanya, Carol and Bill all felt their relationships with their other children had been different as a consequence. For example, Angela talks about her other son and states, *"I think he would probably say that he did feel at times he got pushed out. But he, But I suppose because he could manage, we let him manage*. *But I think, I think as a child he didn't get probably everything he should have done".* Tanya also reflected on her relationship with her other son and stated, *"I think I've relied on him not as a son, more of um, another adult male to help me."* And later adds, *"We do have a mother son relationship but it's more like I rely on him. And I think he's missed out maybe on some of his childhood because of that".* This is consistent with research that suggests mothers often recognise siblings as a source of support when caring for a family member with ASD (Orsmond and Seltzer 2007). Both Barbara and Eileen also made reference to their son's being an only child linking to the loss

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[24] The link between Sub-Plots has been demonstrated within Diagram 3 with an arrow showing the movement between Sub-Plots.

of a larger family as Eileen states, "*I mean I regret that I never had any other* children" adding *"And I did imagine getting married and having a few children. But I found Max such hard work".* When asked if she felt this may have been different if Max had not been her first child she replied, *"Oh yes, I do think so. Yeah".*

Sub-Plot 3: Attitudes to 'Blame' and Questioning of Oneself.

All six of the narratives described feeling a sense of blame at various points during their narrative with the need to demonstrate or prove to others that there was a problem. The majority of them indicated this as emerging through the early stages whereby they were originally trying to seek support for their son as a child or adolescent. Barbara explained, *"But I didn't fight because I'm trying to balance being the overprotective overdramatic mother with listening to what the professionals think"* and stated, *"You know, a number of times I've heard from other people. They thought I was being overprotective" and* Angela explained *"Parents will say. I'm told it's my fault. You know that I'm pushy, that I'm this, I'm that, you know".* This is consistent with previous research that suggests parents have felt blamed for their child's behaviour. Hines et al (2001) notes older parents with an adult child with ASD told stories about feeling their sons or daughters behaviours reflected on them as a parent, noting that because there was not an overt physical disability, they felt particularly judged by others. Barbara highlighted that her perceptions of blaming parents have remained over time stating, *"I think that erm, there's still um, an idea that erm, bad parenting is to blame, I still, I still think that's out there".*

Through the narratives there was reference to both feeling blamed by others and placing blame on themselves. *Tanya explained "School teachers assumed it was bad parenting, they didn't even want to think other than that"* but also explained that *"When he was born, um, I've always thought that this might have affected him in some way, I had shingles around my stomach when I was pregnant".* Eileen also storied thoughts of self-blame throughout her narrative explaining, *“And I decided that he had problems because he, I wasn’t the right parent for him and I wasn’t looking after him properly or teaching him properly.”* She also added, *“First of all. I thought it was me….it was my parenting that was at fault. It was difficult, reinforced by family people who you know said things like; she’s got no excuse for him behaving like that.”* Eileen’s story indicated however that her construction of Max’s behaviours as a result of her as a parent has changed over time, demonstrated by referring to these reflections in the past tense.

The aetiology and the ‘cause’ of Autism is an area that some researchers have attended to (Steyaert and DeLa Marche 2005) and the current understanding is that Autism is understood to be a complex neurodevelopmental disorder. However Gray (1995) highlights that parents can be susceptible to developing their own constructions on the aetiology and causes of Autism which can leave them feeling a sense of blame. In addition blame can be attributed to others or put on the objectified Autism, in order to avoid any blame being put on their son or daughter. This could be observed particularly in Jackie’s story whereby she spoke about feeling others did not know how to manage her son, stating *“the staff weren’t supporting him because they don’t understand him”*. In addition within both Angela’s and Barbara’s stories there was a real sense that blame was being focused away from their son’s and at the objectified Autism, with Barbara making reference to *“the silent, the invisible difficulties that he has with certain functions of his brain”* apparently moving away from any conscious notion of blame.

Through the narratives however there was a sense that concerns about stigma and feeling blamed had changed for some of the parents over time, as this sub-plot seemed to dissipate somewhat as the narratives progressed. Gray (2005) explored the concept of stigma for parents whom have children with HFA or AS, highlighting that little attention had been given to this area as the focus has historically been with children who have ASD with intellectual difficulties. He found that mothers were more likely to experience stigma as opposed to fathers. This may be linked to the lingering narratives of historical research that considered Autism to be caused by a lack of maternal warmth (Bettelheim 1967) with residual narratives of the ‘refrigerator mum’ continuing to exist. In addition, Gray (2003) highlights that a women’s identity is more likely to be threatened with mothers more inclined to blame themselves. Interestingly, Bill did not make reference to feeling blamed through his joint story although Carol mentioned this saying, *“They thought it was my fault [pause] as his mother”* perhaps reflecting such gender differences.

Summary of Plot 1

The narratives presented by the participants illustrated shared stories of struggling with their role, particularly noting the overlap between being a parent and a carer. Parents told stories about how their role impacted further on alternative areas of their lives including social, work and other relationships. Some parents noted that over time this had changed as more support sources were available, although predominantly parents described it as an adjustment process with an element of acceptance of loss of an alternative life. Residual narratives regarding a sense of blame and responsibility for their son’s ASD were also heard through the stories, which included feeling blamed by others and also doubting and questioning oneself.

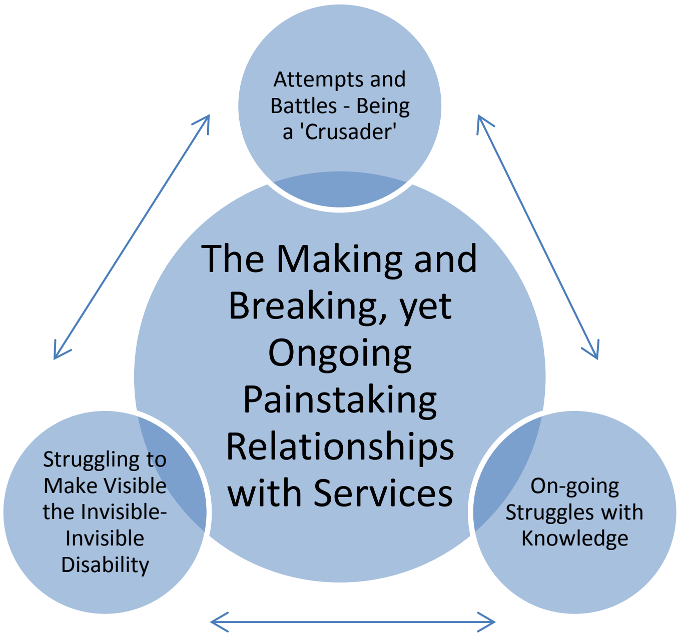

Diagram 4: The Plot of ‘The Making and Breaking, yet Ongoing Painstaking Relationships with Services’

4.6.2 Plot 2 - ‘The Making and Breaking, yet Ongoing Painstaking Relationships with Services’

Sub-plot 1: Attempts and Battles - Being a ‘Crusader’

All of the narrative stories included details of difficulties with accessing helpful and appropriate services to support their son’s. This included educational, health and social care services through childhood and adult years. All of the parents described having to put in formal complaints during their attempts to access support for their son after numerous attempts. Barbara, Tanya, Angela, Jackie and Carol all told stories of *‘battling’* with services. Barbara explained feeling *“no one would support me, the head teacher of the school wouldn’t support me, the speech therapist wouldn’t support me”* when talking about trying to get her son into a more appropriate school. Bill also described having to *“push hard”* for services and he explained, *“Oh we wrote letters galore. We ended up by writing letters to all these people”,* explaining that they would hand deliver them to heads of services, in order to be heard.

McCarthy (2010) published an article whereby she candidly describes her experiences gaining support for her daughter with a diagnosis of AS. The article provocatively entitled ‘Service user vs. Service Provisions’ describes the key areas and attempts of a parent trying to access services for her daughter, many of which are echoed in the narratives of the parents in the current study.

An additional difficulty noted in attempts was related to when their child becomes an adult, as then they are legally identified as an adult, which can bring difficulties. Angela in particular spoke about contact with mental health services and educational services whereby she attempted to help support her son by gaining information about an appointment for the Community Mental Health Team. She described her experience when she phoned and requested to talk to a clinician and reported, *“No she said. They don’t talk to people. They don’t talk to parents”.* She said:

“But I just thought this was really difficult when you won’t talk to me as a parent. You know, I know he’s over 18, I know he’s an adult and he doesn’t know the questions he needs to ask and he won’t ask because he doesn’t want to be there, you know.”

Jackie also reported difficulties when assisting her son with accessing services describing an experience whereby she waited for her son following an appointment with a professional. She explained,

“I didn’t need to go in. But when I said to her when he came out, well what happens now? She turned to him and said can I speak to your mother? And it was the way she said it. Not so much what she said as how she said it. But I said to her I’m only asking what happens next, it’s taken me, you know, 17, 18 years to get this far.”

Within the narratives, all of the parents spoke about some positive experiences with exceptions to overall stories of battling and unsuccessful attempts. Carol was particularly positive and explained positive experiences within the education system stating that their son's school, *'Oh they were brilliant'* and identified certain placements and Doctors that were helpful. Bill explained, "*Doctor Smith*[25] *at Westfield's, she was brilliant; she walked us through the problems".* Reflecting on why these experiences stood out Bill stated that it was, *"Their care and attention, their understanding"* with Carol adding, *"So it's finding someone who knows what they are talking about, that's the main bit".* Tanya spoke about a current social worker working with Luke and stated, *"She doesn't interfere, she doesn't then, but if I ask her she'll do it instantly. Um, and the good thing about her is whenever she (pause), I speak to her, or whenever, she doesn't sort of say instantly about Luke, it's how are you and Chris*[26]*?"* When asked why that was helpful she stated, *"I think it [pause] to me it feels like she really cares. You know, she's really interested in him."* Jackie also described an experience of a social worker helping her son to be accepted into services explaining how he put it into writing to make it more difficult for the rest of the team to dispute it. She stated, *"So there's been some good experiences in that way and, and having staff sometimes being on your side-when the system wasn't".* Further understanding of what constitutes 'helpful and constructive' support is needed to further develop and foster a more helpful approach.[27]

Sub-Plot 2: On-going Struggles with Knowledge

Gray (2002) discusses the unique difficulties that people with HFA can experience particularly in comparison to those with symptoms of Autism that are more profound. This is due to the possible 'invisible' nature of the condition. Lack of recognition and acknowledgement of the condition can lead to poor diagnostic and understanding of the difficulties. Gray and Holden (1992) identified difficulties in obtaining a diagnosis for a child and highlighting that the process can be a long and protracted one. Although this research is

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[25] A pseudonym is used.

[26] A pseudonym used for Tanya's husband.

[27] Hare et al (2004) identified that families had different ideas of what was 'helpful' when accessing services making reference to aspects such as improved day services options, having access to emergency care and higher standard of training for staff to increase understanding of ASD.

now dated, the parents' adult sons in the present research would have been children at this time and thus it is significant when analysing their reports of this experience.

A lack of understanding regarding parents son's needs were storied, starting with challenges at seeking diagnosis, particularly at a time when they themselves as parents were trying to make sense of their child's behaviours. Jackie spoke about her understanding of her failed attempts with trying to get teachers and professionals to understand her concerns explaining *"And I still felt it was just lack of knowledge on people's part. Okay so people not knowing what it could be and lack of knowledge."* Carol also spoke about difficulties with medical staff explaining, *"The first doctor we saw was absolute, he said, oh, Liam needed to get out more and there's nothing wrong with his, err, you know, with his mental health".* Later in their narrative Bill reminisces further about his attitude towards the Doctor stating, *"I remember talking, you are, you do not know what you're talking about".* Jackie described a similar story whereby clinicians did not detect or acknowledge the difficulties, explaining the GP's response as, *"Oh well, it's the pressure of exams cropping up and he'll be all right once he's done his exams and everyone fobbed me off. Nobody wanted to take it any further".*

Jackie spoke about this continuing over time though different service provisions even following diagnosis, reporting that, *"Because we're having, as parents….. we were having to support them. Because the staff were having to learn from us".* She spoke about the lack of knowledge continuing into her son's adult years and living in a specialist care provision, but feeling there was an on-going lack of understanding, saying *"The staff weren't supporting him because they don't understand him".* Barbara also spoke about the lack of knowledge on the part of professionals, continuing to the present day stating *"I think that, and this is still the case. I think that people don't know what they don't know about Autism".* She explained, *"I think that even these so called professionals, who are still debating whether erm these children are just being difficult and manipulative".* When talking about the complexity of her son's difficulties Barbara states, *“But that’s work I put in because I understand how I’m going to achieve success with him. How do you transfer that across to other people who are not thinking outside of their own box, their own traditions?”.* Jackie also felt that even specialist services demonstrated a lack of knowledge stating, *“And they really, for a supposedly Autism specialist college, had absolutely no idea”.* Tanya also made reference to the lack of understanding of the importance of a holistic approach stating, “*I think where professionals are concerned my big gripe is that they, they don’t take on board the whole package of a person. Okay, Luke comes with three other people; he comes with two dogs”*. Acknowledging the system that an individual operates in as opposed to solely an individual is perhaps an area that thus requires greater attention.

Jackie storied an experience of feeling a lack of knowledge by staff about the unique nature of an ASD, which led to an inappropriate placement as she described, *“There was one other lad with Asperger’s and they had wanted the two of them to share on the basis….well they’ve got the same diagnosis, no they haven’t, they are totally different people”.* Barbara also talks about feeling irritated about professionals who may not understand the individual and unique nature of ASD and states, “*That’s the thing and it’s actually people understanding…..there are some common threads”* and later continues with, *“You have to spend time with people like my son to begin to understand what makes him tick”.* This reflects narratives within the Autism community whereby attempts are made to raise awareness of such unique differences between individuals (Wallace et al 2013).

In Carol, Bill’s and Barbara’s narratives they spoke about feeling that the level of knowledge from others had changed over time. Carol stated, *“When we first knew he had Asperger’s, when he was diagnosed, nobody had heard of it at all….’* Carol explained, *“As Liam’s grown up, it’s grown behind him. So now I think a person with Asperger’s in school would be recognised”* with Bill adding, *“A lot quicker”.* Barbara also spoke positively about increased understanding and acknowledgement stating, *“There are changes, there are* *changes. I think that erm Autism and Asperger's is on everybody's lips erm I think that the perception is slowly changing".*

Sub-Plot 3-Struggling to Make Visible the Invisible -Invisible Disability

Grey (2002) highlights that those with HFA are expected to enact a typical adult role and emphasises that "*they are people with a disability who must deal with the social world as if they were not disabled"*. Jackie, Eileen, Tanya, Barbara and Angela spoke about the difficulties in accessing services over time, due to the fact that their sons did not have an additional Learning Disability and that their average or higher IQ scores would often make it difficult to be seen as an individual with difficulties and receive appropriate support. Angela explained, *"I rang Logan council to be told, well he hasn't got Down's Syndrome, he's not got a low IQ and he's not at risk so we're not doing anything."* She also reported that when there were times her son was more settled in his behaviour she thought *"And I think this, again, is why medically, they said oh well look he's alright now*."

Carol and Bill also mentioned that their son's IQ meant that he was considered not suitable for services explaining. "*The Learning Disability Team, who were one of the first people I contacted when he was first ill saying; he's not our problem, his IQ is above whatever it was meant to be".* Taylor & Seltzer (2010) explored changes in Autism behavioural phenotype and concluded that due to insufficient or lack of daytime activities, those individuals with an ASD but without an LD were less likely to have shown an improvement in their behaviour as they transitioned to adulthood. Gray (2003) also noted that parenting a child with HFA/AS may in some ways be more stressful as their child is more aware of their difficulties and may be more 'connected to the real world' as opposed to those with additional profound learning difficulties.

Feeling that the level of difficulty was not visible, in the absence of an additional LD was a storyline that appeared across the narratives. Eileen also explained a memory of a Doctor whom she recalled saying to her, *"Oh well I* *expect you're pleased Max is not like, whoever it was in the waiting room, who was, had quite severe problems…Erm and really put us down you know".* All of the narratives contained examples of the parents feeling that the problems were not being seen or realised by others. Eileen explained, *"Over the years I tried support groups but I just found that it didn't really work because Max was….sometimes people would say to me…oh your son is very bright you know….why are you here sort of thing?!"* Tanya explained *"They thought he was just a wayward teen",* communicating a sense of relief when *"they finally decided to work out what was wrong with him".*

Summary of Plot 2

The plot demonstrated the continuous struggles that have been faced by the parents when attempting to have their son's needs met. A prominent narrative heard included the difficulties in clinicians over-estimating their sons abilities in the absence of a learning disability and the barriers this presented when attempting to access services. Lack of knowledge regarding the unique nature of ASD and the individual differences that exist between individuals with ASD was also present in the stories told. This is in line with previous research suggesting that expectations from others add an additional difficulty for those with ASD and their families (Grey 2002).

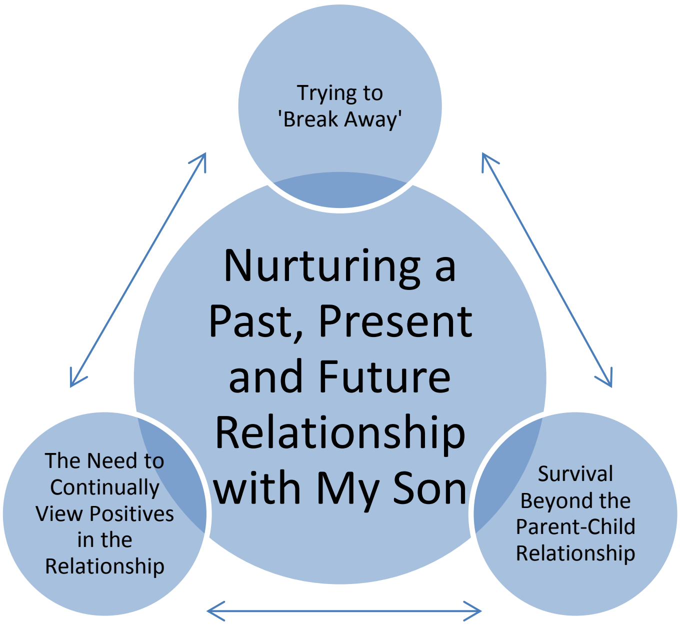

Diagram 5: The Plot of 'Nurturing a Past, Present and Future Relationship with My Son' and the recognised Sub-Plots within the narratives.

4.6.3 Plot 3 - 'Nurturing a Past, Present and Future Relationship with My Son'

Sub-Plot 1: The Need to Continually View Positives in the Relationship

Parents were keen to give praise and highlight positive aspects of their children in addition to the challenges faced. This is in line with a recent survey completed with parents and individuals with Autism across the UK (Wallace et al 2013) in which they highlighted that families wanted to discuss positive aspects. This demonstrates that parents portrayal of their child in a positive light may continue through the stories into adulthood as Fleischmann (2004) also identified positive empowerment of the child narratives, in stories of parents with children with an ASD.

Integrated through the narratives were storylines of skills or talents of the parents' children. Jackie explained her son's younger years stating, *"He started off as really the most bright, well the brightest child in the class, because he never went on to reading book scheme 'cos he was reading library books way above his age at five."* Angela also spoke about her son teaching himself coping strategies before diagnosis in his younger years explaining, *"Um he was able to devise strategies to deal with things that were going on."* Eileen also noted some praising memories of her son as a child stating, *"but he did quite clever things. Yes you see there was a lot more depth to how he really was".* Broderick & Ne'eman (2008) highlight the potential political risks that can influence and direct away from any positive discussion of the spectrum with a cultural fear that it could unhelpfully divert fundraising and policy support away. An existing cultural narrative may be that more negative discussion is a more helpful way of gaining the support and help needed. However, within these parents narratives the positive storylines may represent a conflict within parents whom have a desire to raise awareness and share their experiences of the negative impact but also have a desire as a parent to highlight the positives.

Both Angela and Tanya spoke about their sons making changes and developing skills. Angela explained, "*He is meeting up with people who are empowering him. You know, he's…I think it's great, I'm so proud of him. I really am because I think he's blossomed, um, that's, that's the best way to describe it."* Tanya also explained, *"He's kind of grown to show love, he never could show love. Um, but he'll always cuddle me now". Eileen noted, "Yes, yes a big change. Erm, he's more aware of things going on around him now".*

Sub-Plot 2: Trying to 'Break Away'

A continuing and present storyline amongst all of the narratives was related to attempts to try and make changes to their relationship with their son to foster independence and adjust their parent-child relationship. Eileen explained, *"Yes, sometimes I feel like yes I am doing too much for him and I should get him to do more things on his own and that is a big problem. And it always ends up….it's easier for me to just arrange these things for him….which is not really the best way of doing things".* Jackie spoke about attempts to show some separation as a parent when describing visiting her son's residential placement explaining, *"And they were expecting parents to go up every time* *they wanted a meeting to sort this latest incident out. And in the end I said; is there no advocacy? Because we can't all keep traipsing up, it's expensive".* Tanya explained;

"One of my hopes is that I can get Luke as independent as I can. So that he's not gonna need as much support, 'cos he won't allow support from anyone outside of our little unit. So my hopes are that I can get him independent enough where he's not gonna be, not a burden but, do you know what I mean? Such a, a big job really."

Although the majority of narratives included the parents describing their relationship with their son as *'close',* the desire to produce some distance or to perhaps move to a more Western cultural understanding of a 'normal' adult-child and parent relationship was present. Carol explained, *"And there was a point when he said, oh, you've got to let me come home or something, when he was home from hospital…And I went to him well. I'm sorry, but you know, I'm, I just can't, I don't have to take you back".* This theme of 'breaking-away' was not always delivered with clarity however as Barbara spoke throughout her story about wanting her son to be less dependent although acknowledged difficulties and contradictions in that process as she explained, *"They've got to be allowed to be themselves, and that's something I found very difficult to accept. That my son is his own person and must be allowed to be his own person and not the person that I want him to be".* She also noted, *"I would have to feel that he's made much greater progress in his independence before I could move and leave him".*

Sub-Plot 3: Survival Beyond the Parent-Child Relationship

The future and concern regarding care for their sons was explicit in all the narratives. Eileen, Barbara, Carol and Bill and Angela all made reference to having thoughts about what would potentially happen when they die and are no longer around to support them. Smith et al (2012) note the additional challenges that parents may feel as they continue being primary caregivers for their children into adulthood and also cope with coinciding processes associated with their own aging. Greenberg, Seltzer & Greenley (1993) explored the gratifications and frustrations of later-life caregiving in aging parents who care for adults with disabilities, noting the potential changes in perceptions of being the carer, as they themselves get older.

Although the parents in the present study may not necessarily hold the same role as those parents whom have children with Learning disabilities, there are some overlapping sets of stressors. Greenberg et al (1993) highlight that parents have to adjust and cope with on-going worries and concerns about what will happen when they are no longer able to offer care and support to their child. These concerns were also identified within Hare et al's (2004) study that explored the needs of carers supporting adults with ASD, as they found that the majority of participants expressed concern and anxiety about what would happen to their child, when they were too old or sick to care for them. Concerns were raised within the narratives about both financial support and aging, for example Bill states, "*But hopefully I'll have left him enough money",* with both Angela and Barbara making reference to their age as Angela states, *"Cos we're getting older and we're not going to be here forever".*

Summary of Plot 3

Through the narratives, all parents told stories that included sharing positive aspects of their son in addition to challenges. This may represent the balance of parents communicating areas of difficulty to gain appropriate support but still wanting to feel proud as a parent. The stories demonstrated the on-going negotiation of encouraging some level of independence for their adult child whilst still having a strong parent-child relationship into adulthood. The future was a concern for all parents who all spoke about being aware of what may happen to their adult child when they, as parents, were no longer here. Such narratives highlighted additional concerns that may occur for parents with adult children as they become aware of their own mortality.

4. 7 Social and Cultural Context of the Narratives Told

Across all the narratives there were references both explicitly and inexplicitly to the context of the narratives that were being delivered. Riessman (2001) highlights that storytelling is a collaborative practice emphasising that both teller and listener interact within a particular cultural and historical context. Some of the prominent contextual narratives observed within the stories are presented below.

4.7.1 Gender Narratives

Of the stories told six of the mothers spoke about having differences of opinions with their husbands or partners regarding their beliefs about their son's well-being in part of their story. Tanya and Jackie and Barbara explained that at times they would feel that they were battling their husbands, as well as external services, in order to feel understood. Jackie explained, *"My husband just couldn't see"* whilst Tanya explains *"Even my husband thought he*[28] *would not be able to live independently"* and *"We were always quite divided on his discipline or basically all aspects of him growing up, my husband and I were quite divided on that".* Hartley et al (2011) describe the differing roles that mothers may take regarding their adult child's ASD and the potential different impacts in comparison to the father's role. Such stories may reflect the social context and potential gender differences in coping strategies and expectations between the roles of a mother in comparison to that of a father. May (2008) examines how women may present a 'moral self' in relation to public norms and that through life stories, individuals may attempt to account for certain actions. This is significant in term of how each mother may have felt compelled to present themselves, recognising the impact of possible gender stereotypes and biases on their narratives.

As Bill was the only father included in the research and his narrative was co-constructed with his wife it was not possible to consider further how a father's narrative may differ if delivered independently. However Bill also made

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[28] 'He' is referencing her son

reference to his different approach in comparison to his wife. He explained, *"But the social workers were [pause] Carol's got a softer opinion [pause] were close to useless"* perhaps indicating he perceived his own responses as 'harder' or 'more masculine'*.* Within their narrative they also spoke about the different roles they adopted in response to their son's physical challenging behaviours as Carol explains, *"Once the physical side, once he moved into Shire's, Bill kind of took over and I think a lot of the fathers did in that, in that environment….which is quite a masculine sort of environment"*. Hartley et al (2011) suggest that the roles of fathers and mothers can change over time with fathers perhaps assuming a closer relationship to their child with ASD as they enter adult years. Although this pattern is yet to be further explored within research, the gender roles within each person's narrative was present with all six mothers reporting a prominent role when interacting in early school liaisons, when their child was younger, which may reflect such gender roles.

Stern et al (1999) noted that people may use culturally available storylines, such as gender narratives, to make sense of experiences or dilemmas. Gender roles and possible 'taken for granted' assumptions regarding existing dispositions of men and women may be present and cultural discourses embedded in the personal narratives of the women in the study. As all the parents in the study have sons, it may also be that gendered stereotypes contributed to the emergence of the 'Trying to break away' Sub-Plot. For example, Fivush & Buckner (2003) highlight that part of establishing a male identity is assumed by breaking away from their mothers. Within the narratives, the 'break-away' may therefore be an indication of mothers wanting to foster this idea. It may be possible that if a mother-daughter relationship was discussed in the study, alternative storyline's would have been identified.

4.7.2 'Normal' Family Functioning

Jackie, Tanya and Angela all spoke about moments in their stories whereby they would compare or judge their child's behaviours based on their views of other 'normal' functioning children or families. Jackie described making comparisons against developmental norms explaining, *“I felt he was being dragged down by seeing his brother do normal things”* and when talking about her son’s special interest in bridges explained *“which compared to other children was not normal”.*

The concept of how individuals perceived ‘normal family functioning’ was particularly apparent when some of the parents gave historical accounts of trying to communicate with teachers or doctors that something ‘was not right’ but professionals ‘normalising’ the behaviours, citing exam stress or divorce, concluding that their sons were displaying ‘normal’ behavioural responses. Angela displayed attempts to attribute some ‘normalisation’ to her own experience explaining, “*They just, you know, do what they’ve got to do, stay at home with us, we keep them on an even keel, we have ups and downs, as all families do”.* Her experiences have become ‘normal’ for her and she draws similarities with other families, despite recognising in other parts of her narrative that their experience is quite unique.

4.7.3 Role of the Parent

May (2008) highlights the western portrayal of motherhood as part of a nuclear family unit that is defined by strong social norms. The role of the parent for a child appears to have greater clarity in terms of what is morally and socially expected from society. For example, Ribbens McCarthy, Edwards & Gillies (2000) interviewed parents and found that they voiced a strong moral imperative of putting their children’s needs first and that making moral choices was itself, seen as indicative of caring about children. However, what is not clear is when or if there is ever a shift in this moral obligation as the child becomes an adult. For the parents in the present study such moral dilemmas are perhaps even more complex as their child has additional needs that may be lifelong, thus further conflicting with the dominant social understanding of the role of the parent. Barbara stated *“There’s all of that, emotion about what you’ve missed as a parent, and you, your role as parents are so different”.* Additionally, there was an implicit cultural narrative about a parent's responsibility in how their children develop and any deviation from what is considered 'normal' is fundamentally considered the responsibility of the parents. This was observed through the storylines of parents experiencing blame from others, having had their parenting style questioned.

4.7.4 Independent Living

All of the narrative stories involved parents stating that a goal or hope for the future was regarding their sons increased or improved independence. This is important to note as such narratives can be seen in the context of a dominant narrative regarding nurturing and fostering independence which is very reflective of a strong western social norm (Hayley 1976). Angela spoke about the realisation of not being able to comply with that social narrative explaining:

"We forget about our transition[29]*. And actually what it does, it alters our aspirations, cos our aspirations were that we would get our children, um, we'd bring them up, they'd leave home, like we did you know, we'd give them the skills that our parents gave to us. To be able to live independently, to be able to build relationships, to go out in the world to work. And we would have the next part of our life".*

Angela's descriptions are in line with the dominant norm of nurturing a child's independence, although she describes having to deviate from those expectations and states *"Once you, you know, you know, your aspirations for that child have gone"*. Expectations will be heavily influenced by cultural norms and thus her narrative is about common 'taken for granted' assumptions that we develop about how the world and families work (Burr 2000). Both Jackie and Barbara also describe aspirations for their sons with Jackie stating, *"Well my dream's always, I will get him in a job and I'll get him in his own flat"* and Barbara commenting*, "I'm aiming for my son to be independent….I'm not wanting him to remain dependent".*

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[29] Transition as a carer.

Kitayama, Duffy & Uchida (2007) discuss cultural differences in the way independence is viewed commenting on differences between Eastern and Western cultures. Kitayama, Park, Sevincer, Karasawa & Uskul (2009) speak about the historical context of existing social narratives noting that historically and presently for many individuals; the western frontiers represent opportunities and personal freedom and independence. They consider how such narratives have evolved, referencing the historical events of Reformation and Renaissance across Western Europe which introduced novel ideas of individuals being independent from others and a general conception of 'the self' was developed as independent and autonomous. Such dominant narratives regarding helping their son in achieving independence was noted through each parents narrative and may reflect how 'success' or 'achievement' is measured within this cultural context.

4.8 Untold Narratives

Although not initially identified as a focus of analysis, the analysis process did identify that some attention may need to be given to stories untold. This is due to my feeling that there were traces of supressed narratives present that were not being fully included in the spoken story. Wells (2011) discusses 'silence' narratives and highlights that untellable stories will relate to the social and historical context of the story.

In the analysis it was identified that Rogers (2007) refers to the 'unsayable' in reference to omissions or themes that individuals may leave out of their story. Rogers (2007) highlights that such omissions can be important in interpreting a life pattern. Examples may be detectible within the present study. For example, within the parents stories, only Barbara spoke about feeling that she wanted to escape the position of being her son's mother explaining *"We just wanted rid of Joe, we just couldn't cope"* and explains *"I felt this incredible burden".*

The potential reasons for other parents not revealing such a position however, does not mean that it was not necessarily present or relative but those stories may be supressed due to cultural expectations. Goffman (1963) reported that individuals may fear portraying a ‘spoiled’ identity and as they aim to present a morally acceptable self, they align their narratives with cultural expectations. Potential fears of being judged by stating such a position may mean that parents feel unable to reveal the extent of such feelings. Some of the parent’s narratives hint at such a position with Tanya stating *“I didn’t know what was the matter with him, I didn’t know how to help him. But once I kind of knew, I thought well okay.”*

Dominant social discourses may result in a suppression of particular storylines and thus are absent or only hinted at within story-telling. For example, dominant discourses regarding what it means to be a parent and what cultural expectations may be placed on that role may impact on stories told, as highlighted by Kall (2009) who suggests that the notion of indestructible and unquestionable love is the dominant discourse of motherhood. Stories that may make any deviations or alternative constructions of that role, may therefore be difficult to share. Therefore, although considering ‘Untold Narratives’ was not a particular area of analysis identified within the present study, it may be that future research could helpfully consider whether supressed narratives are an important aspect to access with this population.

5. CONCLUSION

The stories of seven parents whom have an adult child with a diagnosis of HFA/AS have been explored within this study. The aim was to further understand how parents make sense of this experience over time and their constructions of their role and identity within that experience. This was considered important as there is a lack of research that enables a rich exploration of this area with parents whom have *adult* children with a diagnosis of HFA/AS. Previous research has focused mainly on the experiences of parents whom have a *child* with HFA/AS or with adult children with Autism and additional cognitive deficits (Fleischmann 2004 & Hare et al 2004).

5.1 Summary of Findings

The results have revealed both individual unique storylines AND a reservoir of shared experiences for parents, that could be utilised to increase our understanding of the level of support that is needed for parents whom have an adult child with HFA/AS, in addition to individuals with HFA/AS. The strongest storylines across the narratives were regarding changing roles and identity as a parent and as a carer. In addition, storylines included the on-going challenging relationships with a variety of service provisions, including educational, health and social care, with an overwhelming parental sense of having to advocate on behalf of their child. The impact on other social and other family member relationships was also storied, in addition to narratives related to the future for their adult child.

The stories also highlighted the contextual influence of existing dominant discourses regarding others understanding of ASD which impacted on their role as a parent. This emerged in collective storylines regarding *'On-going Struggles with others Knowledge'* predominantly that of professionals and '*Struggling to Make Visible the Invisible'*. All of the stories involved storied experiences of *'battling'* to get their child's needs recognised, acknowledging that this has continued through the transition from childhood to adulthood.

Importantly, the lack of an additional learning disability and the somewhat ‘invisible’ nature of HFA/AS was significantly raised across the narratives, with parents describing the subsequent consequences including being rejected by services and their discomfort and guilt at having to constantly communicate and highlight their adult child’s difficulties, in order to feel that others understood. It emerged that the impact of perhaps more historically stronger narratives of ‘blame’ towards the parents still exist or certainly their residual impacts are still felt.

5.2 Strengths and Limitations

An important strength of this study is that it has enabled an area to be explored that at present has been given limited attention. This is because the impact of ASD on parents has been explored as an overarching diagnosis (Hines et al 2011), but the different storied experiences of the parents of adult children with varying specificities of HFA/AS, enabling a rich and in-depth analysis, is novel. The narrative analysis approach has also enabled this to be considered over time, recognising the changes in the impact or sense-making experience for the parent longitudinally in the present study. This approach has also enabled stories to be situated in the social and cultural context, which I think is particularly significant, given the past and existing dominant cultural narratives of ASD (Broderick & Ne’eman 2008).

Due to the complex analysis process and the scope within this research study, a small sample size of seven participants (six interviews) was included. As a small sample size therefore it needs to be noted that the findings cannot be generalised or presumed to represent all parents who have an adult child with HFA/AS. Nevertheless, qualitative research does not aim to generalise findings, instead, with a contextualising of the sample, it may be that some of the stronger storylines found here may perhaps have some degree of ‘transferability’, to other parents with similar experiences and contexts.

The studies sample included six mothers and only one father, who told his story in conjunction with his wife. An important area for further research may be to consider how narratives of fathers may differ in comparison and whether different plots and subplots emerge. Although the current research has considered the gender narratives that may have influenced the participant's stories, further understanding of the contextual influence of such narratives may helpfully further inform understanding of parent's experiences. The impact of gender may also need to be further explored, as in the current study all of the parents' adult children were male. This is likely to be due to the higher ratio of males being identified with AS/HFA than females (Brugha 2009). It would be helpful to consider whether those parents with adult daughters have varying or comparative experiences, particularly as there may be existing gender narratives that may contribute to what a parent hopes for in relation to children of different genders. Taylor & Seltzer's (2010) research found that gender played an important role when exploring changes in positive affect between mother and child, in the transition period of leaving high school. They found that mothers reported greater increases in positive affect in the mother-child relationship with daughters following school years, when compared to sons, suggesting alternative themes might emerge.

In addition, as all of the mother's had sons, the relationship dynamic with six of the participants was that of a mother and son relationship, with only a singular father and son relationship. Hartley et al (2011) highlights that fathers are infrequently included in research and that there is a lack of studies that explore differences between mothers and fathers of their parenting experiences of having an adult child with ASD. Gender dynamics between the parent and child relationship may be important to consider. Burr (2003) suggests that what we do and learn is affected by the way we think about ourselves in relation to the categorization being placed upon us. Being female and being a 'mother' are labels that do have social and cultural expectations of what your gender and role entail thus impacting on stories told. Alternative relationship dynamics may enlighten understanding of whether different or comparable storylines are delivered.

All participants in the sample were White British and therefore the dominant cultural discourses will also have informed the stories told. Alternative research that has explored the well-being of mothers of adolescents and adults with an ASD in Taiwan, found cultural differences in regards to social support accessed, coping strategies and family adaption (Lin, Orsmond, Coster & Cohn 2011). Therefore, it needs to be considered that alternative stories may be told in different cultures not identified within this study. There may also have been a sample bias towards those seeking help as all of the participants were accessed via local support groups. The stories told by those who are not accessing any support network may be different and therefore it needs to be understood how those stories can be accessed and heard. This is important when considering that stories are socially and culturally dependent (Emerson & Frosh 2004), as being from the same support groups may have influenced the stories told, acknowledging that even within the groups there may be differences between those who wanted to tell their stories and those who didn’t.

A further limitation of this study is that only the narratives of the parents were collected. It would be helpful to consider the narratives of the individuals with HFA/AS themselves - as an understanding of how they may make sense of their experience and identity could also assist in better meeting the needs of this population. Broderick & Ne’eman (2008) highlights that despite the individuals with an ASD themselves having undergone difficult experiences, the focus and dominant Autism narrative appears to often be about the suffering of family members. He claims that the parent narrative about Autism has had more time to disseminate and thus may monopolise public perception of relevant issues. Inherent difficulties within the diagnosis need to be considered, however, as although individuals with AS or HFA do not show marked language impairments as adults, there may still be marked social difficulties that could impact on their narrative abilities and thus their ability to share their story. Colle, Baron-Cohen, Wheelwright & Van der Lely (2008) studied the narrative abilities of adults with HFA and AS, commenting that the ability to tell a story demonstrates both linguistic and social-cognitive abilities. However, they found that although the group with AS produced less well cohesive and organised stories when compared to a control group, they were able to sustain a story structure using narrative devices. This further supports the value in collecting the storied experiences of these individuals.

5.3 Reflections on Methodology

A life story approach as utilised within the present study can have some constraints (Riessman 1993). This is as the visibility of the construction of narrative structures can be impacted by transcription conventions that are not always fully specified, or are based on a researchers approach to the transcription process. As consideration is given to all information that could impact on interpretation it may be that use of a video recorder in the present study would have enabled further opportunity to detect and include elements of the story-telling that could be missed when utilising an audio recorder. However, Smith (2000) notes that video recording can induce greater self-consciousness and thus the impact on the story-teller may influence the stories told. In addition, within the present study each participant was only interviewed once which may have impacted on the level of depth of the stories. Riessman (2008) notes that ideally participants would be interviewed more than once, acknowledging that with one interview it is only a representation of that person's story at that particular point in time. Multiple interviews may offer an opportunity for a storyteller to provide additional accounts, enabling a richer exploration as they potentially benefit from being able to place increased trust in the listener (Cotterill 1992).

My own clinical experiences and personal values and beliefs will also have impacted on the interpretation and the analysis process which may be a limitation of this methodological approach. Riessman (1993) notes that what features of an individual's narrative account are chosen as elements to write about by the researcher, are ultimately linked to the researchers own personal biography, values and theoretical and epistemological position. Although I have aimed to be transparent about this throughout the research, highlighting my own role and part in co-constructing the narratives, my clinical background will also have compromised my position as a researcher, due to the dual role and nature of both my clinical and research experience. Edwards (2002) identified that this can be particularly problematic if studying areas that involve one's profession, as one attempts to negotiate a research relationship rather than a therapeutic one. Although the present study was not directly concerned with clinical professions, part of eliciting stories from parents involved asking about their experiences with professionals, which included stories about therapists. However, utilising a reflexive approach and keeping a reflective journal was helpful in negotiating this dual role.[30]

Within the methodology a semi-structured interview was utilised with the aim of providing prompt questions for potentially quite complex stories. However, the semi-structured interview may have been too directive, forfeiting an appropriate level of freedom for the parents to tell their story. It is questionable as to whether an unstructured interview may have offered this freedom. Corbin & Morse (2003) explored the use of unstructured interviews when dealing with sensitive topics, highlighting that participants can tell their story as they experience it, see it and feel it and can determine the starting point, the order of topics and what to include and exclude. However, although the semi-structured schedule was utilised within the present study, the parents all chose different ways of structuring their story, suggesting that they maintained some control over the direction of their narratives, with most answering or going back to questions as and when they chose. Therefore although it needs to be noted that potential storylines may have been affected by a semi-structured approach, this is still consistent with narrative research and retained the likelihood that parents still felt able to expand or elaborate and change the direction of the interview, as identified in the transcripts.

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[30] See Appendix G (Extract 4) for an example of a Reflective journal entry related to negotiating the dual role.

5.4 Clinical Implications - What do we need to consider from hearing these stories?

5.4.1 Parental Involvement

The findings of the study have highlighted that the well-being and role of the parent for an adult with HFA/AS is an important and integral area that needs to be fully understood, particularly when considering the amount of support that parents provide ‘behind the scenes’ from childhood and throughout adulthood. The unique contribution that parents can offer in informing appropriate care and support services needs to be acknowledged (Drysdale, Jahoda & Campbell, 2009). Valuing the expert knowledge that a parent can bring, about their adult child, in informing service provisions will enable more successful support strategies to be implemented. In addition, the parental support offered has a direct influence on service demand as many parents are meeting needs when they cannot be met by services (McCarthy 2010) highlighting the need to continue to review and understand current service provisions for adults with HFA/AS *and* their families.

5.4.2 Focused and Targeted Service Provision

Current UK government legislation such as The Autism Act (2009) has been an important part of ensuring that such active strategies are in place to transform services for adults with Autism with ‘Fulfilling and Rewarding lives': The strategy for adults with Autism in England (2010a) being the first ever strategy put together by government to improve the lives of adults with ASD in England.

In line with this strategy, clinical services need to be thoroughly set up to ensure the needs of those individuals with ASD are being met. The role of the parent in these individuals’ lives is a significant and vital part of these individuals well-being and needs to be considered by adopting a more holistic care approach. Implications of an individual’s ASD on the whole family unit needs to be considered, as if parents are absorbing the responsibilities that services need to be providing, the impact will affect the whole family unit. The narratives of the parents in the present study highlighted the cascading impact on all relationships both within the family unit and beyond.

5.4.3 Fostering a 'Non-blame' Culture

The need to provide a service and channel of communication whereby parents do not feel judged or blamed has been highlighted. This is to allow and enable parents to be valued as holding a helpful and significant role in the support of individuals with HFA/AS. Barbara stated, *"there is something magical about being with people who are in the same position"* alongside other parents whom made reference to the benefits of being able to meet other parents. It may be that additional attention needs to be given to peer support within this area, with greater connectivity within the community that does not need to rely solely on dedicated and voluntary workers.

5.5 Future Areas for Research

Further research that would be helpful to develop understanding would be in exploring joint storylines when delivered by couples and families as a whole, acknowledging that individuals may have different perceptions. In line with the epistemological positioning of this research, a joint narrative would not be acknowledged as impacting on the 'true story' as the social constructionist stance would be that there is no true story, only different stories and perceptions of stories. When considering ecological validity, it is worth highlighting that although the analysis of joint narratives can be a complex and difficult task, it is important to note that stories are often co-constructed and that such combined stories can be further informative (Bamber 2012). Future research could be helpful in considering how stories within couples are shaped to give value to both contributors.

It may also be important to consider how the narrative approach could be further expanded to add further to the stories told, for example, Bamberg (2007) makes reference to the importance of 'little stories' in addition to a 'big story' that may not be captured in a one-off interview, but can be captured in e-mail or telephone calls. Additional strategies of collecting stories can be varied as Etherington (2004) highlights that one can be creative with the ways stories are gathered and collected, identifying written stories, journals and diaries.

The current research considered the role of 'blame' particularly parents feeling blamed by others that appeared in each narrative. Although the storyline of 'blame' was present, further research and consideration into how feelings of blame are managed and what if anything helps stigmas or dissolve over time. Also clinically, it highlights that these discourses need to be addressed with parents, individuals with ASD and wider societal discourses. Such understanding would better inform services regarding how to foster a non-blame and less judgemental attitude through the lifespan of the individual with ASD and their family.

5.6 Personal Reflections- My Relationship with the Stories

This research has been a very personal project due to my passion in wanting the voices of parents to be heard. This passion has undoubtedly been borne out of my privileged experiences of working with individuals and families of individuals with an ASD. It therefore feels important to consider my personal reflections regarding the process.

Working with a narrative analysis framework has been testing for me, primarily due to the variety of strategies that can be applied to analysing stories (Smith & Sparks 2009). Initially feeling overwhelmed, I spent time wanting to fully understand the potential approaches to analysis within narrative, to ensure that I felt I was able to present them adequately. Working from a position whereby I acknowledge the co-construction of the process, also made me feel an increased sense of responsibility about my role in representing these stories. However, by utilising Narrative analysis, I have felt fortunate in being able to understand the stories in depth, by not only considering the content of the stories, but also attending to the way those stories are told and the context in which they are embedded.

Listening to the interviews presented some personal challenges for me, as being a clinician meant that when parents discussed the difficulties associated with professionals, it evoked a sense of feeling that *'we'* as services had let them down. I felt I needed to be mindful of not becoming too disheartened that service provisions are not adequate. However, hearing about missed opportunities for support and significant worries about their adult child's future did leave residual feelings of sadness and helplessness, which stayed with me following hearing the stories[31]. Nevertheless, this was in parallel to feeling extreme admiration for each parent considering the ways that they had attempted to make sense of their experience and *'battle'* on, despite such difficulties. I hope that the parent's courage and honesty, demonstrated in sharing their stories can encourage further story-telling and listening in parents *and* professionals to both aid understanding and to enable the development of service provision for individuals with ASD.

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[31] See Appendix G (Extract 5) for an example of a Reflective journal entry related to residual feelings of sadness.

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7. LIST OF APPENDICIES

Appendix A: Literature Review Search Strategy

There were several stages to reviewing the appropriate literature, all listed below in sequence.

Stage 1:

An initial exploratory search strategy was implemented by utilising the University of Hertfordshire library book search facility. I also searched for electronic references by conducting searches on Google Scholar and all major Psychology and Social Sciences databases including PsychINFO and Web of Science.

The search terms used were:

'*Autism* Spectrum Disorder'

OR

'High-Functioning Autism'

OR

'Aspergers Syndrome'

AND

'Parents'

'Family impact'

'Coping'

Stage 2:

Secondly, I followed up on appropriate references, noting additional relevant articles by identified authors. I also searched for additional helpful references cited within the articles identified from the initial stage

Stage 3:

In parallel with stage 2, I contacted individual researchers informing them of my research questions and enquiring whether they were aware of any key references that were relevant that I should be aware of. In addition I spoke with both my principal supervisor and field supervisor regarding appropriate references to source.

Stage 4:

An in-depth search of the literature was then carried out over a 12 month period.

References were included based on the following criteria:

- Papers were in the English Language (or versions that had been translated)
- Peer Reviewed Journals
- Papers focused on the impact or experience of parents who have a child or adult child with an ASD

References were excluded if:

- Studies focused on impact on siblings

Dates searched were:

- 1995-2013

The search terms utilised to locate studies within the inclusion criteria were:

- Autism Spectrum Disorder- Autism Spectrum Conditions, ASD, Autism, Asperger Syndrome, High-Functioning Autism
- Parents-parental role, carer, caregiving, mothers, fathers
- Experiences- transition, diagnosis, support services, relationships, identity
- Family- Child, Adult Child, Adolescent
- Narrative- Stories, storying, sense making, story telling
- Coping- adjustment, impact, effect, psychological impact, psychological well-being, emotional adjustment, transitions, resilience
- Qualitative methodology- credibility, rigour, grounded theory, social constructionism, epistemology, narrative analysis, IPA.
- Culture- dominant discourses, cultural narratives, cross culture.

General Web Searches:

- NICE guidance
- National Research Ethics Service
- The Centre for Narrative Research

The following search engines were used:

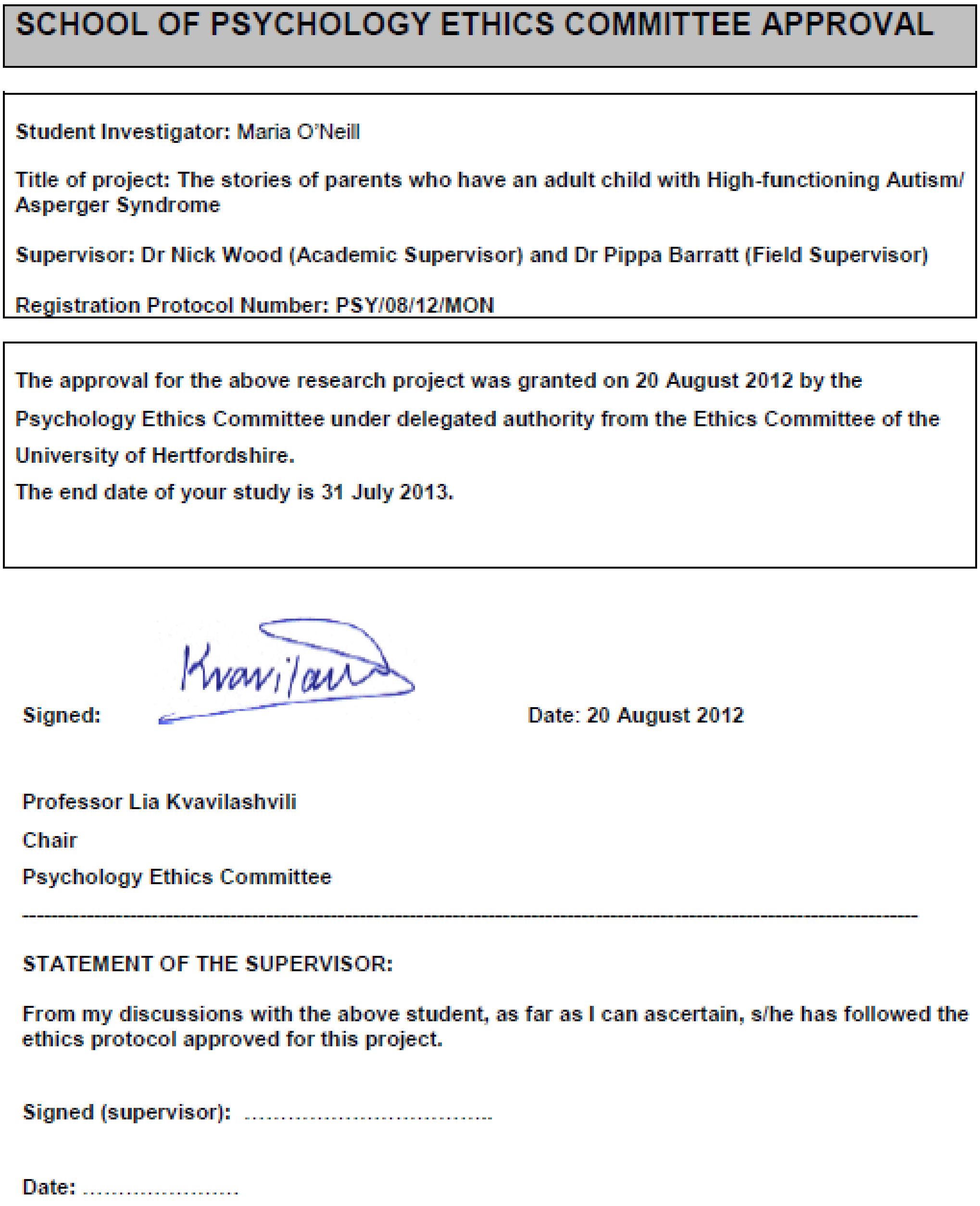
- Psyc Info
- Pubmed
- The Pro quest Theses & Theses database
- Directory of Open Access Journals

- Cochrane review
- Web of Science (Science Citation Index (SCI and Social Sciences Citation Index (SSCI)
- Google Scholar

Searches were conducted in the specific individual journals:

- Autism: The International Journal of Research and Practice
- Journal of Autism and Developmental Disorders
- Good Autism Practice
- Autism Research
- Research in Autism Spectrum Disorders
- Narrative Inquiry

Appendix B: UOH Ethical Approval Certificate



SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE APPROVAL

Student Investigator: Maria O'Neill

Title of project: The stories of parents who have an adult child with High-functioning Autism/ Asperger Syndrome

Supervisor: Dr Nick Wood (Academic Supervisor) and Dr Pippa Barratt (Field Supervisor)

Registration Protocol Number: PSY/08/12/MON

The approval for the above research project was granted on 20 August 2012 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.

The end date of your study is 31 July 2013.

Signed: Date: **20 August 2012**

Professor Lia Kvavilashvili
Chair
Psychology Ethics Committee

STATEMENT OF THE SUPERVISOR:

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

Signed (supervisor): ……………………………..

Date: …………………..

Appendix C: Consent Form

The Stories of Parents who have an Adult Child with High-Functioning Autism (HFA) or Aspergers Syndrome (AS) - A Narrative Study

I have been told the purpose of the above named research project ☐

I am willing/ happy to participate in the above named research project ☐

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

I understand that the information provided will be kept confidential and viewed by authorised persons only ☐

I understand that I am able to request to view the findings of the study after completion ☐

I understand that my interview will be audio recorded ☐

I understand that the research is being completed as part of Maria O'Neill's Doctorate in Clinical Psychology and will be submitted and assessed as part of the training qualification ☐

Name ....

Signature ....

Relationship to individual with HFA/AS……………………………………………………………………..

Date ....

Appendix D: Participant Information Sheet

The Stories of Parents who have an Adult Child with High-Functioning Autism (HFA) or Aspergers Syndrome (AS) - A Narrative Study

Who is completing this research?

My name is Maria O'Neill and I am currently employed as a Trainee Clinical Psychologist for Cambridgeshire and Peterborough NHS Trust. I am inviting you to take part in a research study exploring the experiences of parents who have an adult child with High-Functioning Autism or Aspergers Syndrome.

What is the purpose of the research?

The purpose of this study is to explore the experiences of parents who have an adult child with HFA or AS and understand how you create and construct your experiences in relation to others over time. The aim is to understand the potential impact of key changes, such as life stages (the child moving from childhood to adulthood) and how you make sense of these changes and their on-going role. This research is being carried out as part of the Doctorate in Clinical Psychology (D.Clin.Psy.) training. **This study has been approved by the Psychology Ethics Committee at the University of Hertfordshire, Registration Protocol Number: PSY/08/12/MON**

What will I be required to do?

If you choose to take part in this study you will be asked to complete an interview with questions regarding your experiences as a parent. The interview will last up to two hours and will involve questions asking you to share your experiences of this role. The interviews will be audio recorded, anonymously transcribed and then destroyed. Your identity will also remain anonymous when the results of the research are reported. All information provided will be confidential between the participant and the researcher and only anonymised information will be available to my supervisors and thesis examiners.

Can I choose whether to participate in this research?

It is up to you whether you wish to take part in the study. If you decide to continue you are free to withdraw at any time and do not have to give any reason. If following participation you would like to withdraw, your information will be omitted on request from the study. You can also use the contact details below if you feel that you experience any adverse effects by participating in the study or if you have concerns regarding your involvement in the study. If you are happy to take part in the study then a consent form will need to be completed.

Can I view the results of the research?

There will be an opportunity to access the research once completed if you wish to do so and details will be provided if requested.

How can I contact the researcher?
If you have any questions or concerns regarding the above you can contact me on the following details:

Maria O'Neill
Trainee Clinical Psychologist
Doctoral of Clinical Psychology
University of Hertfordshire
College Lane
Hatfield
AL10 9AB
Tel: 07734822520
E-Mail: m.oneill@herts.ac.uk

If you have any comments or complaints to make about your involvement in this research, please contact my supervisor, Dr. Nick Wood, or the Ethics and Research Chair, whose details are below.

Name of supervisor: **Dr Nick Wood**; Email: N.1.Wood@herts.ac.uk

Department of Clinical Psychology
University of Hertfordshire
College Lane Campus
Hatfield
AL10 9AB
Tel: 01707-284767

Prof. Lia Kvavilashvili
Chair: School of Psychology Ethics Committee 2H264
Faculty of Health and Human Sciences, University of Hertfordshire (01707 285121)

Thank you for participating in this study.

Appendix E: Participant De-Brief Form

The Stories of Parents who have an Adult Child with High-Functioning Autism (HFA) or Aspergers Syndrome (AS) - A Narrative Study

Thank you for being involved in the above named research study. Your participation will be helpful in gaining an understanding of the experiences of parents whom have an adult child with HFA or AS.

The information provided by you in your interview will now be anonymously transcribed and written up to be included in the research findings. If you would like to receive a copy of the overall research findings please contact us.

If you have any further queries and wish to contact the researcher, you can do so by using the following details:

Maria O'Neill
Trainee Clinical Psychologist
Doctoral of Clinical Psychology
University of Hertfordshire
College Lane
Hatfield
AL10 9AB
Tel: 07734822520
E-Mail: m.oneill@herts.ac.uk

If you have any further need of support, please contact ***The National Autistic Society***:

http://www.autism.org.uk/

The National Autistic Society
393 City Road
London, EC1V 1NG
United Kingdom

[Administrative offices only]

- **Tel:** +44 (0)20 7833 2299
- **Fax:** +44 (0)20 7833 9666
- **Email:** nas@nas.org.uk

The research is being supervised by Dr Nick Wood, Clinical Psychologist and he can also be contacted on the following e-mail address: n.1.wood@herts.ac.uk.
Thank you for your participation.

Appendix F: Semi-Structured Interview Schedule

Role

- Can you tell me a little about your son/daughter and your current level of contact with them?
- How would you describe your relationship with them and the role that you now have?
- Can you describe your experiences regarding diagnosis for your child or when you initially identified difficulties?
- Have your perceptions of your role changed/developed over time?
- What sense have you made of your son/daughter's difficulties over time?

Relationships

- What, if any has been the impact on your own personal relationships with partners and friends?
- Is there any impact on your relationship with your other children (if appropriate)?
- Tell me about your experiences with professionals (education, health professional's etc.) in relation to your child's difficulties.

Support

- What are your experiences of accessing support for your son/daughter?
- Are there past or present sources of support that have been particularly helpful/ unhelpful?
- Tell me about your experience for your child, moving from childhood to adulthood and what was that like?

The Future

- How do you feel about and your son/daughter's future?
- What are your hopes and/or fears for the future?

Appendix G: Examples from Reflective Journal

Extract 1: *'I am aware that in Eileen's story, I may have been asking more prompt questions then perhaps I had anticipated. Reading back over the transcript has made me more aware of this. I wonder whether this has been my attempt to try and scaffold and facilitate her story given her tentative performance, although at the time I was weary of doing this.'*

Extract 2: *'Barbara delivered her story confidently and as the researcher I felt very little need to provide many prompt questions, as many of the questions in the interview schedule she spontaneously referred to without questions. I felt she was taking control of her narrative although I felt that she was clear in wanting to be focused in answering any questions I did ask. I got the impression that she was well-rehearsed in talking with others about her experiences and portrayed a position that had a balance of confidence and vulnerability. I wondered whether her experiences with sharing her story had meant that she had felt positioning herself in that balanced way, was most effective for her to feel heard.'*

Extract 3: *'Following Angela's story, I am aware that I needed to be careful about not 'over-interpreting' meaning to the performance aspects of her story. Although important to note, I feel that interpretation could impact on my responses as the researcher, and despite recognising my part in the interview, I wanted it to be Angela's narrative. I tried to therefore consider how she performed the story and what she may have been trying to convey whilst not making assumptions.'*

Extract 4: *'In Eileen's story I came away feeling worried that I may not have been able to offer her quite what she wanted, as I felt she wanted more guidance and possibly even 'therapy'. I felt I needed to stay focused on not stepping into the therapist role as although I did ask additional questions to try and scaffold her story I did not necessarily want to evoke or guide new thoughts as one may do within a therapist role! In the next interviews, I think I need to be clearer before we begin the interview that I will be listening and asking some prompt questions but that my role is to listen to their story. This may help clarify participant's expectations regarding my role.'*

Extract 5: *'Both the stories I heard today have made me feel upset and frustrated, as I find it difficult to make sense of how such a gap in services has been able to exist for so long. The only positive way I can frame these mothers' experiences is by admiring their strength. Barbara does actually refer to her husband as her 'best friend' and states that had they not been through such challenges, that they may not have the relationship they do now.*

Perhaps I need to take some positivity from that. I wonder if the more stories I hear, the more absorbed I am becoming as the listener, making stronger connections and extending my repertoire of heard stories!'

Appendix H: Transcription Agreement

University of Hertfordshire UH

Doctorate in Clinical Psychology

Transcription Agreement

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

Maria O'Neill (The 'discloser')

AND

The Transcription Service (The 'recipient')

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

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

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

Signed…...……….……………..

Name…..………………………..

Date…………………………….

Appendix I: Audit trail of process of analysis for Barbara’s story

Stage 1- First Reading and Post-Interview Reflections

The transcript was read through twice to immerse myself in the story and to re-familiarise myself with the narrative. Following the initial reading of the story I re-read some of my post-interview reflections which are documented below, considering two broad questions:

- **What was the personal impact of hearing Barbara’s story?**

I came away feeling that I could listen to her story all day, noting the way she used descriptive and creative metaphors- that made me feel very engaged with her story!

The story left me with feelings of frustration, wondering why it had to be so difficult to get her son to the correct school and the sacrifices she had to make to get him there. It left me feeling a little angry that she has had such struggles, a feeling I was familiar with having heard such similar stories in my clinical work.

I felt such sadness about her describing how she avoids friends who have grandchildren as it reminds her of what she will never have.

I worried that at times I was tempted to involve myself too much in her story, as I was aware of wanting to ask lots more questions. However I was mindful of trying to be an active listener

- **What were the most strongly heard stories?**

Barbara’s story was delivered with a sense of vulnerability although I felt she presented herself as a very strong and determined woman.

I mostly heard about how she has battled to get her son what he needs. I think she recognises that she has lost part of who she was, acknowledging all the things she once did, travelling etc. Now, in such contrast she seems to have lost that part of herself, even describing herself as a stag-hand in his production!

I think she wanted to be clear about how much energy, time and focus she gives in supporting her son to live his life, being quite clear that it comes with the sacrifice of having her own life. She talks about her own anxieties and worries about his future and what may happen if others are not able to understand him and care for him if she is no longer around.

Stage 2- Global Impressions

My impression of Barbara was that she was quite a determined and thorough lady. Throughout her account Barbara portrayed her role as that of a full-time carer. To tell her story, she spoke a lot about the 'battles' that she has experienced in trying to get her son's needs met and spoke about many active strategies that she utilises to both get things done and to cope on a personal level. Her narrative is purposeful and is explicit in her aims of sharing her story stating *'I want to turn my negative, the negative impact on my life into something positive, I suppose I'm on a bit of a crusade and a mission, rather arrogantly thinking that I can make a difference so that other people don't have to go through what I go through'*.

She presents herself as someone who is dutifully trying to communicate her experiences in quite a personally exposing way, talking openly about how her own experiences did not fit with her initial expectations of being a parent and expressing the sadness that comes with that.

'I've always been of the view that you have to get all your information before people start telling you what you're going to do. You need to gather everything around you So that you're informed when you listen to the suggestions.'

Barbara gives a sense that she has changed her approach in how she tries to support her son as she talks about changing her focus on not what he can't do but '*how*' she can help him. She summarises this by saying, *'And that's been the story of my life all the way through to try and dig deep, to be resourceful to enable my son to do things for himself'*

Stage 3- Reading for content-across all narratives

When all of the stories were analysed collectively, three plots were identified within the content analysis with three associated sub-plots identified within each, I used colour markers to highlight evolving storylines in each narrative and looked across all six stories noticing the prominent shared storylines. I have therefore used direct quotes and made references to parts of Barbara's story that contributed to the identification of the collective shared plots.

Plot 1-Stories about Losing, Questioning and Ultimately Attempting to Strengthen One's Sense of Self:

Sub-Plot 1: Negotiating the Parental Role

Points linked to the story are highlighted below:

Page Number	Quote
153	‘The support that he needs is kind of been diluted and shared so I still play a really big role in his support’
154	‘So my role is still very much, I feel as if I project manage his health needs’
154	‘he comes here on a Sunday for erm evening meal and often stays over. Um, and then I might see him during the week um, so yes very regular contact. Which I, I think we all enjoy.’
155	‘And that’s where my role is that the social care support staff. There isn’t, for me there isn’t a breed of person actually that combines social care and health’
158	‘So if you like I’m the stage hands in the wings so that he can be front of stage in his own life’
159	‘That’s how I see my role I, I am, sounds a bit naff but I am the wind beneath his wings’
158	‘I’m a facilitator. I, I believe that I am, I am the um, what’s the word erm not alter ego, what’s the word, there’s a word for somebody who, who thinks for him, speaks for him on occasions, not all the time, plans and organises everything for him. I, I am, I am the, the background hub of his computer.’
159	‘And there is a really big difference because that’s, that has evolved over time. I, that for me has been the step back from his total dependence upon me’
159	‘That’s where I’m a discreet supporter really’
162	‘And the danger was that this pattern of behaviour would actually continue into adulthood if I didn’t do something to break that pattern of behaviour. But every time I tried to do that it was a confrontation’
182	‘Because I’ve had all the experience of being so close to him and knowing how his brain ticks’
184	‘So I had to come home, I wish I could show you this because it’s at his flat, I had to prepare notes for staff erm a whole programme of caffeine withdrawal that I knew my son could work with and understand’
185	‘But that’s the work I put in because I understand how I’m going to achieve success with him’
185	‘And that’s been the story of my life all the way through to try and dig deep, to be resourceful to enable my son to do things for himself’
186	‘What does he need from us and it’s interesting because (pause) what they don’t (pause) see and I think what they didn’t see is, or maybe, I still don’t think they see it, is the amount of discreet support that I still give him’

204	‘over the years I’ve realised that Joe himself hasn’t got a clue how to nurture friendship. So now, at the age of twenty-seven, I’ve given up cos I think to myself I can’t keep making his friends for him, can I? And it’s hard work’

Sub-Plot 2: Attitudes to Blame and Questioning of Oneself

Points linked to the story are highlighted below:

Page Number	Quote
160	‘he’s the brightest boy we’ve got in our school. I don’t know what the mother’s going on’
162	‘we had a really difficult period where the school weren’t listening to me. I was the villain’
156	‘And I noticed that then and then I feel guilty because I’m thinking I should of, I should know by now not to trust him to plan or organize or predict’
181	‘I just think that, (pause) that might be a self-imposed feeling.’
181	‘That might be a self-imposed (pause) assessment of yourself because you’re not professional, you don’t have the knowledge’
157	‘I was escalating this through my frustration… And guilt. But I should have known better, I shouldn’t have relied on him to do all the things that I know he can’t do.’
181	‘You know, a number of times I’ve heard that from other people. They thought I was being overprotective.’
176	‘there’s still um, an idea that erm, bad parenting is to blame, I still, I still think that’s out there.’
181	‘But I didn’t fight it because I’m trying to balance being the over protective over dramatic mother, with listening to what the professional thinks.’
207	‘And there’s this kind of, it’s interesting, there is some magic about being with people who are in the same position. Or with their problems. (pause) Not having to explain. Not being judged.’

Sub-Plot 3: Loss (of Relationships and an Alternative Life)

Points linked to the story are highlighted below:

Page Number	**Quote**
164	‘I felt this incredible burden that was only going to get worse’
171	‘My husband and I we were, ppsss. we were at loggerheads, it has huge impact on the family.’

188	‘It’s driven a huge wedge between us. We were quite happy when we got married (laughs) and before we had children (laughs).’
189	‘I’m still the main carer, I’m still doing all that I need to do, I’m still having, if you like, to prioritise his needs over and above my own and my husbands. And gradually you know, the wedge gets deeper and deeper and (pause) If I’m honest . . . I think the only reason that my husband is here now is because he. . . . one he loves his son.’
189	‘The impact on both of us, separately and together is. . . Um. (Pause). Our lives are very limited’
189	‘The choices that we make either for ourselves or each other are extremely limited, uh, we never felt we could move house with Joe because he would be devastated at the change.’
191	‘And, I couldn’t be everything, I couldn’t be superwoman, um and in the end, I, if you like, I turned to my son, gave him (pause) more perhaps, than I was prepared to give my husband because I thought well you’re old enough and ugly enough to look after yourself, I, it’s him I’ve got to look after.’
191	‘And I think, um, the wedge just got deeper and deeper.’
192/193	‘When he went away, to school, you would have thought that that would have been a time of reconciliation between but it wasn’t. It was all too late.’
193	‘The other thing is, um, I know that over the years, the impact of my sons behaviour and needs has actually transposed on to me. So I can tell you, this was a young woman who travelled the world. Went on Concorde, went to Brazil, Lived in Spain for five years became totally travel phobic.’
194	‘I, my life, because my life became so limited. I think the fall out was that I limited myself.’
194	‘So it was all about not taking any risks. I became really risk averse.’
195	‘Um. I haven’t had, the life of a parent that I would like to have had.’
195	‘You know, so, so there’s all of that um, the fact that I’ll probably never be Grandma.’
195	‘About what you’re miss as a parent, and you, your role, your role as parents are so different.’
196	‘My life is different, when I, I’m, I’m sixty-six, when I go out with woman of my age and I listen to them talking about their grandchildren, I’m not a part of that.’
196	‘I go out with friends who haven’t got children. You know what I mean at that? So it kind of limits your social Interactions.’

197	'Um, and still limited. Um, you know, my husband and I, had Joe been different, we would probably consider moving.'
201	'I'm convinced that this is one of the fall outs of being a carer. It's part of limiting yourself, making excuses as to why you can't do something. I'm so good at, at trying make ways for Joe to do stuff and I'm very good at making excuses for myself not to do stuff.'
203	'I do have an envy for people who say, I don't know what I've done without my friends during all of this, you know, they've been so supportive to me, you know, and all the rest of it.'
203	'that was good until they went to school and then as you see, when they went to school, the friends dissipate, especially because Joe didn't go to a local school.'

Plot 2- Stories about 'The Making and Breaking, yet Ongoing Painstaking Relationships with Services':

Sub-Plot 1: Attempts and Battles: 'Being a Crusader'

Points linked to the story are highlighted below:

Page Number	Quote
164	'And I was quite, I was getting desperate because I just didn't feel that, I didn't feel he was making progress in school.'
166	'And I remember talking to her and of course because I was running around like a headless chicken and the penny hadn't dropped for me and I needed somebody else to point me, to signpost me.'
170	'and if I'm honest, by this time I'm getting exhausted, I'm getting emotionally exhausted.'
171	'I'm physically exhausted, I'm getting ermmm you know really finding my own life.'
171	'I remember going out for a meal with her and she just sat there and I said 'I can't do this anymore' and she looked at me and she said, she lent across the table and she said, one more battle, you've got one more battle (tearful)'
171	'And I couldn't face that, I and I knew what it was, I had to get him out of that school and I had to get him into a special school because otherwise I couldn't see, I couldn't see a future.'
172	'And nobody would support me, the head teacher of the school wouldn't support me the speech therapist wouldn't support me.'

173	‘I had to organise if all, but anyway the long and the short of it is we did all of that it costs nearly £12,000 in the end.’
174	‘For that year and we won our case and we got the school that we wanted and not only did we get the school that we wanted but the tribunal agreed that he could go back a year.’
174	‘And of course they were so good with these children that they made them feel good about themselves and that was the secret. Of making my son feel good about himself.’
192	‘We just didn’t want to do it anymore, so, at that point, I think my husband could see, I mean, I was probably teetering on breakdown.’
205	‘I feel I want to turn my negative, the negative impact on my life into something positive, I suppose I’m on a bit of a crusade and a mission, rather arrogantly thinking that I can make a difference so that other people don’t have to go through what I go through. I’m not alone in that, There’s a whole army of us out there doing the same thing.’

Sub-Plot 2: Struggling to Make Visible the Invisible-Invisible Disability

Points linked to the story are highlighted below:

Page Number	**Quote**
166	‘he showed original signs of being, you know, being able to pull him through there were expectations that he would. How do I Say this? Normalise.’
169/170	‘And her response to that was well I’m not interested in this diagnosis because he hasn’t changed and my opinion is I don’t need to change anything.’
170	‘and there was this so called professional lady who was saying to me well it’s of no, you know, it was like, brush you away and I just really felt. I felt, I mean, I’ve gone like this with depression, up and down, up and down and I just felt.’
181	‘But even then, even she at the end of the three year period was (pause) fooled into believing that he was much more capable then he actually was.’
182	‘I really struggle (pause) because I don’t want to be constantly saying he can’t do this, he can’t do that.’
181/182	‘maybe it was other remarks that they made that you know, ’well, well he’s very capable’ And you’re thinking but he’s not!’
182	’ But I also know that the people who expect him, the expectations of other people will not be met because he can’t do certain things.’
182	‘because people, what you see with my son is not what you

	get.’
182	‘But how can somebody in a one hour window of assessment understand the, the, the silent the invisible difficulties that he has with certain functions of his brain.’
186	‘They’re all at different levels of expectations of my son when they first meet him, they can’t see, they’re like “why does he need support? He doesn’t need any support. He’s very independent.’

Sub-Plot 3: On-Going Struggles with Knowledge

Points linked to the story are highlighted below:

Page Number	Quote
170	‘You know explaining why he behaved in certain ways understanding the rigidity and the inflexibility and the lack of prediction, and you know all those things you know understanding all of that.’
172	‘Because it wasn’t serving him any purpose, he was time serving. It wasn’t an education, you know education is for life and he was unhappy.’
176	‘13 years ago I think that, and this is still the case, I think that people don’t know what they don’t know about Autism.’
176	‘I think that even the so called professionals who are still debating whether erm these children are just being difficult and manipulative.’
181	‘so who are you to challenge a professional to say you’re wrong.’
185	‘How do you transfer that across to other people who are not thinking outside of their own box, their own traditions.’
185	‘can you expect society as a whole or individuals even in the professions to be expert psychologists in my sons needs?’
185	‘There are changes, there are changes. I think that erm Autism and Asperger’s is on everybody’s lips erm I think that the perception is slowly changing.’
185/186	‘What I get very irritated about And I still here it, I heard it last week, erm, I was talking to a lady on the phone it was totally unrelated to carer or whatever, she’s a board member of some group and she said erm, to me, “Oh yes,” she said, “well yes’ she said to me ”I’ve worked with people on the Autistic Spectrum”, the lady in the charity shop said “Oh” she said, “I worked with children on the Autistic Spectrum.” People who really know erm people who really know, when you’ve worked with one person with Autism you’ve worked with one person with Autism.’

186	‘that’s the thing and it’s actually people understanding, there are some common threads.’
186	‘I think, I think what um, the services will find it difficult to grasp.’
186	‘You have to spend time with people like my son to begin to understand what makes him tick.’

Plot 3- Stories about Nurturing a Past, Present and Future Relationship with My Son:

Sub-Plot 1: Trying to 'Break Away'

Points linked to the story are highlighted below:

Page number	Quote
155	‘I think we are incredibly close ermm he in times of a crisis he is still very dependent upon me.’
158	‘It’s interesting because she, she started a conversation with him (pause) and immediately he looked at me, and that was, that was the signal, mum I need you to, and from then on.’
159	‘That for me has been the step back from his total dependence upon me. We’ve moved through the total dependence bit, because that’s what it was, and now I’m still there, I’m still there to enable him not in every aspect.’
164	‘You know I did want to look forward to some kind of freedom in the future.’
183	‘I’m aiming for my son to be independent, I’m not wanting him to remain dependent.’
183	‘But in order to get him to be independent, doesn’t matter who you are, whoever’s working with him has got to understand what it is that he needs, what is it that makes him fly.’
197	‘I would have to feel that he’s made much greater progress in his independence before I could decide, that we could move and leave him In the hands of other people.’

Sub-Plot 2: The need to continually view positives in the relationship

Points linked to the story are highlighted below:

Page number	**Quote**
182	‘Instead of saying what he can’t do I try to demonstrate to people how he does things.’

183	‘And there’s a big difference. But I’ve learnt how to do that whereas I can hear other parents who perhaps have got younger people say oh he can’t do that, oh he won’t be able to do that. And I’m thinking and I know why they are doing it because that is there experience (pause) but they haven’t yet moved forward into finding out how.’
187	‘That my son is his own person and must be allowed to be his own person and not the person that I want him to be’
186	‘Yes he’s very sociable; he goes out on his own.’

Sub-Plot 3: Survival Beyond the Parent-Child Relationship

Points linked to the story are highlighted below:

Page Number	Quote
162/163	‘I can remember quite vividly, one thing was handling the here and now, what was going on at the time but I had one eye on the horizon, I always had my eyes on the horizon for my son and for my husband and I and I thought.’
165	‘I was always looking, as I say to the horizon, I wasn’t just living in the here and now, I wanted to make some plans for my son.’
171	‘The whole point of supporting him is to try and help him make progress, now he is making progress, very small steps.’
187	‘A team of people in the hub of an autism community, all you can expect is to keep people safe erm, enable them to lead a reasonable life of what they want to do, they’ve got to be allowed to be themselves.’
189/190	‘Um. Even now, I don’t, Joe’s concept of what the futures gonna look like if my husband, either of us dies, which we will, my husband’s going to be seventy in November.’
190	‘But the loss of this house, we’ve been here over thirty years, it’s been part of Joe’s life but, There’s no way he could live here on his own.’
190	‘So there’s a lot of things on the horizon for Joe to deal with which, you know, I, if my husband goes first, we will deal with it together vice-a-versa.’
194	‘And, you know, that has been, I, I kind of all the time I felt that I’d got to keep safe cos nothing’s going to happen to me cos if anything was gonna happen to me, what was gonna happen to my son?’
198	‘The reason I think I plough so much, invest so much into doing what I do with Joe, and with other people, If you like, even with people like yourself, is because I want to try to set, the base on which people will understand what help my

	son will need throughout his life.’
198	‘And my big, big anxiety is what’s going to happen to him when I no longer do what I do because who knows what’s going to strike me down.’
198	‘I’m acclimatising myself to the idea, that when I’m dead I can’t worry about it anymore.’
198/199	‘I keep a journal. Uh, don’t write in it every day but sometimes I feel so overwhelmed by my sadness at my sons (pause) prospects, that I, I have to write things down in order to dump them.’
199	‘Fundamentally, when you have a child with a disability, you have a different relationship with that child. As they grow older, you, I would use the word I’m haunted by what’s going to happen to my son when I’m not there.’
202	‘The other thing I say to my doctor is I want my son to die before I do. So that he won’t be left here on his own. (pause)’

Stage 4 -Reading for Performance and structure

Performance: How was the story told?

- Barbara uses some terminology that may be used within professional settings suggesting she may be familiar with talking to professionals. I think her story is told in a way that is quite polished perhaps as she is used to sharing her story and wanting others to take her and her experiences seriously (possibly demonstrated by the professional terminology). For example, she talks about ‘executive functioning’, ICD-10, and ‘strategies’ in the following quotes:

‘ Still there to enable him, not in every aspect but in quite a lot of his life, particularly these abstract concepts you know the executive function of not being able to plan or organise or predict..’ (page 159)

‘he fitted the ICD-10 criteria’ (page 167)

‘And overload them but I’ve developed strategies for that’ (page 199)

- Barbara uses my name in her performance perhaps to bring me into the story or an attempt to connect with me as the listener. I wondered if it was her wanting to sustain my full attention. For example, she says, *‘But I think also Maria what you also need to bear in mind…’ (page 168)*

- She also uses strong eye contact and leans in towards me when emphasising elements of her story, particularly demonstrated in the following parts of her story:

‘And I’ll, I’ll tell you some things in a minute that I don’t mind you knowing about because I’ve spoken to my Doctor about this and it’s an eye opener for him as well’ (page 171)

‘I remember going out for a meal with her and she just sat there and I said ‘I can’t do this anymore’ and she looked at me and she said, she lent across the table and she said, one more battle, you’ve got one more battle (tearful))’ (page 171)

- Ghost Stories (Minister 1991): For Barbara’s story it seemed that such ghostly stories were particularly present as she delivered her story in a serious and determined manner, perhaps telling her story to potential carers or services that may assist with her son’s needs.

What was my response as the listener which may have impacted on the story told?

As the researcher I demonstrated the positioning of being brought into the story by finishing a sentence of a phrase often heard within the Autism community. As Barbara says, *‘People who really know….”when you’ve worked with one person with Autism….*’ At which I pre-empted the end of the sentence with …..*’You’ve worked with one person with Autism!.’* This demonstrates my co-construction of the story as the meaning is developed together as I have involved myself in her story.

Structure: How was it organised and structured?

How was it structured?

- *Barbara was very aware of staying on point. She is aware of wanting to answer a question fully and re-directs herself back if she feels she has deviated. I wondered whether it was because she was quite focused on wanting to fully answer the questions in line with her identity as someone working with professionals, researchers, carers to help others understand her son. For example, she says, ‘so, going back to your question about professionals…’ (page 187) and ‘but going back to the dependency’ (page 161)*

- She is quite systematic in responding to the question, listing her responses in turn. *E.g. 'The next people who I thought were very good were…' (page 180)*

What was the narrative trajectory of the story told?

- The structure as a whole is one of 'progression' with several apparently 'triumphant' experiences and 'victories' described through the narrative. Progressive narrative trajectory is noted by Lieblich et al (1998) to be one which advances steadily possibly moving from decline to triumph, a structure which Barbara appears to convey. Barbara shifts easily and consistently through topics, although she is clear at which points she wants to emphasise and clarify as salient points, performing with a competence seemingly honed by previous narrative performances in this area.

Stage 5-Reading for Context and broader narratives

Barbara's transcript was read for broader narratives that were present. Following analyses of all the transcripts, four main broader narratives were identified. I have demonstrated circumstances whereby these are displayed within Barbara's transcript.

Gender Narratives

Barbara talks about her relationship with her husband, alluding to different grieving responses (in relation to the loss of another baby) and coping strategies. She talks about different approaches between them in relation to her sons needs also, which may be alluding to the wider cultural contexts of gender that may identify different responses between males and females

It appears that for she took the responsibility in 'battling' in the earlier stages and describes the point whereby her husband then began to get involved as she says, *'Um, and I think he felt then that, in order to move this forward, he had to be a part of what was gonna happen next which was all the tribunal and that was the first time where I could engage with him on the things we were writing.'(page 192)*

She also talks about his involvement being predominantly practical way stating, '*from a practical point of view and if you like a business point of view it was like a business doing all of this'* (page 192). She also makes reference to them having different views stating, *'My husband and I we were, ppsss. we were at loggerheads, it has huge impact on the family.' (page 171).*

‘Normal Family Functioning’

Barbara makes references to comparing or judging against a socially constructed view of ‘normality’. This is demonstrated in the following quotes;

‘And when I go out with them, I, it’s not that I see what I missed, but it’s all so normal’ (page 195)

‘he showed original signs of being, you know, being able to pull him through there were expectations that he would. how do I Say this? Normalise.’ (Page 166)

Role of the parent

Barbara talked about ‘the life of a parent’ perhaps as if she has an alternative construction of what that should or should not be, perhaps drawing on broader cultural narratives of parenthood. This is demonstrated in the following quotes;

‘About what you’re miss as a parent, and you, your role, your role as parents are so different’ (page 195)

‘I haven’t had, the life of a parent that I would like to have had’ (page 195)

‘My life is different, when I, I’m, I’m sixty-six, when I go out with woman of my age and I listen to them talking about their grandchildren, I’m not a part of that’ (page 196)

Independent Living

Barbara talks about her hopes for her son, a lot of which focuses on wanting him to have a life that is less dependent on her, perhaps fitting with wider cultural narratives of independence. She also makes reference to her aspirations of her son’s independence and future being in contrast to others. This can be seen in the following quotes;

‘my life is, my, my, my perspective on life, you know I listen to people talking about their kids in university, driving a car, getting married, the wedding, the grandchildren and I’m, that’s not my world’. (Page 199)

‘Oh, I wish he could meet somebody, I wish somebody could come along and perhaps somebody normal’ (Page 200).

‘We’ve tried to give him a life. And that’s what we want for him to have a life’ (page 200).

And that's been the story of my life all the way through to try and dig deep, to be resourceful to enable my son to do things for himself' (Page 185).

Appendix J - Barbara’s Transcript

Speaker key:

S1 Speaker One (Researcher)

S2 Speaker Two (Barbara)

Total: I hour 24 minutes 12 seconds

Speaker	Transcript
S1	Okay erm so can you tell me a little bit about your son and your current level of contact with him?
S2	Right okay well, erm, Joe is 27 and erm I see and hear from him uh quite regularly erm a number of days in the week. What’s quite interesting he um, he moved into a flat last year in November, this is the third attempt at supported living
S1	Okay
S2	And this is the first erm project if you like where I actually don’t hear from him as much as I used to, erm I used to get phone calls at 5 o’clock in the morning, 2 o’clock in the morning
S1	Right
S2	When he was with other, in another project, but now he’s living on his own
S1	I see
S2	In a flat and he gets 5 hours support a day from the National Autistic Society in the form of support staff going in and doing stuff with him um
S1	Right okay
S2	Uh, which is actually quite good and that means for me, at this point in time, the support that he needs is kind of been diluted and shared
S1	Right
S2	So I still play a really big role
S1	Yeah
S2	In his support and that’s mainly because he has additional health needs that’s the, that’s the other big thing
S1	Okay

S2	And there is a huge gap between what the social care support staff can and will do
S1	Right
S2	And what his health needs require
S1	Okay
S2	So my role is still very much, I feel as if I project manage his health needs
S1	Right
S2	Um, ‘cos the gap is still there between social care and health
S1	Sure
S2	And like many other carers I pray for the day when it will be a joined up collaborative
S1	Yeah
S2	Joint initiative where even perhaps the funding for his care will be a, a one pot and not
S1	Sure
S2	That budget and that budget
S1	Yeah
S2	So erm I mean I saw him yesterday it was me that took him to the hospital yesterday for his feet, um, we had coffee together so I have very regular contact, he comes here on a Sunday for erm evening meal and often stays over
S1	Okay
S2	Um, and then I might see him during the week um, so yes very regular contact
S1	Sure
S2	Which I, I think we all enjoy.
S1	Yeah
S2	Um, my husband takes him out err biking on a Saturday morning errr and a lot of err a lot of our participation as parents is really because of his health, he’s, he’s got diabetes so it’s really important that he is encouraged and reminded to stay focused on what managing diabetes is all about

S1	Sure
S2	So when you look at that health condition and then you factor in the autism
S1	Yeah
S2	There are pluses and minuses. The pluses are that he is very rigid about his routine, about his blood testing and this sort of thing but he, he has such poor organisation and planning ability there are certain areas around managing his diabetes that he needs support with.
S1	Right I'm with you
S2	And that's where my role is that the social care support staff
S1	Yeah
S2	There isn't, for me there isn't a breed of person actually that combines social care and health
S1	Right, okay
S2	To actually support him.
S1	Sure
S2	But our regular contact is um (pause) is, is there erm the contact isn't always positive
Se	Right
S2	there is quite a bit of friction between my son and I on occasions because I'm the one who challenges him all the time, I'm the one who pushes his boundaries
S1	Right.
S2	Um
S1	So how would you describe your relationship with him then do you think?
S2	I think it is a bit of a paradox.
S1	Right
S2	I think we are incredibly close ermm he in times of a crisis he is still very dependent upon me.
S1	Right

S2	Erm I think at times he is very irritated by me
S1	Right
S1	So it’s, it’s quite, erm quite a difficult relationship to handle erm because sometimes erm yesterday was a really good example erm we had to go to the hospital for his feet uh in St Albans, so I picked him up, he does charity work on a Monday morning, he goes to a charity shop for 3 hours
S2	Okay
S2	So I picked him up from there. I had made him lunch because we didn’t have time so I made sandwiches
S1	Right
S2	And we were fine um good interaction, conversation and then when we got to the clinic erm he’d failed to bring with him the inserts in his shoes.
S1	I see.
S2	And he really wasn’t wearing the right shoes.
S1	Right.
S2	And I noticed that then and then I feel guilty because I’m thinking I should of, I should know by now
S1	Right
S2	Not to trust him to plan
S1	Right
S2	Or organize or predict and when we got to the clinic, I was cross
S1	Right
S2	And I and I, I said to him ‘Why didn’t you do this, why didn’t you do that? And that changed the entire mood
S1	Right
S2	Within those 30 seconds and I could have kicked myself for being cross but it was a human reaction.
S1	Sure sure, indeed.
S2	Of saying to this man who’s 27, why didn’t you remember to do this, I told you not to wear those shoes, where are the inserts

S1	Yeah
S2	What do you think, you should have thought about this yesterday. I saw you yesterday and I said to you yesterday, how's your feet, remember we've got the hospital appointment tomorrow, I said and you never said anything at the time and this, I could feel,
S1	Yeah
S2	I could feel that I was escalating
S1	Right
S2	I was escalating this through my frustration
S1	Sure
S2	And guilt.
S1	Yeah
S2	But I should have known better, I shouldn't have
S1	Right
S2	Relied on him
S1	Right
S2	To do all the things that I know he can't do.
S1	Sure
S2	So and and
S1	It's a difficult one
S2	It was a difficult but it changes his mood.
S1	Right
S2	Towards me so in the end, like after a few seconds of this, because you know it doesn't take too long to have this sort of conversation I just walked down the corridor away, just to take some deep breaths and just think about how, and say nothing, silence with my son is often a good anecdote (giggles)
S1	Right okay
S2	Erm to so to, to actually not even say anything else
S1	Okay

S2	And leave it now, leave, leave the conversation, leave all that outside the, the appointment door
S1	Right
S2	And then when we got in I still didn’t say anything but for me I had to watch what, what was the trigger that I could then talk again to the podiatrist, what was the trigger and I had to watch for that
S1	Right
S2	And um it’s interesting because she, she started a conversation with him (pause) and immediately he looked at me, and that was, that was the signal, mum I need you to, and from then on
S1	Yeah
S2	It was fine.
S1	So what kind of role do you think you play in your son’s life?
S2	I’m a facilitator.
S1	Right, Okay
S2	I, I believe that I am, I am the um, what’s the word erm not alter ego, what’s the word, there’s a word for somebody who, who thinks for him, speaks for him on occasions, not all the time, plans and organises everything for him. I, I am, I am the, the background hub of his computer.
S1	Okay
S2	Do you know what I mean
S1	Mm hmm
S2	It’s like you know, you see things, like when you press the button to search on Google for example, there’s all that stuff must be going on in the background
S1	Yeah
S2	It, uh, uh, you know my, minutia activity
S1	Yeah
S2	To bring up the results
S1	Yeah
S2	So if you like I’m the stage hands in the wings so that he can be front of stage in his own life

S1	Right
S2	That’s how I see my role I, I am, sounds a bit naff but I am the wind beneath his wings
S1	Right
S2	So that he can fly
S1	Yeah
S2	That’s how I see my role
S1	Sure
S2	And there is a really big difference because that’s, that has evolved over time
S1	Sure
S2	I, that for me has been the step back from his total dependence upon me
S1	Right, okay
S2	We’ve moved through the total dependence
S1	Okay
S2	Bit, because that’s what it was, and now I’m still there, I’m still there to enable him
S1	Um Hmm
S2	Not in every aspect but in quite a lot of his life particularly these abstract concepts of you know the executive function of not being able to plan or organise
S1	Sure
S2	Or predict
S1	Yeah.
S2	That’s where I’m a discreet supporter really
S1	Right I’m with you
S2	So ermm you know, to enable him to get out there
S1	And can you tell me a little bit about when you noticed that kind of change like you say from total dependence to a slightly different level of dependence

S2	Well it goes back to um, that's quite interesting I don't think there is any one point
S1	Um hmm
S2	Erm what, what was happening, in infant junior school my son was in a special unit for speech and language
S1	Okay
S2	And errm then he had to come out of that unit at the, at year 3 because it was only an infant and he was in juniors what they described as juniors then and then he went into mainstream in the same school and the first year was like a transition year and the second year it became obvious that he was failing, he was failing socially and also failing, even with an assistant in the classroom he had quite, he had 15 hours support a week in the classroom
S1	Right
S2	And he was still failing, I hate to use that word. And then he went off to ermmm, the long and short of it is he went off to a secondary school for children with moderate learning difficulties but they had a year 6 so he went before the secondary year so he went in year 5 towards the Easter at year 5, and then remained at that school and then what I was noticing that, there's a huge emotional, hormonal transition between being a child
S1	Um Hmm
S2	In school and then adolescence.
S1	Indeed yeah.
S2	A huge, and what I found in those years, 11, 12, 13 (pause) he regressed in my view
S1	Right
S2	And the relationship between him and I got worse because I didn't understand why he was regressing. I didn't understand these behaviours in the home.
S1	Right
S2	The school were saying to me "he's the brightest boy we've got in our school. I don't know what the mother's going on about" erm "she's the one with the problem" but what they weren't seeing is what was happening here. What was happening here was that he would come home from school. I'd try and be really positive about encouraging him to do his homework
S1	Umm

S2	And things like that, he would go up into his bedroom, he would put himself under his bed, he wouldn't have any curtains open he wouldn't have the blinds open and he was just lying there.
S1	Right
S2	Erm, he wouldn't do any work here, he, he kept on saying um, "homework is, I don't, I don't understand homework, why have I got to work here? I work in school. Why have I got to work here as well?"
S1	Right sure
S2	Erm, he developed this (pause) movement
S1	Okay
S2	And it got worse and worse and worse because when I was helping him read or or wanting to point something out in a book
S1	Um Hmm
S2	Or over there, it's, and that is to this day it's a really really big thing but I don't rest
S1	Would that have been sought of year 11 time or was that a bit younger?
S2	No, it was younger
S1	Right
S2	Umm, and, he he could, if he was here now he would explain to you that it all started um when he was in speech and language unit, a boy in that unit said it was rude to point
S1	I see
	He took it literally and has carried that with him but only against me
S1	Right I'm with you
S2	You can point, my husband can point everyone else in the world can point but not his mother
S1	Right
S2	and he would tell you he hates these fingers on my hand
S1	Okay
S2	He hates them. He really hates them but going back to the dependency

S1	Yeah
S2	Ermm, I think it was, um, a realisation over time that he was in danger of being totally dependent so he would do nothing. Erm, he would get dressed if I told him to, he would shower, If I told him to, he would take a cup from, he would help tidy the table, if I told him to and I, I actually realised that I was doing everything
S1	Right
S2	And the danger was that this pattern of behaviour would actually continue into adulthood if I didn't do something to break that pattern of behaviour
S1	Okay
S2	But every time I tried to do that it was a confrontation
S1	Sure
S2	Huge confrontation and we had some pretty violent episodes here
S1	Right
S2	Um, when I talk about violence it wasn't, violence at me, my son became quite violent to himself through his frustration.
S1	Right
S2	He would stand in the hall and bang his head on the wall
S1	Okay
S2	And he would be sobbing and screaming and crying so we had a really difficult period where the school weren't listening to me.
S1	Right
S2	I was the villain ermmm
S1	How did that feel for you, kind of
S2	I hated it.
S1	You know, being held in that position?
S2	I hated it, hated it. I felt um, extremely isolated, I didn't know who to turn to
S1	Umm
S2	I didn't know what to do because I can remember quite vividly, one thing was handling the here and now, what was going on at the time

	but I had one eye on the horizon, I always had my eyes on the horizon for my son and for my husband and I and I thought
S1	Mm hm
S2	This young man, he’s already getting quite big and I always, when he was in hospital for a long time in his infancy, I always had this view that I didn’t want my on not to be welcome anywhere
S1	Sure
S2	And so I did challenge, I did push his boundaries I did err, I was quite strict with him, structuring the way he behaved etc. etc. but because in adolescence all adolescent boys and girls
S1	Umm
S2	Are pushing the boundaries but of course what he was doing, he wanted to push certain boundaries in his own way but in a direction that he couldn’t go and his mother was trying to rain him in and trying to push him in the direction that he should be going and so there was this big conflict
S1	Right
S2	And it was really a difficult time because I didn’t know who to turn to.
S1	Sure
S2	I was so despair erm, fortunately I was working
S1	Right
S2	So that was rest bite for me
S1	Okay
S2	Um, and I saw that as rest bite and that was the only place that I could be who I wanted to be with people who weren’t a part of what was going on here
S1	Sure
S2	Erm
S1	So where did you turn to, you said that you felt it was tough to
S2	Well, it, it, actually it was a stroke of luck, what had happened um, I began to have my concerns about whether my son was autistic.
S1	Okay
S2	So I started reading, Lorna Wing. I got hold of some stuff um, that

	she wrote and when I read this document, which I haven't got, well I might have it somewhere but I haven't got it at the moment. Erm, everything she said about a child my son, I had a highlighter pen and it fitted everything so I began to have my suspicions and as a result of those suspicions I started to attend the local National Autistic Society meetings.
S1	Right so how old would um
S2	Joe would have been about 12 or 13
S1	Okay.
S2	So you know he was quite, uh, getting on a bit. And I was quite, I was getting desperate because I just didn't feel that, I didn't feel he was making progress in school, I felt this incredible burden that was
S1	Yeah
S2	Only going to get worse
S1	Right
S2	As he grew to be an adult and I didn't want that for any of us
S1	Sure
S2	You know I did want to look forward to some kind of freedom in the future
S1	Mmmmm
S2	You know, from this burden of care if you like
S1	Yeah
S2	And responsibility
S1	And how did you kind of stumble across the Lorna Wing information, how did you
S2	You know I can't remember, it may have been that in year, year 6 we had a locum educational pyschia, psychiatrist, she wasn't part of county and she came to do an assessment and she had mentioned, because we didn't have the internet
S1	Sure
S2	She had mentioned erm semantic pragmatic difficulties
S1	Oh okay
S2	And I think, I think when I went, when I went to one of the branch

	meetings, somebody, somebody gave me this document, maybe she gave it to me, maybe she did, somebody gave me this document and I sat reading it and it was like reading a profile of my son about the history of Thomas the Tank, pebbles on the windowsill, the planets,
S1	Right
S2	you know all the traditional, Egyptology, all these things
S1	Yeah
S2	You know and I thought all these things, you know, can it be that simple?
S1	Sure sure
S2	Erm but at one of these meetings erm a lady came to talk about erm support in London and I can't remember what organisation it was now and I listened to her speak and afterwards I approached her and I said 'Oh I'm really interested' because I was always looking, as I say to the horizon, I wasn't just living in the here and now, I wanted to make some plans for my son.
S1	Yeah
S2	And I'm, I've always been of the view that you have to get all your information before people start telling you what you're going to do. You need to gather everything around you
S1	Sure
S2	So that you're informed when you listen to the suggestions.
S1	Or the options.
S2	And I remember talking to her and of course because I was running around like a headless chicken and the penny hadn't dropped for me and I needed somebody else to point me, to signpost me
S1	Sure
S2	And as I was talking to her I was blabbering, I was saying to her like, you know he's got long term medical conditions, he's Wrexham Hospital blah blah and she just stopped me and she said, 'he's under Wrexham Hospital?" and I said "yes", she said "well can't you ask his consultant to make a referral to the consultant psychiatrist at Wrexham Hospital?" D'you know it never occurred to me.
S1	Right
S2	And that is exactly what I did

S1	Right, Okay.
S2	And I asked his consultant gynaecologist, umph. Gynaecologist?! Um, gastroenterologist
S1	Umm
S2	If he would kindly refer and I explained all the problems, he was aware of the problems that I was experiencing with him
S1	Right
S2	He could see this boy was not developing in the way that, he showed original signs of being, you know, being able to pull him through there were expectations that he would.
S1	Yeah
	How do I Say this? Normalise.
S1	Right
S2	But instead of which by the time he was getting to 10 or 11 he was actually regressing and the behaviour was getting worse
S1	Sure
S2	And he was getting depressed and all the rest of it. So through that he did make a referral to um Professor Jamie who was the Consultant Psychiatrist at Wrexham Hospital at the time in 1999?
S1	And how old would Joe have been then?
S2	99, he was 14.
S1	Right, okay.
S2	And we saw Professor Jamie erm in the September 99 and I took Joe up to see him and I can remember it quite vividly, um, he took Joe in his room err with me and he started off just talking to him you know as they do, very skilfully
S1	Right
S2	And it was very revealing. Um, he said, I remember it was September and he said when's your birthday and Joe is very much erm, 11th October 1985.
S1	Right
S2	Right and he said to him, so how many weeks is it until your birthday? And Joe couldn't answer that question

S1	Sure
S2	One, because he didn't understand the question and two, because he couldn't calculate
S1	Yeah
S2	And there are other things like that so after about erm, was about ¾ of an hour
S1	Yeah
S2	He said to Joe 'Would you mind going out to the reception? He said I'd like to have a word with your mum' so Joe did as he was dutifully told and he said to me I'm very concerned about his language he said, very concerned and he said what I'd like to do, he said, I'd like to refer you to the institute of Child Health to the Logan Centre
S1	Okay
S2	He said where I've got a team, he said, I think we need to reassess this young man
S1	Right
S2	And he said 'I think he needs a thorough assessment because he said I'm not sure (pause) and what happened was he went to, we didn't get an appointment 'til March 2000.
S1	Right okay
S2	And actually they did two sessions, they didn't just do one they did two, so the first time he saw the developmental consultant, he saw a clinical psychologist and a speech and language therapist
S1	Um hm
S2	And then they wanted him back again and they did a second session which is, you know they really took their time
S1	Yeah
S2	And what emerged from that was that he fitted the ICd-10
S1	10
S2	Criteria so they gave the diagnosis of high-functioning Autism. Now Professor Jamie, interestingly enough was not entirely comfortable with that diagnosis because what he said was that he felt that because Joe had been so ill for such a long time, he's got a very chronic bowel disorder
S1	Right

S2	Very, he's got an autoimmune disease
S1	I see
S2	And he felt that he'd suffered brain damage
S1	Right
S2	And that he felt that ermmmm, (pause) that that, the outcome he didn't argue with the diagnostic outcome because he fitted the criteria but he said the, the, the journey's not a straight forward developmental journey
S1	Okay
S2	It's probably acquired brain damage
S1	Okay
S2	So that's what he, that's what he said
S1	I'm with you.
S2	But I think also Maria what you also need to bear in mind, the background of all of this is not just erm the journey to get to the diagnosis for high-functioning Autism
S1	Umm
S2	But it's also the journey that we had through, through Wrexham Hospital, I mean he was in and out of Wrexham Hospital, on and off until he was 18
S1	Right
S2	It was only in the later years in the teenage years that he spent less time in hospital then he spent in because of one thing or another
S1	Physical health difficulties?
S2	Physical health difficulties.
S1	Right
S2	So you know and he, today he's on a raft of medication
S1	Right
S2	Because his pituitary gland doesn't function.
S1	I see
S2	So, you know, you've go factored into all of this behaviours and

	challenges if you like
S1	Yeah.
S2	Um, are all the different aspects of all the different medications that he takes
S1	Sure sure
S2	You know he's been on testosterone since he was 11 erm so
S1	Right
S2	You know there's all of that going on and from a carers point of view that's a huge, complicated, it's quite a complicated profile
S1	Absolutely. Um, I'm wondering, kind of following the diagnosis and time at the Logan Centre did things change for you, did it feel different?
S2	(laughs) No!
S1	No?
S2	I was relieved.
S1	Relieved, right.
S2	I, I felt a sense of relief because I felt that it had, I, at the time I thought well its exonerated my suspicions.
S1	Right
S2	I felt, Oh I, you know, and actually talking to other parents you often hear parents say or a professional ay 'oh mum knew all the time', or the parents knew all the time, or the parents had an inkling.
S1	Mmmm
S2	So I felt a sense of relief and in my naivety, I went to the school, remember this was a school for children with moderate learning difficulties, and the one person who I thought could be a, a kind of an ally if you like was the speech and language therapist at the school
S1	Right
S2	And I said to her well look, this actually does kind of change a lot of things because in my view this means that he doesn't learn in the same way as everybody else.
S1	Right
S2	And her response to that was well I'm not interested in this diagnosis

	because he hasn't changed and my opinion is I don't need to change anything.
S1	Right, okay.
S2	And I was like
S1	What was that like for you hearing that?
S2	Well it was like a smack in the mouth to be honest
S1	Yeah
S2	I just looked at this lady and I, I felt that I'd gone from a degree of elation and relief at getting an acknowledgement of my own suspicions
S1	Yeah
S2	And, and having something tangible that I felt could help my son and that included our parenting as well
S1	Yeah
S2	You know explaining why he behaved in certain ways understanding the rigidity and the inflexibility and the lack of prediction, and you know all those things
S1	Yep
S2	You know understanding all of that, and there was this so called professional lady who was saying to me well it's of no, you know, it was like, brush you away and I just really felt. I felt, I mean, I've gone like this with depression, up and down, up and down
S1	Right
S2	And I just felt
S1	With your own depression?
S2	What am I going to do. Yeah. And I thought, I feel isolated again, now what do I do?
S1	Right
S2	What do I do next? And there was a friend who I used to see quite regularly who's son also um, had, well he has an Aspergers diagnosis and ermm, he was younger than my son at the time and err I remember going out with her one evening and if I'm honest, by this time I'm getting exhausted, I'm getting emotionally exhausted,
S1	Yeah

S2	I'm physically exhausted, I'm getting ermmm you know really finding my own life, I was a very happy go lucky young woman I was friends with everybody, laughed all the time, and here I was, I didn't know who I was I didn't recognise who I was
S1	Right
S2	My husband and I we were, ppsss. we were at loggerheads, it has huge impact on the family
S1	I was going to ask kind of the impact on relationships and things?
S2	Dreadful, dreadful, dreadful.
S1	Right
S2	And I'll, I'll tell you some things in a minute that I don't mind you knowing about because I've spoken to my Doctor about this and it's an eye opener for him as well
S1	Yeah
S2	But, this friend, I remember going out for a meal with her and she just sat there and I said 'I can't do this anymore' and she looked at me and she said, she lent across the table and she said, one more battle, you've got one more battle (tearful)
S1	Yeah
S2	And I couldn't face that, I and I knew what it was, I had to get him out of that school and I had to get him into a special school because otherwise I couldn't see, I couldn't see a future
S1	Sure sure
S2	That was anything different to what we had.
S1	Yeah
S2	And you can see it makes me quite emotional
S1	Yeah definitely
S2	To face that and as I said to you I was working and I made a decision, I'd been talking to different people, I'd heard about people who had gone to tribunal and won their cases and I'd heard about one family who had gone and did it all themselves and I heard about another family and I picked up this man's name, his name was Anthony Jones.
S1	Right
S2	And he was a solicitor in Stroud in Gloucester

S1	Yeah
S2	And he had a really positive track record with families and what I felt I needed. I didn't want any old solicitor to just take my money
S1	Yeah
S2	I wanted somebody who was going to say to me 'look you're wasting your time' or 'I think we've got a case'
S1	Yeah
S2	So I contacted Anthony (pause) ermmm and this was in the, um, oh no, err no I, I in the, I asked for reassessment, I asked the authority to do a reassessment in the light of the diagnosis
S1	Okay
S2	And nobody would support me, the head teacher of the school wouldn't support me the speech therapist wouldn't support me and in the December 2000
S1	Mmmhhhmmm
S2	The authority rang me up and said erm, we, we will reissue the statement but his current school can meet his needs, and that was like errr, it was like
S1	So you were hoping for a reassessment for him to have another statement?
S2	Yep, well I said I wanted him to go off to another school
S1	Okay
S2	Because I didn't feel the school was meeting his needs
S1	And for that to happen they would need to do a reassessment and
S2	Yes which they did, but, what, what was happening was that everything was like, there was some very minor changes but the big changes, I wanted him out of that school
S1	Right
S2	Because it wasn't serving him any purpose, he was time serving
S1	Sure
S2	It wasn't an education, you know education is for life and he was unhappy
S1	Yeah

S2	We were unhappy erm it was awful at home and so in the December I got the phone call at work (pause) and erm I was devastated em my boss, and I'll tell you I worked for the fire service here in Hertfordshire and my boss was the deputy chief fire officer
S1	Um Hmm
S2	And he went along to the chief fire officer and the chief fire officer came and he said to me, whatever support you need we will give it to you, he said, you can use the photocopier, he said you can use the phone he said you just do what you need to do which was amazing
S1	Aww, yeah
S2	And I rang uh Anthony Jones and I said to him this is my position I'd like you to look at the papers and tell me do you think we've got a case
S1	Right.
S2	And I sent him all the papers that I'd got err and that was just after Christmas
S1	Yeah
S2	And he rang me up in January and he said 'You have a case'
S1	Yeah
S2	He said and this is what I'd like you to do. You are to go and see this lady in North West London who's a chartered uh clinical psychologist, a chartered psychologist and an expert witness
S1	Okay, yes.
S2	You're to go down to bath to see this speech therapist down in
S1	Right
S2	Erm, bath in Somerset. And you're to go to this lady in erm, err, Tring who's an Occupational Therapist.
S1	So all independent?
S2	Absolutely independent, and of course I had to coordinate all of that
S1	Yeah
S2	I had to organise if all, but anyway the long and the short of it is we did all of that it costs nearly £12,000 in the end
S1	Right. That you had to fund?

S2	Which we paid and that was my years salary
S1	Yeah
S2	For that year and we won our case and we got the school that we wanted and not only did we get the school that we wanted but the tribunal agreed that he could go back a year
S1	Right
S2	So he went to year 10 not year 11, so it was quite late in his education
S1	Yeah
S2	And he had 4 years at Alderwasley, Alderwasley school in Derbyshire
S1	Right
S2	Which at the time.
S1	So that was a live-in school, that’s a boarding
S2	It was a boarding school
S1	Yeah
S2	Um, which the authority had to pay for and that was a huge, it, it was a huge relief for us
S1	Yeah
S2	A huge thing for Joe (pause) erm, I’ve spoken to him recently about how he felt about going up there and they did it very well because he spent 3 days up
S1	Yeah
S2	There for assessment
S1	*Cough* Yeah
S2	And of course they were so good with these children that they made them feel good about themselves and that was the secret.
S1	Yeah
S2	Of making my son feel good about himself.
S1	And what was the specialist areas of the school, was it specific?
S2	A third of the children were on the Autistic Spectrum

S1	Right
S2	But it was communication difficulties and it was an average IQ, it wasn't, you know what I mean
S1	Yeah, sure
S2	It wasn't, It was, it was a whole range of children, some of whom did GCSE's you know erm
S1	So it wasn't for Learning Disabilities, it was.
S2	No, no, it wasn't.
S1	It was for average and above?
S2	Yeah it was and a third of the children had an Autistic spectrum diagnosis
S1	Yeah
S2	And it was obvious to see, it was really funny, when we first went to the school I saw lots of Joe's, I saw (laughs) you know I saw lots of like
S1	Yeah
S2	Similar young men
S1	Sure
S2	And it was the best thing we ever did for him
S1	Yeah
S2	So, but for him that was a huge thing erm and I had to sell it to him I had to sell him the idea over time, I actually took him out of school in the Summer term.
S1	Right
S2	Erm I decided to take him out of school and I don't know what we would have done had he not won the tribunal
S1	Yeah
S2	I don't know what we would have done, I don't, I couldn't even think about
S1	Yeah
S2	I, I just felt I had right on my side I just felt so strongly that we were going to do this

S1	Yeah
S2	And I needed to feel, I mean I’ve got lever arch files of all the papers and everything and it was a huge undertaking even with the support of the solicitor
S1	Yeah
S2	So
S1	And looking back over the years I guess I’m, I’m interested in what services you think have been particularly helpful or particularly unhelpful? I mean obviously it sounds like that specific school didn’t feel that helpful
S2	I think what I would say is erm, I think when you go back, we’re going back what Joe was 14, he’s 27 now
S1	Yeah
S2	13 years ago I think that, and this is still the case, I think that people don’t know what they don’t know about Autism
S1	Yeah
S2	Erm, I think that erm, there’s still um, an idea that erm, bad parenting is to blame, I still, I still think that’s out there
S1	Right
S2	I think that even the so called professionals who are still debating whether erm these children are just being difficult and manipulative
S1	Right
S2	Erm I think, if I go back, I go right back my son came home here at the age of, he was in Wrexham Hospital for 18 months and he came back here, we were the second family in the country to bring him home on intravenous feeding
S1	Right
S2	And we did it here, 12 hours a night, he had a central line, I don’t know if you know about central lines
S1	Okay
S2	Erm, they’re Hickman catheters
S1	Right
S2	Erm because of his chronic bowel disorder and erm when I got him home I didn’t have any support from the community.

S1	Right
S2	the only support I had was from my GP and erm the first, the first sniff of support was when I was asked to take him for a local developmental erm assessment after he came out from hospital
S1	Mmmhhhmmm
S2	So by this time he was 18 months old so he hadn't been seen, I mean my health visitor at the time she knew what was going on but all the developmental assessments, all the monitoring were going on at Wrexham Hospital and this lady erm I don't know how it happened but she was an audiologist
S1	Right okay.
S2	I remember her, Mellissa Bell and she said to me, because by this time he must have been about 18, he wasn't 2,
S1	Right
S2	He was under 2 and she said to me, has anyone mentioned to you that your son's not speaking and I looked at her and she said he's not even babbling and do you know, I'd spent ages in silence with him
S1	Yeah
S2	And he was, the noises he was making was mmuu muu muu like that
S1	Yeah
S2	And it hadn't occurred to me and from then on she, she um was instrumental in doing two things. She made a referral to the Oaks speech and hearing centre in Waterloo road
S1	Yep
S2	And she linked me in with social services and there was this, and those two things were extremely helpful.
S1	Yeah
S2	Hard work but helpful. The Oaks speech and hearing centre
S1	Yeah
S2	Put him on a waiting list and they saw him every week, a lady called Jenny Smith she'd devised a, her own programme, she's very eminent lady and he saw Jenny Smith, I used to take him on the train in the pram every single week to the, to the Oaks and we would do a programme of sounds

S1	Right
S2	So we had picture, so a candle was “pu” and ball was “bu” and a motor car was “mu” and we went through the hierarchy.
S1	Right, okay
S2	Of sounds and I worked with him for 10 minutes every single day
S1	Right
S2	But she put us on that path and she saw him every single week
S1	Yeah
S2	And after the first year he was talking in phrases
S1	Right.
S2	And she said I could never, she said to me I could never have anticipated what progress he would make.
S1	Yeah
S2	So that was that
S1	So that was a particularly really helpful service
S2	Yeah
S1	It sounds like they were able to detect things quite early and
S2	Exactly
S1	Give you what you needed?
S2	And the social worker came here and she just shrugged her shoulders and she said what can we do to help you, what you also have to remember in those days I had incredible diarrhoea to deal with, with Joe
S1	Right
S2	Poo everywhere
S1	Right
S2	If you’d have visited me 26 years ago
S1	Yeah
S2	You would have seen, in the end we pulled it up, you would have seen carpets with holes cut out

S1	Right
S2	Because of the diarrhoea
S1	Right.
S2	Erm
S1	And this was all to do with his bowel difficulties?
S2	Exactly, exactly, and no language (laughs)
S1	Right, okay
S2	And also what I didn't realise until later on looking back, his rigidity about clothes
S1	Right
S2	When I put things on him he would scream and tear, take them off and I didn't
S1	Right
S2	And food I mean just awful
S1	Yeah
S2	So anyway but what she did for me, she turned the service on it's head and she said I'm going to fund, I'm going to arrange to fund because at the time all the home help service had gone, it was called home help at the time
S1	Right.
S2	She said I'm going to turn this on its head and I'm going to fund two things for you, she said I'm going to fund somebody to come in and do your ironing and do your housework, she said if you feel confident she said perhaps you could just go out for a walk for half an hour while that persons here with Joe
S1	Okay
S2	So so there was that just to take the pressure off me
S1	*cough* Yeah
S2	And then when I was looking around for playschool nobody wanted him because he was pouring diarrhoea out of him
S1	Yeah
S2	And there was one playschool that said "we'll take him" and she

	arranged for him to have 1:1
S1	Right
S2	In a mainstream playschool
S1	The social services did? Lady?
S2	Yeah and the, and the, what they did they used existing staff
S1	Mmmhmmm
S2	And all the staff were wonderful, Joe used to go to playschool
S1	Yeah
S2	With a rucksack full of a change of clothes, a bowl, hand washes, rubber gloves you know everything for staff to be able to manage his diarrhoea basically
S1	Sure
S2	And at the same time he had central line catheter that was the other thing
S1	Right
S2	Hugely risky thing to have because you can get septicaemia if that gets infected because it goes, it went straight into his heart
S1	Right, right I see
S2	So there was a lot of stuff going on,
S1	A lot going on
S2	So that was the first lot. The next people who I thought were very good were the speech and language therapist at the speech and language centre that he attended school. He was admitted with a statement he went to school, he started school with a statement and went to a speech and language unit attached to a mainstream school
S1	Right
S2	And the speech and language therapist there was really amazing
S1	Okay
S2	And bought him on in terms of language
S1	Right

S2	But even then, even she at the end of the three year period was (pause) fooled into believing that he was much more capable then he actually was and her recommendation was that he actually goes into mainstream. My gut feeling was that he shouldn’t of done at that point.
S1	Right
S2	But I didn’t fight it because I’m trying to balance being the over protective over dramatic mother, with listening to what the professional thinks.
S1	What made you feel that ‘over-protective, over-dramatic mother’ do you think? What made you feel that way?
S2	I just think that, (pause) that might be a self-imposed feeling
S1	Right
S2	That might be a self-imposed (pause) assessment of yourself because you’re not professional, you don’t have the knowledge
S1	Right
S2	That other people have got so who are you to challenge a professional to say
S1	Right
S2	You’re wrong, so, so you class yourself as as you think they are classing you
S1	Okay
S2	Err, errr, uh.
S1	Right
S2	It’s quite interesting but I think.
S1	Yeah, okay
S2	You know, a number of times I’ve heard that from other people
S1	Yeah
S2	They thought I was being overprotective, I had
S1	So it had felt that other people had commented about you in that way?
S2	Yeah or (pause), maybe it was other remarks that they made that you know, ’well, well he’s very capable’

S1	Right
S2	And you're thinking but he's not! And actually, it's interesting I still have this problem, I still have this problem even with my son as an adult
S1	Okay, tell me a little bit about that.
S2	(Pause) When people are (pause) wanting my son to do things
S1	Mmmhhhmmm
S2	Because I've had all the experience of being so close to him and knowing how his brain ticks
S1	Mmmmm
S2	I really struggle (pause) because I don't want to be constantly saying he can't do this, he can't do that
S1	Yeah
S2	But I also know that the people who expect him, the expectations of other people will not be met because he can't do certain things
S1	Right. So how does that make you feel? When people are putting demands on him or requests or?
S2	Well it depends on the situation I mean I'll be honest with you I'm really very anxious about the round of assessments that he is going to have to go through because of all the benefit changes
S1	Right sure
S2	And I think he's going to end up losing benefits because people, what you see with my son is not what you get.
S1	Right
S2	But how can somebody in a one hour window of assessment understand the, the, the silent the invisible difficulties that he has with certain functions of his brain
S1	Mmmmm
S2	How do you, so, when all the time, I think what I have done in the past, I try not to do it so much now I try to, I try, instead of saying what he can't do I try to demonstrate to people how he does things.
S1	Right okay
S2	And there's a big difference

S1	Yeah
S2	But I’ve learnt how to do that whereas I can hear other parents who perhaps have got younger people say oh he can’t do that, oh he won’t be able to do that
S1	Yeah
S2	And I’m thinking and I know why they are doing it
S1	Yeah
S2	Because that is there experience (pause) but they haven’t yet moved forward into finding out how
S1	How. So it might be different from somebody else but there may be a way it’s just how
S2	Yeah, and it depends at what stage you are
S1	Yeah
S2	And it depends on you as an individual what your aiming for
S1	Yeah
S2	I’m aiming for my son to be independent, I’m not wanting him to remain dependent
S1	Yeah sure
S2	But in order to get him to be independent, doesn’t matter who you are, whoever’s working with him has got to understand what it is that he needs, what is it that makes him fly.
S1	Yeah
S2	I can give you a really really hot example
S1	Okay
S2	Last Thursday he went to hospital in London because he is under university college for his diabetes
S1	Right
S2	We had to declare, um, I didn’t want to betray my son, I had to explain this to him during the appointment and afterwards. He is obsessed with tea and coffee, I mean really, 5 teaspoons of coffee in a mug
S1	Wow, okay

S2	2 or 3 teabags in a mug
S1	Right
S2	And this has been going on a long time and I’ve spoken to him about it but mum, what does she know?!
S1	Yeah
S2	And I know that you know you can get caffeine addiction, all the rest of it
S1	Yeah
S2	Low and behold he saw Professor Betteridge on Thursday and when I said to him he drinks a lot of coffee so Prof looked at him and he’s really good with my son. He said ‘how much coffee?’ he said well quite a lot you know and anyway we teased it out of him and he said to Joe in a very nice way he said ’you’re an addict’. Well of course for my son (gasp) the professor has told me I’m an addict
S1	Right okay
S2	And he said to me afterward I thought I was obsessed but I didn’t think that I was an addict
S1	Right
S2	So that for him is like, drugs!
S1	Yeah
S2	That’s his
S1	His association, yeah
S2	But in order to get him to not withdraw straight away because that may actually give him really bad side effects and professor said to me in the appointment he said, ’don’t let him just come off will you?’ He said ‘Don’t exchange everything for de-caff, he said, start gradually
S1	Yeah.
S2	He said start with the last drink in the evening and work back
S1	Yeah
S2	So I had to come home, I wish I could show you this because it’s at his flat, I had to prepare notes for staff erm a whole programme of caffeine withdrawal that I knew my son could work with and understand

S1	Yeah sure
S2	And it was, it's a folder.
S1	Yeah
S2	Now by doing that he will follow that programme rigidly
S1	Yeah
S2	But that's the work I put in because I understand how I'm going to achieve success with him
S1	Yeah.
S2	How do you transfer that across to other people who are not thinking
S1	Yeah
S2	Outside of their own box, their own tradition, can you expect society as a whole or individuals even in the professions
S1	Mmmmhhhmmm
S2	To be expert psychologists in my sons needs?
S1	Yeah sure
S2	And that's been the story of my life all the way through
S1	Yeah
S2	To try and dig deep, to be resourceful to enable my son to do things for himself
S1	And what do you think, I mean thinking about professionals, what do you think your expectations are, have they changed over time?
S2	There is, there are changes, there are changes.
S1	Right
S2	I think that erm Autism and Asperger's is on everybody's lips erm I think the perception is slowly changing, what I get very irritated about
S1	Um hmm
S2	And I still here it, I heard it last week, erm, I was talking to a lady on the phone it was totally unrelated to carer or whatever, she's a board member of some group and she said erm, to me, "Oh yes," she said, "well yes' she said to me "I've worked with people on the Autistic Spectrum", the lady in the charity shop said "Oh" she said, "I worked

	with children on the Autistic Spectrum.” People who really know
S1	Hmmm
S2	Erm people who really know, when you’ve worked with one person with Autism you’ve worked with one person with Autism.
S1	You’ve worked with one person with Autism! (giggle) Yeah.
S2	Yes yes and that’s the thing and it’s actually people understanding, there are some common threads
S1	Yeah
S2	I think, I think what um, the services will find it difficult to grasp and of course the resources don’t help because there isn’t an infinite pot of money
S1	Mmhhhmmm
S2	You have to spend time with people like my son
S1	Yeah
S2	To begin to understand what makes him tick and it’s quite interesting ‘cos he’s got Julie, Carl, Karen and Ian, he’s got four people working with him and they have been working with him for a yeah, well, nearly a year, and it’s really interesting because at different, they’re all at different levels of their understanding
S1	Sure
S2	They’re all at different levels of expectations of my son
S1	Yeah
S2	When they first meet him, they can’t see, they’re like ‘why does he need support?’
S1	Yeah, sure
S2	’He doesn’t need any support. He’s very independent’
S1	And you said he is very verbally able.
S2	Yes he’s very sociable, he goes out on his own
S1	Yeah
S2	What does he need from us and it’s interesting because (pause) what they don’t (pause) see and I think what they didn’t see is, or maybe, I still don’t think they see it, is the amount of discreet support that I still give him

S1	Sure
S2	To fill in the gaps, because, cause it’s not a babysitting service and it’s not a taxi service
S1	Yeah
S2	The whole point of supporting him is to try and help him make progress, now he is making progress, very small steps, so going back to your question about professionals
S1	Mm Hmm
S2	It’s a tall ask, it’s a big ask isn’t it of people
S1	Yeah sure
S2	To work with people on the spectrum.
S1	Sure Sure
S2	Erm, you know, if ever there was a case for developing Autistic communities, is this one?
S1	Yeah
S2	Where they can all, they can all do their own thing live, live, live behind their own front door but if you think about it if there was a err, err, a team of people in the hub of an autism community, all you can expect is to keep people safe erm, enable them to lead a reasonable life of what they want to do, they’ve got to be allowed to be themselves
S1	Yeah
S2	And that’s something that I found very difficult to accept
S1	Right
S2	That my son is his own person and must be allowed to be his own person and not the person that I want him to be
S1	Do you think that changed as he got older?
S2	Yes, yes
S1	Yeah
S2	And I still have the conversation with my husband when I say to him sometimes, yeah but that’s you take on it all.
S1	Yeah

S2	Joe’s got a completely different.
S1	Understanding?
S2	Perspective.
S1	Erm you mentioned earlier a little bit about your relationship with your husband having impacted. Would you be able to tell me a little bit more about kind of your relationships, the impact on your relationships?
S2	It’s driven a huge wedge between us.
S1	Right, okay.
S2	We were quite happy when we got married (laughs) and before we had children (laughs). No I think, erm
S1	Does Joe have siblings?
S2	He had a, well, well, his, his sister was born before him. She died before he was born
S1	Right
S2	And he knows about it um and um, I always remember when he was nine years old, he wrote a Christmas list and at the top of that list was my sister and I think that was an indicator of how he was beginning to feel.
S1	Yeah
S2	Actually. I think, and I think he, we talk about her and um, not in a big, you know, not in your face all the time but, you know, she is talked about when it’s appropriate or when it’s mentioned and when it comes up and when her birthday comes around and now, only now um, is he beginning to say I wander what my life would have been like if my sister had been alive.
S1	Right.
S2	You know, how she might have been, we might have argued and I say to him, well, she might be in Australia she might be in the other side of the world and he says “Yes, and I could go and visit her couldn’t I?”
S1	Yeah
S2	You know, so I think there is a loss there for him certainly a loss for us
S1	Yeah

S2	Um, so, so, we had all that before Joe was born.
S1	Yeah.
S2	And um, and then because Joe was in hospital for so long
S1	Umm hmm
S2	That was the first that was the first hit of the wedge.
S1	Sure
S2	Because I spent all the time, I mean spent the first three months living there
S1	Yeah
S2	And then, you know, he was in there for eighteen months and then when I got him home, I'm still the main carer, I'm still doing all that I need to do, I'm still having, if you like, to prioritise his needs over and above my own and my husbands.
S1	Yeah
S2	And gradually you know, the wedge gets deeper and deeper and (pause) If I'm honest . . . I think the only reason that my husband is here now is because he. . . . one he loves his son
S1	Right
S2	And he has a deep sense of responsibility for his wife and his son and his family
S1	Right
S2	And he's not a man to walk away.
S1	Sure
S2	Um. And I think from that point of view I've been very fortunate but um. . . The impact on both of us, separately and together is. . . Um. (Pause). Our lives are very limited
S1	Right
S2	The choices that we make either for ourselves or each other are extremely limited, uh, we never felt we could move house with Joe because he would be devastated at the change.
S1	Sure.
S2	Um. Even now, I don't Joe's concept of what the futures gonna look like if my husband, either of us dies, which we will, my husband's

	going to be seventy in November
S1	Right
S2	Um. And nobody knows what's round the corner but not only about the loss of either or both parents,
S1	Um Hmm
S2	But the loss of this house, we've been here over thirty years, it's been part of Joe's life but,
S1	Yeah
S2	There's no way he could live here on his own
S1	Sure
S2	So there's a lot of things on the horizon for Joe to deal with which, you know, I, if my husband goes first, we will deal with it together vice-a-versa but, you know, there's lots of things there so. . . From my husbands and I point of view, um (pause). He has been a good friend to me.
S1	Yeah
S2	Um, it took him a long time to (pause) I think originally, the last thing he ever wanted was, as he said all those years ago, um, because we both got married late, he was thirty-eight and I was thirty-six when we got married
S1	Right
S2	And I was his first wife and he was my second husband
S1	OK
S2	And we never thought to have children really when we got married but then when we did and we had our daughter and she died, I mean that was just so devastating for him
S1	Course
S2	And he carries a lot of anger around that, which I don't think he's ever dealt with or worked through
S1	Right okay
S2	So I think he still holds that anger um. . . *cough* Then, um, cos my daughter died as a result of medical negligence, and then when Joe was born it felt like lightening striking twice and he just could not cope, so when he was rushed to Great Ormond Street from Maternity Hospital, what I remember vividly is I'm in the cubical all

	gowned up with the doctors and the nurses
S1	Yeah
S2	You know with this tiny little baby, my husbands pacing up and down outside and then the next thing I look and he’s gone.
S1	Right
S2	Because he couldn’t take, he couldn’t cope.
S1	Yeah
S2	And that went on for a long time, years . . . that went on for years.
S1	Right, so when Joe growing up, maybe in the younger years
S2	Yeah and I mean he used to do shift work so he was sometimes here in the mornings sometimes not in the afternoon and, and, there was this process of separation.
S1	Yeah
S2	Uh, because of the needs of the child.
S1	Right
S2	And, I couldn’t be everything, I couldn’t be superwoman, um and in the end, I, if you like, I turned to my son, gave him (pause) more perhaps, than I was prepared to give my husband because I thought well you’re old enough and ugly enough to look after yourself, I, it’s him I’ve got to look after.
S1	Right, so it would change the nature of your relationship with your husband
S2	Absolutely, absolutely.
S1	Yeah
S2	And I think, um, the wedge just got deeper and deeper
S1	Hmm
S2	And, it wasn’t until the tribunal. . .
S1	Right
S2	When we got to tribunal where we got to making that decision that this was how we were gonna move forward in the year.
S1	Hmm

S2	2000
S1	Yeah
S2	I think my husband had seen the pressures on all of us, and it kind of hit home and I think he like me, were at that time, we just wanted rid of him.
S1	Right
S2	We just wanted rid of Joe, we just couldn't cope with anything else, we just wanted him out of our lives, we just wanted, we didn't want to do it anymore.
S1	Sure, sure.
S2	We just didn't want to do it anymore, so, at that point, I think my husband could see, I mean, I was probably teetering on breakdown.
S1	Right
S2	Um, and I think he felt then that, in order to move this forward, he had to be a part of what was gonna happen next which was all the tribunal and that was the first time where I could engage with him on the things we were writing.
S1	Right
S2	Reading, get him to read the reports
S1	You felt there was unity at that time?
S2	Yeah, at.
S1	Yeah
S2	I felt we pulled together at, to make and it was costing us a lot of money
S1	Yeah
S2	So there was that as well and I think that um, (pause). That was, that was good from a practical point of view and if you like a business point of view it was like a business doing all of this
S1	Right
S2	You know and (pause) when he went away, to school, you would have thought that that would have been a time of reconciliation
S1	Sure
S2	Between but it wasn't

S1	Right
S2	It was all too late
S1	OK
S2	Um, and um, you know, my husband and I haven’t slept in the same bedroom for years
S1	Yeah
S2	Um, and we’ve accepted that that is, that is how it is.
S1	Right
S2	So, so, *uh*, our relationship between us is different
S1	Yeah
S2	To perhaps. . I mean I’m not saying other couples don’t come to that conclusion when they get to be fifty or sixty
S1	Right
S2	But, but I believe that that is as a direct result of the. . . all the things
S1	The pressure and the stress
S2	It’s had that impact
S1	Yeah
S2	So that’s one thing
S1	Yeah
S2	The other thing is, um, I know that over the years, the impact of my sons behaviour and needs has actually transposed on to me
S1	Right
S2	So I can tell you, this was a young woman who travelled the world
S1	Right
S2	Went on Concorde, went to Brazil
S1	Right
S2	Lived in Spain for five years became totally travel phobic
S1	Right

S2	Wouldn’t even go on the motorway.
S1	OK
S2	I, my life, because my life became so limited
S1	Yeah
S2	I think the fall out was that I limited myself
S1	Right
S2	And, you know, that has been, I, I kind of all the time I felt that I’d got to keep safe cos nothing’s going to happen to me cos if anything was gonna happen to me, what was gonna happen to my son?
S1	Sure
S2	So it was all about not taking any risks
S1	Yeah
S2	I became really risk averse.
S1	Did you um, yourself access any services?
S2	Well, what happened was when he went off to school I was at work, I’d taken on a new job, quite a big job with fire safety department, I was there team leader and I was doing all the admin and all the finance for the whole department
S1	Right
S2	And um
S1	*Cough*
S2	Joe went off to school in the October and in the following uh March, it was yearend at work. And um, I was in a meeting
S1	Right
S2	We were talking about how we were gonna cope with yearend, you know
S1	Yeah
S2	The auditors and all the rest of it and the tear came down my face and I couldn’t stop crying.
S1	Right
S2	Just could not stop crying. . And I was off work for six months

S1	Right
S2	And, there's still a lot of emotional *tearful*
S1	Sure
S2	Grieving, I thinks the word
S1	Yeah
S2	To do, um, because, I suppose, and that's for my husband
S1	Yeah
S2	He hasn't got the son that he wanted
S1	Right
S2	He, he's got somebody different. Um. I haven't had, the life of a parent that I would like to have had
S1	Yeah
S2	I have a friend um who has two young children um, she's my neighbours daughter and I'm very close to her and she's got two girls, six and eight
S1	OK
S2	And when I go out with them, I, it's not that I see what I missed, but it's all so normal
S1	Yeah
S2	It enables me to be the Aunty Sue that I wanted to be the Mum
S1	Yeah
S2	You know, so, so there's all of that um, the fact that I'll probably never be Grandma
S1	Right
S2	Um, you know um, there's all of that, emotion
S1	Yeah
S2	About what you're miss as a parent, and you, your role, your role as parents are so different
S1	Yeah
S2	And, and the wedge between my husband and I is a big wedge but,

	what’s happened is, if you like, we’ve started off like this, we’ve come apart, we’ve pulled back together. . . In a completely different relationship
S1	Right.
S2	it’s almost like, he’s, he’s my best friend
S1	Yeah
S2	And I wouldn’t, you know, I’d look after him if he needs it and he’ll look after me
S1	Sure
S2	And in some ways, that almost like a richer relationship
S1	Right
S2	Than perhaps if we hadn’t had these experiences
S1	Yeah, sure
S2	But it’s different
S1	Yeah
S2	My life is different, when I, I’m, I’m sixty-six, when I go out with woman of my age and I listen to them talking about their grandchildren, I’m not a part of that
S1	How does that feel, for you, do you think?
S2	Well, I generally avoid it.
S1	Right
S2	I go out with friends who haven’t got children
S1	Right
S2	You know what I mean at that
S1	So it kind of limits your social
S2	Yeah
S1	Interactions
S2	Yeah
S1	Yeah

S2	Yeah, because I . . . . It hurts, but it's, they're not hurting me.
S1	Yeah
S2	It's the whole situation
S1	Course
S2	That's hurting me
S1	Of course
S2	Um, but you can sort, see, we have a nice home
S1	Yeah
S2	I love my home, and I've got so much to be thankful for
S1	Sure
S2	You know, we're not, it's not as if we're lacking in money
S1	Yeah
S2	You know, we, we can do, we can do what we want to do, (pause) financially we can do what we want to do, it's what we choose to do which is quite limited
S1	Yeah, definitely
S2	Um, and still limited. Um, you know, my husband and I, had Joe been different, we would probably consider moving
S1	Right
S2	Um, but every time we think about moving, we're conscious of all the strong networks that Joe's got in this area which is why we chose for him to live in a private flat in Potters Bar
S1	Yeah
S2	Cos he knows the GP, he knows the chemist, everybody in the town knows him, the proximity to the London Hospital, I would have to feel that he's made much greater progress in his independence before I could decide, that we could move and leave him
S1	Yeah
S2	In the hands of other people
S1	Sure
S2	So that's a restriction, that's very limiting.

S1	I wanted to ask a little bit about that, about the kind of, your ideas, hopes, fears for the future for Joe?
S2	That's a big ask, because um. . I say it now openly, sometimes it forms and I know I'm not alone in this, I haven't got the monopoly, I haven't got the monopoly on misery, I haven't got the monopoly on anxiety or stress or worry but the fact of the matter is, the reason I think I plough so much, invest so much into doing what I do with Joe, and with other people
S1	Mmm hmmm
S2	If you like, even with people like yourself, is because I want to try to set, the base on which people will understand what help my son will need throughout his life.
S1	Yeah, sure
S2	And my big, big anxiety is what's going to happen to him when I no longer do what I do because who knows what's going to strike me down
S1	Sure
S2	Or when I'm not here.
S1	Yeah
S2	And, there is a part of me that is, um, what's the word when you um (pause) oh, what's the word when you force yourself into uh, what's the word?
S1	Like a void? Or?
S2	No, no, when you. . . It's an "ise" word, um (pause), acclimatise
S1	Right, OK
S2	I'm acclimatising myself
S1	Right
S2	To the idea, that when I'm dead I can't worry about it anymore.
S1	OK
S2	But, that doesn't mean to say that, every day when I, every night when I go to bed, there are times when I feel, I, I keep a journal
S1	Yeah
S2	Uh, don't write in it every day but sometimes I feel so overwhelmed by my sadness at my sons (pause) prospects

S1	Right
S2	That I, I have to write things down in order to dump them
S1	Sure
S2	And overload them but I've developed strategies for that
S1	Right
S2	And I can see other people, my husband hasn't got that strategy
S1	Yeah
S2	Um, and it's, it's you know, it (pause), I suppose, fundamentally, when you have a child with a disability, you have a different relationship with that child
S1	Yeah
S2	As they grow older, you, I would use the word I'm haunted by what's going to happen to my son when I'm not there.
S1	Right
S2	I think that's the word, you're just haunted by it so it's different, my life is, my, my, my perspective on life, you know I listen to people talking about their kids in university, driving a car, getting married, the wedding, the grandchildren and I'm, that's not my world.
S1	Yeah, do you. . .
S2	And may never be my world
S1	I was going to say, do you ever feel that it could be, do you ever see Joe meeting somebody?
S2	I would love Joe to meet somebody, I would love him to meet somebody, I'd love him to meet somebody who, I suppose in truth, to take over what I do.
S1	Right
S2	He has no social live, I'm afraid he doesn't go anywhere to meet anybody, I've mean I'm even said to him "Why don't you go on the internet?"
S1	Right
S2	No, no, he wants to meet real people
S1	Right

S2	And the other thing is interesting. . . I think he'd run a mile, I think he's, he's a lot of bravado
S1	I see
S2	He loves oriental ladies
S1	Oh OK
S2	But you know, there's, I fantasise about what I'd like my son to do and it isn't a, what's interesting and don't get me wrong, I'm not giving myself any brownie points for this but I listen to other people, me, I'm fantasising about, "Oh, I wish he could meet somebody, I wish somebody could come along and perhaps somebody normal."
S1	Right
S2	And say, "come on Joe, we're gonna go on, I'm gonna take you on trip around Europe in my van" or something
S1	Right
S2	You know, somebody I could trust, show him world, get him out there
S1	Yeah
S2	Give him these experiences even if they don't, even if they end up a dead end, what does it matter
S1	Yeah
S2	He's gonna, we've tried to give him a life
S1	Yeah
S2	And that's what we want for him to have a life
S1	Right
S2	But, you know (pause), always there's that, going back to what I said, it's not about can't do, it's about how
S1	How to do it?
S2	How and who
S1	Yeah
S2	How and who
S1	Sure, (pause) yeah

S2	I said to my, GP about the the travel, um, cos I got myself into a state this year cos I went to the Isle of White with my friend, she asked me to go
S1	Right
S2	Months ago, and I just said yes and I thought about it and I got into an absolute state about going to the Isle of White.
S1	Ok, what do you think that was about, what was the worry?
S2	Anxiety.
S1	Right
S2	It's deep rooted anxiety
S1	OK
S2	Um, and I went to my doctor, who's wonderful
S1	Yeah
S2	And he said, cos I'm getting vertigo
S1	OK
S2	And I said, I said to him, I talked it through with him and I said you know, I'm convinced that this is one of the fall outs of being a carer
S1	Right
S2	It's part of limiting yourself, making excuses as to why you can't do something. I'm so good at, at trying make ways for Joe to do stuff and I'm very good at making excuses for myself not to do stuff
S1	Sure, sure, yeah
S2	And perhaps that's because, I haven't got the emotional energy for both.
S1	And over the years it would have been, from what you've said, prioritising
S2	I know
S1	Joe all the time
S2	I know
S1	Yeah
S2	I know, so, I'm going to live to one hundred and twenty and the other

	thing I say to my doctor is I want my son to die before I do.
S1	Right (pause), yeah
S2	So that he won't be left here on his own. (pause)
S1	Because it sounds like that's the real worry, because as you say there won't be anybody here necessarily with him. Um, what about extended family, obviously there's yourself and husband
S2	*Laughs*
S1	Any other family or
S2	My husband has a brother and a sister
S1	OK
S2	They're both older than him
S1	Right
S2	So sister's seventy-six and his brother's seventy-three or seventy-four. Um, they've got partners, well, my sister-in-law's got a partner, her first husband died and she's got this partner who's also over seventy.
S1	OK
S2	My brother-in-law's got a wife who's ten years younger than me and there are, she's got two children
S1	Right
S2	Who would be step-cousins if you like
S1	OK
S2	And we never see any of them
S1	Oh, OK
S2	So that's another thing that Joe used to say about, I don't have Grandma or Grandpa
S1	Yeah
S2	Never had Grandma or Grandpa cos my parents were dead before he was born
S1	Right
S2	Um, and, um, Malcolm's mum died when he was about two or three

S1	Hmm
S2	So he’s never had Grandparents either so extended family I laugh hysterically because there is no extended family.
S1	Right
S2	And the other thing is, it’s interesting, a friends *Sigh* I do have an envy for people who say, I don’t know what I’ve done without my friends during all of this, you know, they’ve been so supportive to me, you know, and all the rest of it
S1	Right
S2	And Malcolm and I actually, we have this conversation sometimes and we think, perhaps people don’t like us because
S1	Right
S2	They drop by the wayside.
S1	Oh, so it feels like friends have come and gone in some way does it?
S2	Um, um
S1	Over the years
S2	Yeah, yeah, yeah, I mean, I, when Joe first came out of hospital, because he couldn’t go to a playgroup, I, I had a kind of group here, I had a kind of circle of people with children, I’ve still got the photo’s somewhere, and they would all descend on me um, on a Wednesday or a Tuesday for half a day
S1	Right
S2	It was so funny cos Joe would sit in the middle room crying his eyes out, when all the other kids played with each other
S1	Right, OK
S2	But that was, but that was good until they went to school and then as you see, when they went to school, the friends dissipate, especially because Joe didn’t go to a local school
S1	Sure
S2	He went to a school fifteen miles away and even in that school, when I really did try to make an effort to forge friendships with
S1	Parents
S2	You know I’d drop him and go to the school, I wouldn’t rely on the taxi I would often go to the school

S1	Oh, OK
S2	And forge relationships with parents to, you know to try and
S1	Yeah
S2	Get him integrated and it didn't really he got invited to some parties and things
S1	Yeah
S2	But it was no, and then, over the years I've realised that Joe himself hasn't got a clue how to nurture friendship.
S1	Right
S2	So now, at the age of twenty-seven, I've given up cos I think to myself I can't keep making his friends for him, can I? And it's hard work
S1	And how about your own friendships, have they changed?
S2	Yes but I think, don't you think perhaps life has changed as well?
S1	Sure
S2	There's a lot more pressures, um, I. . . I. . . actively work to retain contact with people so
S1	Right
S2	A lot of, I have um, a friend um, who, I'm actually seeing her this Thursday and it's the first time this year, she lives over in Essex, and she's now got problems with her husband
S1	Right
S2	So she's quite a carer with her husband but even so, she's always busy prioritising other things in her life cos I think she, she has problems with her husband and she needs to get out there and get away from those problems
S1	I'm with you, right
S2	And that. . Doesn't. . include me
S1	Yeah, OK
S2	Um, I have a friend who I met through a previous project where my son was living
S1	Um hmm

S2	Um, one of the, well it wasn't a Mum, it was a Grandma, Grandma Grandpa'd been guardians of this young man and we're now quite friendly with both of them
S1	Right
S2	I'm mean he's eighty-six and she's seventy and, we have them here for lunch and that's quite nice
S1	Oh, OK
S2	But it's the schematic; it's the same old, same old. Uh, I've got a, a friend um, she's a widow, she married a man huge, many years older than herself, he was ninety-one when he died and she's my age
S1	Right
S2	And he's been dead about eight years
S1	Right, OK
S2	So, um, and she lives down the road but she's got her own circle of people that she travels with and goes out with
S1	OK
S2	But we do, you know
S1	Mm hm
S2	Part of my activity is, going to carers events,
S1	Sure
S2	Being involved, I feel I want to turn my negative, the negative impact on my life into something positive, I suppose I'm on a bit of a crusade and a mission, rather arrogantly thinking that I can make a difference so that other people don't have to go through what I go through
S1	Sure
S2	I'm not alone in that,
S1	Yeah
S2	There's a whole army of us out there doing the same thing
S1	Sure
S2	And through those contacts, you kind of, um, you gravitate towards people who,

S1	Course
S2	Can sometimes be your friend, I set up a very small, very informal group here in Potters Bar
S1	OK
S2	I was walking round the streets and I was seeing Mums with kids and I'm thinking, I know he's autistic, you know.
S1	Right, OK
S2	And I feel there's a huge amount of un-met need
S1	Right, OK
S2	Everywhere, not just here, everywhere. So what I did, I stuck a note in a couple of the surgeries and said, my name's Barbara, um, anybody who's looking after somebody with Asperger's, or high functioning Autism or Autism, um, like to get together for a tea or coffee, no work
S1	Yeah
S2	No campaigning, no funding, just sit and chat
S1	Just chatting, yeah
S2	And, there are there could be nine of us but usually there's only three or four of us
S1	Yeah
S2	Different people come according to their commitments and um, they keep coming so we must be doing something right and basically
S1	Right
S2	What we do we sit round a table, we drink tea and coffee in the foy, the foyer in the theatre down here, the theatre it's very accessible and we listen, we talk, we cry, we laugh
S1	Yeah
S2	We give advice to each other we tell each other what strategies we've used and, and they're still coming so
S1	That's excellent
S2	So that's
S1	Something you were able to set up and start

S2	Yeah, it's very informal
S1	Yeah
S2	I didn't want it to be affiliated to the National Autistic Society
S1	Yeah
S2	I don't want to be affiliated to Carers, I just want people to feel they can drop in
S1	Yeah
S2	And there's this kind of, it's interesting, there is some magic about being with people who are in the same position
S1	Yeah
S2	Or with their problems
S1	What do you think is helpful about that, what is it particularly?
S2	(Pause). Not having to explain.
S1	OK
S2	Not being judged
S1	Which can feel the way with other people do you think?
S2	Yeah and not being able to explain why your child is different, I think that's the thing
S1	Yeah
S2	Cos an awful lot of people say, oh, my Jonny does that, Oh, Michael, he didn't talk till he was four, oh they wetted the bed
S1	Right
S2	You know, and we're sitting here talking sixteen year olds, twenty year olds
S1	Yeah
S2	And so the young Mum, she's got a five year old
S1	Um hm
S2	Who's got incredibly, in my view, complicated food issues
S1	Right

S2	And what I've, what I've tried to do is sign post her, trying to explain to her that I think they're beyond her ability without help
S1	Yeah
S2	And saying look go talk to your GP because it's alright while he's five, it might seem novel but when he's fifteen
S1	Yeah
S2	You know, he could be obese he could be anything so and and, what I do, where I see gaps in services
S1	Yeah
S2	I try and escalate that to other people and say look, there's no service that gives people strategies to deal with problems in the home
S1	Yeah
S2	You know, there's no, you know
S1	Yeah
S2	And sometimes, a little bit of input that'll cost you a few hundred pounds to help that mother to cope with these food issues
S1	Yeah
S2	Might save a huge bill further down the line so (pause) you know
S1	Sure
S2	There's, I believe it's a win win all round.
S1	Agreed. Absolutely. Um, I'm aware we've covered quite a lot today, it's been so great you've shared so much with me, might turn this off now if that's OK
S2	Yeah sure.