Exploring the Experiences of Fathers Raising Sons with Asperger Syndrome: An Interpretative Phenomenological Analysis.

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Declaration

This work has not previously been accepted for any degree and it is not currently being submitted for any other degrees.

This research is being submitted in partial fulfilment of the requirements of the University of East London for the degree of Applied Educational and Child Psychology.

The thesis is the result of my own work and investigation, except where otherwise stated. Other sources are acknowledged by explicit references in the text. A full reference list is included in the thesis.

I hereby give permission for my thesis, if accepted, to be available for reading and for inter-library loans, and for the title and summary to be made available to outside organisations.

Tina E.J. Axup

July 2012

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Abstract

My study explores the life-worlds of fathers who are raising a son diagnosed with Asperger Syndrome. It was inspired by previous research where I considered the emotional journeys of parents and the support offered for parenting this group of children (Axup, 2003). Mothers were more accessible and willing to take part than fathers. Findings suggested that fathers had a very different experience from mothers and were rarely heard. This study seeks to uncover this group of fathers' specific needs and recognises they have an important story to tell. Exploring fathers' stories could aid both understanding and support offered, whilst giving them a voice. Fathers' journeys suggested cyclical patterns, where events and transitions surrounding their sons triggered feelings of denial, guilt, worry, frustration, hope and fear (Roll-Pettersson, 2001).

I took a relativist epistemological stance, whereby multiple realities are assumed and social construct, interpretivism and the concept of phenomena are important in uncovering how participants make sense of their experience (Smith, Flowers and Larkin, 2009). The methodology I selected was Interpretative Phenomenological Analysis (IPA). Nine fathers took part in individual semi-structured interviews where I explored their experiences of raising a son with Asperger Syndrome. I analysed my data case by case and identified six main themes. These revolved around different aspects of selfhood which featured within the fathers' stories: Self through time, the importance of identity, relating to the syndrome, position within the family dynamic, their place in the world, and the practice of parenting. I also explored core values and beliefs in relation to fatherhood and their sons' difficulties.

My findings revealed the significance of the phenomena of being a father raising a son with Asperger Syndrome pervading all aspects of their lives. All had a great deal to say, yet some had never been heard by family, friends or professionals. Although a small-scale study, the narratives are supported by literature which suggested that fathers are frequently isolated by their families and professionals (Page, Whitting and Mclean, 2008). Research implications for

Educational Psychologists and wider children's service professionals suggested pro-active work is needed to help fathers engage with their sons and services. Fathers felt a caseworker whom they could trust would help them make sense of bureaucratic systems and provide support from the early years, during diagnosis and transition periods into adolescence and adulthood.

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Abbreviations

AC	Autism Continuum
AD	Asperger Disorder
AS	Asperger Syndrome
ASD	Autistic Spectrum Disorder
Athens	Access Management System, simplifies access to the electronic resources
BBC	British Broadcasting Company
CD Rom	Compact Disc - read-only memory
CWD	Children with Disabilities
DCFS	Department of Children Schools and Families
DfES	Department for Education and Science
DoH	Department of Health
DSM - 1V	Diagnostic Statistical Manual
DTI	Department of Trade and Industry
DWP	Department of Work and Pensions
EBSCO	Publisher of online databases
e.g.	For example
EoC	Equal Opportunities Commission
EP	Educational Psychologist / Psychology
EPS	Educational Psychology Service
HFA	High Functioning Autism
HM	Her Majesty's
ICD (10)	World Health Organisation Classification of Diseases
i.e.	That is
IPA	Interpretative Phenomenological Analysis
IQ	Intelligent Quotient
LA/s	Local Authority/ies
MMR	Measles, Mumps and Rubella Vaccine
MoJ	Ministry of Justice
NAS	National Autistic Society
NICE	National Institute for Health and Clinical Excellence

OCD	Obsessive Compulsive Disorder
PDD	Pervasive Developmental Disorder
Psyc INFO	Abstract database of psychological literature
SAFE	Support for Asperger Families in Essex
SCIE	Social Care Institute for Excellence
SCD	Social Communication Difficulty/ies
SEP	Senior Educational Psychologist
TDA	Training and Development Agency for Schools
UK	United Kingdom of England, Scotland and Northern Ireland

Chapter 1: Introduction

1.1 Chapter Overview

This introductory chapter outlines the context and aims of my research into the experiences of fathers raising sons with Asperger Syndrome (AS). The socio-political context acknowledges that many fathers struggle to balance emotional support for their families with employment. Two different models of government intervention which aim to ease this dilemma are considered. The chapter moves from generic issues for fathers to those affecting fathers of children with disabilities, and finally, specifically for those raising sons with AS setting the scene for the literature review.

1.2 Research Context

AS is a social communication difficulty believed to be at the higher end of the Autism Continuum (AC) (Attwood, 1998). Unlike many young people diagnosed with 'Classical Autism' those with AS have average to above average intelligence and are able to communicate verbally. Issues arise from the large developmental gap between cognitive skills and social abilities (Jordan, 2002; Ghaziuddin, 2005). The Diagnostic and Statistical Manual of Mental Disorders (DSM-1V) and World Health Organisation Classification of Diseases (ICD-10) are commonly used to diagnose AS. Medical evidence is increasingly making a genetic link, suggesting that some fathers may share traits or are on the AC themselves (Baron-Cohen and Hammer, 1997). Meeting their own difficulties through their sons may make diagnosis hard to accept (Ives and Munro, 2001). Such factors could affect expression of feelings and experiences, parenting ability and research engagement.

This study originated from my prior research on the emotional journeys of parents raising children with AS. It considered the support parents actually received and

wished they had received. Only mothers volunteered for interview (Axup, 2003). Parent research often focuses on mothers as they are more accessible and usually the primary carers (Rohner and Veneziano, 2001). Previous research and professional anecdotal evidence suggested that important issues unique to fathers are often overlooked (Axup, 2003; Wilgosh and Scorgie, 2006; Harrison, Henderson and Leonard, 2007; Meyer, 1995). The researched literature argued that fathers often felt isolated within the family and few had a voice in working with professionals and general decision-making pertaining to their child (Harrison et al, 2007; Meyer, 1995).

Evidence of relationship breakdown between parents is more common amongst those sharing a child with a disability, particularly a child on the AC, (Gaines, 2001; Axup, 2003; Harrison, et al., 2007; Meyer, 1995). Fathers can play a crucial role within families enduring parental stresses in raising a child with disabilities. In my professional experience young people with AS, brought to the attention of Educational Psychologists (EPs), are usually boys. Therefore, it was felt that father-son relationships would be of particular interest.

In enabling fathers to participate in the research I drew upon my experience over fifteen years in supporting children with AS and their families. My adult counselling experience was also invaluable in encouraging participants to tell their stories. As the Specialist Senior Educational Psychologist (SEP) for ASD I also facilitated the local multi-agency Autism Steering Group; a forum for influencing strategy and potentially disseminating findings.

The following research focused on fathers remaining in the family home. It was hoped that this might shed light on coping mechanisms employed. Much of the previous literature was anecdotal, whereby the fathers' stories were taken at face value. This research intended to consider issues arising for participants at a deeper level, beginning with their story, but using interpretative phenomenological analysis (IPA) to explore and uncover the essence of the experiences and their meaning for the participant's 'life-world' (Smith, 2009).

1.3 Research Aims

The research title highlights the area of study and the method used: ***Exploring the experiences of fathers' raising sons with Asperger Syndrome: Using Interpretative Phenomenological Analysis***. The aim of the study was twofold. Firstly, to explore the experiences of this group of fathers gaining insights through the findings to improve evidence based knowledge and practice across children's services, particularly that of EPs. Secondly, to give participants a voice, heard directly within the interviews, and through dissemination to a wider group of professionals and parents.

This study is unique and makes a distinct evidenced based contribution to educational psychology. My aims were compatible with qualitative methodology and a personal epistemology, which is relativist, emphasising the importance of perception and the changing nature of human dynamics (Figure 2, p.69). Given the experiential focus IPA was chosen for capturing and analysing idiographic data, which focused on individual experiences of the phenomena. The methodology increased the potential for gaining deep insight into complex psychological issues and meaning through in-depth interviews and analysis.

Nine participants were interviewed; one acted as a pilot for the interview process and schedule. Analysis was completed on eight transcripts. Choosing participants who had stayed within their family followed the positive psychology model of studying what has worked (Seligman, Stern, Park and Peterson, 2005). A systematic literature review, between1980–2006, suggested that positive father involvement equated with a range of desirable outcomes for children (The Fatherhood Institute, 2007). There were also pragmatic considerations, participants were easier to contact and perhaps more willing to take part given that they came from a position of success. It may be important to families and professionals to find out how they achieved this.

1.4 The Socio-Political Context

1.4.1 Introduction

This section outlines the socio-political context. It considers how fathers' involvement within the family has changed over time. Relevant legislation concerning fatherhood is reviewed, particularly in relation to children with disabilities. Although individuals were the focus of my study, they all existed, within, and are affected by, the socio-political time and space.

1.4.2 Fathers' Cash/Care Dilemma

The socio-political concept of fatherhood shifted throughout the 20th and 21st centuries with the integration of women and, subsequently, mothers into the labour market. This blurred once polarised gender roles in relation to paid work and care-giving, introducing the cash/care dilemma into family life (Collier, 2009). Many men appeared increasingly dissatisfied with balancing pressures of paid work and family life. This, according to Kilkey (2006), had increased over the past decade, as younger men desired more involvement in child rearing. Kilkey criticised 'gender neutral' policies relating to parental leave, time off in emergencies and part-time working.

The Labour Government (1997-2010) gave fathers an explicit focus, indicating a perceptual shift towards an increased caretaking role within the family. Paternity leave was introduced in 2002, as a 'right to opt into' but not a parental obligation (DTI, 2000). Despite the new legislation flexible working practices for fathers continued to be problematic. Fathers' anecdotal evidence suggested employers were not as willing to allow men time off for paternity leave or childcare responsibilities (Harrison et al., 2007). This was particularly true for fathers of children with disabilities where family demands were greater and flexible working crucial (Meyer, 1995). Kilkey (2006) suggested that the UK should follow the Nordic

example, with explicitly gendered policies and non-transferable ‘daddy days/months’ which men use or lose (Brandth and Kvande, 2001). They justified this by suggesting society’s emphasis should move away from work toward the importance of the family. In my view this change in values could benefit children and thereby transform society through future generations.

1.4.3 The Norwegian Model

The intention of Norway’s government was to enable the burdens and benefits of working and family life to be shared between parents, strengthening father-child relationships. Fathers were granted paid paternity leave, which they were expected to take, in fulfilling their family obligations. This could not be transferred to the mother.

> *Norwegian equality politics, which expects working life to adapt to family policy, contrasts sharply with what we see of new trends in working life whereby the workplace is becoming more and more seductive and greedy...the implicit gender division, where responsibility of reproduction has been seen as irrelevant to the organisation and placed outside the organisation, becoming invisible. The possibility of combining parental responsibilities with responsible, exciting and time-consuming jobs may be difficult. (Brandth and Kvande, 2001, p.255)*

Brandth and Kvande (2001) explored the strengths and difficulties involved in the move from possible shared leave with the mother, to a choice of use it or lose it. The main reasons fathers took the paternity quota were: wanting to stay at home with their child; beliefs that children should be cared for by their parents for as long as possible; and that children need their father’s presence. Lesser reasons were: it is a right, lost if not taken up; it is paid leave; and the mother insisted. Fathers not using their full quota reasoned that: leave and jobs could not be combined; the mother was at home; it was agreed that their job was a priority and income loss could occur. Less commonly they expressed: mothers should care for young children; disagreement with the compulsory nature of the leave; and an unwillingness to stay at home. This demonstrated how the state could lead in changing perceptions of fatherhood. However, most countries, including the UK, have regarded enforced measures with scepticism, preferring opportunities for individual solutions in developing active fatherhood (Kilkey, 2006).

In the UK the Choice for Parents Report increased paternity leave, with an option to transfer a proportion of maternity leave to fathers (H.M. Treasury, 2004). Following this, The Work and Families Act (H.M. Government, 2006) gave fathers the right to 26 weeks paid paternity leave, if the mother returned to work. This reflected increased recognition of fathers in the UK. Yet balancing fathers' parental rights, the equality agenda and business interests continued to be controversial in an era of financial crisis and political turbulence (BBC Radio 4; BBC1, 2010). How far would my participants feel their position as a father of a child with AS was supported by the UK model?

1.4.4 The UK Government's Perception of 'Father'

On the whole, UK government legislation had focused on negative aspects of the fathers' role, although this began to shift from the late 1990s onwards. Political discussion and policy literature in the UK had tended to employ gender neutral terms, e.g. 'families' and 'parents', reflecting traditional perceptions of father as bread-winner and mother for childcare (Page, Whitting and Mclean, 2008). Where fathers were specifically mentioned they were viewed as problematic, i.e., absent, teenage, non-resident, under-age, linked with the criminal justice system but rarely 'normal' (Page et al., 2008; Kilkey, 2006).

> *Fathers were seen as less likely than mothers to respond to communication...that was not addressed to them, did not refer directly to fathers or did not include positive images of fathers and their children. (Page et al., 2008, p.7)*

The Labour Government (1997-2010) realised that a new, affirmative approach to fathers was needed to encourage a positive impact on families and increased involvement in child-rearing. Constructive language and images of fatherhood were vital in promoting changes. Every Parent Matters (DfES, 2007) recognised that advice and support for all parents should be available across services, suggesting the prior, neutral language encouraged practitioners to overlook the importance of fathers' involvement, due to work, non-residency or simple exclusion.

Page et al., (2008) found

> *Where recognition of fathers does exist in national policy, it was focused on certain family services, predominantly Sure Start Children's Centres, teenage pregnancy services and schools, though there was some recognition of fathers in policy relating to parenting support services and youth offending services too. There was little or no recognition of fathers directly in relation to other types of family services* (p.5).

During the past decade several pieces of legislation, relating to fathers, emerged from a range of government departments. Fathers' involvement could foster positive outcomes for children in the areas of health, education and future adult lives (H.M. Government, 2005). Positive relationships between young people and parents were linked with greater academic achievement and stronger mental health (DfES, 2007).

Rights of equal contact were granted for parents living away, mainly fathers. The Work and Families Act (2006) reflected attempts to move away from the blaming and traditional breadwinner perceptions of fathers. Work-life balance was considered, suggesting, although often problematically, fathers were a potentially important family resource over and above economic factors (Kilkey, 2006). Although initially vague as to what fathering entailed it was suggested that the government was moving toward a focus on the caring role of fathers. This bill extended father's rights in taking paid childcare leave and widened the scope for flexible working. The direction the new coalition government will take is currently unclear. However, the prime minister and his deputy promote personal images as 'hands on dads.'

1.4.5 Fathers' Early Involvement

Pregnancy and birth services have traditionally focused on mothers. Fathers may be inaccessible due to work or non-residency (DfES, 2007). Nonetheless engaging fathers more effectively has been considered (DfES, 2007). The DfES and DoH (2004a) claimed that fathers played a significant role in supporting the mother. Services were looking to involve potential and new fathers in the lifelong, wellbeing of their children. Pregnancy and birth provided unique opportunities. It is possible that such involvement could contribute to father's staying within the family home. Pleck and Masciadrelli (2004) suggested that positive relationships between parents

is a key indicator of fathers' involvement in children's early years. Page et al., (2008) argued that health care workers did not know enough about how to engage fathers effectively. Further investigation, by collecting father's views, was recommended prompted by a consultation drawing on the views of parents, children's centre staff, local health practitioners and children (DoH, 2010).

The Teenage Pregnancy Strategy (DCSF and DoH, 2010) highlighted the necessity for mediating positive relationships between babies, mothers and fathers. This strategy indicated that fathers may need support in taking a positive role, yet this could be impeded by services not appreciating the role they play or could play. The report suggested that fathers felt judged and excluded from health, maternity services and Children's Centres. All of these factors could be more potent for fathers of son's with disabilities as their need for services are greater and longer term.

1.4.6 Fathers and Disabled Children

Fathering children with disabilities is under-researched, although anecdotal literature is increasing (Harrison, et al., 2007; Meyer, 1995). According to the DfES and DoH (2004b) fathers played an integral role when children were disabled or had complex health needs, but many felt excluded from aspects of childcare. Work to help fathers feel involved in accessing services and support was recommended. The kinds of issues facing fathers of children with disabilities in the UK were documented through father's stories in Harrison et al (2007), (Table 1, p.9).

Table 1: Fathers' Experiences

Themes raised in the reported experiences of several fathers of children with a range of disabilities in the UK (Harrison et al., 2007).	
Fear for child's safety, future	Professions, Resources and Meetings
Cash / Care balance	Maintaining Leisure time
Transformative experience	Public Reaction
Hopes particularly for sons	Children's behaviour
Isolation	Work and Flexibility
Hidden Difficulties e.g. ASD	Extended Family
Pregnancy, Birth and Babyhood	Identity and Role
Relationship with Partner	Impact on Child's Siblings
Having another baby/siblings	Impact of fathers' own parenting
Having trustworthy carers	Diagnosis
Significance of Other Parents	Significance of Friends
Lack of Sleep	Lack of Respite

The same issues were raised by fathers in my educational psychology practice, yet they remained anecdotal. There was clearly a need for qualitative research to gain a deeper understanding of this group's experiences and needs. Unsurprisingly parenting children with disabilities was a more widely researched area than my specific focus of fathers raising sons with AS. Yet overall the literature focus was mainly on the mother (see section 2.3 of this thesis).

1.4.7 Importance of Fathers in Children's Emotional Well Being

It seemed important to service providers to understand the factors which increased the chances of fathers staying in a family where a child had a disability. Much evidence suggested that parental separation adversely affected children. Correlations had been found between parental separation and early school-leaving age, behavioural disorders, criminality, poor health and low attainment (Amato and Keith, 1991; Haveman and Wolfe, 1994; Amato, 2001; Walker and Zhu, 2007). Parental involvement, including fathers, was identified as a key factor in educational

achievement and social-emotional adjustment, including high self-esteem, better peer relationships, lower criminality and substance abuse (Desforges and Abouchaar, 2003; Page et al., 2008; Flouri, 2005; Goldman, 2005). When fathers left, their time, influence and money often went with them (Page et al., 2008). However, Piketty (2003) researched families in France from 1968-2002, and concluded that parental conflict, rather than separation, had negative effects on children. Walker and Zhu (2007) found that boys, and children with disabilities, were most likely to be affected by conflict and parental separation. Goldman (2005) found that the quality and content of fathers' involvement mattered more for children's outcomes than quantity of time spent with children (DCSF, 2008).

1.4.8 Importance of Fathers in their Children's Education

Government reports drawing on research literature suggested that since the 1970s fathers' involvement with their children had increased, especially with children under five. This varied greatly depending on family structures and increased numbers of fathers not seeing their children daily (Department for Children, Schools and Families (DCSF), 2008). This DCSF commissioned research found that 70% of fathers in general and 81% of non-resident parents, mainly fathers, wanted more involvement in their children's education. Yet only 25% of children had seen their father reading. Research suggested that school links with fathers were important, as a father's interest in his child's schooling had been linked with positive educational outcomes (Ferri and Smith, 1996). Engaging fathers in supporting their children's education via school events would contribute to such outcomes (DfES, 2008). Correlations had been found between fathers' involvement with their children at seven and positive educational outcomes up until the age of twenty (DfES, 2007). The extended schools agenda promoted parents learning alongside their children (H.M. Treasury, 2007). Fathers' own negative experiences of school influenced their involvement and virtual modes of contact could be more father-friendly (DfES, DWP and DTI, 2004). Special school engagement with fathers was particularly low. Reasons suggested were the family context and fathers' difficulties accepting and responding to their child's disability (DfES, 2004; Harrison et al., 2007).

1.4.9 Including Fathers in Family Services

Page et al (2008) studied DCSF and related government policies for the specific recognition of fathers. They were found to be '*partial and uneven' with, 'little or no explicit recognition of fathers in terms of 'legislation'* (p.4). Fathers raising children with disabilities were particularly under-represented. Local Authority (LA) inspections and reviews did not require evidence of support for fathers. Yet some authorities had taken steps to address fathers' access to services, e.g., employing a fathers' worker. There were few authorities who took a strategic lead and where this occurred practice was sporadic and based on individual interest. Father-friendly practices were not regarded as mainstream, '*virtually all local authorities and family services reported that engagement with fathers was substantially lower than with mothers*' (p.6).

Page et al (2008) suggested that there were barriers for fathers accessing services as they were not perceived as a priority group by LAs. She found that the predominantly female workforce lacked training and skills in understanding fathers' needs and the fathers surveyed did not feel services were tailored to them. Staff barriers were policy overload and difficulty tracing some fathers. Page et al (2008) recommended father specific, rather than gender neutral language and services, as 'parent' had often been synonymous with 'mother.' Suggested services included providing help during out of work hours, in father-friendly settings, employing male practitioners and an 'Every Father Matters' document.

Limitations to Page's study included a small sample of only eight UK authorities. Whilst in-depth analysis and interviews with staff exceeded 250, these represented staff perceptions. Potentially, reported perceptions are influenced by what respondents feel researchers or employers want to hear. However, consistent messages of father involvement were linked to positive outcomes for children with the need for increased engagement. Engagement was most likely if individual fathers' needs and motivations were taken into account. Two influential documents, Every Parent Matters (DfES, 2007) and Aiming High for Children: Supporting Families (H.M. Treasury and DfES, 2007) acknowledged that services had

difficulties engaging fathers. The DCSF (2007a) Children's Plan: Building Brighter Futures recognised that both fathers and mothers were vital in improving children's lives.

Ghate, Shaw and Hazel (2000) argued that there were no simple solutions and systemic societal changes were needed to combat a powerful combination of socio-cultural and individual barriers, together with a feminised culture of service provision preventing fathers' engagement. This may have been further impacted by fathers who did not perceive themselves as having an important parenting role or an impact on their children (H.M. Treasury, 2004). Time will tell whether the current coalition government will prioritise this work.

1.4.10 Recent Developments

Every Child Matters (H.M. Government, 2003) outlined an agenda of change necessitating multi-agency work focused on outcomes for children, schools and families. Children's Centres were developed within the community providing parent outreach services. The Training and Development Agency for Schools (TDA) (2010) suggested a new focus be placed on fathers as they carried out a third of direct parental childcare and had a strong influence on the growing child, albeit positive or negative (DfES, 2007). The role father's played and specific engagement with them was important in developing Children's Centres. Fathers felt uncomfortable attending parenting classes and experienced parent support services as negatively judging their parenting skills (TDA, 2010). Recommendations for better access included the communication and engagement with fathers by information gathering, outreach work, more male practitioners and services specifically for fathers, shaped by fathers (DfES, 2007).

Every Parent Matters (DfES, 2007) recommended that schools and services were flexible and sensitive in meeting different fathers' needs; redressing the practitioner gender imbalance. In 2009 The Lamb Inquiry recommended greater access to information for parents regarding special education needs and disability resulting in

LAs being duty-bound to provide information, advice and assistance via their Information Service Departments (Capita, 2009).

In practical terms 98% of respondents of a survey of LA staff suggested that mothers continued to be the group who most accessed services (DfES, 2004). A range of government documents suggested that fathers were unrepresented in universal services (DfES, 2006a) and there were issues of equality regarding access to childcare (EoC, 2007).

Having placed the area of study in a socio-political context there was a clear rationale for my research. Fathers appeared neglected in both legislation and LA provision. It was likely that fathers of children with disabilities felt even more marginalised, particularly those whose sons had AS, a social communication difficulty which impedes parental attachment relationships.

1.5 Thesis Outline

The thesis outline is as follows: chapter one introduces the context of the research, giving a brief summary of the research area, the methodology, and the socio-political arena within which the research was completed. Chapter two reviews relevant literature relating to the role of fathers in general and those parenting children with disabilities, particularly AS. It also considers the theoretical nature of AS using the medical, family systems and the social disability models. Chapter three outlines the ethical and methodological research decisions made. These are reflected through a practical account of the steps taken to complete the research process. Chapter four describes and discusses the findings through the themes and considers the limitations of the method. Chapter five summarises the findings, leading on to implications for professional practice and final reflections.

Chapter 2: Literature Review

2.1 Overview and Rationale

The previous chapter outlined the study and its socio-political context. It raised complex issues surrounding fatherhood illustrating the gradual move in policy and practice towards recognising fathers' importance in their children's lives, particularly children with disabilities.

This literature review drew upon a range of sources: journal articles; lecture/conference notes; books; internet sites; television and radio programmes. Potentially relevant research was identified using peer reviewed journals accessed using databases via Athens: EBSCO; PsycINFO and Ingenta. Search engines were used including findarticles.com and google-scholar. It is acknowledged that some sources were of higher academic weighting than others. In terms of quality the following criteria was applied, relevance to the research area; methodological transparency; clarity of purpose; insightful analysis and journal status. Articles which appeared superficial, generalised or merely opinion rather than evidence based were excluded. Original research studies are rarely available in full and as far as possible peer reviewed articles were referenced with awareness of their partial, selective focus. Specific searches included: fathers and AS; fathers and sons; parents and AS; boys and AS. 27 studies significant to my research were critically reviewed and are summarised in Appendix A.

This chapter begins by reviewing and critiquing the literature on the generic experience of fatherhood moving towards experiences specifically facing those raising children with disabilities, particularly those on the AC, including AS. The nature of AS is also discussed within the context of three psychological frameworks: medical model (DSM-1V); psycho-dynamic family systems model (Alvarez and Reid, 1999) and a social model of disability (Oliver, 1990). The aim was to identify what

was known forming a context for further research into fatherhood. It also identified limitations and gaps within the existing research and the explanatory power of theoretical models.

2.2 Generic Experience of Fatherhood

The literature on fatherhood was important in capturing issues relating to the generic experience. The participant group all have sons with AS yet the father-son relationship related to wider experiences and stages from conception, through pregnancy and later development of the father-son dynamic.

In a survey completed by the National Childbirth Trust (in Hinckley, Ferreira and Maree, 2007) fathers reported feeling ill informed and disregarded by professionals. Gaining practical support in dealing with experiences of pregnancy, labour and baby care was difficult. Studies of expectant fathers suggested fathers may move through stages of identity change relating to the physical manifestations of the foetus and/or the baby's birth. Habib and Lancaster (2006) suggested the first stage marked the *'germination of a new identity status, becoming a father'* (p.236). The father's perceived status may predict the primary role he will play e.g., '*supporter'* of the mother or the '*provider*' (p.238).

The literature suggested that cross-cultural issues existed regarding the transition to fatherhood and the role of father. In many countries, including the UK, gender roles were changing and blurring (Hinckley, 2007). Hence fathers' perceptions traditionally influenced by cultural 'masculine' images and views of childcare as 'woman's work' were changing as a new generation of men sought a more active role in child-rearing (Hinckley et al., 2007; Collier, 2009). Parents often felt unprepared when entering parenthood. A common belief was that motherhood came naturally, whereas fathers' skills required formal learning (Smith, 1995).

Studies of father-son relationships suggested a unique quality different from mother-son relationships (The Fatherhood Institute, 2007). It was not always clear in the literature what the relative impact was of nurture or nature within the father-son

dynamic. The relational attachment history might have been intergenerational and longitudinal research suggested that father-son attachment has had lifelong implications for sons (Parkes, Stevenson-Hinde and Marris, 1993). Shifts occurred throughout life, related to sons' developmental changes and the simultaneous development of the father role. The implications of this work are reflected in the use of the Adult Attachment Interview, which has extensive research validation, for assessing parenting capacity (Main and Goldwyn in Siegel, 1999). The next sub-section considers how such parenting capacity begins to emerge in the preparation stages of becoming a father.

2.2.1 Becoming a Father

When first becoming a father a man would not know that his son has AS, as it is not identified during birth or babyhood. My research is related to the experience of being a father in its entirety and it is prior to the birth that many hopes and dreams about a child would be developing. Very little research has focused on the man's experience. Despite cultural differences, it could be argued that becoming a father is a global experience and some commonalities are likely.

The literature suggested that fatherhood is a major transition and there may be certain resilience factors which make this easier and more successful. Services need to know what these, and any inhibitors are. During pregnancy, birth and baby-care societal focus is usually on the mother. Unsurprisingly research largely reflected female experiences (Johnson and Baker, 2004). There appeared to be gaps in the research on the experiences of fathers in the UK. Literature from Australia (Boyce, Condon, Barton and Corkindale, 2007), South Africa (Hinckley et al., 2007), USA (Holland-Wade, 1998) and Sweden (Roll-Pettersson, 2001) were informative. However, findings may or may not be cross-culturally relevant. Draper (2003) was the only other relevant UK study apart from Johnson and Baker (2004).

Johnson and Baker (2004) sought to identify English men's coping skills following pregnancy, childbirth and miscarriage in a longitudinal study. Coping was defined as *'constantly changing cognitive and behavioural efforts to manage specific internal and/or external demands that are appraised as taxing or exceeding the resources of*

the person' (p.87). Two main strategies emerged for fathers to be, coping and avoiding. Findings suggested those using coping strategies were more able to deal with the transition to fatherhood and suffered less anxiety. Johnson and Baker (2004) acknowledged that pregnancy and birth were major life events, which could raise negative emotions, high stress levels and anxiety in men. Stress levels appeared to increase at the birth and remained high for some time, falling after a year, whereas depression increased.

Pregnancy commonly provoked family stress and anxiety and an interest in fatherhood and the transition process grew. Johnson and Baker (2004) suggested that pregnancy could have negative effects on men's psychological and physical health. Stress arose in supporting partners, providing financial resources and losing their source of support, the mother. '*The person the man is supporting is the very person from whom he himself often receives his own support, thus removing from him the availability of an important coping resource'* (Johnson and Baker, 2004, p.88).

Holland-Wade (1998) wrote that personal transformation in fatherhood hinged around a dilemma which caused individuals to 'ignore' or 'face'. She suggested that extreme anxiety could cause avoidance, making transformation impossible at that point. It was critical, wrote Holland-Wade (1998), to release old ways of knowing and become receptive to new views of self, experience and context. This could raise feelings of excitement, freedom and loss. Where the new was incorporated into daily life the individuals emerged more creative and with increased resilience. Holland-Wade (1998) emphasised there was no going back, but possibility for further evolving transformation. The transformation often began at a critical point, possibly pregnancy, birth or a diagnosis, which could be the case for my study's participants.

Draper (2003) tested the framework of ritual transition theory to understand men's transition experiences of pregnancy, birth and early fatherhood, drawing on longitudinal ethnographic interviews with a small sample of men from the UK. The sample was not representative, mainly middle-class, tertiary educated men in stable partner relationships. This suggested caution in generalising results across cultures and socio-economic groups. Draper (2003) argued that considering men's

experiences in the context of transition theory enhanced understanding, leading to possible provision changes in meeting such needs.

Inherent in the men's accounts was the acknowledgement that they were changing status; from non-father to father, or already-father to father-again. For many this was accompanied by a sense of role uncertainty and how different life might be.

Draper's (2003) theoretical frame for analysis was based on Van Gennep's (1960) theory of rites of passage. This suggested cross-cultural patterns consisting of three stages: separation, transition and incorporation. The 'separation' stage involved removal of the individual from normal life, a social detachment marked by particular customs and taboos. The 'transition' stage was a 'no man's land' or non-status position, a time potentially psychologically distressing, *'concerned with preventing or containing danger, pollution and harm'* (p.68). The final stage, 'incorporation' involved rituals marking a new status, whereby the person re-emerged having incorporated a new persona. Collective rituals marked the 'sacred' nature of the experience, 'set apart' from profane or daily experiences. For example waiting with a group of male friends for the moment to come and 'wetting the baby's head'. The journey to the hospital marked the couple moving from the ordinary to their new world.

Turner (1974) developed Van Gennep's theory with a particular interest in the transition stage, which he described as 'liminal.' The person was marginal and invisible in status in a period of 'social timelessness,' presenting a potential threat to social stability. There was a loss of status with peers, with individuals *'reduced to an equality of fellow initiates regardless of their pre-ritual status... they were part of a community of passengers*' (p.232). This could apply to the man's experience of pregnancy (Draper, 2003). It could be argued that fathers of children with disabilities could remain stuck never reaching the destination they envisaged as an expectant father (Harrison, 2007). Draper (2003) suggested that emphasising 'individuality' has produced a ritually impoverished western society. She claimed that the nature of ritual in the west was changing and becoming increasingly diverse. Draper's interview data also reflected three theoretical phases, with transition being marked by marginalisation and vulnerability. Crossing the boundary into fatherhood was explored alongside the continuous nature of transition.

During pregnancy men reported a lack of knowledge of the process, felt an inability to engage and a sense of being redundant. Where women have visual signs of their changing status men do not. Pregnancy was described by some men as a 'limbo state', with the inability to physically experience the pregnancy and no direct feeling of what their partners were going through (Draper, 2003). Draper described labour and birth as an ambiguous period for men. In recent times men are more likely to be present at the birth, however most felt out of place, powerless, vulnerable and not sure what to do.

Following the birth, men expressed difficulty making the choice between staying with their partner or the baby. For some this marked the beginning of negotiating their role between father and partner; which is particularly difficult when their child has a disability and the future is unsure (Harrison et al., 2007). Draper (2003) pointed out that only recently have men moved from a traditional masculine role of bread-winner and authority figure with clearly different parenting roles. Male rituals such as, smoky waiting rooms, are disappearing. Men may be stuck in a social limbo between the 'traditional' and recent cultural and political changes in family practices; shared employment, division of household chores and a changing notion of fatherhood. Draper questioned a potential need for new rites of passage in pregnancy, birth and the physical and emotional care of children for fathers.

Boyce et al (2007) completed a longitudinal study to find out about the prevalence and nature of psychological distress in expectant fathers during pregnancy. 312 first time expectant fathers in Australia took part. Findings suggested no increased risk of clinical depression but reported experiences of significant distress, poorer quality of life, irritability and depression particularly early in the third trimester. Whilst men had nine months to prepare for fatherhood they had major psychological tasks to complete. Firstly the transition from dyadic to triadic relationships, sharing their partner's affection with a baby and contributing to its care, often with little preparation, '*Men who feel threatened by this are likely to have a less secure relationship with their partner and have poorer social support systems outside that relationship*' (Boyce et al., 2007. p.723).

Marital difficulties formed a major risk factor for mothers suffering post-natal depression, which might exacerbate fathers' feelings of isolation. Secondly, preparing for identity changes included: adapting to new responsibilities; increasing importance in providing emotional, financial and practical support to the mother and less freedom. '*Men with higher levels of neuroticism and who use more immature defence mechanisms would be less likely to cope with these changes and thus experience distress*' (p.723).

Participants felt marginalised, their role of protector being taken over by medical professionals. Women often turned to female friends and men could lose some friendship intimacy from their partners. Men were further isolated by no longer having the freedom to participate in activities which provided them with a social network. It was common for men during this time to grapple with their concept of 'father,' considering their own fathering and what kind of father they wanted to be. Vulnerable men often had no experience of caring for infants, no personal father role model or experienced low care or over protection from their own fathers (Boyce et al., 2007). Did the use of standardised scales and questionnaires bring about a self-fulfilling prophecy in such findings? Further research was suggested, using an alternative methodology to broaden understanding.

Hinckley et al (2007) completed a small scale study in South Africa to investigate the needs of expectant fathers. What kind of guidance was sought and how could it be best communicated? 65 men completed a telephone survey and four of them took part in in-depth telephone interviews. Data captured via telephone has been critiqued for loss of non-verbal communication (Robson, 2002). It may however be advantageous in encouraging information flow with men challenged by face-to-face communication. They found that during pregnancy fathers required more information on fulfilling their role and developing early childcare skills. Both professional guidance and role models were lacking. There was a strong bias towards television as the best potential source of information although cultural and individual differences may affect generalisability. Many men did not have father figures, leading to insecurity and in some cases withdrawal. This is important in considering the 'life-world' of the father, which begins with his experience of being fathered as a boy. Hinkley et al (2007) suggested that highlighting the 'expectant father's' role

could prepare and empower men for fatherhood, promoting healthy father-child relationships.

The studies above considered fatherhood experiences in Australia, South Africa, USA and the UK. Only Draper (2003) used qualitative methodology and analysis. The others handled larger cohorts using methods which could fail to capture fathers' experiential reality (Appendix A). A major limitation appeared to be participant representation of mainly middle to high socio-economic groups (Draper, 2003) suggesting difficulties attracting men from other groups. Turner and Van Gennep's work on the transition or 'liminal' stage may have particular resonance with men raising son's with AS. Fathers of children with disabilities often speak about living in a state of unknowing (Harrison et al; 2007). Within professional dialogue with parents of sons with AS, fathers did not appear to fully achieve their perceived status of fatherhood (Axup, 2003).

It will be interesting to consider my study's findings in the light of transition and life-cycle theories (Roll-Pettersson, 2001; Draper, 2003). Fathers may feel marginal and invisible in status for much longer if expectations of their child are not met. If the child with AS is not achieving expected milestones the father in parallel may not achieve his. Some may be stuck in the 'liminal stage,' finding it difficult to reconstruct their persona where there are feelings of guilt, disappointment or failure. Draper's suggestion, regarding the focus on individuality producing a ritually impoverished society, may have pros and cons relating to fathers of children with disability. Perhaps in today's society there is less taboo, but also less informal community support and uncertain role definition.

2.2.2 The Role of the Father in the Family

The role of fatherhood has evolved over time, as spouse and parent, with increasing recognition of the fathers' part in their son's development. More women are working and fathers are increasingly expected to fulfil childcare roles. '*In (post) modern times, parenting is viewed as a true partnership, a joint venture where all parenting responsibilities are shared by husband and wife.*' (Hinckley et al., 2007 p.462).

However, increased parental choice and flexibility poses risks to work-life balance, (Brandth and Kvande, 2001; Collier, 2009), (see section 1.4.2 in this thesis). Countries have addressed this in different ways. Norway adopted a state feminist system, strongly promoting active fatherhood (see section 1.4.3 in this thesis). UK employment legislation more tentatively, promoted greater involvement through increased paternity leave (Draper, 2003) and equality of access (EoC, 2007).

It is clear that the role of father has changed in our society throughout the last century (BBC4b, 2010) and the popular media has suggested that fatherhood is currently suffering from an identity crisis, whereby fathers no longer know what is expected of them (BBC1; BBC4a; BBC Radio 4, 2010), (see section1.4 in this thesis).

According to Smith (1995) between the 1950s and 1990s the percentage of women receiving help in the home from their partners rose from 38%–82%. The past 20 years has seen an increase in cross-discipline academic study of fatherhood (Draper, 2003). Habib and Lancaster (2006) argued the media has polarised between completely absent fathers or highly involved caregivers. Value judgements as to how fathers should behave and the role requirements carry increased social pressure to conform, regardless of individual '*self-meanings*.' There is a shift in research, *'away from focusing on fathers as absent/present breadwinners to understanding their diverse roles in families…understanding fatherhood from the perspective of the experiences of men themselves' (p.235).* This is the area my research particularly focused upon.

Mothers were assumed to be biologically pre-disposed to childcare (Amato, 1998), fathers being relatively unimportant for child development (Cabrera, Tamis-LeMonda, Bradley, Hofferth and Lamb, 2000). Fathers were commonly regarded as distant figures, breadwinners and disciplinarians (Habib and Lancaster 2006; Rohner and Veneziano, 2001). Fathering meant no more than planting the seed but mothering suggested nurturing and child-caring, the gender neutral term 'parent' often acting as synonymous with 'mother'.

Success in the roles of husband and father were linked traditionally with economic support of the family; Rohner and Veneziano (2001) found this remained

widespread. They suggested that 'father-love' is a powerful force in child development and the triadic relationship of mother-father-child rather than the traditional mother-child dyad needed to be recognised (Rohner and Veneziano, 2001; Simons, Whitbeck, Conger and Melby, 1990).

Habib and Lancaster (2006) were interested in applying identity theory to the relationship between paternal foetal bonding in the third trimester and the development of 'father status.' This transition to the role of father and the relevance of the father-child bond during pregnancy was a mixed method study of 115 first time Australian fathers using identity measures via short narratives, vignettes and Likert response scales. Although this study benefited from a large sample it was unrepresentative, similarly to Draper's (2003), mainly high socio-economic status men responded. There are likely to be limitations in the depth of the findings, due to methodological aspects which reduced the fathers' experiences to numerical values. This suggested scope for deeper exploratory, qualitative research with fathers, for understanding their experiences further.

Despite such limitations Habib and Lancaster's (2006) findings revealed that expectant fathers primarily identified with spousal and father role status, beginning with the emotional tie to their unborn baby. Participants considered identity a key issue (Boyce et al., 2007; Habib and Lancaster, 2006). Prior to the pregnancy the man's identity was likely to consist of varied roles, e.g., worker, friend, husband, son, brother. Habib and Lancaster's (2006) findings revealed four prominent role identities of: partner-husband; worker; friend and emerging father-to-be. By the end of the first trimester, 'husband' was uppermost followed closely by 'father-to-be', 'worker' and 'friend'. Perceptions of other roles included; play/coach, emotional supporter and caregiver. This moved into post-natal roles for which there are a variety of psychological theories, some emphasising individual roles, others relational factors as to how the father is positioned.

Theories, including social learning, cognitive developmental and attachment have focused on the mother-child bond (Bowlby, 1953; Phares, 1996). Bowlby's son, Richard, actively promoted the father's role in the attachment process as providing opportunities, enabling the child to develop capacities for excitement and adventure, complementing the mother's calm, nurturing influence (Bowlby, 2007). Parkes et al.,

(1993) found that parents' childhood experiences of attachment were important in developing resilient relationships and child-rearing. Simons et al., (1990) suggested fathers were more likely to engage if they realised the impact of their role within child development.

The impact of a father's role engagement might be positive and/or negative. Lamb and Laumann-Billings (1997) suggested that fathers increased their positive effect on child outcomes if they contributed indirectly to the financial and emotional wellbeing of the mother and directly to close, responsive relationships with their children. Single parents were more likely to suffer economic stress (Walker and Zhu, 2007), also losing emotional support when partners, often fathers, left. The child suffered abandonment and might witness parental conflicts (Lamb and Laumann-Billings, 1997). Jaffee, Caspi and Moffitt (2001) acknowledged that some fathers may have difficulty providing responsive, supportive parenting, associated with positive outcomes.

The Fatherhood Institute's (2007) systematic literature review (1980–2006) suggested that positive father involvement equated with a range of desirable outcomes for children (Pleck and Masciadrelli, 2004). These included: better peer relationships; less behavioural problems; less criminality or substance abuse; better educational/career achievement; a higher capacity for empathy; flexibility regarding childcare and earning; more satisfying sexual relationships and higher self esteem/life satisfaction (Flouri, 2005). Findings suggested that positive outcomes relied on fathers' involvement with their children being through choice and agreement regarding the nature and degree of the role (O'Brien 2004; Ashley, Featherstone, Roskill, Ryan and White, 2006).

The quality of fathers' engagement with their children is important. The worse the fathers' behaviour, the poorer the likely outcomes are for children (Jaffee et al; 2001). Research as early as the 1960s found that fathers had an equal, or greater, influence on their child's behaviour than mothers (Becker, 1964). Children having no relationship with their father could idealise or demonise them (Kraemer, 2005). They often blamed themselves for their father's absence (Pryor & Rodgers, 2001).

The concept of more equal co-parenting has evolved (BBC 4b, 2010). However, Biller (1993) suggested that as recently as the 1980s men felt it 'un-masculine' to spend time with children, their role perceived as supporting the mother emotionally and economically. Fathers were viewed as incompetent to look after children and their influence of less importance. If mothers spent more time with children they were likely to become the most important care-giver by default (Phares, 1996).

Research where fathers were participants, rather than merely the subject of research with mothers, began in the 1980s. Fathers were found as capable as mothers in childcare (Bronstein and Cowen, 1988). Rohner (1986) found that children who spent more time with their fathers felt more accepted and cared for by other significant adults. Although the research was U.S.A based, Rohner and Veneziano (2001) conducted cross-cultural research raising findings common for 186 societies, suggesting that aspects of fatherhood may be universal, perhaps biological, rather than culturally-based.

Amato (1994) was interested in the long term effect of parent-child relationships into adulthood. He conducted a study of 471 young adults via telephone interview and found that perceived closeness to their fathers made a unique contribution to happiness, life satisfaction and low psychological distress, more so than perceptions of closeness to mothers. Although this is an interesting finding there are difficulties in drawing conclusions. We do not know why participants felt fathers had such a long term impact compared with mothers, and the uniqueness of family and individual dynamics within systems make it difficult to generalise. Lamb and Laumann-Billings (1997) echoed this, suggesting that contributions from both parents and the crucial parental dynamic need to be studied. Amato's (1994) longitudinal study also found that poor spousal relationships impacted on the closeness of parent-child relationships twelve years later, with sons more distant than daughters.

Veneziano completed several cross-cultural and intra-cultural comparative research studies which suggested that paternal warmth was an important aspect of the father's role in the family which was overlooked, (Veneziana, 2003, 1998). In his 1998 study he used multiple regression analysis comparing 32 societies and found that a lack of personal warmth, rather than time spent with a child, correlated with

young male inter-personal violence (Veneziano, 1998). It seems that much of the research not only highlighted the importance of paternal relationships, but the nature of parental time spent with children impacting outcomes in later life. Lamb and Laumann-Billings (1997) suggested that parental warmth, nurture and closeness were associated with positive child outcomes irrespective of the parental gender. As the focus of my research is fathers raising sons with AS, this dynamic is considered within the next sub-section.

2.2.3 The Father-Son Relationship

There were few studies specific to the father-son relationship, but interest in this area is growing. Habib and Lancaster (2006) suggested that the relationship between father and son began in the centrality of the 'father-to-be' aspect of identity (see section 2.2.1 in this thesis). This was crucial to bonding with the foetus and the strength of this status could influence 'father to be' behaviour, which was mainly psychological at this stage. According to Condon and Corkindale (1998) a phenomenological view of the bond could manifest as, *'a subjective feeling state of love for the unborn child, rather than an attitude or belief about the child…at the heart of the man's early parenting' (p.239).*

Habib and Lancaster (2006) found no evidence suggesting their respondents saw themselves in single dimensions of caregiver or breadwinner. Whether or not the fathers focused more or less on the breadwinner role had no significant bearing on the strength of the psychological bond between them and their unborn child. Their regression analysis suggested correlations between those who most identified with the father-to-be status measures and strong feelings of bonding with the foetus. Some participants focused on play/coach after the child's birth but this did not relate as highly with foetal bonding. Habib and Lancaster (2006) noted that anticipated behaviour might not necessarily match reality when the child was born. There may have been more emphasis on the care-giving or breadwinning and where there were problems, particularly a disability, change in anticipated behaviour was more likely.

There were implications for fathers of sons with AS in Habib and Lancaster's (2006) study where they suggested that the centrality of the 'father-to-be' aspect of identity

was crucial to bonding with the foetus. Could this crucial bond with the foetus exacerbate the trauma of disappointment if stronger foetal bonding increased expectations of the father-son relationship which the son cannot deliver due to social communication difficulties?

Several studies suggested that 'father-love' was as significant as 'mother-love' in predicting outcomes for children. This appeared to be a cross-cultural phenomenon (Rohner and Veneziano, 2001; Rohner, 1986, Veneziano, 1998, 2003). Barber and Thomas' (1986) study of 527 adolescents used factor analysis which revealed four dimensions of parental support; general, physical affection, companionship and sustained contact. Paternal physical affection and sustained contact was more towards daughters than sons. Yet companionship was expressed more within the father-son relationship than father-daughter. The fathers' sustained contact found to be the best predictor of high self esteem for sons. Although these are interesting results further hypothesise are needed to attempt an explanation as to why this might be the case. The importance of fathers within the context of attachment theory (Bowlby, 1953) might be one explanation. Attachment theorists have argued that fathers interact differently to mothers, creating a unique and important experience for their sons. This included rough and tumble, developing more risk-taking behaviour, independence and competitiveness at an early age (Parkes et al., 1993; Blatt 2007; Bowlby, 2007).

Elkins, McGue and Lacono (1997) explored genetic and environmental influences on father-son relationships through twin studies, self-report and questionnaires. Findings suggested that genetic influences passed from father to son became increasingly evident with age. The environmental influence of the father-son dynamic was lessened for those with irregular contact with their fathers, giving the son's personality more influence over father-son interactions. As sons reached adulthood similarities and differences between them and their fathers became increasingly apparent. Changes in the genetic influence within the dynamic as the child aged and developed could be important, particularly during adolescence when it was suggested that gene environment correlations increased (Caspi and Moffitt, 1993; Scarr and McCartney, 1983).

Elkins et al (1997) also suggested that children's hereditary characteristics had more power than previously thought over family dynamics. Their study compared the perceptions of a large number of parents and children within the US. Further studies were planned to consider whether the findings were gender specific.

Diamond (2007) noted the fluid dynamic between fathers and sons. He claimed that children introduced fathers to the world in a different way to that which the fathers introduced their children. This occurred at each transition and stage in life throughout the life-cycle. Different fathering skills appeared relevant at different stages, with some fathers better at some stages than others. *'It is a complex interaction during which the father influences the way his child develops, and simultaneously, his son affects the way that his father handles his own parallel transitions.'* (p.8)

Jaffee et al (2001) completed a 26 year study in New Zealand of 499 males in an attempt to address three questions: Which individual and family-of-origin characteristics predicted the age at which young men made the transition to fatherhood? Did the same characteristics predict how long these men remained living with their child? Were the individual differences in the amount of time associated with the father's psycho-social characteristics in young adulthood? This study used a variety of data which included interviews, life calendars and data from schools, parents and courts. Findings suggested that the father's attachment history and personal characteristics correlated with becoming a father at an early age. Boys raised by single teenage mothers were most likely to father children young, less likely to remain within intact families and most likely to be involved in drugs and criminality. It concluded that positive father involvement was important, as was the understanding of developmental histories in meeting fathers' needs. Despite taking place outside the UK, Jaffee et al's (2001) study was significant being longitudinal and using of a variety of both qualitative and quantitative data. Their results supported UK studies such as Parkes et al (1993) who found that early attachment impacted not only through individual life-cycles, but was commonly intergenerational. Katz (2002) highlighted the importance of the wider family, particularly during adolescence, when they need both self-sufficiency and parental support.

2.2.4 Section Summary

The studies in this section were informative. In analytic terms, however, care is needed not to interpret a 'factor correlation' as a 'causal relationship.' Where researchers pre-identify categories it can help to focus and streamline research but may preclude equally significant aspects of participants' experience. Considering such data alongside more qualitative findings could be mutually beneficial. The perennial research problem between generalisation, statistical manipulation and in-depth quality analysis was evident. The larger samples supported the former, the smaller the latter. Again the representativeness of the samples was an issue in the literature cited.

The studies supported the increased focus upon the fathers' development and the significance to their sons' development. Findings regarding fathers' attachment history and the developmental aspects of the father-son dynamic prompted the collection of developmental histories within my interviews. There was much boundary crossing in conceptual terms between familial roles and interpersonal relationships. Refining the literature further the next section focuses more specifically on parenting children with disabilities.

2.3 Parenting Children with Disabilities

The previous section considered the generic experience of fatherhood. This section focuses on parental experiences of raising children with disabilities in general, due to the lack of specific literature on raising sons with AS, (Russell, 2003; Baxter, Cummins and Yiolitis, 2000; Pain, 1999) and in anticipation of areas of similarity. Research literature included work on raising a child with Autism, as AS is thought to be on the AC (Huws, Roberts and Ingledrew, 2001; Woodgate, Ateah and Secco, 2008). Specific issues relating to AS are addressed in section 2.4 of this thesis.

Key themes researched on parenting children with disabilities included:- experiences of fathers who are faced with disability in pregnancy and the early years; family

stress, including spousal relationships; siblings of the disabled children; impact on the extended family. Other themes include balancing work and family demands, the experience of diagnosis and professional support and finally the transformational aspect of the experience of fatherhood.

My research focused on fathers' stories relating to raising their sons with AS. Recently political leaders have shared their personal experiences of trauma in raising their children with disabilities. They have highlighted the importance of 'hands on' fatherhood and of work-family life balance (Collier 2009; Harrison et al., 2007). This has raised both the profile of children with disabilities and the role of the father. Several books have been written recently by fathers about their experiences (Meyer, 1995; Harrison et al., 2007). Although anecdotal their existance suggests that fathers are beginning to find a public voice and readership. *'One of the ways parents manage to cope is to know that others have been through the same experiences. Then you learn that it isn't just about coping–there are positive stories to tell.'* (David Cameron in Harrison et al., 2007, p.7)

Some family studies included mothers and fathers with data disaggregated to show differences (Seiffge-Krenke and Kollmar, 1998; Little, 2002; Gerdes, Hoza and Pelham, 2003). Fathers were generally overlooked in the formal research, perhaps because mothers tended to be primary carers accompanying children to therapies or medical appointments, where surveys were administered. When surveys were sent to families, the mother typically completed them. Additionally, mothers were more likely to respond to requests for interviews, therefore fathers need to be purposively targeted. Roll-Pettersson (2001) in her study of parenting children with cognitive disabilities identified the life-cycle process, which parents revisited as their child achieved or failed to reach significant stages of transition. This was echoed in my findings of a study of mothers raising children with AS (Axup, 2003). In pregnancy and the early years research focus has been predominantly on mothers, the significance of fathers is considered in the next sub-section.

2.3.1 Pregnancy, Birth and Babyhood

During pregnancy men described a lack of knowledge about the process, an inability to engage, and a sense of being redundant (see section 2.2.1 in this thesis). Where there were problems in pregnancy birth fathers might experience prolonged, intensified feelings of isolation (Harrison et al., 2007). Where the child had a disability this could continue for years or reoccur (Roll-Pettersson, 2001; Meyer, 1995). Roll-Pettersson (2001), similarly to Draper (2003), investigated the nature of parental transitions where children had learning difficulties. She found the 'life-cycle theory' important, reflecting how such parents went through a continuous bereavement process, throughout their child's life.

The life-cycle model of evolving bereavement through transitions might be relevant to my participants. In my professional practice and prior research (Axup, 2003), I have found that family difficulties remain but shift in nature (Baxter, Cummings and Polak, 1995).

Fathers' reactions to diagnosis, at any point in their child's life, were often intense (Herbert and Carpenter, 1994; Hornby, 1992). They frequently experienced it as a greater crisis than did the mother (Lamb and Laumann-Billings, 1997). Adjustment could be lengthy, the process turbulent (Hornby, 1992; Harrison et al., 2007). A father's grief often went unexpressed and professionals rarely recognised their need to be included (Herbert and Carpenter, 1994).

Herbert and Carpenter (1994) completed a small scale qualitative UK study, interviewing nine fathers of young children with Down's Syndrome. They explored fathers' perceptions of professional's views and reflections of their own role. Fathers' raised issues of disclosing the diagnosis, information seeking, support received, planning for the future, professionals' predictions and responses to them as fathers. Findings suggested that fathers' experiences may be exacerbated by beliefs they should be strong for their partners. A deep sense of failure could develop when this was difficult or impossible. The authors felt that a deeper insight into fathers' perceptions of their experience could aid local authority provision planning and inform professional practice. This was similar to my study in considering perceptions

of a small sample of fathers to develop a deeper understanding than previous quantitative studies or those using structured interviews. It is likely that the lack support for fathers can exacerbate family stress, which is considered in more depth below.

2.3.2 Family Stress

Research into family stress in relation to children with disabilities suggested it is not limited to the period following diagnosis but affected families and decision-making at different stages of life (Baxter et al., 1995). This suggested the 'family systems model' should be considered in professional practice, rather than a narrow approach of the problem residing purely within the child (DfES and DoH, 2004b).

Baxter et al (2000) studied differences in parental attribution of stress within the family dynamics. They suggested that normalisation of disability influenced parental stress. This normalisation was attempted where children's difficulties were not immediately obvious and families were trying to function within mainstream social settings. The family stress of parenting children with disabilities is less understood in non-specialist settings. My participants' family stress may be high as children with AS are commonly faced with normative societal expectations.

Baxter et al (2000) stated that stress *'is now conceptualised as a variable which mediates the relationship between life events and negative personal outcomes'* (p.107). Previous 'stress' definitions focused on an event, assuming people experienced things in the same way (Dohrenwend, 1973), thus denying individual experience (Gersten, Langner, Eisenberg and Simcha-Fagan, 1977). My research embraces this idea in exploring the experiences of fathers though individual perceptions of their 'life-worlds'.

Perceived stress has been considered as an outcome predictor. Baxter et al (2000) hypothesised that stress, as experienced by parents, changed over time according to their worries and their child's developmental stage. Ongoing stress provoking issues were found to be the child's intelligence, behaviour at home and in public, and access to help. Speech, as a worry, lessened most, perhaps because the child

developed speech or alternative means of communication. This study found family members had difficulty pinpointing their stress within the complexity of events and family dynamics. The researchers felt that healthy family dynamics and personal resilience were both stress reducers.

Dellve, Samuelsson, Tallborn, Fasth and Hallberg (2006) also studied parental stress and well-being amongst parents of children with rare diseases in Sweden. Their sample was taken from the National Centre of Children with Rare Diseases. Possible cultural differences need to be accounted for in considering the findings, which suggested that fathers showed high stress levels relating to perceived functional incompetence and limited practical skills. Stress levels fell after an intervention, although there were individual variations. The mothers' stress resided more in areas of physical and emotional strain. Initially, fathers reported higher levels of support from their spouses than vice versa. In a follow-up this had decreased, perhaps due to interventions increasing the capacity of fathers. *'Children's adjustment and function in daily life are related to family empowerment.'* (Wallander, Varni, Babani, Banis and Wilcox, 1989, in Dellve et al., 2006 p.393)

Family adaptation was found to be a complex and multi-dimensional phenomenon (Baxter et al., 2000; Dellve et al., 2006). Resilient parents were strengthened by creating new meaning from difficult circumstances. Others were more vulnerable to internal and external factors influencing family functioning. Good adaptation was associated with acceptance and family/social support (Dellve et al., 2006). Strains on family life included marital relationships, emotional stress and both ongoing stresses of daily caring tasks and periodic crisis. Dellve et al., (2006) found that fathers worried about the future, stress on their wives, and threats to their marriage. Traditional gender roles were stronger amongst parents of children with a disability. This influenced the stress experienced, wellbeing and coping strategies (Gray, 2003). Parents' needs for normality and certainty, information and partnership were identified as stress reducers (Fisher, 2001). The spousal relationship could in itself be a stress or resilience factor as explored in section 2.3.3 in this thesis.

2.3.3 Spousal Relationships

Caring for a child with disabilities could be stressful and potentially harm marital relationships. Fathers and mothers often experienced different areas of stress and reacted in different ways. Much research focused on individual perceptions rather than externally objective features of spousal relationships.

Satisfaction within the marriage was a strong predictor of coping with stress (Trute, 1990). A higher level of parental care was required and negative feelings between parents of children with a disability could increase. Some suggested the divorce rate was higher (Kokkonen, Saukkonen, Timonen, Serlo and Kinnunen, 1992). Others found no difference and reported that parents formed a closer unit because of the child (Moren, 1985 in Taanila, Kokkonen and Jarvelin, 1996). According to Flynt and Wood (1989) some families never came to terms with the disability.

Little (2002) studied the differences in stress and coping for mothers and fathers of children with AS in the USA. The 70% email survey response was largely from white, middle class, married couples, making wider generalisation problematic. Findings suggested that mothers suffered more stress than fathers, yet accessed more coping strategies, mainly medication. There was high employment amongst the fathers, therefore less contact opportunity with their children. Little (2002) concluded that men were less likely to speak about their emotions and coping, for fear they were perceived as weak. This, she argued, also prevented them from accessing professional help. Although methodologically very different from my study, it helpfully raised awareness of sampling issues and difficulties in stimulating talk amongst fathers on sensitive subjects, such as marriage and disability. There may also be cultural differences in a UK sample.

Lamb and Laumann-Billings (1997) found that mothers and fathers dealt with experiences of raising children with disabilities differently. Fathers could find themselves very alone, particularly if their partner was unwell or the relationship had ended. Fathers of children with disabilities suffered additional stress in such circumstances (Foundation for People with Learning Difficulties, 2007; Harrison et

al., 2007). Mothers experienced more daily stress but fathers' had general dissatisfaction with family life, including spending less time as a couple (Foundation for People with Learning Disabilities, 2007). Fathers expressed experiencing 'parental inferiority' (Cummings, 1976), perhaps because work commitments and gender stereotypes restricted their family involvement (Lamb and Laumann-Billings, 1997). The dates of these studies suggested little change over time.

Harrison et al (2007) emphasised the importance of communication in spousal relationships, encouraging mutual support with common parenting goals. Some fathers' found partners were ahead of them in accepting and coping with the disability, due to differing daily responsibilities. They mentioned taking second place to the child in their partner's life and losing the sense that they could save the situation. Some fathers suggested that mothers were stronger, able to take charge and turn to friends for support. Fathers' friendships often disappeared, due to them isolating themselves and a reluctance to share with others or ask for support.

> *I felt like an observer... a spare part basically ... It was like my partner was the one going through it, and I was expected to stand there waiting to pick up the pieces...The other consequence was friendship and social relationships... Our marriage was finished. The stress and pressure of it all just really did it in* (p.102).

In Harrison et al (2007) differing parenting styles divided partners, with individual identities defined by the child and the disability. Marital breakdown, divorce and forming new relationships were complicated for fathers of children with disabilities. However, some fathers described their partners as allies, sharing positive and difficult experiences, and commitment grew. The ability of fathers to support and be supportive was highlighted as a positive feature of resilience within a marital relationship.

Simmerman, Blatcher, and Baker (2001) researched the perceptions of American fathers' involvement in parenting a child with severe intellectual disability. They considered the impact on care-taking and marital adjustment. Participants were actively involved with childcare and 88% were married. Three aspects were considered namely the perceptions of mothers and fathers of contributions to childcare and satisfaction with this; relationships between the fathers' involvement

and the general care-taking burden, and the relationship between fathers' involvement and marital adjustment. Fathers appeared to be involved with childcare and mothers stated satisfaction with their help. Over the two points in time parents' perceptions were similar regarding the amount of help given. Moderate correlation between actual help and satisfaction suggested 'help' needs to be seen within the relationship context, related to the mothers' requirements, rather than the quantity per se. This suggested couple communication was important. Mothers' perceptions related more to marital satisfaction than fathers:

> *if the parental relationship is cohesive, and mothers and fathers are in agreement about family functioning as well as about the care of their child with a disability, then the likelihood of either parent feeling overwhelmed with burden may diminish (Simmerman et al., 2001, p.336).*

These authors' findings suggested that the challenges of disability could affect mothers' well-being and were linked with the fathers' support. This could relate to coping both personally and together. Satisfaction related more to indicators of family well-being than extent of the help, highlighting the importance of spousal perception and positive relationships. It was important to view family functioning at different points in time. This clarified the fathers' involvement and relationship within the family.

Combined roles of husband and father, giving the mother daily physical and psychological support and contributing to childcare might be demanding. Fathers were involved with playing, nurturing, discipline and deciding on services, less so with hygiene, therapies, dressing, teaching, feeding and taking children to appointments. Fathers were more likely to rely on their partners for support, yet perceived they were getting less support from their partners than they were giving (Carpenter, 2002). This might have implications for fathers and their relationships with children's service professionals (Simmerman et al., 2001), (see section 2.3.7 in this thesis).

In Finland, Taanila et al (1996) considered the long-term effects of children's early-onset of disability on family life, marital relationships and the process of accommodating adolescents about to leave home. The children had a range of diagnoses and again cultural differences might complicate generalisation.

Researchers felt that a third of the families had not come to terms with the disability, affecting most parents on a personal level. Regardless of disability parents felt insecurity, sorrow and continuous concern about the child's health, wellbeing and future. The disability did not always affect the marriage and family life in a negative way. Most of the families had stayed together and most of the parents felt their feelings for each other were unchanged or enhanced. Some parents felt their marriage had suffered due to time spent caring for the child and lack of time together. Insecurity and conflicts were caused by the child's demands, unequal distribution of care-taking tasks and a lack of time for hobbies. To some extent results showed marital issues were most relevant for those with university or higher occupational education. This might reflect greater expectations, the disability preventing parents fulfilling their own needs for their children. Taanila et al (1996) found that adequate information about the disability could protect the marriage, allowing parents to form ideas about the future, realistic expectations and the sense of consequences for the child/family and practical advice.

The same study also found that the birth of a child diagnosed with a disability often caused problems in relationships between parents and family functioning. Sorrow and regret were often felt. The importance of helping the child to come to terms with the diagnosis and its implications to lead as normal a life as possible was emphasised. Partners working together predicted better parental well-being and quality of care for the child (Bristol and Scopler, 1984). Taanila et al (1996) also found that mothers of children with severe learning difficulties reported their spouses were the greatest source of support together with friends and relatives. Mothers were more prone to depression, felt insecure about the childcare they gave and experienced most difficulties within their marital relationship. Fathers reported more difficulty attaching to their child (Beckman, 1991). Professionally I have found this is particularly common for fathers of children diagnosed with AS, where a sense of identity as both father and son could be disrupted.

2.3.4 Diagnosis and Identity

AS can be diagnosed at any age and such a life-long diagnosis can be an important marker within the family. Anecdotal and research evidence suggested that fathers were more concerned about long-term implications of disabilities than mothers, and

might be especially disappointed if the child with disabilities was a son. Fathers were often more involved with sons, particularly first born and less impaired children, yet involvement was frequently inconsistent (Lamb and Laumann-Billings, 1997). Some disabilities affected the activities children could engage in and fathers felt limited as to how to include their child in their lives, *'he'll never even play rugby. Those thoughts can eat you alive, and need to be dismissed.'* (Harrison et al., 2007, p.42)

The assessment process leading to diagnosis contributed to men feeling increasingly isolated and sometimes depressed, *'I was outside everyday family life and the assessment process.'* (Harrison et al., 2007, p.61) Resentment and denial were common. Parents often tried to prove the diagnosis wrong, before adjusting their perceptions. Some fathers told themselves that boys were slower to develop. Such thoughts helped them with their feelings of disempowerment. *'I'd learned that to be a father was to protect and support…Some protector I had been, failing to prevent this enormous hurt to my precious wife and child…unable to make things right or explain things away'* (Harrison et al., 2007, p.117).

Research suggested diagnostic information and follow-up support was often inadequate, an anti-climax after numerous appointments with professionals (Axup, 2003; Scorgie, 1996). Scorgie, (1996) argued that diagnosis could be devastating, confusing, isolating and difficult to accept.

Behaviours were no longer quirky but part of a condition,

> *…the critical questions that parents deal with at the diagnosis of their child reappear at other child and family markers, requiring a reworking of images and meanings and provision of a new range of choices. Professionals should be aware that parental adjustments to disability are not always linear, and thus use this awareness to not judge parents and to serve as catalysts for continued positive life management and transformation throughout the life-cycle.*
> (Wilgosh and Scorgie, 2006, *p.211)*

Scorgie et al (2004) developed a 'parent transformation process' model where parents were confronted with 'critical emergent questions' from the point of diagnosis, falling into three categories:

1. Life trajectory, identity-orientated:

   Who is my child and who can he/she become? Who am I as a parent and who can I become? How will this diagnosis change life, now and in the future?

2. Existential meaning-orientated:

   Why did this happen? How can I make sense of it?

3. Personal and family choice-orientated:

   How are we going to react to and live with this diagnosis? What choices are available to us?

As parents attempted to answer these questions, new images of their children, themselves and their lives might be activated and old, lost ones grieved.

Scorgie et al (2004) argued that meaning, image and choice-making was a socially constructed knowledge set influenced by the people and places parents encountered. Choices were often influenced by professionals' views of disability. One father stated, *'When you get the diagnosis, that's overwhelming for any parent. You have to get that in your head. The shock, the guilt and everything else that happens.'* (Wilgosh et al., 2006, p.214) Parents relayed how the diagnosis of their child's disabilities required them to 're-image' themselves. The cultural image of male identity influenced how fathers perceived and coped with a diagnosis. One father said *'I think more men need to check their egos at the door...Because it's got to be about the child ... Don't be selfish; it's not about you now. You've got to let go of those barriers.'* (p.215)

Familial trans-generational factors could also influence responses. Fathers recounted how they had to make a deliberate choice to accept responsibility. This sometimes involved breaking dysfunctional patterns of their own absent fathers (Harrison et al., 2007). One father talked about gaining strength from his own mother as a role model (Wilgosh et al., 2006).

Some mothers reported that diagnosis contributed to their divorce, *'men are more in* denial *... the man is so proud of being a man. He won't accept. I'm a macho. I can't have a handicapped [child]. It's the machismo, 'the manhood,' and unfortunately a lot of them don't accept.'* (Wilgosh et al., 2006, p. 215) Although Wilgosh et al

(2006) used a small sample their findings suggested cultural and family resilience were important factors, as was the message society gave parents about the value of their children. *'One father expressed anger that the special education classrooms ... were located at the back of the school... a "double whammy" ...a disability and ... segregation.'* (Wilgosh et al., 2006, p.216)

Fathers in the UK expressed feelings of anger and frustration (Harrison et al., 2007). Similar questions were asked, why me and my child? Religious belief influenced perceptions and related to coping mechanisms, positively and negatively. Faith was questioned fearing diagnosis was God's punishment. Guilt blame and stigma were common experiences some felt guilty for feeling sorry for themselves. Others felt that God had given them a special child to care for because of their strength and faith (Harrison et al., 2007).

Fathers' concept of their own life cycle and identity shifted. Some were disturbed by their child's diagnosis of disability. Fear of the future was a common theme within anecdotal accounts and research literature. Fathers worried about their mortality in relation to their child's care. Father's asked, will he ever be independent, go to college, get married or have children? Could he have a pre-disposition for other disabilities or mental health problems (Harrison et al., 2007)? The literature suggests that diagnosis and identity are likely to be significant aspects of fathers' 'life-worlds' within my research. Father's work, career aspirations and retirement could not necessarily follow the expected pattern either personally or socially (Harrison et al., 2007). Work is clearly an important feature of male identity and experience which impacts on fathers' parenting behaviours in different ways.

2.3.5 Work

Some fathers of children with disabilities returned to work soon after the birth and worked for longer hours than usual (Herbert and Carpenter, 1994; Harrison et al., 2007). Some used work to cope and avoid involvement, '*somewhere buried in the back of your mind is the knowledge...you can still carry on going to work so you don't actually have to feel the major impact of the disruption that a disabled child clearly brings to the family'* (Harrison et al., 2007, p.130).

Alternatively many fathers shared childcare responsibilities with partners and altered their working patterns. Some changed careers or became unemployed (Foundation for People with Learning Disabilities, 2007).

> *Time off, job security, an understanding employer and knowing your rights are essential, as raising a child with a disability can take its toll on fathers' careers, lowering their chances of promotion, due to shifting priorities and time needed for appointments and child illness. Financial pressure to work long hours...can further detach fathers from family life... Breadwinning is difficult and important, and an inability to attend every appointment does not imply a lack of concern and does not indicate a bad husband and father' (Harrison et al., 2007, p.148).*

According to Harrison et al (2007) some fathers worked part-time allowing their partners to pursue careers. This adjustment might affect the identity of a man as the breadwinner and the social expectations of upward career mobility. The carer role is often tailored to women rather than men, leaving them isolated and emasculated. The world of childcare appeared to offer women support networks within wider social circles, but these were not necessarily accessible to fathers.

2.3.6 Wider Family, Friends and Time Out

Where children presented with challenging behaviour parents could be alienated from family events or opt out due to stigma or practical difficulties (Axup, 2003). Public outings and socialising were particularly difficult for fathers raising a child with a hidden disability, including AS. They felt judged in relation to their child's behaviour; public comments were difficult to cope with. Some felt that their child did not have a disability until they stepped out of the door where wider society lacked acceptance. In Harrison et al (2007) one father reported death threats from neighbours, due to noise made by his child.

Fathers spoke of making new friends, often in the same situation, as it was hard to find time for socialising and relationships outside the world of the child. Events for fathers helped as the people there had more empathy than their old friends. However, valued friends kept in touch regularly, *'just listening, not trying to sympathise because in his words he 'couldn't even begin to understand' how I felt.'*

(Harrison et al., 2007, p. 35) Some fathers continued playing sport, it was important in letting off steam and gaining time for oneself. Seeing their friends' children getting married and meeting other social milestones was difficult to bear.

Fathers who were the primary carer found it difficult to develop friendships for their child outside school as the social/parental scene was mainly female. Therefore they experienced isolation with their child, paralleling that of the child. Fathers felt parents with healthy children should value them more. Strong feelings were expressed about pregnant women and parents who smoked around their children and shouted at them. They felt that such parents, who were not behaving responsibly, did not deserve healthy children, something they had been denied (Harrison et al., 2007).

Waisbren (1980) found that parental acceptance of the child was influenced by their own parents' reactions. Grandparents and wider family member's reactions could be either supportive or devastating. In Harrison et al., (2007) fathers reported that the wider family could find disability frightening. Attempts to find environmental reasons for the disability were common, denying any chance of genetic links. Fathers felt they had to deal with both their own and their extended family's upset. Boys could be particularly problematic due to family/cultural perceptions, including continuing the male-line.

Throughout the literature there is a theme of isolation for fathers of children with disabilities. All around them are friends and colleagues and relations with children who follow the normal biological and social developmental patterns leaving them on the outside of a world in which they expected to belong. It would be useful to gain insight into how my participants experienced isolation from, or difficulties with, varying social groups. This could have a bearing on the types of support required from local services. Support from others seemed to be a double edged sword, an escape from a painful reality but also a reminder of what could have been.

2.3.7 Support and Resources

Professionals often ignored, dismissed or treated fathers as outsiders (Cummings, 1976; Lamb and Laumann-Billings, 1997). Yet fathers were described as hard to reach (McConkey, 1994), invisible, (Ballard, 1994) and peripheral (Herbert and Carpenter, 1994). I found no current research indicating this situation had changed. Economic problems and labelling in relation to social taboos bothered fathers (Price-Bonham and Addison, 1978). Some men suggested that they would prefer information and contacts to be established through virtual, rather than face-to-face media (Hinckley et al., 2007; Meyer, 1995).

Fathers had difficulties attending meetings due to work commitments. They often felt they were there to back up partners, regarding problems, '*a weapon, fighting for rights and resources.*' (Harrison et al., 2007 p.45) When asking questions or challenging professionals, a power imbalance was experienced by fathers. They were often told their child was not disabled enough for the support they felt was needed. '*On many occasions I have found myself in meetings where my ideas were dismissed and given no respect.'* (Harrison et al., 2007, p.45)

> *I think that dads are treated differently sometimes, as it is assumed (perhaps rightly in some cases) that we are less intimately concerned with the disabled child. It is not always appreciated that work may legitimately prevent the breadwinner attending all hospital and other appointments. This should not be misinterpreted as evidence of unconcern,* (p.148).

Fathers experienced professional involvement as handing over their child to professionals. The child became defined by their disability. Fathers spoke of seeking the child they had lost. It was felt that a role for professionals might be to develop bonding activities for men with their children (Harrison et al., 2007).

Increasingly public information appeared to encourage mistrust of professionals e.g., the MMR debate (Casiday, 2007), where there had been claims that giving the combined vaccination caused ASD (Dyer, 2010). This is an example of where parents could access both evidenced based and less reliable research information

creating uncertainty as to what and whom to trust. The importance of skilled professionals who can build relationships with parents based on trust cannot be overlooked.

Fathers reported feeling left out when correspondence was addressed to mothers only, even when the father was the main carer (Harrison et al., 2007). Some fathers experienced professionals as politer and calmer with mothers, and questions about them were directed to mothers in front of them, causing some to back off (Harrison et. al., 2007). Neglect of fathers by professionals contributed to the alienation often felt in relation to their partners and children. Herbert and Carpenter, (1994) suggested that this could be a factor in high rates of separation and divorce, believed to be higher in couples parenting children on the AC (Gaines, 2001; Hartley, Barker, Seltzer, Greenberg, Bolt, Floyd and Orsmond, 2010)

Parents reported numerous calls from schools about their child's behaviour. SCIE (2005) wrote that long term reactions to a child with a disability varied according to the behaviour of the child and access to resources. Some fathers felt that professionals needed to be more sensitive to their concerns (Harrison et al., 2007). Lamb and Laumann-Billings (1997) claimed that lower income and less educated fathers were more adversely affected by a child with disabilities and spent less time with them. Some had learning difficulties themselves. Fathers with good organisational, negotiating and assertiveness skills felt more able to work with professionals (Foundation for People with Learning Disabilities, 2007).

Fathers were less likely to receive professional help (SCIE, 2005) or seek emotional support than mothers (Pelchat et al., 2003). However they were more likely to seek outside support particularly programmes where they were encouraged to be actively involved with their children (Lamb and Laumann-Billings, 1997). Fathers of children with disabilities found that professional help could reduce family and general stress. Information for fathers helped them assume an expert role alongside the mother and programmes involving fathers could increase involvement in the home, fostering more secure attachments with their children and contributing to their child's development (Lamb and Laumann-Billings, 1997; Taanila et al., 1996). This also provided the mother with respite (Bailey, Blasco and Simeonsson, 1992).

In line with my research, Bristol (1984) tried to ascertain how families adapted successfully to raising a child with autism. She reviewed the literature and her previous work in implementing an education programme for children on the AC. Bristol (1984) concluded that fathers should be more involved, but it was not clear whether training for fathers should focus on working directly with the child or providing support for the mother. It was suggested that fathers felt isolated and opportunities for them to discuss their concerns with other fathers in a similar position helped both to reduce their sense of isolation and to support mothers more effectively.

Often fathers' groups were developed along the same lines as those for mothers, without gender and practical differences being acknowledged. Fathers groups frequently disbanded quickly as the support group approach did not appeal to them (Harrison et al., 2007). Support designed specifically for fathers via consultation was particularly beneficial, this tended to involve activities rather than sitting and talking (Foundation for People with Learning Disabilities, 2007; Harrison et al., 2007). Professional support was needed for both parents throughout the child's life. Parents found support decreased as their children got older (Suelzle and Keenan 1981). These issues were compounded as families grew and other children demanded support from parents. This raised issues where the focus was on the child with a disability rather than across the sibling group (Axup, 2003). Fathers often have additional children to consider creating complex family dynamics in relation to siblings.

2.3.8 Siblings

In Harrison et al (2007) fathers expressed concerns about siblings needing their support, *'The position of other children in the family is badly distorted'* (p.143). Fathers found themselves managing sibling stresses where children with disabilities released their frustration targeting their brothers and sisters. .

Baxter et al (2000) in a comparative study found double the amount of stress was attributed by parents to the child with a disability than to the youngest sibling without a disability. The sample included a range of socio-economic groups and data was

collected via interviews, using scaling. Stress attributed to any family member might have been an indicator of general family stress, which was rarely understood. Axup (2004) interviewed parents about the effects on family life of raising a child with AS, supporting siblings was a concern. Parents described how siblings needed a great deal of tolerance in coping with their disabled brother or sister, particularly as a child with AS struggled with developing empathy and participating in the normal 'give and take' of sibling relationships. Parents felt that siblings sacrificed a great deal living in a house where there were rigid structures in place to support the child with AS. They received disproportionate parental attention and often took the role of young carer. Parents felt guilty that they were not able to provide a 'normal' childhood for all of their children.

There is very little research available in this area. It would be interesting to know the long term effects on children growing up with a sibling with a disability, particularly AS. There might be positive as well as negative outcomes similarly to fathers who had described raising a child with a disability as a transformative experience.

2.3.9 Transformative Experience

Although research and anecdotal evidence highlighted difficulties there were reports of positive transformative experiences in raising a child with a disability. Wilgosh et al (2006) focused on how parents managed effectively on a daily basis, rather than stresses and crisis management. This focus on the positive is echoed in my sample choice of fathers remaining in the family home. Hopeful images of their children and competent images of themselves were deemed necessary. Processing the meaning of the situation was important for many fathers. Meanings were culturally influenced, ranging from a spell, test or curse, believing 'everything happened for a reason,' to the notion that 'the child is a blessing,' bringing enrichment and a sense that they were chosen to parent this child because they could handle it.

Wilgosh et al (2006) study was small scale. In-depth interviews were carried out with 18 parents all of whom reported being positively changed by their children. Findings suggested that self-efficacy beliefs, where parents perceived themselves as capable of performing parenting tasks effectively, was an essential component of positive

practices. It perhaps supported the view that when parents were asked to report positive outcomes, they could often find them and this was a liberating experience after a continual focus on the negative.

Other writers included accounts of fathers who had re-evaluated their lives and spoken of personal growth and transformation as a result of successfully coming to terms with their child's disability (Meyer, 1986; Dellve et al., 2005). Resilience, the ability to face and overcome challenge, was a primary quality for families of children with disabilities. It was important to capture positive aspects of families and the complexity of their experience in research (Blacher, 2002 in Wilgosh et al., 2006). Scorgie et al (1996) suggested that over time families learned to cope more effectively with problems, often experiencing positive transformation.

Harrison et al (2007) gave examples of fathers who, through their child, rediscovered the essence of life, appreciating small things which went unnoticed before. *'I now see beauty in* things *I would once have walked straight past without a moment's notice, all this because Matthew was born with a disability.'* (p.34) Fathers reported seeing their child's development differently to others, losing an old life and gaining a new one.

> *'It is important that the distant problems don't swamp the simple pleasures of the present: the first bit of eye contact, the genuine laughter, the first garbled communication that you understand, and the look and their face when they realise you are on their wavelength. Never forget you have a child, not a problem.'* (p.52)

A diagnosis of AS provoked searching questions for fathers (see section 2.3.4 in this thesis). These included; what is it, why does it manifest in certain people and are there genetic factors?

2.3.10 Section Overview

The literature on parenting children with disabilities raised a number of topics as indicated in this section's subheadings. Research articles suggested diverse methods were used each with advantages and disadvantages (Table 3, p.64). Overall findings suggested fathers experienced increasing role uncertainty,

marginalisation and more complex relational dynamics and stressors. These filtered through circumstances and perceptions from the intimacy of pre-natal hopes to wider social networks of the extended family, health, leisure, work and education. Few clear predictors emerged as to how fathers would conceptualise and manage additional stresses of parenting. This makes design of more inclusive support and resource structures difficult, suggesting the need for further research. Whilst many findings might be generalisable across disabilities this should not be assumed without evidence. There was a particularly noticeable lack of research in relation to fathers of children with AS and fewer explorations of their experiences in personal depth.

The 'problems' of AS are complex as it is understood in a variety of different ways. It is a particularly difficult diagnosis for fathers to come to terms with as there are no physical markers; much is therefore hidden. Furthermore, a genetic link through the male line has been suggested since Hans Asperger identified this group in 1944 (Jordon, 2002). The next section considers the nature of AS and why it raises specific issues for fathers.

2.4 The Nature of Asperger Syndrome

This section looks at how AS is framed and the implications this has for families and professionals supporting them. Firstly, there are built in assumptions related to the medical origins of the construct. The medical model is considered along with two alternatives, the family systems model and social model of disability. Although these models can raise awareness and understanding of differing aspects of the condition, they can also be confusing to parents who work with a variety of professionals from differing theoretical frameworks.

2.4.1 The Origins of the Asperger Syndrome Construct

AS is named after Hans Asperger, a psychiatrist in the 1940s. Within his daily clinical practice he identified certain personality traits in a group of his patients. '*Asperger…saw autism as reflecting an extreme version of traits found primarily in males,'* (Jordon, 2002 p.23). He believed there was a familial link noting '*a ghosting or shadow of similar characteristics in the parents (particularly fathers) of the children he saw,'* he proposed AS might be inherited (Attwood, 1998 p.141). Fathers were often highly intelligent and Asperger identified at least one parent with a similar personality trait in almost all the patients he saw (Ghaziuddin, 2005). This suggested that father-son relationships could be particularly complex, as both may have traits reflected in poor social communication skills.

AS was relatively unknown in the UK until the 1980s. Since then diagnoses have increased and are 15-30 times more prevalent (Mayes and Calhoun, 2003). Prevalence is unclear, estimations range from 2.5 in 10,000 (Fombonne and Tidmarsh, 2003) to 4% of the population (Ehlers and Gillberg, 1993). There are no biological markers, although research into identification using brain-scanning is progressing (Frith, 2010; Baron-Cohen, 2010; Blakemore; 2010). Currently diagnostic criterion considers behavioural and developmental patterns from observation and parental report (Jordan, 2002). Jordan noted that parents had different degrees of knowledge about normal development, depending upon whether it was their first child. There might be differing family behavioural expectations of children and varying tolerance levels. Diagnostic tools and checklists have been developed, e.g. The Autism Diagnostic Interview-Revised (ADI-R) (Rutter, LeCourteur and Lord, 2003) and The Childhood Asperger Syndrome Test (CAST) (Williams, Scott, Allison, Bolton, Baron Cohen and Brayne, 2005). Although not very prevalent such children are typically in mainstream schools. EPs play an essential role in supporting staff and children to understand and manage atypical social communication, behaviour and high anxiety levels which can restrict access to the curriculum. The National Institute for Health and Clinical Excellence (NICE) guidelines suggested that EPs are an essential part of the diagnostic team (NICE, 2011).

AS, thought to be on the AC is a pervasive developmental disorder (PDD) affecting social interaction, communication and flexibility of thought, known as the Triad of Impairments (Wing and Gould, 1979). People with AS have difficulty making sense of experiences in a complex social world, struggling to understand and respond to others' thoughts, feelings and needs (Baron-Cohen, 2010). Social communication does not develop naturally. Instead of a wide range of interests, people with AS tend to give attention to detail and develop narrow specialised interests. Routine is important, as change is difficult to cope with, often giving rise to high levels of anxiety, compensatory rituals and repetitive behaviour patterns (Attwood, 2008).

The commonly understood features of AS are described below by key practitioners/researchers for whom Autism is their specialism. AS is rarely recognised before age three, although the child might appear 'odd' prior to this (Wing, 1988). It is characterised by average to above average intelligence, good rote memory and normal speech. Language might be odd, pedantic and stereotyped in content. Non-verbal communication is often poor with little variation in voice tone, few facial expressions and inappropriate gestures (Jordon, 2002; Ghaziuddin, 2005). Motor co-ordination could present with an odd gait, posture and clumsiness (Jordon, 2002). Hyper-sensitivity to noise, textures, smell and/or visual stimulus can also feature, hence higher anxiety levels. There are cases where later onset from the age of two has occurred with skills lost, such as speech and social /play skills (Jordon, 2002). Such cases fuelled the MMR debate for parents, as they linked the vaccine with a loss of skills (see section 2.3.7 in this thesis). This indicated the power the medical model has had in our society. Its predominance within the field of AS is discussed below.

2.4.2 The Medical Model

AS is a distinct disorder with its own criteria (DSM-1V). Its overlap with autism is unclear. The genetic origins of autism appear to have been established, yet there are few such studies in AS (Ghaziuddin, 2005). A study of a 1000 families found fathers and grandfathers of people with AS more than twice as likely to work in engineering (Baron-Cohen, 2002; Baron-Cohen, Wheelwright, Stone and

Rutherford, 1999; Jordon, 2002). Baron-Cohen (2000) found strong familial links in people with AS, implying genetic aetiology. A linkage on chromosome seven in affected individuals has been reported (Bailey, Bolton and Rutter, 1998). In discussing the implications of this, Baron-Cohen (2000) suggested this was at *'best evidence of difference and in no way implies that the genotype of AS/HFA is deficient*' (p.491). There were sampling limitations in these studies. A standardised criterion was needed and researchers used participants who were diagnosed by different practitioners, using various classification systems. Studies mixed those diagnosed with Autism and AS, or adjusted the criteria (Ghaziuddin, 2005). A proposal has been made to reclassify AS a subset of ASD in DSM-5, due for publication in May 2013 (American Psychiatric Association, 2012). This might be an attempt to standardise the AC under a single umbrella as it is currently confusing due to several diagnostic categories which have different names but similar traits, e.g. PDD, AS, ASD, AC and Autism. Current research, including my own, should work towards a clearer understanding of AS for parents and professionals.

Ghaziuddin (2005) studied familial links between parents and their children diagnosed with AS. The small sample included those diagnosed with PDD, an IQ of 70 plus and the presence of a biological parent in the interview. They were then considered under DSM-1V as to whether they met the criteria for diagnosis of AS. The children were seven years plus; as it was felt that focused interests often did not develop before this. Family histories were taken through second and third generations. Findings supported the view that AS has family links, with prevalence for other psychiatric disorders, e.g., depression and schizophrenia. Depression was perhaps a secondary difficulty, due to an inability to cope with AS. Traits of AS were seen in just under 5% of siblings and ASD, including AS, in 50% of second or third degree relatives. The findings suggested AS clusters in families and gave limited support for research suggestions that AS is more 'strongly genetic' than autism (Van Krevelan, 1971; Volkmar, Klin, Schultz, Bronen, Marans, Sparrow and Cohen, 1996). The study concluded a wider community based research sample was required to support or refute the findings. Even a small scale study such as mine can inform this debate in considering how actual or perceived genetic links can impact on fathers raising sons with AS (see section 4.2.1.2 of this thesis).

Attwood (2008) felt that the family connection might be valuable in helping parents to understand their child, *'unfortunately, some parents will refuse to accept the syndrome, as to do so means they have to accept they share the same condition'* (p142). The familial links might suggest a causal role, but it is inconclusive. Early pre-natal and birth trauma appeared to play a part in many cases (Jordan, 2002; Attwood, 2008). Research findings suggested genetic, viral or bacterial infections in early life, pre-natal /early experiences affecting the brain were all potential causes (Attwood, 2008).

Gillberg and Cederlund, (2005) studied 100 boys with AS and their families. Findings suggested 71% had one or more first and/or second-degree relatives who had a diagnosis or had raised suspicion of suffering from AS, 1/6 had a relative formally diagnosed. 58% had serious problems in the birth, pre-natal or peri/neo-natal period. 87% showed familial and/or pre and peri-natal risk factors. The parent interviewed was usually the mother suggesting,

> *the person suspected of suffering from an autistic spectrum disorder on the basis of this information was* almost *always the father. The rate of familial loading may however be inflated by some degree of reporter bias'* (p.164). '*Familial loading for autistic disorder and AS is extremely strong in clinical cases of boys diagnosed as suffering from AS* (p.166).

Although it might be difficult to engage fathers in research, it is critical for services to extend their understanding and to the whole family. The family systems model is helpful in considering the roles each member plays within the dynamic.

2.4.3 The Family Systems Model

Researched literature has shifted from the view of AS caused by inadequate parenting, although it recognises that a child with AS could change family relationships (Frith, 1989). In the past '*frozen mother syndrome'*, *'the intellectual emotionally detached woman'* (Frith, 1986, p.55) was blamed. The Tavistock Clinic moved to a 'family systemic approach' to AS (Alvarez and Reid, 1999), where poor parent-child bonding has been considered an effect rather than the cause. This incorporated the father's role. Links were previously made with particular socio-economic groups i.e. the phenomenon was found mainly in high income families

with educated parents however, Schopler, Andrews and Strupp (1979) reviewed all available studies and found a sampling bias. Such parents accessed medical professionals more readily than other groups, knew more about autism and were therefore more likely to gain a diagnosis. However, as knowledge and identification have become widespread children diagnosed with AS in immigrant and lower socio-economic groups have increased. *'The full picture of causes and effects, the biological interwoven with the psychological, will eventually be revealed, but this grand tapestry has to be worked on by many hands and for many years yet'* (Frith, 1989 p. 68).

Frith (1989) suggested that parents often sought environmental rather than biological explanations predicting more chance of a 'cure' if the environment could be changed. Alvarez and Reid (1999) wrote of two traditional camps, one believing the cause was an organic, inborn cognitive deficit leading to parental hopelessness, the other linking with childhood fear and defence mechanisms, leading to parental guilt. Arguments of nurture or nature were combined into a complex picture of multiple-causality. Alvarez and Reid believed their family systems approach developed communication and cognitive skills through relationships, suggesting that social impairment was symptomatic rather than causal (see section 2.5 in this thesis). This suggested a place for research focused on the family dynamics rather than merely within child. The social model of disability widens this lens further.

2.4.4 Social Model of Disability

Until recently the medical deficit model of AS had been widely accepted as prescribed by DSM-1V (American Psychiatric Association) and ICD 10 (World Health Organisation). This was categorised by limitations. The resulting focus was how to deal with AS, rather than how to understand it from a perception of 'difference' rather than 'disorder' (Baron-Cohen and Hammer, 1997). Baron-Cohen (2000) argued that diagnosis was usually based on abnormalities, whereas *'the neurobiology of AS/HFA is no better or worse than in typical development'* (p.491). There is no period of language delay and IQ is within the normal range, although

social, communication difficulties and inflexibility are common to both. This could be a disability created by social expectations,

> *In a world where individuals are all expected to be social, people with AS/HFA are seen as disabled. The implication is that if environmental expectations change, or in a different environment, they may not necessarily be seen as disabled* (p.497).

In my professional practice the framing of the AS phenomena is important to parents and how they raise their children. According to Baron-Cohen (2000) 'difference' was a more neutral and value-free term, '*akin to being told that the child is right or left-handed*' (p.489). Currently the medical model is maintained as its diagnostic labels are used as criteria to provide or deny services and resources. Baron-Cohen (2000) moved the argument towards the social model of disability whereby the social/physical environment inhibits or enables the person with AS. He argues that the nature of difference should command resources similarly to a 'disability' label, creating environments where people with AS have greater control, where an eye for detail leads to success in areas such as mathematics, computing, music, science and linguistics. Framing AS, a different cognitive style has been suggested by a number of professionals within the field (Happe, 1999; Frith, 1989; Baron-Cohen, 2000). The 'social model' of disability (Oliver, 1990) provides an important alternative for parents and professionals in influencing how people with AS perceive themselves and are viewed by society. However, whilst 'disability' rather than 'difference' dictates financial and other support available to families this fundamental shift in perception is unlikely to be fully achieved.

2.4.5 Section Summary

The research outlined above suggested there are a lot of unknown factors in considering AS aetiology, it argued for multi-causality. Three models have emerged taking a medical, family systemic and social perspective. These echoed moves to consider AS from a multi-faceted and indeed multi-agency view (NICE, 2011). A strong male genetic link suggested father-son exploration was required complementing the medical research with a socio-relational perspective. What then

does the literature have to say about the particular stresses that fathers may experience in parenting a son diagnosed with AS?

2.5 Parenting Children on the Autistic Continuum

Few studies have specifically researched the challenges, coping strategies and effective ways to serve families parenting children with AS (Lasser and Corley, 2008). Prior studies have discussed the hidden nature of AS within social settings (Attwood, 2008; Baron Cohen, 2000) (see sections 2.3 and 2.4 in this thesis). In my professional practice I have observed higher levels of parental stress and a 'need' to explain their child's behaviour, as anticipatory anxiety often occurred within mainstream settings. Some parents may have perceived their child as 'different' rather than 'disabled,' (Baron-Cohen, 2000). This will be revisited in considering parental coping strategies. Lasser and Corley's (2008) concept of constructing normalcy is critical in this context. Alvarez and Reid (1999) noted how a family could come to define its systemic 'normality' differently when parenting a child with AS. The painful reality of parenting children with communication difficulties should not be overlooked.

2.5.1 The 'Autistic Family'

Those using the 'family systems model' acknowledged that caring for children on the AC could place extreme stress on families. Parents struggled to make contact with their child, due to the nature of the 'autistic mind',

> *…the burdens of living with an apparently uninterested and unreachable child may produce a state of permanent hurt, shock and grief: outside the home, the families of these normal-looking but severely handicapped and strangely behaved children are often exposed to public and humiliating embarrassments. Their lives may become severely limited, with consequent stress on the parents' marriage and effects on the mental health of everyone* (Alvarez and Reid, 1999 p.3).

Alvarez and Reid (1999) using this model found miscommunication within these families was common.

They suggested support at each developmental stage was important, particularly during diagnosis. Feelings about the diagnosis could affect childcare and cause helplessness which resulted in insensitivity or hyper-sensitivity to the child's needs,

> *To ask for help and to give it are mutually reinforcing experiences, whilst to have one's hand grasped without even a glance at one's face is a deeply dehumanising experience. Such repeated emotionally exhausting experiences can wear away at parents' ordinary human warmth and spontaneity, so that, in the end, the hand may be given reactively and unreflectively without any expectation or demand of anything more* (Alvarez and Reid, 1999, p.8).

Damaged parental self-worth could result where children presented as dependant only for physical needs, the provider seemingly unimportant.

Families commonly felt that the child took a lot of resources but gave little back. Siblings felt marginalised. Families could lose contact with wider society due to their child's embarrassing behaviour (see section 2.4 in this thesis). Without exposure to the outside world, '*autistic family life*' could become the norm. *'Gradually … parents and other siblings can get sucked into the world of the autistic child rather than the more ordinary situation where it is the parents' task to introduce their child to their world and the world beyond.'* (Reid, 1999, p.25)

Reid (1999) suggested that parents needed time to mourn the child they had hoped for and come to appreciate their child's capacity for development. Alverez and Reid (1999) felt that each family member could be suffering a degree of post-traumatic stress.

Families and children were unique despite the shared diagnosis. Reid (1999) regarded the family's capacity to support change in the child as crucial. Parental feelings about each other, professionals and their child should be acknowledged, including anger, guilt, blame and hopes for a cure. Listening and noting parental observations of their child was extremely important for professionals using the model. Family empowerment within a realistic framework was seen as important.

> *Children with autism are inflexible and unreasonable so that their families seem to end up fitting in with them…The family imprisoned by the child is now a very familiar story. It seems to be reflection on the*

imprisonment of the child within the autistic condition (Reid, 1999, p.24-25).

Whilst under such stress it was common for parents to perceive professionals as critic or persecutor. This might have implications for my dual roles of researcher and SEP. These unconscious processes at work within family systems are acted out in practical challenges facing parents. How parents coped with such challenges could be highly variable as illustrated below.

2.5.2 Parental Coping

Several studies considered parental coping strategies (Lasser and Corley, 2008; Holland-Wade, 1998; Bristol, 1984), some highlighted possible gender differences (Dellve et al., 2006; Gray, 2003; Little, 2002).

Lasser and Corley (2008) interviewed 20 parents of children with Asperger Disorder (AD) to improve understanding of the parental experience. A central phenomena emerged from this study, 'constructing normalcy' i.e., adapting the environment for their children. How they met challenges and their parental meaning-making were discussed, as summarised in Table 2 below.

Table 2: Challenges Facing Parents

Meltdowns Need for and seeking support Avoidance of some settings Extra planning for the child Worry Frustration Strategies Parent coping Wondering about origins of child's AD What's normal/not Optimism/perseverance Special skills of the AD child, Selective about child's social world Need for more information on AD Stress	Mismatch of child/environment Comparison to peers Parental responsiveness Visualizing their child in the future Social isolation of the parent and child Diagnosis Limitation of family activities Preparation for the future Social support Advocacy Uncertain about future Building on strengths Child and family needs Hard work and anxiety

These themes were commonly raised by parents in their qualitative interviews. They may be critical to parental mental wellbeing, coping strategies and continued whole family functioning. Lasser and Corley (2008) concluded that '*those working with children and adolescents with AD might find a discussion of normalcy to be a productive avenue for management of behaviour and social skills or to raise children's awareness of parental experiences'* (p.345).

Gray (2003) interviewed 53 mixed gender Australian parents about; the onset of symptoms, referral, experience and diagnosis, symptoms and the effects on the family, family roles, coping strategies and the effect on parental wellbeing. Participants were asked to distinguish between three types of coping: practical, emotional and general. The results suggested that despite mainstream gender roles changing, traditional gender roles held in many activities. Women provided most domestic labour and childcare, even when working in jobs outside the home. Almost all fathers worked. This had an impact on the perceived effects of the child's difficulties on parents.

> *The most striking difference between the mothers and fathers was the differing personal impact of their child's autism. Although most fathers noted the severe difficulties that their child's autism presented for their families, they usually claimed that their child's condition did not have a significant effect on them personally... This is not to say that having a child with autism did not affect the fathers. Rather they perceived the effect to be indirect... They believed that the most serious impact that their child's autism had on them was through the stress experienced by their wives.* (Gray, 2003, p.643)

In some cases marriages were threatened as parents grew apart. Fathers' work provided a buffer for them in less childcare, separation from the home and a chance to escape.

Reid (1999) found that fathers increased their working hours, turning to work for sanctuary. Such experiences could evoke memories of childhood of how available one's own father had been. Gray (2003) agreed many had a greater commitment to work, preferring work to home. Work provided daily respite. However, the AS adversely affected fathers' working lives, fatigue and stress with less likelihood of promotions or moving for career reasons.

Thoits (1995) found that men coped in a stoical, inexpressive way, whereas women were more likely to seek outside emotional support. Sigmon, Greene, Rohan, and Nichols (1996) suggested that men were more likely to be problem-focused, women emotion-focused. Problem-focused coping attempts to change the nature of the problem; emotion-focused distracts individuals affected by discussing feelings, praying or withdrawing. Lazarus (1996) argued that the nature of problems demanded particular strategies, regardless of gender. Parents used a complex mix of coping techniques. Whilst there were assumptions men and women reacted differently to the same problems, Lazarus suggested fathers had different family roles, encountered different problems and had different expectations (Lazarus, 1993; 1996).

Fathers' concerns for their child's future revolved around job prospects, being independent and getting married. Worries about children going into institutions when parents died, or being a burden on siblings, were common (Draper, 2003; Gray, 2003). Gray (2003) found parental coping strategies commonly included taking one day at a time and anticipating difficulties before they happened. Fathers' practical coping techniques consisted of going to work and keeping the child busy. Women tended to work with the child to improve behaviour and kept siblings separated to maintain order. Parents tried to suppress emotion in dealing with the child, expressing feelings at other times forcibly. Fathers talked about suppressing feelings of anger and frustration in particular, as a coping strategy, but acknowledged this often failed and could result in unreasonable angry responses.

It could be argued that fathers who have traits of AS may be less adept at using emotional vocabulary thereby struggling to express emotions in a healthy way, through talking. Gray (2003) found that fathers had a more philosophical perspective, fewer general strategies and a tendency to revert to traditional roles. This may have related to earning potential. Many men wanted the mother to work and pick up the burden of home and childcare. One participant said his wife was on the front line dealing with anything to do with childcare. '*Fathers were much more likely to see themselves as being a reserve source of support for their wives, someone who their wives could rely on for support during periods of extreme stress.' (p.635)*

Hastings, Kovshoff, Ward, Espinosa, Brown and Remmington (2005) echoing Grey's (2003) findings suggested that fathers might have felt that their role was supporting the mother, rather than the child directly, (see sections 1.4.5 and 2.2.3 in this thesis) '*fathers might tend to cope with their child's behaviour problems by avoiding their children and engaging in other activities unrelated to the direct care of their child.'* (p.641). Hastings et al (2005) completed a systems analysis of stress and positive perceptions in parents of pre-school children with autism. They found that the triadic relationships between the child and parents were important variables. Parents commented on their child's characteristics, their own stress, and mental health. Depression in either partner disrupted marital support thus raising stress levels. Those who relied most heavily on their partner were most likely to be affected.

In the Hastings et al (2005) study fathers reported less mental health issues than mothers but there was no difference in reported stress. Fathers also had a less positive perception of the child and their positive perceptions were negatively correlated with their partners' stress and depression. Fathers' stress was positively correlated with both maternal anxiety and maternal depression. This suggested greater reliance in the father upon the mother's mental wellbeing. Axup (2003) found the mothers in her study reported that such fathers often left the family home. What then are the factors which encouraged some fathers to remain? They may include appropriate forms of information and support.

Huws et al (2001) studied parents' of children with autism using an e-mail group. Parents used the group to support their search for meaning, adapting to change, providing and gaining support and encouragement, narrating experiences and sharing strategies. This provided an alternative information resource between those in similar situations. Huws et al (2001) study proposed that this could legitimate parental experiences and develop wider views of autism. E-mailing addressed problems of families having to travel for support, providing privacy and anonymity. Research suggested that fathers preferred electronic communication forms (Hinckley et al., 2007; Huws et al., 2001). As an Educational Psychology Service provision it might be useful to implement an e-forum for fathers.

A lot of the above studies have focused on gender differences in parental coping, however there is likely to be another dimension when considering fathers raising a

son with AS as the characteristics may be shared. Attwood (1998) argued that when characteristics of AS affected one or both parents with poor social skills, obsessive behaviour, mismatch of skills, cognition and language difficulties, it was difficult to generalise. Significant difficulty with social involvement had the potential for causing great socialising problems for the child and family, throughout life. Fathering and mothering such children could be extremely difficult.

> *There is no one experience of being a father. Mine will be different to the man's down the street. Fatherhood is mediated by age, ethnicity, biography, experience, economics and life-course. It will vary over one father's life. (Collier, 2009, p.5)*

2.6 The Rationale for this Study

Previous research has suggested that fathers struggled to balance raising a family, earning a living and negotiating the roles of partner and parent. The isolation fathers felt was highlighted throughout much of the literature, particularly when raising a child with a disability. Support and services were mainly designed around meeting the needs of mothers.

2.6.1 Why Fathers?

Fathers are under researched compared with mothers. Society has become increasingly aware of the influence fathers have on the wellbeing and outcomes of their children, for better or worse. In order to harness the potential positive influence fathers have to offer their children it is important that services such as the EPS hears what their needs are and provides appropriate support for them. This could help break trans-generational trends of absent and struggling fathers.

2.6.2 Why Focus on Asperger Syndrome?

The implications of an AS diagnosis are often misunderstood by professionals and wider society. There are few well targeted resources to meet the children and families' needs. The child's difficulties are hidden by their average to above average cognitive ability and lack of physical markers. This results in parents having to manage and explain odd and inappropriate behaviours to themselves and within

mainstream public forums, including schools. Fathers particularly struggle with these children as they may have AS traits themselves, due to genetic links commonly found in the male line.

2.6.3 Why Sons?

The majority of children diagnosed with AS are boys. The relationship between the father and son is important in most cultures as boys are expected to continue the family name and other traditions. This relationship evolves from pre-natal anticipation and shifts over time through the experience of fatherhood. The research emphasised the significance of father and son activities for a secure attachment and healthy dynamic. Due to their social communication difficulties a son with AS is unlikely to fulfil their fathers' ideals for the father-son relationship and their sons' futures.

2.6.4 The Distinctive Contribution of this Study

My research combined these three elements addressing important gaps in existing literature and answering the call of many academics and practitioners for further study (Axup, 2003; Baxter et al., 2000; Hastings et al., 2005; Hews et al., 2001). I was not replicating existing research or addressing the phenomena from a different epistemological stance. Rather, I aimed to achieve an in-depth understanding of the 'life-worlds' of fathers raising sons with AS who had stayed within the family home. Such understanding could shine new light on the problems experienced by these fathers, influencing better targeted support and resources. This was framed within my relativist epistemology, using IPA (Chapter 3).

This research aimed to collect data to inform professional practice and empower this marginalised group (Figure1, p.68). Such information would bring new perspectives on the needs of fathers and the families of sons with AS. It was hoped that factors supporting fathers to remain within the family home would be identified. Findings could then be considered by professionals in terms of existing and future provision.

2.6.5 Conclusion

This chapter has given a literature overview of areas related to my study. Overall a gap in the literature has been identified giving rise to my research focus. The next chapter outlines methodological decisions, theoretical and personal underpinning, and outlines the practical steps of the research process.

Chapter 3: Research Design and Methodology

3.1 Chapter Introduction

This chapter outlines my research decision making processes and gives a reflexive consideration of my multiple roles. Ethical thoughts and decisions regarding the research and processes to support validity, coherence and reliability are stated. Following this a practical breakdown of data sampling, collection, recording and the analytic stages are outlined. A brief consideration of research outcomes and dissemination concludes the chapter.

3.2 Methodological Decisions

3.2.1 Introduction

The literature review identified the broad area of study, giving rise to the general question, 'what is the lived experience of fathers raising a son with AS' (Figure 1, 68). To consider how best to gather information addressing this question, a range of decisions were necessary, involving epistemology, ontology and methodology. These resulted in a choice of IPA as the research framework.

3.2.2 Qualitative or Quantitative?

In general terms design choices included qualitative, quantitative or mixed methods. All approaches have their advantages and limitations (Table 3 p.64). Silverman (2001) noted that a concern to explore people's life histories or everyday behaviour favours qualitative methods. Sanders and Liptrot (1994) suggested that '*accurate*' measurement is impossible where situations constantly change. The act of measuring can precipitate changes and '*measurement is an insult to, or violation of,*

the human processes we are seeking to sensitively understand' (p.5). Qualitative approaches, therefore, suited my research aims (Figure 1, 68) and epistemological position (Figure 2, 69).

Table 3: Differentiating Qualitative and Quantitative Methods.

Qualitative Methods	Quantitative Methods
Seek to understand meanings	To discover predictive 'truths'.
Acknowledge existing contexts	Tries to control context/variables
What is experienced important	What can be observed important
Inductive	Deductive
Limited samples	Larger sample to seek generalisation
Seeking narratives	Seeking proof
Un/semi-structured data collection	Structured data collection
Focus on language/text analysis and reporting	Focus on numbers/counting analysis-reporting
Subjectivity acknowledged	Aim to be objective
Researcher participant relationship is important	Attempts to neutralise researcher contamination

Discovering the 'truth' of experience is not straightforward. As Silverman (2001) notes, '*Even scientists only observe 'facts' through the use of lenses made up of concepts and theories … whatever we observe it is impregnated by assumptions about what constitutes knowledge and how it can be known.'* (p.1-2) In my study the kind of 'truth' being sought was relative to each participant and was grounded in an exploration of their experience, views, opinions and emotions. This in itself revealed my epistemological position.

3.2.3 Epistemological Position

Epistemological positions within research combine the assumptions and beliefs of a paradigm and a researcher. Each research paradigm has its own set of philosophical assumptions about what can be known and how (MacDonald and Stodel, 2003; Denzin and Lincoln, 2003). Whilst theories provide the backbone of research, no ultimate theoretical stance is without difficulties. As an EP, I apply a

range of positions from positivist cognitive tests to relativist observations within classroom settings.

A research approach develops out of an epistemological framework to consider something in a particular way. Each of us has a model of the world and seeks new evidence to modify, validate or alter that model (McLeod, 2003). Yet, can we believe anything without evidence? McLeod suggested that although personal and official theories are usually connected, research is '*a systematic process of critical inquiry leading to valid propositions and conclusions that are communicated to interested others.*' (p.4).

Figure 2, p.69 shows my philosophical position and the nature of my research question as relativist, interpretivist and phenomenological. This required acceptance of 'subjective truth' relative to the situation, research context and other human or circumstantial variables. The relativist standpoint recognises the inevitability of change. Repeating the encounter cannot replicate it as both researcher and participant will have changed through the dynamic of the first process (Willig, 2001). Whilst intending to give voice to a marginalised group I had no explicit emancipatory intentions. Thus an interpretivist, rather than a critical theorist, stance was felt appropriate.

According to MacDonald and Stodel (2003) interpretivism concerns itself with understanding the social lives of people and how they construct meaning through experiences. It recognises that people's lives are based on social interaction and socially constructed meanings within constantly shifting conditions. Everyone assigns their personal meaning to a situation, which influences their response.

Branches of interpretivism apply different emphases including constructivism, grounded theory, IPA, ethno-methodology and phenomenology. In an attempt to capture a holistic view of the fathers' experiences whilst considering their social context, IPA was chosen.

3.2.4 Interpretative Phenomenological Analysis

My research aim was to understand an under-researched phenomena and uncover experiential realities not build new theory. Grounded theory, like IPA, analyses data without prior hypotheses, but data analysis is more prescribed, i.e. open, axial and selective coding (Silverman, 2001; Glaser, 1999; Charmaz, 2006). Participant interviews were chosen as opposed to observations in their own environment. Therefore this was not an ethno-methodological piece of research.

Phenomenology focuses upon the essence and taken-for-granted aspects of an experience. This was only part of my research aim. From my EP perspective practical implications were important. This required taking an interpretative role, but grounded within the participants' 'worldview'. Various methodologies share this stance. IPA has much in common with a narrative approach (Smith, Flowers and Larkin, 2009; Bathmaker and Harnett, 2010) both aim to understand and elicit participant stories ideographically and contextually. Riesman (2004) suggested narrative analysis has a fourfold framework.

Table 4: Riesman's Fourfold Framework.

Thematic	Structural	Interactive	Performative
Story content - focus on descriptive and interpretative meanings.	Story form and cultural resources of telling.	Dialogic story functions between teller and listener	Actions of the story in the telling and words

Thematic analysis is clearly shared by narrative and IPA methodologies. There is debate as to whether thematic analysis is a methodology in its own right or an aspect of several others. Braun and Clarke, (2006) suggested thematic analysis is less constrained by a theoretical framework compared with methods such as IPA. However, Pringle, Drummond, McLafferty and Hendry (2011) stated that '*a sense of depth and purpose'* (p.22) are added where there are strong theoretical roots, benefiting IPA over thematic analysis. According to Brocki and Wearden (2006) IPA aims to go beyond a standard thematic analysis. IPA may acknowledge all four

aspects (Table 4, p.66) but moves away from the maintenance of the structure of the story. This relates to the emphasis on the double hermeneutic (see section 3.10.1 and Figure 4, p.83 in this thesis) and a predominantly psychological focus within the later stages of analysis. Rather than alternatives IPA and a narrative approach seem complimentary. Where IPA better met my research aims was in telling the stories of the themes rather than the individual narratives. This supports the move to practical implications and evidenced based practice.

IPA originated in the field of health psychology (Smith, 2009; Brocki and Wearden, 2006) but is becoming increasingly popular in Educational Psychology (Hews and Jones, 2008). This is due to a growing interest in qualitative research focusing on specific groups of children and their families, influenced by the 'Every Child Matters Agenda' (DfES, 2006). My experience as an adult counsellor also influenced my decision to use this form of in-depth qualitative analysis. I believe that uncovering meaning as to how participants think and feel about their experiences is important in gaining insight into how to design support packages and improve EP practice. Focus on the journey and learning process, rather than purely the destination, seemed important for myself, the researcher, and the participant in IPA, with the goal of truth being replaced by the goal of understanding (Smith and Osborn, 2003).

IPA is concerned with the particular, therefore making limited claims of generalisation. Smith et al (2009) noted, '*It is possible to think in terms of theoretical transferability rather than empirical generalizablity.'* (p.51). Methodological choice influenced sampling, data collection, recording, analysis and presentation of results (Figure 3, p. 70). It is argued that there is a danger of undermining the benefits of in-depth, small scale research by using quantitative concepts, such as generalisation and triangulation. Smith (2009) suggests a more appropriate quality criteria for IPA would be the representativeness of participant quotations within themes. This maintains the ideographic commitment to the individual whilst highlighting both commonality and uniqueness.

Figure 1: Research Aims and Outcomes

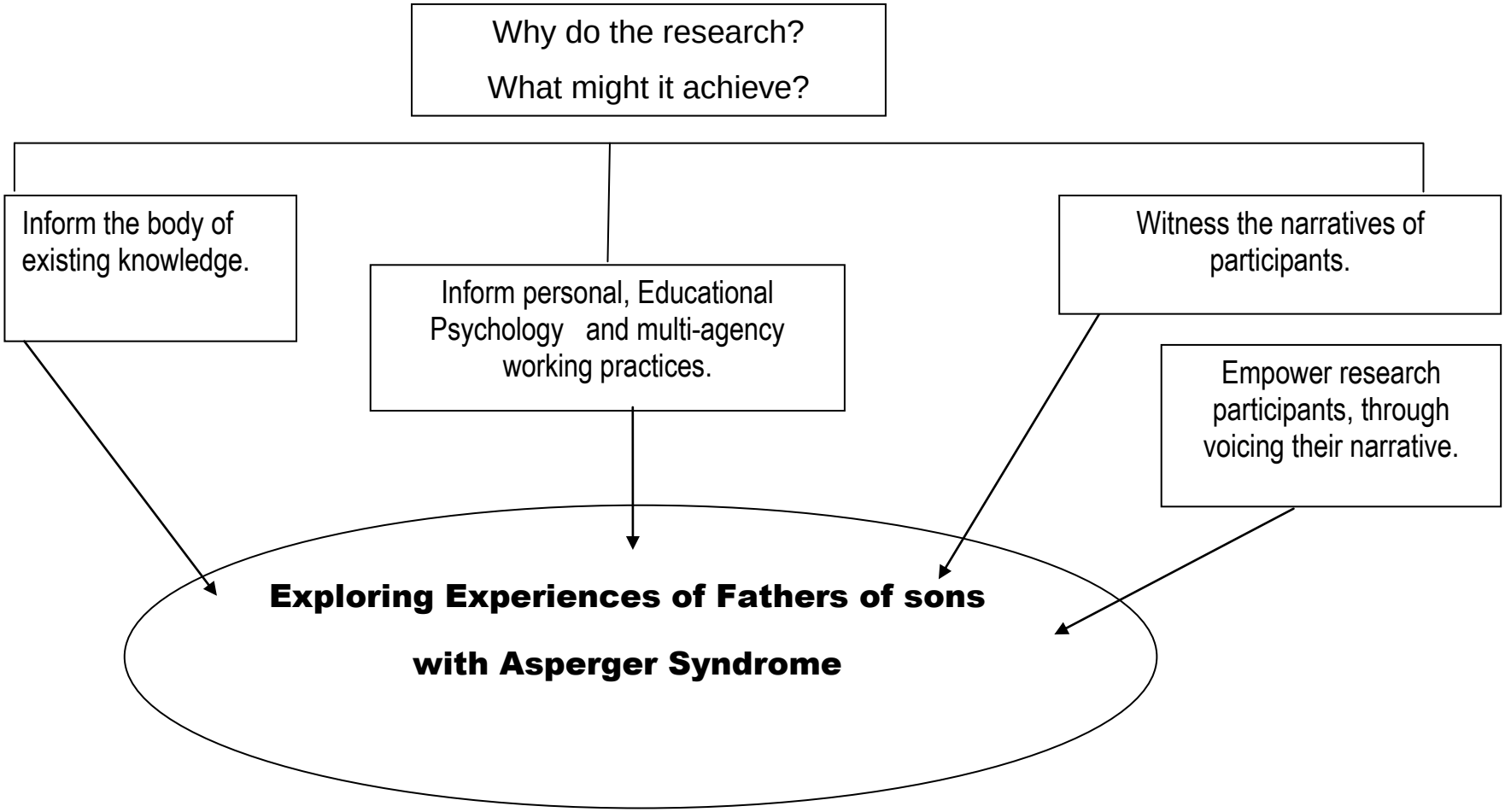


Figure 2: Epistemological Position

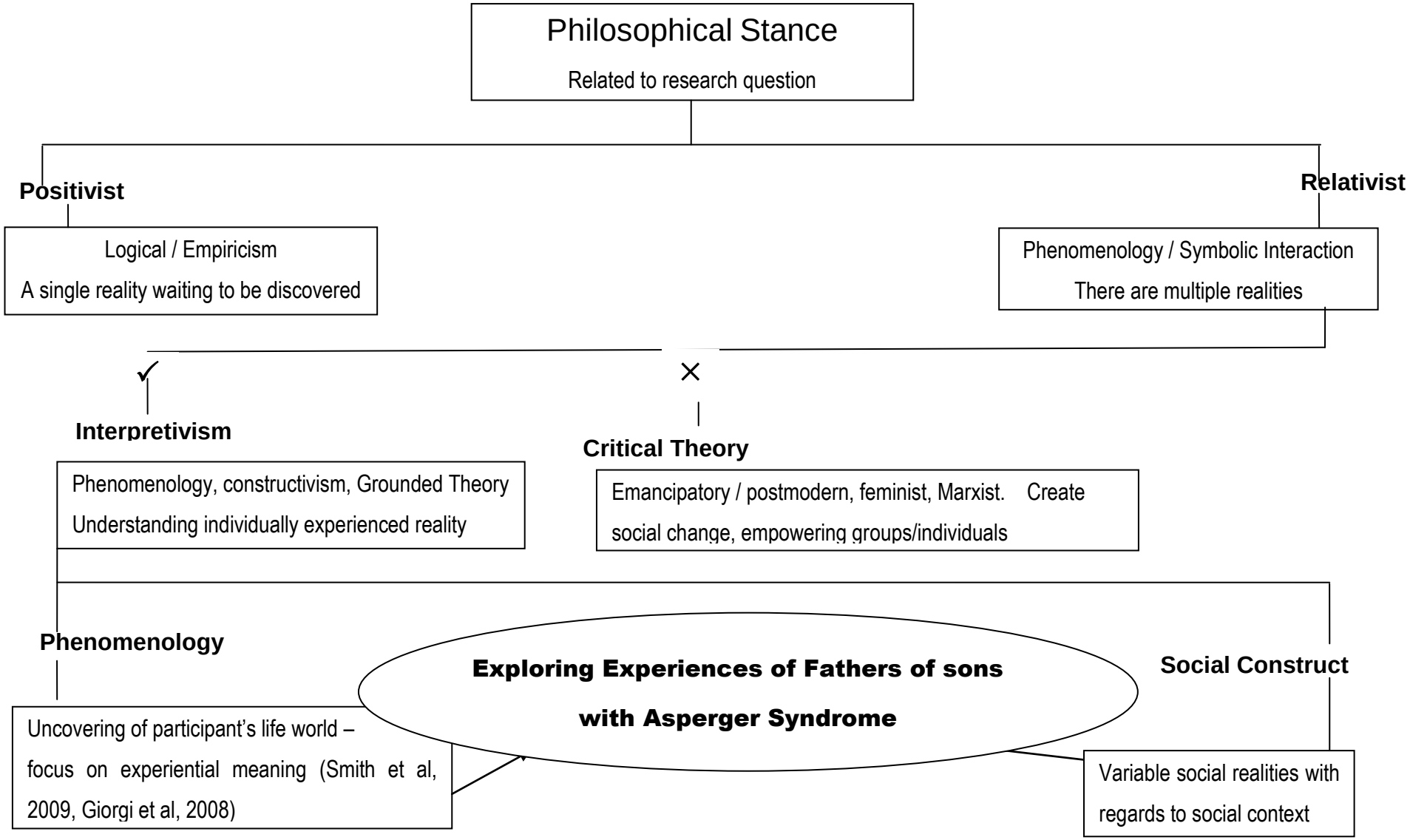
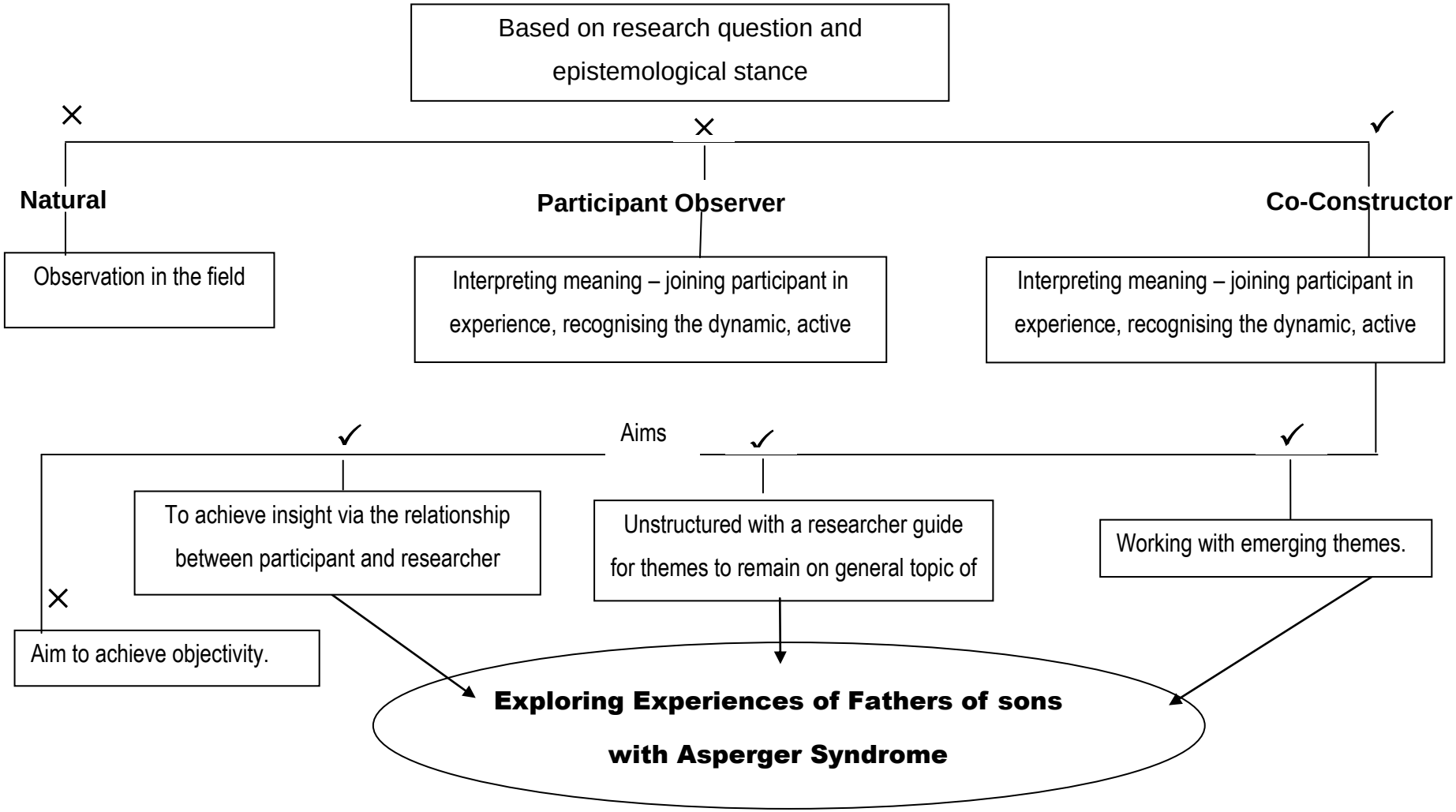


Figure 3: The Role of Researcher/Educational Psychologist



3.3 Roles within Research

I took the position of a relatively neutral co-constructor (Figure 3, p.70). Sanders and Liptrot (1994) stated that the role of the researcher is different within each epistemology. In more relativist stances (Figure 2, p.69), the researcher is a co-constructor with awareness of their own and participants' subjectivity (Figure 3, p.70). In IPA the narrative data is interpreted making use of researcher subjectivity through awareness of their fore-understanding or assumptions (Smith et al., 2009). The researcher considers how to study a world in which they are integrally a part, and to be transparent about what they bring into the process (Morris, 1999).

EPs often assert that their practice is evidence-based, reflecting the importance of research within the profession (Gersch, 2004). Research contributes to wider psychological knowledge and roots practice within firm, theoretical foundations, thus moving beyond 'a good idea.' The Every Child Matters Agenda (2003) has necessitated a widening of Educational Psychology practice and research from the child, to the family and into the community. Multi-agency working has brought a rich diversity to Educational Psychology through a broader spectrum of research methodology, impacting on my decision-making process. Roles of EP, researcher and counsellor all blended within my epistemological stance, research aims and objectives (Figures 1, 2, 3, pp. 68-70).

EPs increasingly support and liaise with significant adults within a child's life. This raises a shared responsibility for finding solutions. A 'team around the child' approach helps to dispel the notion that the problem is exclusively the child's. My previous research and experience of families raising children with AS posed questions regarding the father's role (Axup, 2003). There appeared a paucity of research literature in this area (Chapter 2). Ideas from positive psychology could influence research by reframing problem-focused questions and traditional deficit research, in order to look at what works and why (Seligman et al., 2005). Evidence-based theory and practice are necessary to support fathers and parental partnerships as fathers often leave the family home when their sons have AS. Within a positive psychology framework this exploration of fathers' experiences

focused on those who had remained. This could reveal significant factors that contributed to their decision to remain in the family home.

3.4 Reflexivity

This research combined my roles of SEP, adult counsellor and IPA researcher. Demands for reflective practice are embedded in all three. Finlay (2002) noted that reflection is not synonymous with reflexivity. According to Webster (2008) reflexivity is a poorly defined, slippery and multi-dimensional concept. Two dimensions of reflexivity were considered the personal and the social. The former is introspective, the latter raises questions of power relations from the personal to the professional. Lynch (2000) described six types of reflexivity, three of which seemed relevant; methodological, meta-theoretical and interpretative.

Firstly 'Methodological,' arising from introspection and examination of my own beliefs and assumptions as a 'being-in-the-world' (Smith et al., 2009) through journaling and peer discussion. The first stage of my research was a process of reflection, thought and intuition on my pre-understandings of the area of study, Finlay (2002) named this 'phenomenological' reflexivity, e.g., how the choice of research related to my previous study (Axup, 2003). Placing this in a comprehensive literature review allowed an attitude of openness but also the challenge of 'knowing too much,' requiring a degree of bracketing (Finlay 2002; Smith et al., 2009). However not all personal understanding can be known prior to interpretation (Smith, 2007).

The 'Methodological' overlapped the second category, 'Meta-theoretical' (Lynch, 2000) i.e., examining the taken-for-granted in academic epistemology and philosophy. This is summarised in figures 1, 2 and 3. The production of which took the form of philosophical mind-mapping (Buzan, 2005). This category echoed Bourdieu's concept of 'epistemic reflexivity' (Moss, 2005).

Thirdly, 'Interpretative' reflexivity was held in mind throughout the analytic research process, a hermeneutic examination of thinking and acting (Figure 4, p.83).

This could take many forms but the most consistent was membership of an IPA group. Within this forum I undertook both personal and social critique of my thinking and practice. It was also an interpretative endeavour in a social constructionist sense (Smith, 1994; Finlay, 2002). This action learning group consisted of applied psychologists across the fields of health, social care and education (Tileaga, 2008; IPA Group: London, 2006-10). Interpretation also occurred in the data collection, planning and implementation stages.

Client-centred working was familiar to me within counselling and EP practice, e.g., encouraging disclosure and reflections about feelings and events. It also prepared me for psycho-dynamic reflexivity (Finlay, 2002; Josselson, 2004). The interview is a power structured relationship at both conscious and unconscious levels. Despite this familiarity I felt slightly anxious transferring such skills to research interviews. As Smith (2009) noted, novice IPA researchers often need more structured interview planning (Appendices H, I). Whilst an interview schedule addressed my anxiety somewhat it raised uncomfortable feelings of disrespecting participants by pulling them onto my own agenda, something a counsellor is trained to avoid. This represented contradictory needs, those of my research to be focused for service planning and my personal quest for authentic human data. As a compromise I explained to participants I had a written interview schedule, yet kept it hidden to avoid its distraction, formality and power implications. This allowed participants to tell their stories and for me to refer to the structure occasionally, keeping the interview focused on the phenomena I was exploring. I am aware that I may have gained different data had I just asked them to tell me about their experiences.

As an SEP I had extensive foreknowledge about most of my participants and their families which influenced the interview dynamics, the data collected and its interpretation. Within interview I saw myself as a witness with a particular 'psychological attitude' (Giorgi and Giorgi, 2003), my role was significant, *'a voice with no listener is silence*' (Langdridge and Butt, 2004, p.31). In this way I translated counselling skills into a hermeneutic of empathy (Smith, 2007), without taking on the mantel of counsellor. This helped to ground interpretation in the participants' voice, rather than being driven by myself or theory. I see 'meaning' as co-constructed, a

concept which captures the flow and ever-changing nature of encounters (Finlay, 2008).

There is also a role for the hermeneutics of suspicion/questioning (Smith, 2007; Josselson, 2004). Mentally, I used an internal supervisor to question the dynamic within the room, in terms of what belonged to me, the participant and the event. There were some obvious differences, e.g., my gender and non-parental status, but there may have been similarities, e.g., my experience of being parented. Hermeneutic questioning at a later stage could reveal less obvious similarities and differences for interpretative insight (Smith et al., 2009).

Difficulties in reflexivity are its time consumption and inevitable 'partial, preventative and provisional' nature (Finlay, 2002). It might skew data away from the participant turning into researcher 'navel gazing,' getting trapped in the hermeneutic circle never to leave it. To do it properly is difficult, particularly where there are practical as well as psychological constraints, *'reflexive exploration is usually strangled by the constraining word limits set by scientific journals'* (Finlay, 2002, p 543).

A participative approach involving interviewees in reflexive dialogue during analysis and evaluation, as exemplified in Smith (1994), was not possible in this research. There were practical and ethical considerations working against this (see section 3.5 in this thesis).

3.5 Ethical Considerations

In planning and completing this research careful consideration was given to professional ethical guidelines, (British Psychological Society, 2006; University of East London, 2008). Ethical approval was granted in June 2009 prior to contact with potential participants (Appendix B). Anonymity, confidentiality and the potential for stress were carefully considered.

Stresses for participants were considered at all stages of the research process. The initial interview schedule was adjusted to introduce the least sensitive questions first. This aimed to help build a comfortable and trusting atmosphere. Participants'

psychological/emotional and practical needs were carefully addressed (see section 3.8 in this thesis). It was made clear that participants could opt out at any time during the research process, e.g., one participant asked for the tape recorder to be turned off, but wanted to continue with the interview. This negated my data collection needs I felt he wished to place me in the role of counsellor rather than researcher or SEP. Counselling skills were used to monitor the ebb and flow of the interviews, in order to support participant wellbeing. Endings were particularly important as participants needed to be emotionally prepared for returning to the outside world. This included an option for taking sensitive issues opened up in the interview to a counsellor working within the EPS. It was envisaged that the interviews could be emotionally challenging to participants therefore it would be insensitive and unethical to ask them to revisit the data.

Confidentiality was particularly important to emphasise given eight out of the nine participants' families were known to me within my EP role. This could have inhibited participants, fearing their stories might in future be available to their partners or sons' schools. In speaking about family members loyalty is often an issue, as are feelings of guilt and vulnerability. Conversely it was felt the established relationship might encourage disclosure. In professional terms such contact could be regarded as part of the ongoing support relationship with the families. Boundaries were clarified verbally and in writing (Appendix C). Questions were raised as to whether to append transcripts. It was felt that wives of participants could, and would, search to identify their partner and this would compromise participants' confidentiality. As such, transcripts would be copied onto a CD Rom and made available only to examiners. The audio-taped interviews and other personal information were stored in a locked cabinet and password protected computer.

3.6 Validity, Coherence and Reliability

A range of sources were utilised to establish the coherence, validity and reliability of the data. Whilst the primary interview data was idiographic, this was contextualised within the literature reviewed and my personal and professional experiences of this group '*The power of the IPA study is judged by the light it sheds within this broader context'* (Smith and Osborn, 2003 p.52). MacDonald and Stodel (2003) argued that

the validity of an interpretation is always in relation to somebody. Validity like reflexivity is a multi-dimensional and slippery concept. Criteria for assessing validity depend upon who that person is and what role they play (e.g., researcher, reader or participant). Empathic understanding, albeit imperfect, was used to understand participants' inner experiences.

It is argued that trustworthiness and credibility are better terms for qualitative research than validity and reliability (Yardley, 2000). Credibility checks were employed via journaling and peer/tutor support. It was planned to audit findings through inter-rater checking to ensure analysis was grounded firmly in the data. An IPA group would read and discuss transcript selections and carry out their own analysis (January 2010). This would be compared and contrasted with my analysis. Involving other professionals in a critical forum of my interpretations increased analytic validity. In IPA this is concerned with 'prevalence, representativeness and variability' (Smith, 2009). Such a process allows methods and evidence base to become transparent. Debate also highlights the plausibility of themes and their grounding. It further increases the depth and breadth of my research engagement and helps raise awareness of foreknowledge in my analytic role. This is done in recognition that multiple meanings can occur in IPA given the role of the researcher in 'sense-making' (Smith et al., 2009). That is the double hermeneutic.

Journaling continued from the research inception to its completion. Regular, practical, emotional and reflexive thoughts were written as a stream of consciousness. Some aspects were discussed with colleagues and peers, serving a similar function to the IPA group. Themes would be considered by peers and tutors to assess whether the essence of the phenomena had been identified. All these processes were recorded providing a paper audit enabling reviewers to judge the quality of the interview schedule, interview practice, transcriptions and the analytic themes identified from the data. In tutorials more succinct terminology developed using the original themes as descriptors. This was also a forum for checking consistency between my application of IPA, my research questions, my epistemology and the data voices of participants. In more personal terms, discussing and comparing interpretations brought my assumptions and foreknowledge to the surface revealing my role in the double hermeneutic.

In research with a concern for practical implications 'catalytic validity' was important (Angen, 2000). This asked the question how far the research could give rise to new understandings. In my research this would be relevant in my roles of researcher and SEP, for participants and their families and by dissemination for other families and professionals. For example preliminary findings regarding implications for practice were discussed in a workshop (Educational Psychologist's Regional Conference June, 2010). Post-research reflections and working practice assisted with identifying personal catalytic validity. Participants were asked to email their reflections on their experience of the research (Appendix K).

3.7 Sampling

3.7.1 Criteria

Sampling in IPA is concerned with identifying a relatively homogeneous group ensuring rich experiential representation of the phenomena. Qualitative IPA research proposes smaller purposive samples in order to achieve this, giving scope for great depth and insight in exploring the phenomena.

My sampling criteria consisted of:

1. Fathers of sons who have been diagnosed with AS (DSM-IV)
2. Sons aged 11 and above
3. The family unit consisted of resident fathers, mothers and sons with or without siblings.

The diagnosis AS based on behavioural characteristics provided some consistency regarding sons' who were indirectly a focus of this research. The age marker ensured all fathers in the participant group had gained a range of experience within the stages of child development up to adolescence. This could include the transition from primary to secondary schools.

3.7.2 Participant Recruitment

Posters were placed in schools (Appendix D) and the Support for Asperger Families in Essex (SAFE) newsletter April-May 2009 (Appendix E). Letters were sent to seventeen fathers known to meet the criteria (Appendix F). It was practical to consider a local participant group to facilitate face-to-face interviewing and important for service outcomes to collect local data. It has been found that men are more difficult to engage than women. '*It can be notoriously difficult to recruit men for research about* 'family *things'* (Davies, 2008, p.5). Therefore existing professional contact with families and schools was used to advantage. Interested fathers were asked to make contact via a work e-mail address for further details. It had been suggested that men find the distancing of e-mail contact easier to engage with (Huws et al., 2001). Once contact was established participants received a research information sheet (Appendix C) and were invited to interview on a mutually convenient date. Seventeen contacts were made but only nine interviews were practical in respondents' working schedules during July 2009.

3.7.3 Research Participants

The participants consisted of eight fathers who met the research criteria. One, who did not meet criteria three, was interviewed as a pilot (see section 5.4 of this thesis). Four to ten interviews are considered acceptable for professional doctorate IPA research (Smith et al., 2009). Demographic information to contextualise the interview was collected immediately prior to the interview (Appendix G). The demographic pattern is indicated in Table 5, p.79. All participants were white-British, with occupational indicators to suggest mainly middle-class. A range of sibling numbers were represented. MacDonald and Stodel (2003) suggested that participants should be chosen as good examples of a phenomena rather than representative of a larger population.

Table 5: Demographic Pattern of Sample Participants.

Father's Pseudonym	Father's Age at time of Interview	Nationality	Highest Educational Qualification	Employment	Length of time with partner	Mother's Pseudonym	Mother's Age	Mother's Employment	Son's Pseudonym	Age of Son at time of interview	Age of Son At Diagnosis	Other Children Gender/ Age
2. James	47	White British	A'Level	Local Govt Officer	20	Anna	46	Learning Support Assistant	Len	12	2	M 10
3. Stephen	50	White British	Graduate	Carer/home maker	15	Nina	46	Software Tester	Tim	11	5	F 10
4. Dave	49	White British	0'Level	Assistant Manager	25	Mary	48	Homemaker	Nigel	18	7	M 21 F 23
5.Otto	45	White British	A'Level	Manager	17	Hilary	44	Manager	Morris	15	8	M 12
6.John	45	White British	City and Guilds	Postman	23	N/A	40	Nurse	Dan	11	11	F 6 M 3
7.Patrick	50	White Irish	HNC	Sales Manager	22	May	40	Mother/home maker	Ned	12	3	F 18 F 16 M 14 M 10
8.Andrew	58	White British	Certificate	Baptist Minister	33	Ellen	54	Retired	Mark	15	13	None
9.Simon	56	White British	A'Level	Company Director	26	N/A	55	Arts Development Director	Keith	19	8	None

N/A – not referred to by name in the interviews/transcripts

3.8 Data Collection

In-depth interviews are commonly used within IPA, along with diaries, websites and narratives (Langdridge and Butt, 2004; Struthers and Penden-Alpine, 2005; Willig, 2008). My primary data collection method was a single, in-depth, semi-structured interview. The intention was to reflect on participants' development as fathers, rather than observing them over time. Therefore multiple, temporal interviews were not felt necessary. Structured interviewing could lead rather than voice the participants' views and unstructured interviewing might not fully address the research focus. Semi-structured interviews allowed flexibility to address the 'life-worlds' of the participants and my needs as an EP to inform service delivery. Interview schedules enabled interviews to remain subject focused aiding later thematic analysis (Willig, 2008; Stodel and MacDonald, 2003; Smith and Osborn, 2003).

A flexible interview schedule (Appendices H/I) was prepared (Smith et al., 2009). Design took account of a developmental focus and refined questions from more generic and least sensitive to the more personally specific. Open questions reflected key topics in the literature reviewed, prior research and working experience. They aimed to encourage participants to engage with what was significant for them in the topic, '*in dialogue whereby initial questions are modified in the light of participants' responses and the investigator is able to probe interesting and important issues which arise*' (Smith and Osborn, 2003, p.55). Various supplementary prompts and questions were anticipated. The first version (Appendix H) was adjusted as a result of pilot interviewing and tutorial discussion (Appendix I).

Whilst video-taping would have included non-verbal data, I considered it potentially intrusive for such a sensitive topic. Immediately following the interviews my impressions of non-verbal communication and the relationship were audio-taped. An inconspicuous digital recorder was used with participant agreement. It was made clear this could be turned off at any point on request. This recording method was chosen to enable more attentive listening whilst capturing the data for later analysis.

On the basis of prior research experience (Axup, 2003) one venue was selected, my personal counselling office. Participant's homes and EPS premises would not have

ensured confidentiality or uninterrupted privacy. On arrival, participants were offered a non-alcoholic drink. This allowed them time alone to gain ease with the room, re-familiarise with the research information sheet (Appendix C), complete an informed consent form (Appendix J) and demographic questionnaire (Appendix G). I countersigned their consent form, and gave them a copy. They chose their pseudonyms (Willig, 2008). A list of prior pseudonyms was available to ensure no duplications. The flexible interview schedule (Appendix I), giving priority to their views, was introduced. The tape was turned off when all areas had been covered or on request of a participant.

During the de-briefing period participants were asked how they experienced the interview and provision for counselling was offered to address any arising issues. This was taken up by one of the participants who had become distressed during the interview. After a few days participants were e-mailed requesting their reflections on the interview process (Appendix K). They were given counsellor contact information to ensure support was available, given any later distress. They were thanked for their participation and a pledge was given to disseminate the research findings to them.

3.9 Transcription

Transcription is not a neutral, but an interpretative process with analytic implications (Lapadat and Lindsey, 1999). Each person involved brings an interpretative element. An audio-typist with knowledge of IPA performed the initial transcription. This was due to personal time constraints and limited typing skills. The risks of this are potential transcriber bias in grammatical layout. *'Mistakes can change the meaning of the phrase, making it appear to be the opposite of what was actually said. This could be due to missing or misinterpreted words.'* (Easton, McCornish and Greenberg, 2000, p.706). The advantages were that, on the first listening, audio-files could be checked against the text without the distraction of transcribing.

For IPA it is felt sufficient to transcribe the linguistic text with any significant pauses or utterances noted in brackets. Each change of speaker initiates a new line in the table. Following examples in existing IPA studies, the transcripts were placed in columned charts with the following heading order (Table 6, p.82).

Table 6: Transcription/Analysis Headings

1.Section No.	**R Or P**	**2. Text** Significant comments, feeling words & metaphors highlighted from transcript.	**3. Exploratory:** Summary and Analytic comments.	**4. Chronological Themes:** Single word or Short phrase.	**5. Psychological Frames:** Technical terms Or concepts

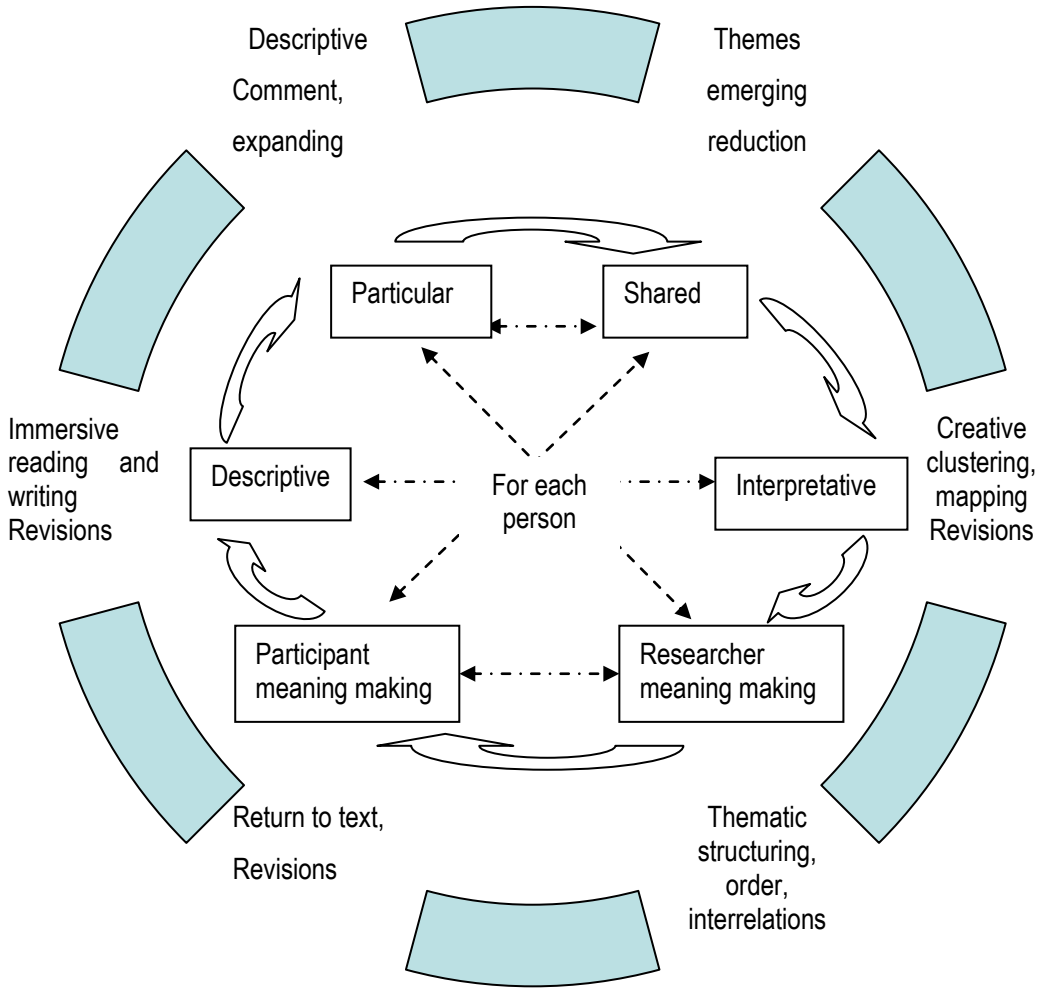
R=Researcher P=Participant

3.10 Data Analysis

3.10.1 Introduction

IPA recognises the importance of the roles of participant, researcher and the interrelationship between them. As illustrated, in Figure 4, p.83 it embraces a 'double hermeneutic;' which is the researcher's interpretation of the participant's interpretation of his world, based on a combination of empathic and questioning hermeneutics (Smith and Osborn, 2003).

Figure 4: The Double Hermeneutic Process



(Thomas, 2011 p.21)

All participants were interviewed before any transcripts were analysed to reduce cross-contamination. This limited ongoing adjustment of the interview schedule and process. Analysis was completed on each transcript before moving to the next, a cross case analysis was then undertaken (Smith et al., 2009). Initially, my pre-conceptions were contained in 'mental brackets' in order for the participant's narrative to be fore-grounded (Gearing, 2004). During later analysis data was consciously interpreted using theoretical and professional knowledge. Analysts have some flexibility for preferred patterns of working within the inductive process of IPA. My analytic cycle is outlined in the sections below.

3.10.2 The Individual Cycle of Analysis

Individual cycles of analysis for all eight interviews took a period of four months. In entering into participant worlds, there was an awareness of the transference and counter-transference (Freud, 1910). For example I felt transference occurred when a participant demanded the tape recorder be turned off five minutes into the interview, he had commented on the uselessness of professionals and brought this anger into the room and our relationship. He could not take on the role of participant in the research relationship and needed to have the control he longed for with other professionals in his past. During both interview and analysis I could respond to data from my unconscious perspective. I may have been particularly moved by the data on sibling relationships due to my own experiences with my brother. The process was emotionally demanding, due to the honest nature and intensity of the narratives. This demanded dividing the analysis into manageable time periods of half an hour interspersed with ten to fifteen minute breaks of movement and other activity. To sustain focus, within an existing workload, transcripts were carried whilst travelling and between appointments, a form of symbolic holding (Bion, 1984).

3.10.3 Immersion and First Impressions

Firstly, the computerised transcript was read whilst listening to the audio-file. Transcript changes for mishearing, gaps and grammar indicators were made. Names and places were anonymised. For further immersion in the participant's story a second listening of the audio-file was completed. This supported greater familiarity with the overall interview. The transcript was printed and re-read, highlighting text felt relevant to the research area, of particular significance for the participant and researcher resonance. The following sections outline each analytic step in the data analysis.

3.10.4 First Analytic Step: Familiarity and narrative

Retaining a perspective of empathy (Smith, 2004) highlighted text was summarised relatively descriptively. This used verbatim quotes and everyday terminology. Feeling words and metaphors were underlined in column 2. The aim was still immersion. Familiarisation with the participant's words, raising awareness of the researcher role in the interview and the overall relational dynamic was important. In hindsight areas which might have been probed were missed, revealing a tension between relational flow and coverage of research questions and at times more disclosure than could be held in the moment. Analytic immersion brought a greater appreciation of the whole, whereas the interview moved through parts, e.g. early in Otto's interview he spoke of his difficulty with the idea of his son being 'disabled' (Otto: 4); this appeared a common parental struggle. However, my later understanding, based on the whole interview was that his dilemma was whether he too was 'disabled' or a unique individual. '*I am trying to make sense of the words, but I am also trying to make sense of the person who has said the words*.' (Smith, 2007, p.5). That is a double hermeneutic.

3.10.5 Second Analytic Step: Initial chronological themes

Thematic labels, again close to the text already highlighted, were identified in column four. The aim was to arrive at a chronological flow of succinct phrasing to capture the essence of the participants' words (Struthers and Penden-Alpine, 2005). Where a theme re-emerged with further comments the same theme label was allocated. Although I consciously tried not to force the data to fit themes, some core convergence of thematic ideas was recognised. A separate list of emergent theme names was built for my reference throughout the analytic processes (Appendix L). On occasions an issue overlapped two themes, even though one appeared dominant. Where this occurred both theme names were used. This allowed me to suspend my decision until later as to where it belonged, either in one theme or both. For example James reflected, *"sometimes we still think that was the reason why he got this Aspergers … we still have an issue around that …*" (James: 18). The major theme was 'diagnosis' but clearly he was also talking about a possible 'cause.' At this point in my analysis theme labels were not exclusive or firm categories. IPA's

iterative process would ensure my return to these themes at many points. The aim was to hold on to the whole story whilst finding what was most significant within it. There was a constant analytic tension between the narratives of participant and theme.

3.10.6 Third Analytic Step: Use of psychological perspective

The transcript was re-read returning to the whole narrative. There was engagement in a hermeneutic of questioning: 'Why' was something significant, what was happening at that point (Smith, 2009)? A psychological mindset was employed but not driven by any single theory. Participants themselves used psychological language, indicating the filtering of theory into everyday thinking, e.g., denial (James: 80). Synthesising professional counselling and EP understanding, for a greater depth of insight into participant's stories, was invaluable. Considering both explicit and implicit indicators of participants' states of mind and attribution to meaning was important. My aim was to understand not simply what and how participants experienced an event, but the meaning they attributed to their 'existential moments' (Smith, 2007). For example, Patrick said of Ned's birth *'it was so impersonal, it was like a conveyor belt*,' (Patrick: 16). This explicitly suggests a mechanical process. Implicitly this also dehumanises and excludes him from key 'life-world' event in his family. As psychological insights arose words/phrases were noted in the fifth column, e.g., shadow, Otto stated, "*the things that anger me so much in Morris are actually things that I'm seeing in myself*" (Otto:10). In this way my themes were enriched without being driven by psychological theory, (Smith et al., 2009 p.105).

3.10.7 Fourth Analytic Step: Individual mind-maps

Within a dedicated book, mind-maps were drawn for each emergent theme for each participant (Appendix M). Within the mind map the identified theme was positioned in the centre. My summarised examples from the transcripts with section references were mapped outwards. For example, BEHAVIOUR- frustration/anger- lack of control- 3.86. Further lines extended the analysis with thoughts, ideas, comments

and transcript references. Single pages were initiated for topics which would be common for all participants, namely:

- Reason participants gave for volunteering.
- Feeling Vocabulary used
- Powerful use of Language/Metaphor
- Psychological frames identified

(Appendix O)

This four step cycle was repeated for each data set. A table listing each participant's themes bridged the move into cross-case comparison (Appendix P).

3.10.8 The Collective Cycle of Analysis

Each tabulated theme, with the interview numbers in which they occurred, were written onto Post-it notes. This indicated the most prevalent cross interview themes. If a theme appeared frequently or particularly strongly for an individual it was given equal significance. Theme intensity may have little to do with frequency. A participant could use a striking metaphor or give verbal and non-verbal indicators of an intensely emotional reaction. For example, Simon's language around those trying to diagnose his son was consistently angry in tone and words. Intensity was interpreted when a theme was returned to several times throughout an interview or was expressed with great depth of emotion. Frequency of content should not be over-emphasised in IPA as it is significance rather than content per se that is thematic (Smith et al., 2009).

Cross-case clustering was an intuitive, inductive process, arising from prior immersion in the data, rather than formulaic. Notes were made as to the sense gained of over-arching themes from Post-its, aiding consideration for grouping themes. Some themes could have been subsidiary to a number of super-ordinate themes. Decisions were made by reflecting on the original narrative, and where necessary re-reading the text and re-listening to audio-files, gaining a better sense of underlying meanings. This resulted in some merging or splitting of themes. Post-Its were shuffled under over-arching themes, culminating in six super-ordinate themes. Everyday language moved into more general, abstracted theme titles.

Although still grounded in participant data they attempted to represent the 'breath and context of personhood' (Tomkins, 2010, p.3). e.g., 'past experiences' to the construct of 'Self in Time' (Smith, 2004), (Appendix Q).

Returning to the participants' individual themed mind-maps, not all aspects of the stories were easy to fit to a theme. For organisational purposes each theme was allocated a colour and copies of each mind map were colour coded (Appendix N). Doing this allowed me to revisit the whole and see new patterns between thematic parts. Themes were originally pulled from the narrative and thus the question was; where was the theme for that participant? The colour coding process was a refinement of my analysis asking the question, where are the participants within that theme? For example 'behaviour' was relocated to areas of the self (Figure 4, p.83). This grounded my thematic narrative write up (Chapter 4). It was acknowledged that I could further develop themes during this write up process. The themes did remain the same, but some of the participants' experiences were shifted between themes as they often encapsulated more than one theme. This highlighted how the complexity of human experience is very difficult to categorise and understand in a single dimension, without losing the richness of the idiographic data.

3.11 Research Outcomes

A range of research outcomes were hoped for (Figure 1, p.68). Informing the service would be achieved by research dissemination with professional colleagues throughout children's services. Dissemination to participants, those in similar situations and the wider public is important in highlighting difficulties and solutions, promoting empathy and understanding for fathers. Personally I sought to grow as a researcher, practitioner, and a witness to participants' experiences (Dadds, 2008).

Chapter 4: Analysis and Discussion

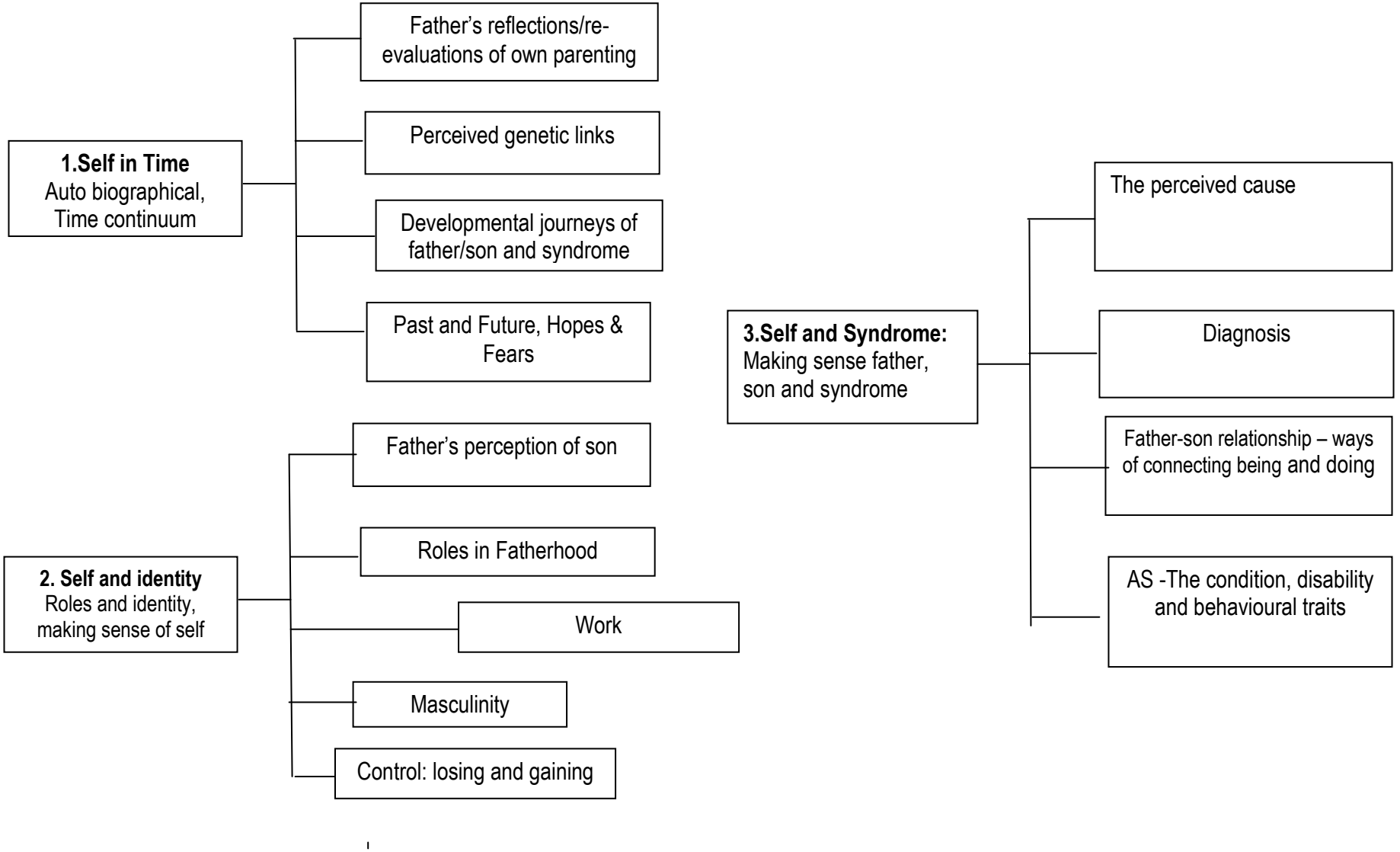
4.1 Introduction

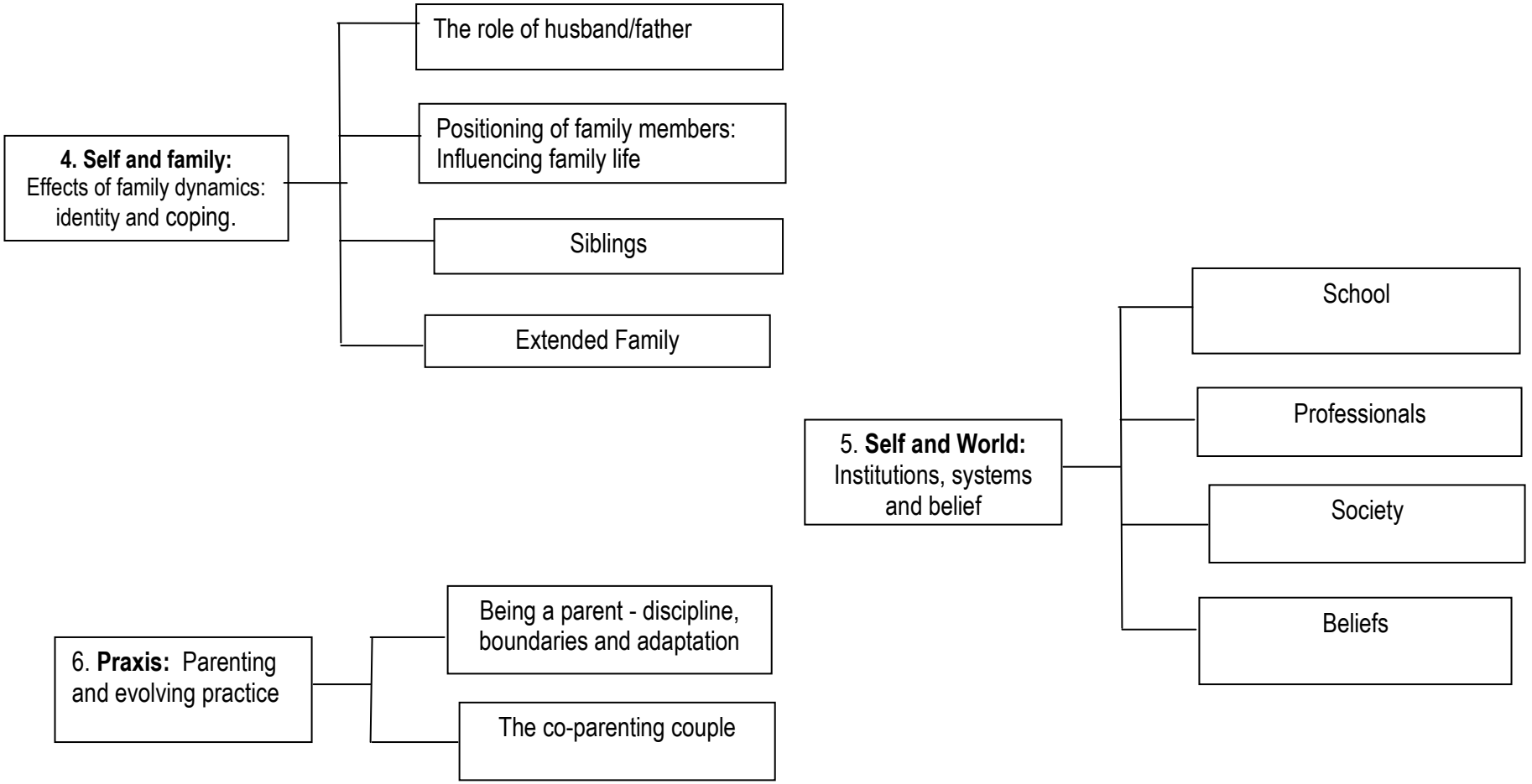
This chapter presents six super-ordinate themes and underpinning sub-themes. In illustrating the richness of the participants' stories through these themes a balance has to be struck to avoid simplification and loss of the individual (Smith et al., 2009). The analysis and discussion are illustrated by direct quotations to stay as close as possible to individual life-worlds. Transcript references have the participants' pseudonyms followed by the number of the transcript section, e.g. Otto: 200.

4.2 Themes

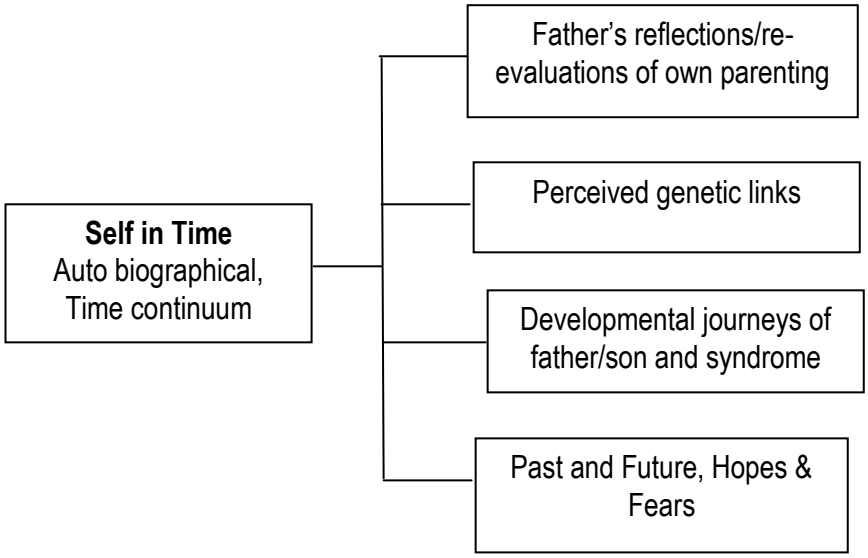
Six super-ordinate themes were identified by clustering 28 themes emerging across eight case analyses (Appendices P and Q). Clusters were given a general descriptor, putting the themes in the context of selfhood, encapsulating the 'life-world' in line with IPA and social constructions/the perceived context in line with the social constructivist epistemology. The themes represent paternal perspectives namely; Self in Time, Self and Identity, Self and Syndrome, Self and Family, Self and World and Praxis. Each is described and discussed in this chapter beginning with an overview (Figure 5, p.90).

Figure 5: Summary of Key Findings / Themes




4. Self and family:
Effects of family dynamics: identity and coping.
The role of husband/father
Positioning of family members: Influencing family life
Siblings
Extended Family
5. Self and World:
Institutions, systems and belief
School
Professionals
Society
Beliefs
6. Praxis: Parenting and evolving practice
Being a parent - discipline, boundaries and adaptation
The co-parenting couple

4.2.1 Self in Time



All narratives revealed a sense of time. Fathers reflected on their childhood experiences, contextualising their relationships with their sons and the AS diagnosis. Interviews appeared to further participants' insights, linking their past and present family members in relation to AS traits and possible genetic links. All queried whether they had AS, wondering about responsibility for their sons' characteristics and diagnosis. Most acknowledged that neither their own, nor their child's position, was static. The terms 'development' and 'journeys' were common. The journeys described how AS manifested within their son's development and their adaptations as fathers. Future hopes and fears were prominent given their own mortality and their sons need to be prepared for independence (Dellve et al., 2006).

4.2.1.1 Fathers' Reflections/Re-evaluations of their Own Parenting

Fathers were asked whether their own parenting had influenced the way they had parented. This stimulated much thought. Many fathers initially felt they had not drawn upon their experiences, but on recalling their childhood realised they may have chosen to parent differently.

> *I guess I didn't see him as much or didn't have as close a relationship as I have, I believe I have with both my boys...I mean I hug them both...I know he loved me but I don't think he ever hugged me* (James: 34).

James took a more hands-on approach to fatherhood, perhaps fulfilling the experience he had longed for? This compensatory tone was also illustrated powerfully for Patrick. He spoke of parental abandonment and neglect and was determined his children experience the love and stability he never had.

> *We wanted a normal life for our kids. We wanted them to be able to express themselves. We wanted them to come home knowing there was going to be peace at home. There would be no violence that we cared for them... It made me feel determined that my children would be happy but not in a way that they would do everything they wanted but that they would do everything within guidelines and proper parental guidelines with love, love along with it. So that is why my parenting skills are different* (Patrick: 24-26).

Several participants alluded to healing their childhood experiences, getting it right this time. This dual task of cross-generational healing involved giving children a positive experience and vicariously re-experiencing fatherhood themselves (Patrick: 24) (Bradshaw, 1991).

> I'm '*competing against the things that I think have maybe hampered me in the past...You know my upbringing my relationship with other members of the family. Maybe that is what it is.'*
>
> *[Int] You think there is something about succeeding through your children?*
>
> *I think there is in a way* (Patrick: 38-44).

Patrick used the word 'competing' both in the context of the past and present time. His past was part of him was something to battle with, perhaps forming a 'shadow' which 'hampers' him. In competing he was making a concerted effort to give his children a more positive experience than he had, breaking trans-generational family patterns of violence and abuse (Patrick: 24). He played the wounded healer (Jung, 1923/1991) for his son and his own inner child (Parks, 1994).

The concept of 'getting it right' was strong, a self-pressure on fathers to 'be perfect.' James felt '*guilty'* if '*not doing something'* with the boys, offering what he could to avoid being distant like his father (James: 32). Many suggested a strong sense of changing something bad into something good (Boyce et al., 2007).

Western society's changing image of fatherhood may have helped fathers' wishes for more involvement with their sons (Collier, 2009). Balancing discipline and accessibility whilst generating respect from one's son can be difficult. Sons with AS often fail to understand social hierarchy and respectful behaviour (Jordan, 2002), e.g., John found his son's rejection of advice hurtful, challenging his hopes for the father-son relationship.

> *If you try to sort of like tell him what to do, like, 'try and get out on the wing' or something like that. It's 'you idiot you don't know what you're talking about'... I think as a dad that is hard. Because they always come over as, they don't take your advice on and you sort of, well I think you sort of think you're going to have all the answers for your son. You know, you're going to be this big wise man that will be able to pass it down to you, and you hit a brick wall really* (John: 16).

Many fathers spoke of their own fathers, alive or dead, embodied within as a 'critical parent' (Berne, 1964). Andrew stated that his father filled him with fear and trembling,

> *he still haunts me …he's there as my er critic. And Ellen struggles because she thinks I think of her as being like my dad. So yeh I mean that's a whole complex issue. And my mum was quite soft with us and quite kind to us* (Andrew: 66, 68).

He saw shades of his father manifested in his wife, re-experiencing childhood through his wife's criticisms of his son. This maintained Andrew's 'victim' role. His critics, living and dead; remained alive to him. He had tried to be accessible and '*laid back'* with his son (Andrew: 68). Modelling his fathering on his soft, gentle mother, he questioned continually whether he was doing the right thing. This made co-parenting dynamics difficult, raising the question of how far to push his son in achieving his potential whilst protecting Mark's mental health.

> *Um, there are tensions between Ellen and myself about how much we push Mark and how much we discipline and how much we let him get away with things. Erm, I tend to be quite soft with him...I sort of love him I have my fears for him and also my hopes for him...it helps at times to remember how I felt as a teenager. When you know I can see Mark's struggles* (Andrew: 8, 72).

Andrew's 'laid back' quality and his wife's 'go getter,' personality reflected similar polarities in family members across generations, not simply Andrew's parents (Andrew: 68,189).

At least two of the fathers suggested that faith in God played an important part in understanding the time continuum of their lives. Stephen thought aloud with his dilemma as to whether events are random, or '*there by the grace of God*' with a pre ordained master plan (Stephen: 64). Andrew believed there was a plan that life goes on after death in the form of a *'judgement day'* (Andrew: 62). As a Christian and a Baptist Minister his life was led based on the faith that there was a wider time continuum than this life. This both reassured and worried him, as he believed if people were caught up in 'self-centredness' they would be not only unhappy in this world, but not achieve salvation in the next (Andrew: 161). He implied this might be so for his wife Ellen and son Mark (Andrew: 32). Andrew struggled with reconciling the diagnosis of AS and his belief system. This is an example of what Scorgie et al (2004) referred to as 'existential meaning-orientated' questions, which need to be answered to support the transformational experience (see section 2.3.4 in this thesis). This will be discussed further in section 4.2.5.4 of this thesis.

Some participants tried to weave their own childhood experiences into those of their children (Andrew: 185). Otto gave a moving account of trying to recapture idyllic family holidays for his children, unsuccessfully.

> *Taking my children at the same age, so when Morris was 10 or so, to see that bit of Herefordshire. That was the worst holiday… because Morris didn't have a Play-Station in the cottage* (Otto: 142).

Several fathers found recounting their childhood very painful (Otto: 24; Patrick: 24). Others worried about their fathers' judgments, keeping up the standards reflected in the perceptions of their father's view of their parenting (Stephen: 38; Dave: 38). There was an expectation to be a 'good dad', but no definition of this, particularly given a son with AS. John queried, whether his dad would think he was a bad parent? We were '*seen but not heard'* (John: 16). Respect was important. *'I think my dad and that thought oh he's just got no respect for him and he kind of probably thinks I should give him a good clout half the time' …*(John:34).

Most fathers looked back through the generations to understand their personalities, childhoods and the nature of their children (Otto: 68). This could raise difficulties due to changing socio-historical discourses throughout the generations. This was illustrated by Patrick's comments about the changing societal perceptions of disabilities and those of fathers from generation to generation.

> *… in those days people with Autism were called spastics and stuff like that . Yea, there was no real name for them apart from that and I think, that generation, it bred that sort of feelings towards disabilities... I mean I was never ashamed of Ned of what he was going through with any tag that was given to him* (Patrick: 22).

Language used was symbolic of the way fathers perceived their sons and seemed crucial to parenting. Patrick did not feel the shame related to the label and his son's behaviours which would have existed in his father's generation. He was concerned to be provider and protector, a powerful ideal within the accounts and one often lacking within some of the participants' pasts. Some participants' felt that their fathers' undiagnosed AS was an explanation for their behaviour.

Stephen, Otto and Andrew all reflected on their fathers and fathers-in-laws as having '*got some' (AS).*

> *outsiders would say that my dad was eccentric... I don't think we had a sort of typical upbringing. My dad was quite er erm I suppose selfish is the word that springs to mind. Cos he did what he wanted to do... he wanted to build a boat so he built a boat...it is interesting because obviously there's a lot of work about you know, where does Autism come from. And er, it's when you start looking at my dad and looking at Nina's dad, some of the characteristics in them. You start to think, well you wonder if you start taking these genes, it comes down and you know you come out with, you might end up with somebody like Tim... I suppose in that sense I certainly wanted to make sure that you know our family life was more normal. So hopefully I've been successful on that score* (Stephen: 42-44).

Participants reframed personalities within previous generations, their own past and behaviour in attempting to understand the AS origins somehow 'normalising' the situation (Huws et al., 2001). This raised issues which re-emerged frequently throughout the interviews regarding the concept of normality, quirkiness and the notion of syndrome or disability (see section 4.2.3 of this thesis).

For instance Otto found behaviours and rules instilled as a child difficult to break,

> *you pass behaviours on to your children. Um, my dad always made me eat all my meat cos he was in the war, and you always had to eat all your meat. And I always made my children eat all their meat...I find it hard to actually break that behaviour, you know, that was drilled into me as a child* (Otto: 68).

Those, whose parents were still alive, described a mixed experience of acceptance for grandsons with AS. Some were unable to accept the difficulties, as they had similar traits (Otto: 72). Patrick found it could be positive, where *'other people see him differently. Like my mum...she's very tolerant in a way of all the little quirks and behaviour'* (Patrick: 94).

Caring for elderly parents and sons could feel frustrating and disempowering. There were ongoing relationship difficulties for Otto, yet his father's successful career was reassuring, despite perceived AS traits.

> *They've got very successful happy lives you know...one of the things my dad is really good at is that obsessive, being really good at his profession. And I think that's something that I definitely do. I see what I do as mirroring what he did... in my own field* (Otto: 72).

Difficulties accepting diagnosis was commonplace for parents (Axup, 2003). For some fathers accepting an 'abnormal' son precipitated a reassessment of 'self.' Denial could be accompanied by polarised views (Otto: 164). Otto confronted his own normality with his parents, as they blamed his wife for Morris' difficulties (Otto: 112).

> *I had to confront my parents with this, to say no, I, I I'm not normal. Even something that I don't acknowledge myself that I don't think I have Asperger's but that whole thing of saying, no, you're saying this is normal or explainable in normal child terms. But I don't think it is. So using that, so it made me realise that I'm different...a perpetual cause of problems, me not communicating stuff that means that because Hilary and they don't talk freely, if I don't make that, bridge that sort of thing, all manner of problems erupt. So, should I have learnt to talk to them more? I wish I could. But then we'd have to deal with all these issues. It's so much easier to bury your head in the sand* (Otto: 88,172-4).

Grandparents with autistic tendencies could have difficulties caring for their grandson's with AS, due to inflexibility on both sides, psychologically and practically.

Fathers initially linked their parenting influence with same gender parents. However some reflected on the influence of their mothers. John felt it was natural to think of a paternal role model but his mother was important too.

> *the way she parented me. I suppose you think straight away it's the way your father parented you like your looking up to a role model. But then again it's also your mother you're taking bits from that don't you... Yea, I haven't really thought about it till you said like that, it could be me mum, I suppose I'm more like me mum than dad anyway* (John: 38-40).

All participants experienced traditional parenting roles, yet parenting as a joint venture was regarded as important, then and now. This did not mean roles remained the same over time, in social and gender terms changes were acknowledged. Despite wives taking on most of the childcare, they were often recognised as equals and admired (John: 36).

Moving away from one's own experience of fathering could be difficult. Where grandparents and family members of previous generations were still alive, the past converged with the present. Part of being accepted by their extended family relied heavily on the behaviour of their sons. For Patrick, returning to his childhood, home success revolved around his son being accepted by that previous generation.

> *...my Mum took him round the people that she lives with. It is quite a close knit community and they were all in love with him. That is probably the most success where you want your child to be liked for who he is* (Patrick: 65).

For some fathers the past was described in great detail and over more than one generation. Temperament and social class featured (Andrew: 68). Past figures were defined by their employment and ability to accept or move beyond their social status (Otto: 72-74).

The past influenced all the fathers' accounts. It could be argued that this is usual within all parenting relationships. However, actual or perceived genetic links add a

biological element to the social/familial time continuum. This influenced how they perceived themselves, their son's and the father-son relationship.

4.2.1.2 Perceived Genetic Links

Paternal understanding of AS appeared driven by perceived genetic links. All of the fathers in this study queried how much they were sufferers or carriers of AS. (Stephen: 44). Otto recognised traits within himself.

> *I've never, I suppose I've always thought in the way I am, very obsessive um and compulsive in the way that I do things, and yet seem to manage to turn that into something manageable and liveable with to some degree. You might question that with the people around me... I am someone who's very willing to say 'yes, I'm disabled' erm in some ways I'd be more than happy to get Morris a diagnosis to say you've got Aspergers, and tell everybody, it's not a secret. Isn't this a good thing that we've got a diagnosis? And yet here am I with you know some a.., one of the things I often feel is the things that anger me so much in Morris are actually things that I'm seeing in myself. It's a wish that he wasn't exhibiting those behaviours that I know that I do. I think the things that he does disable him whereas I suppose I don't perceive it as disabling me. So, I suppose one of the things I'm keen to do is if there is some, some of it is some self analysis here. As I myself saying do I actually have Asperger's or something like it...I don't know* (Otto: 8,162).

Otto touched on social and medical models of disability. Is AS another way of being, rather than a disability? He reflected on whether it was from his gene pool and whether he bore responsibility? He questioned his happiness for his son to have a diagnosis, but discomfort in the idea of his own characteristics being labelled. *Am I unique or do I have a syndrome?* (Otto: 88) Otto raised important issues related to constructs of diagnostic labelling or 'pathologising' developmental difference (Baron-Cohen, 2000). From a psycho-dynamic viewpoint Otto might have be engaged in splitting, moving feelings about his son, he could not bear, away from himself (Klein, 1952). He was unique. His traits had not disabled him but his son was 'disabled.' Was this a defence mechanism to cope with his shadow side? (Otto: 10), (Jung, 1923/1991).

> *...even if it's subconsciously, think of the things that I do. The behaviours that I have that's syndrome based, if that's the right way of saying it, you know, rather than just, totally nobody else like me on the planet* (Otto: 88).

James also queried whether the AS came from him? He described himself as reserved. The diagnosis provoked him to look for traits in himself and his father. Amongst others who experienced their sons' birth difficulties, James debated internally the causality. Was it genetic, birth trauma or both? (Attwood, 1998) In most of the narratives there was this search for truth, which could never be answered conclusively. Participants were left with the choice of forever searching or coming to terms with living with not knowing.

> *...as a father you think 'is it you?' I mean I'm a very reserved, quiet person. I know I am, this is probably the longest I've spoken for ever (shared laughter). For any period of time, I suppose I've always been reserved and quiet. And you can't help thinking, is it me? My father was quiet and reserved as well. Er, so you wonder whether it's you really. Was it a difficult birth? Is it something else rather than Aspergers. You always question, it goes round in your mind. And I don't know the answer really* (James: 26).

Genetics were not always viewed negatively, inherited talents were mentioned (James: 12). It was not restricted to one parent. Although the research focused on fathers passing on traits (Ghaziuddin, 2005) Andrew and his wife saw AS traits in each other, both extended families and previous generations. Andrew's belief that he had traits caused him social fears but he was positive about an affinity with his son. He admitted interpreting others' emotions was difficult for him.

> *I like to be logical but I don't think I am particularly sensitive to you know reading between the lines, and always you know picking up on other people's emotions. I think that's probably part, er part of what bothers me er frightens me a little bit in my job (as a church minister)* (Andrew: 119).

Perceived genetic links both empowered and disempowered fathers. Some saw it as something they could not take responsibility for. It was beyond their control. Others felt directly responsible. For some the genetic aspect might exonerate them from accusations of bad parenting. However, this required them to accept AS as a lifelong disability which could not be cured regardless of their parenting efforts. The genetic component could create practical barriers within the relationship, where both

fathers and sons were inflexible (Reid, 1999). Psychologically, fathers could experience a part of themselves they had suppressed. However, where there were similar fears between father and son, paternal empathy could be heightened (Andrew: 72).

Social skills within the interviews appeared to contradict some fathers' claims to have AS traits. The genetic perception might be media driven. The inter-play between perceptions of self-development and father-son relationships was likely to influence the journeys of father, son and syndrome. The next section considers these complex relationships.

4.2.1.3 Developmental Journeys of Father/Son and Syndrome

Within each father's account there were individual and parental developmental journeys. These might run in parallel or be integrated. Sons also had at least two journeys, as individuals and individuals with developmental disorders. For example an adolescent with AS has a similar journey to a neuro-typical peer, but additionally struggles to manage the journey due to emotional immaturity and a lack of social awareness, both characteristics of AS. Integrating these journeys can be problematic and such lack of integration can lead to serious levels of anxiety. Possibly, each individual within the family, and the families as a whole, have their own journeys relating to living with a child with AS.

Developmental narratives were important and beginnings had great significance. Recent research supported the biological and social importance of fathers during the pregnancy, birth and early years (Brennan, Ayers, Ahmed and Marshall-Lucette, 2007). Participant stories varied regarding the births of their sons. All of the fathers who were able had attended the births of their sons. For two it was not possible as their babies had been delivered via caesarean section. Most participants felt excited about the new arrival. However one expressed his worry throughout the pregnancy and the birth (Patrick: 14). Worry was a common feeling during early development, prompted by their sons' failures in meeting early milestones. (Stephen: 50). Eating difficulties and constant crying were particularly distressing and confusing (Stephen: 30). For some fathers early experiences of a son's compensatory behaviours were

worrying. Patrick described '*foibles and rituals*,' (Patrick: 16), resulting from anxiety, along with screaming and a strong reliance on routine. He volunteered for interview as he wanted to know if others had made the same journey with their sons. Early difficulties were often the first indicator of a problem (James: 18-20; Patrick: 16).

Although previously infant attachment to mothers was the focus (Bowlby, 1953), more recently there has been an emphasis on the important bond between infant and father (Sunderland, 2007; Bowlby, 2007; BBC.4, 2010). Most fathers in my study referred to attachment in the early years and the lifelong impact (James: 18; John: 32; Patrick: 16). They felt that it was important to give their children time and build relationships in the early years. Some were aware that their partners had made the primary attachment due to greater contact. This was related to work commitments and in one case hospitalisations. Several fathers felt having a child with AS, who relied mostly on the mother, meant they formed closer attachments with the siblings as a compensatory measure (John: 32). There was a common belief that their attachment to their sons was as important as the mother's, throughout the child's life. Perhaps this contributed to them remaining in the family home (John: 34; James: 18).

Dave worried about his son being different to other children, when he started nursery (Dave: 32). James expressed his delight as he vividly described witnessing his son's first steps. '*It was fantastic you know there he was walking and we've probably still got it on video'* (James: 18). However, a couple of fathers explained how problems persuading their sons to eat were unbelievably difficult, (James: 20; Stephen: 30).

> *I did worry, when is he going to start talking? And er, all the usual things you know, like getting him to eat solid foods and weaning him. And you thought he's never going to start eating, and I thought how can you not like this food? I think that was the most distressing time actually. Having a child that's crying when you're trying to feed it and going hungry? 'Food' And he doesn't want it, won't take it and you'd put it in his mouth and he'd spit it out. I found that, I think if anybody'd told me how difficult it was I wouldn't have believed it. But then it came and it went, you know, you forget* (Stephen: 30).

Many of the sons' *behaviours* described, even at an early age, communicated rejection. Through the food Stephen was nurturing, symbolically and practically

giving his child love and life. It is confusing and hurtful when this is 'spat out.' (Winnicott, 1956). This was so devastating it felt that life had stood still. This would be forever. Diagnosis could reinforce this. For these fathers the journey of coming to terms with the diagnosis was ongoing, involving endless reflection and internal debate.

> *…as a father...self-denial and eventual acceptance that he has got a condition...but not Aspergers. But I do now recognise that it is Aspergers...As a dad, yes, yea erm, I suppose when, when we got the label I, I probably still didn't quite accept it. Still felt he was alright and things would be alright. A part of me still does feel that. But less so now, I more recognise that he has got a condition. But because it seems to be he's er, highly functioning, many people say 'oh we'd never have known he's got Aspergers'. But you only have to live with him, and sometimes when you're er (laughs) you realise that he has. Erm, to me as a father it was, I probably was in denial for quite a while* (James 26).

Despite AS being termed a developmental disorder the concept that anything will change was lost. The idea of development and the benefit of hindsight could bring hope or dismay. Otto pointed out that AS developed in different guises, sometimes creating co-morbid diagnoses, e.g., OCD (Otto: 16). Individual adult development and that of fatherhood were recognised retrospectively. James mentioned evolving and changing as a dad, yet he felt guilty that he could have handled the early stages differently (James: 46). There is less emphasis in our society on adult developmental stages (Wilber, 2000; Erikson, 1980). The sense of time bought hope as well as fear of the unknown.

Otto worried that his son's current behaviours could affect future opportunities and development (Otto: 14). Some fathers found the developmental aspects of their sons hopeful (James: 62). They were able to look back and see how far their sons and they as a family have progressed. When asked about the most positive aspect of raising Ned, Patrick said, '*I think it's the way he* has *developed. 'When at five or six he was behaving the way he was then, I think I couldn't see beyond that.'* (Patrick: 22*)*. '*You forget as difficulties come and go'* (Stephen: 30). Developmental contexts were important to identify progress. This inspired hope and empowerment (James: 62); this is something professionals could support.

In the past Otto had believed his son would grow out of his AS. He had abandoned this dream and coped by thinking only of the next six months (Otto: 212). His initial hope was based on his own development. He described himself as increasingly '*less ASish*' as he moved into his twenties, he became more social (Otto: 106-108).

In terms of developmental norms, as well as the existence of the syndrome itself, there was a strong debate between being 'normal' and individuality throughout the transcripts (Patrick:16). These were difficult issues for fathers to disentangle, particularly during their sons' adolescence (Andrew: 72). James found that he had an ongoing internal debate about the truth of the diagnosis. He was struck when he noticed, typical behaviour. This was self-assuring and gave a sense of normalcy. '*He's becoming almost a typical teenager because also it's quite difficult to get him out of bed* (James: 12). There were celebrations of achievements, and sinking feelings when the development of a sibling highlighted the developmental delays of the son with AS, evidence that '*something wasn't right*.' Fathers had internal battles between evidence, perception, acceptance and their dreams for father-son relationships.

> *He's got a younger brother who is able... very enthusiastic, wants to do lots of things. I think perhaps, that's dreadful, he's the boy perhaps I wanted as Len. That sounds awful really, not that he's not the boy that I wanted to have but typically as a father you want the boy you can play football with* (James: 26).

For those with neuro-typical siblings they realised they worried more about the future for one child than the other (James: 44).

> *I can't see how Tim's going to suddenly develop into an independent adult. You know, much as I would like him to be, and I hope he does. I hope I'm wrong. And I've got to be careful that you know that my inner fears don't actually become realised because I don't give him the opportunity to, or help push him in the right directions. Where you see I don't have that with Holly. I just, I don't see what she's going to do now but I fully expect by the time she gets to the end of secondary school or wherever she goes, that she will have found something that she moves into* (Stephen: 106).

The dynamics of individual development and parallel interweaving journeys, between father and son, could be related to the fathers' value/belief systems (Andrew: 147; Stephen: 60). What is important to them? Andrew was particularly

interesting. As a Christian he struggled with the ego-centric focus of his son and whether there was the prospect of liberation from this,

> *He's got an uphill struggle that he's got to fight against his self-centeredness. As I say I hope he'll eventually, you know, get to somewhere where he, cos I, you see in my Christian beliefs there's an awful lot of freedom and liberty. When you get to the point where you are no longer at the centre of your universe* (Andrew: 147).

Stephen considered the AS from a socialist viewpoint, respecting Tim's openness as a potential contribution to benefiting society.

> *I often think there are things that we could all learn from children with Aspergers in terms of their openness and like tell it as they see it. You sometimes wonder whether the world might be a better place, less subterfuge going on* (Stephen: 60).

The position from which these fathers constructed their world is crucial in understanding their worldview, particularly their hopes and fears.

4.2.1.4 Past and Future, Hopes and Fears

Participants spoke about the past and their hopes and fears for the future (John: 78, Andrew: 8, Otto: 202). They hoped their sons could lead independent lives, taking responsibility for themselves (Andrew: 97; Stephen: 62). Awareness of their own mortality was common (Stephen: 96) fearing that they would leave their sons unprotected. Some worried about possible institutionalisation (Andrew: 137-141), particularly for those who already found it difficult to leave the family home (Otto: 26).

A common theme was that fathers should love their sons and parent with the best intentions, giving the best start in life (Patrick: 30,130; Andrew: 8; Dave: 12). Otto gradually moved to a point where he acknowledged life cannot be controlled. He responded as issues arose, focusing on the moment (Otto: 180-4). Dealing with worries on a day to day basis was a common coping strategy (John: 80; Dave: 18) (Gray, 2003). Otto worried about his son achieving his academic potential and pursuing a career path (Otto: 6). He hoped that Morris would be able to ask for help and not be isolated (Otto: 210).

> *One of our worries with Morris is its easy for him to go into his bedroom and sit there with....whatever else it is he does on his computer, and be isolated there. Not studying, not reading, not being nurtured by us as parents, but he'll just go there and be lost in his own little world in there...You know that's a problem being stored up for the future* (Otto: 26).

Stephen echoed this, fearing that Tim would be the isolated as '*the weird kid'* (Stephen: 86). Fathers expressed hopes and fears about life events such as 'settling down' and finding a job. Dave took an optimistic philosophical approach, *'it will come together as far as it can*. It will take time' (Dave: 148,146). He felt that functioning within the job market would be difficult for Nigel. '*I think he will be alright job wise, I think he will get there. I think he will learn the hard way on certain things, unfortunately'* (Dave: 144). Stephen hoped that a sensitive employer might be found, but felt this might be over-optimistic these days (Stephen: 62).

Social communication difficulties rendered these young men particularly vulnerable, causing fathers to worry (Stephen: 86). Without parental protection they could be taken advantage of (Stephen: 96). Protection was a common theme, '*I want to make sure that I'm here as long as possible... you act like a guardian to him, which is obviously impossible' (*Stephen: 96*).* The big, bad world seen through the eyes of their naive, vulnerable sons was scary. They doubted the outside world could be trusted to care for their sons, helping them to grasp opportunities (Stephen: 22).

Much of the fear was coming to terms with the unknown (Stephen: 22). Questions about the future, independence, girlfriends, a social life and a job were prevalent within the narratives (James: 106; Andrew: 97). Mental health concerns were common (John: 80; James: 6; Otto: 4) particularly during adolescence. This reinforced fathers' sense of powerlessness and concerns for the future. Andrew planned to empower his son by teaching him to drive and to set up a business with him. A foundation he could leave his son, some reassurance that independence could be achieved. Yet he described the disability as a '*dark tunnel*' and control over his son's mental health was not possible (Andrew: 153). James described how he dreaded the difficulties Len might face (James: 38).

Peer group isolation was an ongoing concern, due to the syndrome's social communication aspect (James: 6, Otto: 26). Doubts regarding the usual expectation

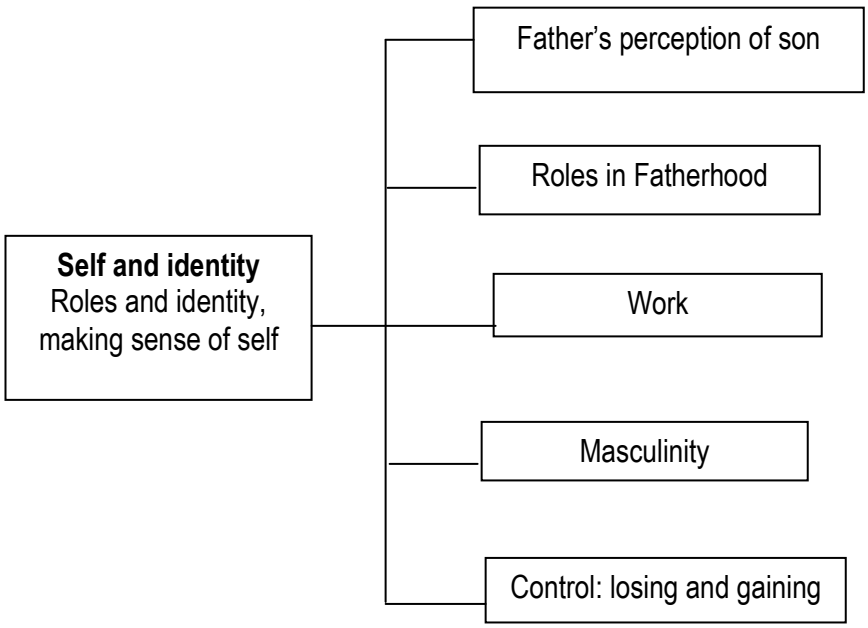
of children leaving home to be with friends or partners meant time spent with one's wife in retirement was questioned (James:106; Stephen: 96).

Fathers spoke of a traditional hope that their children would do better than them (Stephen: 22) but questioned its viability for sons with AS. The fact that many children with AS were academically able raised hope and investment in education. Otto spoke of hopes that services would be there to support Morris through 6th form and eventually a degree course. He felt that Morris' dreams were an important motivation (Otto: 4) yet worried that the past would repeat itself and problems with Morris' mental health could erupt suddenly with Morris unable to cope. Some of the fathers expressed fears for themselves as to how they would cope with the future (Otto: 210). This was particularly the case, where there was co-morbidity, e.g., epilepsy, OCD, Tourette's Syndrome and ulcerated colitis.

> *There was always a possibility that he would grow out of his epilepsy. I mean he hasn't so far. He may never. But then that does limit you in some of the career choices you could make, and what things you could do. It might prevent him driving, for example, which would potentially have a reasonable impact on his life* (Stephen: 56).

For Otto, the Prozac prescribed for Morris had improved the father-son relationship. With the hope that Morris would cope without the medication came fear that the relationship could deteriorate. Otto expressed an uneasy reliance on the medication to reach his son. He worried that positive changes brought about by the medication might not be permanent (Otto: 210). For fathers who recognised themselves as having traits of AS there were conflicting feelings of empathy and frustration for their struggling sons. A sense that, I have done well with these traits, why can't you? This participant group had managed to hold down a job, remain with a marriage and raise a family. Some had gained economic and social status through their careers. This perhaps put an added burden on them and their sons causing mixed feelings of wondering and worrying about the future (James: 44,106; Dave: 104). There were concerns raised by Andrew that Mark might depend on the state as an '*eternal student*' rather than contributing to society. These hopes and fears related to the fathers' sense of their own identity, as men, husbands and fathers. These were social as well as individual constructs and are addressed in the next section.

4.2.2 Self and Identity



Identity is a social construct (Willig, 2001). Perceptions, roles, values and attitudes all featured strongly, impacting the fathers' sense of self and identity when they described experiencing raising sons with AS. The AS diagnosis challenged identity norms as man, son, father, worker and husband. This raised internal dilemmas, as to self perception, roles and responsibilities. Identity is dynamic (Wilber, 2000; Erikson, 1980). In response to their sons' developmental paths fathers' identities were constantly reconstructed. This led to gains and losses across all the fathers' relationships, which influenced their sense of identity and masculinity. The AS meant sons could not communicate with fathers in the usual ways. This left fathers unsure where their responsibilities lay in the traditional areas of family control and what their best coping strategies could be. These sub-themes interconnect as they dealt with aspects of personhood.

4.2.2.1 Father's Perception of Sons

Before their son's were born participants' had perceptions of how they would be within a father-son dynamic. AS challenged this on a number of fronts. The way they described their sons revealed what they valued for themselves, their sons and where this did or did not fit with their perception of society's values. Several mentioned age, academic ability, personality traits, and 'problems' which tended to come at the end of the description (John: 12; Andrew: 8). There was awkwardness,

perhaps feelings of disloyalty, when mentioning less attractive characteristics or even disliking their sons at times (Woolfe and Dryden, 1996).

> *Mark, yea, he's a, he's our only son. He's quite bright. We've known he's had problems ever since he was in primary school. Erm, really he sort of hit the buffers at the start of the second year at Senior School. He got bullied and depressed and stuff. And he's been suicidal at times but he's erm coming through. He's also got this ongoing stomach condition which sometimes causes him difficulty* (Andrew: 8).

> *I suppose I think of him as a problem child, which as I say is a very negative way of looking at it* (Otto: 14).

As they settled into the interview fathers became more open about their sons' difficulties, still valuing sons for being, clever, having nice personalities, being straightforward, honest and likeable (James: 6; Stephen: 12). This suggested they could contain contradictions in their perception of their sons. It was not an easy accomplishment and raised ongoing doubts about their self-image as a 'loving' father.

Some descriptions used very tentative language. '*Er I get on quite well with Mark really. We seem to relate reasonably well... I sort of love him'* (Andrew: 8). It was unclear whether this was due to linguistic style, lack of confidence or an attempt to be accurate about their uncertainty. Fathers could be both '*proud'* (Stephen: 78) and *'disappointed'* (Stephen: 98; Andrew: 16). '*I think it could be easy, you know, to feel disappointed. He's not the son you thought you were going to have... He's very different, difficult to get things right. That's what you've got, that's the way it is.'* (Stephen: 98). A 'stoic' acceptance might have enabled fathers' to stay in the family home, despite 'disappointments' (Thoits, 1995), (see section 4.2.5.4 in this thesis).

John was consistently tentative, he appeared to test with a milder comment followed up with the phrase '*to be honest'* and then disclosed more. Perhaps there were concerns he would be judged on his self-presentation? *'To try and keep a lid on it for yourself sometimes it's very hard. And I don't do it all the time to be honest to you, I'm only human'* (John: 62-64). He was the only father I had not met prior to the interview. His son had recently been diagnosed. As such he was still coming to terms with his son's AS and talking about his feelings with professionals (John: 52).

Otto would have liked to perceive Morris' difficulties as a 'challenge'; that is the socially accepted language. This isn't how it was for him. He struggled with his perception of Morris and felt pressured by professional 'jargon', *'it's not a challenge …this is really hard to deal with …wouldn't it be nice if it wasn't like that … this is how I feel about it a lot of the time'* (Otto: 112). Perhaps today's political correctness has sanitised experiences of these families, promoting language which doesn't always represent their harsh reality (Harrison et al., 2007)? Using negative language appeared to raise guilt, particularly in speaking to professionals who used the positive, 'textbook-based language' in their narrative. Picking up on the language of fathers could give them the opening to accurately express their experience in their words.

For some fathers other identities brought strong self beliefs which conflicted with how they perceived their son and AS (see section 4.2.5.4 in this thesis). For Andrew being a Christian was a major part of his social identity. He felt the egocentric state, which seemingly dominated those with AS, could make salvation difficult for his son,

> *He's a nice lad you know. He's got an uphill struggle that he's got to fight against his self-centeredness* (Andrew: 147) *… to be honest it's a very dark prison really, er, when you have problems at the centre of the universe* (Andrew: 153).

Conversely, some fathers' descriptions were very positive. Simon reframed Keith's AS, as a strength, portraying him as *'a success story... an eccentric, serious boy'* (Simon: 12, 6) Simon's understanding of AS differed from the other fathers. He saw it as an integral part of Keith, using the social model of disability (Oliver, 1990), where the combination of Keith thinking differently and society being inflexible caused the difficulties. Simon spoke of his own differing social style, but unfortunately, most of his interview was not recorded, at his request.

John grappled with a changing perception of his son, who prior to his AS diagnosis had a diagnosis of physical illness.

> *...it has changed yes, put a different perspective on things. (John: 48)... with his behaviour I put it all down to the drugs and things like that. Erm, I could always well, 'don't worry about it, its Steroids'. ...I just have to put up with it, put it down to that. An excuse if you like. Now*

> *it's his personality, and I think it's harder to come to terms with. Then, then just because it's him, you know what I mean* (John: 52).

Fathers commonly found it difficult to accept that the AS diagnosis is based on behavioural characteristics and medical constructs without the proven biological basis of physical diagnosis. Fathers struggled with where their son's personality began and ended, how much was the AS and how much was them? John acknowledged he was in a process of coming to terms with the diagnosis (John: 48). Otto felt the diagnosis made him question his perception of normality (Otto: 56) (Lasser and Corley, 2008) in making his own transition regarding the idea of AS (Otto: 4). This was considered in trying to understand who their sons were (Dave: 3). These fathers grappled with fatherhood ideals and their role identity.

4.2.2.2 Roles in Fatherhood

Positive roles for fatherhood emerged within descriptions of fathering ideals and some experiences of their own fathers. Common traits included perseverance, a strong work ethic, resourcefulness, particularly the ability to make money using talents (Otto: 74-6; Andrew: 10). Fathers who had other children reflected on the comparative differences and difficulties.

John spoke of not being good enough or able to meet either his or his son's expectations. He felt this required shifting what it meant to be a father. He described the discrepancy between his ideal and reality,

> *It's going to be like the Waltons like you know. Like I say, you're going to have all the answers for your kid. You're going to be this big beacon of wisdom, you know, and sort all their problems out. And it don't work out that way* (John: 100).

'Father' for many was portrayed as a godlike figure, guiding and protecting their sons. Paradoxically, sons with AS often needed a lot of support, yet their lack of ability to connect with others made it hard for fathers to provide and sons to accept. Dave described taking on the role of coach as a way of connecting with and supporting Nigel. 'I *coach him with like life skills. I'm not saying I'm an expert. We'd just hit certain scenarios. Certain things would happen, come up and you'd just talk it through'* (Dave: 18). Dave perceived himself as a traditional head of the family,

using an authoritarian style of language. He was Nigel's *defender* when Nigel was wrongly accused (Dave: 108), '*fair-minded,'* Nigel's '*advocate'* (Dave: 104–108) and '*judge*,' making decisions as to who was the perpetrator and who was the victim.

> *...you also tend to side with others as well because you think 'well yes he probably did do that, or there is a good chance'. So when he actually was innocent of something and it was a case of 'oh, it was Nigel's fault' well then you know he got the blame. So it's trying to do a balancing act and quickly sum up in a few seconds whose side you take you know* (Dave: 56).

Guardian and protector were roles fathers believed they needed to play to keep their sons safe (Stephen: 96), as well as protecting others from their sons. '*You're worried about what he's doing, what he's getting up to, who he's upsetting and all that. Because obviously people don't understand it'* (AS) (Dave: 50). As Nigel had grown older Dave felt he had to extend his role of advocate and intermediary into the community (Dave: 55). This illustrated how the role of father evolved according to perceptions of their son's needs.

Worries about getting fatherhood wrong (Stephen: 50) appeared to be exaggerated when parenting a child with a disability. James asked in hindsight, '...*did we damage him by giving him too much attention*?' (James: 46). John illustrated how the 'norms' were not so applicable and made fathering a more uncertain role, '...*a lot of the time just suck it and see sort of. And you have to learn by your mistakes'* (John: 44).

A sense of isolation was common and universality was sought. Patrick for example volunteered for the study because, '...*the views and how* fathers *feel are important...it will be interesting to see at the end of it if everybody thought like me. If they went through the same sort of milestones'* (Patrick: 10). Otto reflected that he wasn't ready for fatherhood, volunteering was a way of understanding himself. He gave a long account of his history as a father and changing priorities from career to fatherhood. This role of father impacted on their working world, balancing fatherhood, career and financial support of the family (Meyer, 1995).

4.2.2.3 Work

Work before fatherhood had been a large part of participants' identity (Habib and Lancaster, 2006). Several participants had made work changes to adapt to their family situation. Some worked from home or gave up work altogether to support their sons. For those in work, the work role differed according to their role perception and family structure. A strong work ethic was evident throughout the transcripts. Many spoke about '*being torn'* between work and family (Andrew: 12). Some gained support (Andrew: 167) and confidence from the workplace to deal with their sons. Roles played at work allowed distancing and objectivity which could be applied at home (Dave: 112).

All participants talked about honesty with work colleagues regarding the pressures of raising a son with AS. Patrick found he was admired at work for raising a large family as well as supporting Ned with his AS (Patrick: 89). Dave valued his contribution as the breadwinner, like other fathers interviewed struggled with balancing time and energy between his job, 'family *and fighting for Nigel's rights, often feeling exhausted trying to be in two places at once'* (Dave: 48) (Draper, 2002).

Otto and Dave found personal experiences of disability had helped them in their work roles (Dave: 40). Otto's changing perception of disability had led him to incorporate this knowledge into his client-base. He employed people with AS '*… and the fact we build accessible websites that help disabled people access information*' (Otto: 60). Dave found his work role gave him confidence to apply skills interchangeably, at work and in the home, managing Ned. *'I sort of deal with people and they say, "oh my son's got this problem because." As soon as they mention certain things, like ADHD, Asperger's whatever, it's oh I can relate to that...'* (Dave: 60).

Although some found working from home easier, others experienced increased pressures. James talked about struggling to spend time with Len, doing things for him whilst meeting work deadlines. Andrew, working a lot at home, found similar

tensions around his use of time and energy. Getting the right balance was difficult. Andrew believed Mark felt neglected by him.

> *...my job at times is emotionally demanding. So when I come home, Mark's there. I sometimes, you know, I haven't got the defences up or haven't always maintained that mental grip of exactly what's going on with Mark* (Andrew: 76).

Andrew's work was people orientated. There was a sense that part of him had to be 'defended' against emotional demands of Mark, his wife and his congregation. He found balancing work and parenting demanding. Perhaps he felt inadequate in trying meet both roles and never fulfilling them to his standards?

Stephen addressed this problem by giving up work and becoming the primary carer. He felt this was an important decision for both him and his family. He found he could be a full time father and both notice and address his children's individual needs.

> *I had the opportunity of taking redundancy and said I'd look after the children. And the children weren't that keen on that thought either (smile/laugh). But it's worked out ok, they're ok, I'm a lot more relaxed with them and I have a much closer relationship with both of them now. So, it's just, I think you know when you're at work you come home, or I used to work from home a lot. It would always be, for some reason everybody would want to have a conference calls about four o clock in the afternoon, just when the kids were coming home and they'd rush to see you and it would be 'go away, go away' (hushed voice)* (Stephen:30).

Otto adapted his work by running his business from home. Previously his coping strategy was to '*bury himself in work.'* (Otto: 26) Otto's story highlighted how 'high-powered' careers, rewarding those who worked hardest and longest, feeds into avoidant defence mechanisms, common in fathers having difficulty coping with their family situation (Holland-Wade, 1998). Otto felt that his job helped him disappear from family life, avoiding difficulties with Morris. He '*left without leaving'* (Otto: 48).

> *...being at work so much of the time. Not supporting Hilary really. Erm, it was so much easier to be at work than you know, with a perfectly good excuse, and then not be supportive. So I think Hilary had a really rough couple of years, you know, looking after Morris who is extremely hard to deal with. Erm without my being there enough,*

> *you know without my actual support... that must have been six years of really not being a very good father, not being there enough...You know, I think I did my best but given what I now see what it was like dealing with Morris* (Otto: 48).

Otto felt the support he gave was financial. In the past he had been able to '*throw money at problems and get rid of them*' (Otto: 194). How much does finance have an influence on fathers staying in the family home? Patrick was out of work and homeless yet remained with his family due to personal beliefs (Partick:14). Work brought pressure on time and energy supplies, but the demands of being out of work and not having enough income also would have had detrimental effects on family stress levels. Andrew illustrated a conflict around social values of materialism, *'I am out of kilter with all of society these days. You know the government and everybody seems to have got more money than sense'* (Andrew: 89). The narratives suggested that relationships with money were complex, practical, but linked with psychological and spiritual values as well as personal status (Otto: 152; Patrick: 14; Andrew, 89).

Otto's interview suggested that status was important to him (Otto: 50). Changing his work to be at home meant a loss. He had to reframe expectations of himself and others regarding professional identity, '*because the main struggle was always this idea that I wanted to be in a professional company, or present that face of a professional company'* (Otto: 56).

Although work and breadwinner roles can be important to fathers, participants appeared to have successfully reintegrated roles to their circumstances (Habib and Lancaster, 2006). This could challenge social beliefs about masculinity and fatherhood.

4.2.2.4 Masculinity

Many participants appeared to struggle with their masculine identity once they became fathers. Most of the fathers talked of an idealised image of the father-son relationship. Many anticipated enacting this in ways socially defined as 'masculine,' (Boyce et al., 2007). Sons with AS tended to have more insular non-sporting

interests making this difficult. Fathers either struggled to engage sons in ways they anticipated, or adapted to their son's interests and personality. Connecting with children with AS usually entailed sharing a specialised interest in the first instance, moving children to a broader more flexible way of interacting with the world around them is secondary (Attwood, 1998). Stephen illustrated this in sharing Tim's interest in trains, as did Andrew playing computer games with Mark (Stephen: 14; Andrew: 10). Andrew had used a shared interest of science fiction to encourage a discussion on values with Mark.

> *..he's er interested er in other things. Not the slightest bit interested in farming which was my old background, but he's quite interested in talking about you know, philosophies of life you know. Or er Battle Star Galactica, which was all you know, all this wonderful philosophy and er about humans creating robots who rebel. And er, the ethics of you know, how they'll cope with all of this. And you know humans, surviving human community lives and relates to one another* (Andrew: 95).

Most fathers expressed disappointment at their sons' lack of interest in sport. Fathers predicted this would be a shared interest, even when they had not '*been sporty'* themselves (John: 14). Dyspraxia commonly co-exists with AS and undeveloped motor skills combined with poor social communication skills makes sport, particularly in teams, very difficult (Jordon, 2002) (James: 12; Andrew: 44).

> *He doesn't like sports. We've tried to do lots of things...we thought it would be good for him to mix with other children... So we took him to football and he wasn't really interested in that. We've taken him to tennis...he's not competitive, he can't really focus on the competitive side of it...He's not really that good at sport... Erm, in that respect I think it is hard for dads because it's one of the things you think to yourself as a dad you'll be taking your son to certain sports. I'm not a particularly sporty person myself* (John: 14).

James was a football lover and struggled to encourage both of his boys to enjoy the game.

> *Well, it's all around football. In the football season we will go to watch...once a month say... Get quite a lot of enjoyment from that. (James, 10) ...typically as a father you want the boy you can play football with, which I can do with Len. But for a long time I couldn't. He couldn't kick a ball. It's only over the last few years, I guess*

> *through perseverance that he's got to that stage where we can have a kick around* (James: 26).

James persisted in coaxing Len to enjoy football to achieve a shared traditionally 'male' experience. James echoed the concerns of several fathers that a lack of sporting interest could create peer isolation (Harrison et al., 2007). Not being '*in the football crowd'* (James: 6) could leave sons not only lonely but vulnerable to bullying (Dave: 5). A social expectation of the 'sporty male' was evident in most of the narratives. There may have been some peer and societal pressure for fathers to engage in 'masculine activities' with their sons. Some appeared lost as to how to spend time with sons who did not play sports (Harrison et al., 2007). Over time many fathers realised their sons preferred them just to witness their activities in isolation or on their own terms (Andrew: 10; Otto: 104).

> *He spends a lot of time sitting on the computer. And often he'll want me to just sit with him in the room. Sometimes he's perfectly happy if on his own and says, "you just sit there." It's ok cos I can be on the computer as well doing something else, but he just likes me in the room with him* (Stephen: 16).

This raised stark comparisons for those with neuro-typical sons who enjoyed 'traditional masculine' active pursuits '*he's got a younger brother who...wants to do lots of things'* (James: 26; Otto: 92). Intense longing for connection and communication with their sons was evident. Social communication issues forced fathers to do most of the work if a relationship was to be achieved (Alvarez and Reid, 1999). This could be demoralising as positive feedback or gratitude, which usually motivates in parent-child relationships, was rarely forthcoming (John: 64).

> *I regard myself as being a patient person. I guess I'm more, quicker to get more uptight. Er, I rant...because you know you just can't get him to understand that you're doing this for him. He won't, won't see it, it's so difficult. It becomes a chore, such a battle* (James: 52).

For fathers who themselves had traits of AS, relationship building could be an impossible task (Attwood, 1998). Andrew spoke of trying to be the 'right kind' of dad but worried about being insensitive to Mark's needs (Andrew: 119). There was a sense that the fathers were also trying to re-establish their identity as men and fathers in the context of their own fathers and notions of masculinity in the past and

present, as well as a sense of what it is to be male for themselves and their sons. The narratives suggest that masculinity is a construct which varies according generation, individual families and other contextual aspects of the individual fathers' and sons' 'life worlds.' For James a love of football symbolised a community of maleness, where it was vital for him and his sons to belong. Patrick expressed how it mattered much less to him than it would have done for his father that Ned has a diagnosis or 'tag' in the context of being part of a community of men. This may be to some extent related to recent individualism and the breakdown of close knit communities, where men tended to live and work in the same place for generations. However Patrick also ended his comments with sadness, being perceived by other men as not having a 'normal' child made him feel alienated, despite doing what he believed was the right thing for Ned.

> *I never had a problem, talking to older men about it and I know particularly from my Dad, there would have been a thing where he would never have wanted a tag for his child. There would have been other men saying 'Oh I couldn't handle that, I don't know how you are going to handle that'...I was never ashamed of Ned of what he was going through with any tag that was given to him but other people would be 'oh gosh,' and step back, 'you haven't got a child that's normal.' And that sort of alienates you* (Patrick: 22).

Masculinity could be culturally defined by social activities, e.g., spending time with other males, involvement in sport and drinking (Meyer, 1995). These activities rely on abilities to develop and maintain friendships, albeit activity based. This is difficult for young people with AS and due to the continuity, closeness and perhaps less demanding relationship with their mothers, more time is often spent in maternal relationships (Baron-Cohen, 2010; Gray, 2003). As a result, fathers can feel sidelined, disconnected or lacking control. These feelings are explored in the next section.

4.2.2.5 Control: losing and gaining

Issues of control were mentioned by fathers in various contexts, particularly in their son's birth and early years (Patrick, 16; Stephen, 30). Both the literature and participants' narratives suggested this was a common male experience from the pregnancy onwards (Hinkley et al., 2007). This lack of control was exacerbated by

its continuation and intensity for those who have children with special needs (Harrison et al., 2007), particularly sons with AS (Lasser and Corley, 2008).

Recent thinking suggests that men who are more involved from the start of their child's life were more likely to remain involved (DfES, 2007). Fathers were insightful in describing how they felt supporting a pregnant wife and witnessing their son's birth (James: 18, Patrick: 14, Stephen: 28). Other situations followed where they felt they lost and sometimes regained control, often by adapting to circumstances and changing their perspective. This impacted on their sense of self. John recounted his feelings at the birth, '*I felt like...I was actually floating. You know I was so excited and that, it was wonderful like'* (John: 32).

He went on to describe his subsequent experiences of fathering a sick son.

> *Erm, but no, we've always been there like, you know the procedures he's been through... he was born. Like and then we were backwards and forwards... for a long time he's been on drugs... he has had bad behaviour and things all his life I suppose, but we've always put it down to his illness...he's had very long spells in hospital...one parent would stay, because he was our only child and up until that time his mum would be with him...*(John: 32).

He powerfully described his loss of control of the situation and of a role within what felt like a dyadic mother-son relationship rather than the triadic father-mother-son relationship he had anticipated with excitement (Rohner and Veneziano, 2001; Simons et al,. 1990).

> *He's got a real big bond with his mum... because he's such a sickly child and you know I've always felt a bit pushed out to be honest with you. That's what I've put it down to sort of thing. But obviously with the Asperger's it puts like a different dimension on it* (John: 32).

John felt the recent AS diagnosis had given him a different perspective on both past and present events, related to his difficulty connecting with his son and feelings of a lack of control.

Stephen had a positive experience at the birth whilst still experiencing a lack of control due to a lack of information from medical staff about his son. '*You know we were in the labour ward and like people coming and going with the little bundles and we're left, the only ones left and sort of 'what's going on?'* (Stephen: 26*).*

Otto described the birth experience as a *'nightmare.'* He felt unreal and wanted to wake up. He witnessed his wife's distress and felt powerless (Otto: 40). Patrick described how he lacked control, physically. He was not able to be involved in the birth due to complications and psychologically had to live in the state of not knowing whether the cause of the AS was birth trauma.

> *the other three pregnancies, you could share in it, but with the caesarean, it's just you feel totally out of it, where with a normal pregnancy you have some control. I am not saying this was abnormal... it was something to share but with this time it was so impersonal it was like a conveyor belt... when Ned came out I actually worried that day because when he came and he needed oxygen. That was always in the back of our minds, you know when he was diagnosed with Asperger's, you know, was it due to that? We have often wondered* (Patrick: 14-16).

For Patrick this lack of control continued in trying to gain support for his son. He felt that having a key person he could trust would have made a lot of difference to his involvement and his sense of control in his son's life (Scorgie, 1996; Axup, 2003).

> *As a father I had to go with the flow, you never felt, and there is no way I am a control freak or anything, but you never felt in control of your life because of what was happening. It was always in the hands of someone else. No matter what, there was nobody there* (Patrick: 71).

This dichotomy of people taking over, yet not being there for the family continued through Patrick's narrative and is an important message for professionals in supporting fathers more effectively, empowering them to feel capable and in control as far as possible. Not knowing the answers to important questions was a re-occurring theme for control. What caused the AS? Parents could feel more control if the cause is environmental rather than birth trauma or genetics (James: 50); they could change the former (Frith, 1989).

Otto appeared to reverse this:

> *I don't think anybody would like to feel that they were responsible for Morris being the way he is. If it was, you know something to do with the way he was born or that sort of thing, that's easy to handle* (Otto: 4).

What do the behaviours mean? AS presents itself in certain behavioural characteristics, which may be representative of perpetual states of high anxiety.

John felt he lacked control of the AS in his son, unlike the co-existent physical illness, '*You can't just shake him out of it. Yea, to be honest with you I do, I do resent the Aspergers'* (John: 52). In truth, this father could not control either illness, yet there is something intangible about the AS, perhaps the underlying hidden characteristics, inextricably merged with his son's personality? How do I support my son and cope? John described himself as lost, involved in an abnormal experience without answers. James similarly spoke of how the '*disappointments chip away at you'* (James: 44). Some fathers described how the lack of control resulted from their inability to connect with their sons. Unlike John's other children Dan showed no gratitude and could be verbally abusive. '*it just cuts you down sometimes, being er rude to you and things like that'* (John: 62).

It is possible that the lack of control fathers felt mirrored their sons' inability to feel in control of themselves and in particular their behaviour. This could be explained by the unconscious process of transference or projective identification occurring within father-son dynamics (Klein, 1952; Alverez and Reid, 1999).

In practical terms control of anger and aggression was a real issue for fathers, particularly as their sons' became young men. John described how he could find himself in a vicious circle of anger and frustration with Dan.

> *I'm a bit harder on him because it is Asperger's to be totally honest... That's something that's a problem with me really, not him... Although it is a label it's a different thing because it's actually his personality. I sort of do take it out on him a bit more. I'm a bit harder on him and not so tolerant I'd say* (John: 56).

Dave described a neighbourhood dispute where Nigel, *'was attacked by a father...yet he was just being him...they* [other children] *ended up kicking his bike and he then retaliates... Then the father chases him and gets hold of him by the throat, the police got involved and all sorts'* (Dave: 50,52*).* This was very difficult for Dave as he felt he had to protect Nigel from getting into trouble with the law, but as Nigel grew older and bigger this became increasingly impossible.

Similarly, Stephen worried about Tim's internal lack of control and his inability to control Tim in a way which will protect him within society,

> *You know is he really going to fly off the handle and not be able to, be able to control his frustration and his anger in, in these sort of situations. And er, you know people would start to think well I don't want my child in the same classroom as some weird kid* (Stephen: 86).

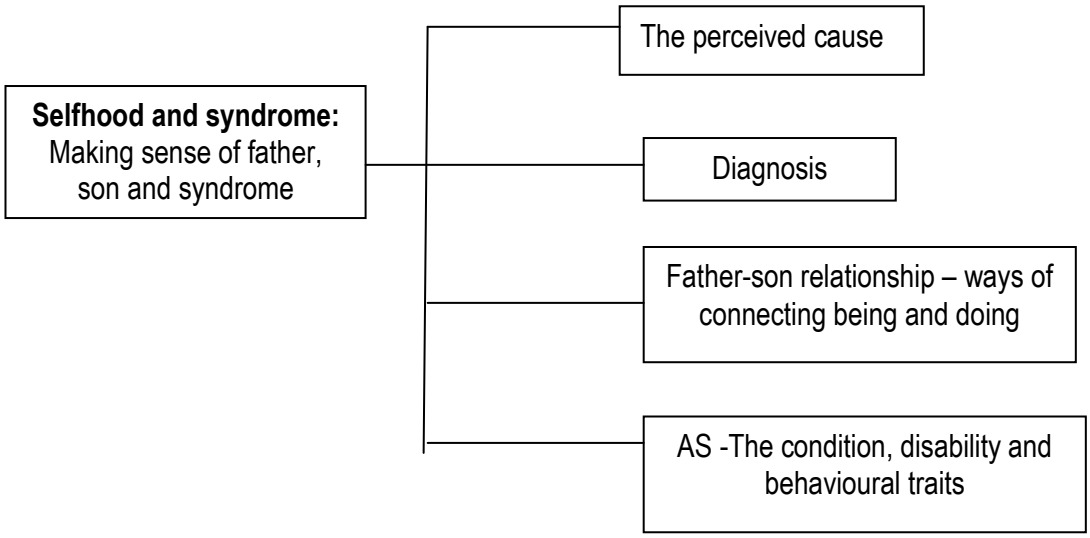
Some fathers described their techniques to remain in control. James re-evaluated his personality as a result of his feelings of frustration,

> *I always thought of myself as a patient person... I almost find I've become less patient with Len, definitely, definitely. Whether it's frustration, frustration on my part I don't know. ...So after you've fought all those battles you er your willingness perhaps to be patient goes* (James: 52).

Dave attempted to maintain control over the situation by playing the role of 'objective' observer. Although a defence mechanism, disassociating one's self from the situation can feel empowering (Reid, 1999). It gave Dave an overview, a sense of the predictability of difficult family situations. *'I'm watching it from the outside and I can see what's happening. Certain things are so predictable'* (Dave: 140). His attempt to play and objective 'judge' was perhaps a masculine coping strategy easier for fathers in a traditional breadwinning role (Gray, 2003).

In contrast Andrew had difficulty stepping back. He was able to recognise similarities between himself and Mark's personality. There seemed to be fear and anxiety passed between father and son (Andrew: 131). Within this Andrew struggled between being in control and creating a dependence which he knew was counter–productive in the long run (Andrew: 127). Handling issues of control appeared to be related to the father's personalities, perhaps influenced by their own parents' strategies, (see section 4.2.2.5 in this thesis). Balance between control and living with the unknown was hard to achieve, particularly with the responsibility of fathering a son with AS. No one way appeared to work. It seemed that coping strategies varied in their success according to the situation and adaptability was critical. However, adaptability is a rare trait in AS, and those fathers who share traits are likely to find coping most difficult (Baron-Cohen and Hammer, 1997).

4.2.3 Selfhood and Syndrome.



In the previous section fathers implied that a sense of control could be gained from knowing the cause of the AS, but research suggests that AS can be multi-causal and it is impossible to give a definitive answer to the cause within each individual (Attwood, 1998). This 'unknown' is hard to comprehend and live with in today's world of modern medicine where answers seem commonplace. Father's perception of causes affected their sense of responsibility and expected actions. Despite traits present from an early age, diagnosis carried meaning for the fathers and their sons. This often related to causal beliefs, how far traits were identified within the father, the wider family or within the child alone, the age of the child and co-existing conditions. Most thought the diagnosis was helpful in moving towards an 'answer'.

The father-son relationship appeared to relate to beliefs as to how integral the AS was within the personality of their son. Some felt the AS appeared like an unwanted invader which emerged sporadically (Patrick: 63; James: 64). Others accepted it was an aspect of their sons' being, which made life difficult but required them to adapt in building connections with their son (Simon: 6; Stephen: 64). The former appears to relate to a medical model of physical illness (DSM-1V), the latter a social model (Oliver, 1990). After attempts to attract sons to engage in activities which fathers' perceived as 'normal,' e.g. sport (see section 4.2.3.3 in this thesis), most found they had to balance 'doing' and 'being' according to their son's interests and anxiety levels. Relationships were often strained by the necessity of taking sons out of their comfort zone to ensure developmental opportunities, independence and

social communication. This was a balancing act between promoting development and causing mental anguish. A greater effort by fathers became necessary as sons grew older, given their comparatively lesser involvement than mothers at the beginning.

Fathers' perceptions of the AS varied from a condition or a disability, to a unique style of thinking. The framing of AS was important in influencing the fathers' sense of self in relation to their sons and the syndrome. The way each father framed the AS appeared to influence not only how they thought about felt about their sons, but also their management of difficulties which arose. Behavioural traits were the observable manifestation of the syndrome and it was these that fathers struggled with most in raising their sons and where most internal debate about selfhood and syndrome took place.

4.2.3.1 The Perceived Cause

The perceived cause of AS was integral to the relationship between self and syndrome. Several fathers reported birth difficulties and found themselves believing these were the cause (James: 78, 26; Patrick: 16). Others believed genetic factors played a part (Otto: 10, Andrew: 119; Stephen: 44). For most AS brought feelings of guilt, fear and loss (James: 26; Otto: 44). Despite locating causes in factors beyond their control there was a sense of doubt regarding parental responsibility. Understanding of attachment theory in relation to AS has changed, accounting for the child's inability to attach, yet there may still be echoes of 'frozen mother syndrome' in the minds of some parents and professionals (Frith, 1989) (see section 2.4 in this thesis).

> *I don't think anybody would like to feel that they were responsible for Morris being the way he is. If it was you know, something to do with the way he was born or that sort of thing, that's easy to handle, but um, that if some behaviour that Hilary has done could actually have caused it or nurtured him being Asperger's...is that cos Hilary's done it* (Otto: 4).

Others agreed with Otto that AS was easier to cope with if nature not nurture was the cause. However, a sense of control might be gained by assuming some

responsibility. Perhaps hope was raised that if they were part of the cause they could be part of the healing too?

> *It's not my fault in the sense you know, like I drank before he was conceived or something like that. But in essence you do sort of bear a certain responsibility because it's you know he's got part of my genetic makeup. Part of that may well be responsible for how he is. er, if that were to sort of limit his life in some way (exhales). I suppose bearing that in mind it makes you a little bit more erm aware of just the sort of randomness of things* (Stephen: 64).

Evidence that something was wrong in early development appeared in the accounts. Delays in meeting milestones supported fathers' acceptance of the diagnosis, at the time for some, in hindsight for others (James: 20, 30; Patrick: 16; Stephen: 30). Inner debates as to why and whether their sons really had AS continued. Fathers asked: Is it AS or something else? (James: 18-20; Stephen: 54) Is this God's will? (Andrew: 3) What does it mean for sons, families and the future? As the following sections illustrate the cause and meaning of the AS were influential in the perception, belief and resulting behaviours of fathers, sons and others.

4.2.3.2 Diagnosis

It was clear from the accounts that diagnosis and the AS were not synonymous. Diagnosis made a difference for all participants depending on how diagnosis was perceived by the fathers themselves, their sons and significant others. The age of the child at diagnosis was important, i.e. how long the child had had AS without a name, '*this is only really the last year we've known he's had Aspergers, but he's had Aspergers all his life'* (John: 48).

Differing perceptions led to a variety of relationships with the diagnosis. Some found the diagnosis could be restrictive and preferred not to become '*obsessed by it.*' '*my dilemma is you know, do I say there's nothing wrong with him or, and just that's life, get on with it mate...I'm not into denial...people can get totally obsessed by it when they get a diagnosis and get into it'* (Simon: 18). Simon's experience of professionals confirmed his mistrust and belief that there were no absolutes in an AS diagnosis.

He was uneasy about giving it much credence and felt it could develop unhelpful perceptions (Simon: 4).

Some participants reflected on how they were initially unable to accept the diagnosis (John: 52, James: 26). James described how denial helped him move on to having another child, '*So perhaps one reassures oneself that it will be different this time. Um there's always that denial aspect, that it's not Asperger's'* (James: 80). It was clear that even many years after diagnosis James engaged in an internal struggle to understand and come to terms with it. This appeared to be occurring as we discussed Len in the interview (James: 22).

> *Diagnosis has been the most difficult thing (pause) the most difficult thing (pause) I suppose coming to terms with it really. It has to be. I was in self denial for a long time, 'he'll be alright, he'll be alright It's not as bad as you think'. And he did improve. But it took a long time for me really to accept that it really did, so I suppose that's been the most difficult thing. You know, part of you still thinks he hasn't got it (laugh) that's blown things out of proportion when I know he has (James: 64).*

Others sought a diagnosis (Otto: 14; Patrick: 16; Simon: 2-6) and although described as a milestone by several fathers, diagnosis was also seen as the beginning of a different journey through fatherhood (John: 12). Some, whose sons were already diagnosed with other conditions, felt they were re-entering this process (Roll-Petterson, 2001). John and Simon described themselves as entering a period of questioning, finding information and comparison with other children with AS. Are they similar, different, better or worse? How severe is he? Simon mentioned several times that Keith was not as bad as others (Simon: 6-10). Each father appeared to have a similar experience of the diagnostic label bringing something tangible to the situation. It became a sign-post in accessing resources (Otto: 14, Dave: 80), '*you read around the subject'* (James: 26); *'we believed that if we couldn't give him a tag we couldn't get him the help he needed'* (Patrick: 16).

The empowerment of diagnosis was tempered with uncomfortable realisations. Several fathers found their hopes dampened, causing them to reassess the future for their sons. John's belief in a short-term problem helped by medication was dashed with this life-long diagnosis that had to be managed rather than cured (John: 54). Psychological reframing, which involved looking at the same situation from a

different point of view, to accommodate the permanency of the AS was commonly difficult (Otto: 212). '*The slow realisation that er the opportunities that are going to be open to him will be very different'* (Stephen: 54). Still, narratives suggested evidence of coping mechanisms. '*You know, it might not have been Asperger's, it could have been something else you know a lot worse, in the sense of its impact on ourselves and on him in later life'* (Stephen: 64). Stephen was consoled by reframing Tim's AS with the idea it could have been worse. It was up to him to make the best of the situation (Harrison et al., 2007).

Naming was an important aspect of the diagnosis. '*Diagnosis has been good...we can tie all those things together and give it a name'* (Otto: 88). Naming is a powerful concept in psycho-dynamic literature. Bion (1984) suggested a problem once named could be contained and fails to be terrifying, it could be talked about. These fathers appeared to affirm this view. The name '*explains the behaviour and therefore helps you research coping mechanisms'* (Otto: 88). Coming to terms with the diagnosis helped Stephen enjoy his son for who he was.

Prior to diagnosis Dave felt isolated and believed he made a lot of parenting mistakes. *'Nigel...didn't necessarily accept the boundaries. As obviously after he was diagnosed we knew, because he didn't necessarily understand them'* (Dave: 38). Andrew worried that diagnosis could limit expectations and create a dependence on others. He asked, how much do you challenge someone with AS, do you accept how they are and forgive? (Andrew: 42). Is there potential for change and how much? Should fathers push their son's without this assurance?

The diagnostic label can carry a strong message within society. Fathers interviewed experienced various reactions. Diagnosis helped challenge and change wider family views of bad parenting (John: 34; Patrick: 101). Dave found that post-diagnosis school staff changed their perception of Nigel (Dave: 12). He was no longer a 'bad parent' but a parent of a child with a disability, who needed support. He no longer felt blamed. All of the fathers wanted their sons' to be understood but not limited by the label. This section suggested that assessment, leading to possible diagnosis, is a bigger and more far reaching decision than many parents and professionals might appreciate.

4.2.3.3 Father-Son Relationship: Connecting, being and doing.

The fathers' relationship with the syndrome raised the questions: Who was their son? Where did the syndrome begin and end? How could fathers connect and build meaningful relationships with their sons?

This area considers father-son attachment. It raised a range of emotions for some as to how their relationships with their sons should be different, especially for those with neuro-typical sons (see section 4.2.4.3 in this thesis). These boys appeared to have enmeshed, anxious attachments with their mothers, affecting the father-son attachment which can be characterised by avoidant characteristics (John: 104, James: 30), (Alvarez and Reid, 1999). For sons with AS it seemed as if the mother remained an extension of the self, rather than moving through the attachment stages to develop an internal working model upon which to build subsequent relationships, particularly with their fathers (Sunderland, 2007; Reid, 1999). This has been observed in my own practice as an EP and creates difficulties for mothers and fathers. Mothers are unable to be independent of their sons, both physically and emotionally, fathers feel alienated on two counts, not being able to develop a relationship with their sons, and their marital relationship also becomes stilted. Fathers commonly feel outsiders in their own marriage and family / household.

There was a sense of urgency and anxiety in the narratives, how can I connect with my 'real son' before he is lost in his own world? Otto felt he could easily lose his connection with Morris. '*It's easy for him to go into his bedroom... and be isolated there. Not studying, not reading, not being nurtured by us as parents, but he'll just go there and be lost in his own little world in there'* (Otto: 26). The desire of sons with AS to be alone concerned fathers, worrying they would miss out on the nurture provided by family life. Stephen pointed out that fatherhood is an experiment which can only be performed once (Stephen: 50).

Where fathers felt unable to connect with their sons sadness, disappointment and regret were common (Otto: 104; Stephen: 98; Andrew: 95). Andrew would have

liked to be able to talk with Mark more. Otto stated he hated Morris' company prior to the medication. Most had realised that they could begin to connect with their sons when they met them on their sons' terms and at the appropriate developmental level (John: 14; Stephen: 74). Andrew described listening to where Mark was at. He could discuss issues with Mark through science fiction and computer games (Andrew: 95). Stephen realised accepting his son on his terms led to a closer relationship: '*Which one of us is the adult here? I've got to be the one that changes'* (Stephen: 38). The lack of reciprocity and empathy in father-son relationships was common. John suggested self-sacrifice was important but difficult to cope with emotionally as there was no room for his needs (John: 22) and James gained no sense of appreciation (James: 152).

> *Sometimes I, I wouldn't recognise myself because I, my patience is not there when I regard myself as being a patient person. I guess I'm more, quicker to get more uptight. Er, I rant...because you know you just can't get him to understand that you're doing this for him. He won't, won't see it it's so difficult. It's a chore such a battle* (James: 52).

Years of feeling taken for granted could be hurtful and wearing. It was easy for fathers to give up if sons offered little emotional incentive to keep working at the relationship (Alvarez and Reid, 1999). Their love for their sons could be challenged by feelings of rejection, which could be marked in comparison to the mother-son relationship. Within several accounts there was a sense of fathers needing to connect, whereas mothers needed to disengage from enmeshed symbiotic relationships with their sons (Axup, 2003). '*I don't think I'd ever have a real strong bond with him. Er, I, I just think we'll er tick along really. I think he'd always go to his mum. His mum is his centre of his universe in that respect. He relies on his mum'* (John: 104).

All of the fathers had tried to reach their sons through adapting their own behaviour and interests. Patrick tried to interest Ned in various sports, but found Ned preferred museums*. 'We like to take him to, you know, maybe a museum...but sometimes I think we are missing what he really needs. Basically it is 1-to-1 contact. I think that is what he craves'* (Patrick: 12). Patrick had noticed that Ned craved individual time, yet the computer could be an obstacle, allowing Ned to be physically present but not emotionally or psychologically, a common complaint of fathers. *'It's difficult because*

his mindset is so much on computers and things and he won't do sports' (Patrick: 12). Most of the fathers mentioned their sons' love of the computer. Although it could be argued that this is similar to neuro-typical peers, those with AS used the computer as a way of avoiding social situations, where they lacked the coping skills. Therefore they might never learn how to function within the family or other social groups without suffering extreme anxiety.

Fathers spoke of their difficulties coming to terms with their son's 'immature' interests and behaviours in contrast to high intellectual and verbal abilities (John: 12). Similar to very young children many enjoyed exploring the world in a sensory way, e.g. a train speeding past, role play and crabbing (Stephen: 14, 16). Both Stephen and Dave emphasised that time spent with their sons during adolescence was particularly important (Stephen: 53; Dave: 42, 68). These were times when fathers could help their sons experience the wider world, developing their social skills, in the absence of a strong peer group. Yet engaging sons in social activities proved difficult. Otto pointed out how it easy it could be providing DVD and gadgets, rather than engaging emotionally with Morris.

4.2.3.4 Asperger Syndrome: The condition, disability and behavioural traits

Most of the difficulties described involved sons' behavioural manifestations of anxiety created by the AS. It seemed important for fathers to know what were 'normal' behaviours testing parental boundaries, particularly in adolescence, and which were rooted in the AS? Vivid metaphors described behaviours and their impact. Otto described Morris' behaviour as a '*barrier'* to their relationship. Several times he used the word '*erupt*.' '*Morris can er generate problem behaviour from nothing. From nowhere, it just erupts.'* (Otto: 114) Morris' behaviour, like a natural disaster, caused devastation to all around. For some fathers the AS was a natural genetic disaster.

Splitting behaviours, regarded as the manifestations of AS from the son's personality seemed an impossible task, yet one undertaken by some fathers, on a daily basis, in trying to reach an understanding.

> *Behaviours that seem to erupt all the time that are, that are impossible for us to understand, you know. Um, Hilary in particular, got a degree in developmental psychology, you'd think she'd have the capacity to understand these things...It* (the OCD*) overwhelmed everything else when it started. Um, it came out of nowhere, totally sideswiped us really* (Otto: 14).

The changing nature of AS was described by Otto as a car crash, where co-existent conditions emerged. The 'side-swiping' behaviours denoted that they were outside Otto's range of vision or expectation, a blind spot. Like an unexpected accident, '*we don't know what to do'* (Otto: 14). The changing nature of the condition and its integration with the child's development was often a surprise, perhaps due to families dealing with the present moment as a coping strategy. Co-morbidity often manifests at the onset of puberty, coinciding with transition to secondary school. The intermingling of psychological, environmental and hormonal changes are rarely understood or appreciated by families and schools. OCD and Tourette Syndrome could develop during this time, as with Morris. Some fathers expressed surprise when the AS '*kicks in,'* through weird, strange and socially inappropriate behaviours (Otto: 7). James spoke of observing his son's development through the AS.

> *I've read a few things...something that struck me...boys with Aspergers from around the age 10 start to have signs of depression...I almost recognise that with Len. I could see it happening. And I think, because he obviously knows he's got Aspergers, he doesn't like the idea of having this, this label* (James: 6).

The idea of a '*condition*' an invading '*it'* which is within their son but not their son *'puts a strain on the family unit...you have sadness around the disability'* (James: 36).

Several fathers described how this hidden disability could trick them, with behavioural traits disappearing and fooling them into thinking everything was alright (Patrick: 22). Yet suddenly, the AS behaviours would kick back in, like a default position providing sons with a safety zone.

> *...seeing the way he is now, he can be charming…lovely... frustrating...I don't want to say normal but it is probably easier for me to say that, but everything a child without Asperger's would do. And I know he kicks back into his Asperger's* (Patrick: 63).

Many participants spoke of coping through compartmentalising different aspects of their lives. Otto illustrated several ways he used the psychological defence mechanism of splitting (Klien, 1952), namely; the AS from his son, himself from his parents, himself from his son, the medication and his son, the AS and himself, the AS and his father. John talked of trying to understand Dan by compartmentalising him into three parts; his physical illness, the AS and the 'normal' boy. Yet he realised the complexities were too great and he needed to begin the task of accepting his son as a whole person, even with the parts which were difficult to embrace and cope with. *'Like I say I don't think you can break it all up, it's one thing, that's Dan. And that's his life and the way it's sort of affected me, affected us as parents'* (John: 74). Andrew's Christianity led him to a similar dilemma of duality. How far is the AS an illness, part of Mark's personality, or a sinful state? '*The Christian gospel is a challenge to people. So how much do you challenge people with Asperger's and how much do you accept'* (Andrew: 42). Without understanding the nature of the problem deciding how to respond was unclear to fathers.

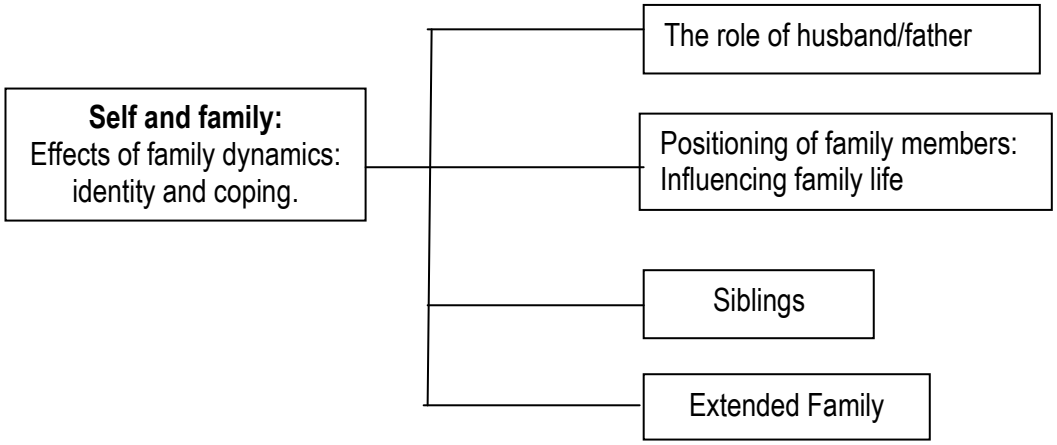
Andrew was able to discuss this by taking a philosophical stance, referring to people with AS in general rather than his son. Intellectualism is perhaps an important and effective way of detaching from the emotional pain whilst working through ideas in a logical way, yet used long term this may be a form of avoidance which could have implications for father-son and parental relationships and fathers' emotional well being. Andrew's dilemma echoed society's 'mad' or 'bad' debate. Where do mental health difficulties and responsibility for undesirable behaviour begin and end (Attwood, 2008)? This is a very real issue for young people with AS who become young offenders. There were hints, within Dave's transcript, that this was a worry. He described an incident with Nigel where the *'police got involved'* (Dave: 52).

The concept of AS, 'a disability' varied between fathers. To some it was a barrier to 'normal' life but thinking of their child as disabled was a struggle for most. The lack of physical traits and commonly high academic achievement contradicted the term

'disability.' However, the underlying difficulties made it clear to fathers that their son's were disabled within a neuro-typical, social society. Stephen and Dave explained, '*You can't assess them against able bodied people. You've got to set different criteria for them'* (Stephen: 62). '*I think it's just a case we've got a son with a disability. And we've had sort of to do learning so perhaps you wouldn't have the same life as others'* (Dave: 50).

It was clear from the transcripts that each family's dynamics was unique. Fathers' identities were related not only to that of their sons but also to their nuclear and extended families. The next section focuses on fathers' life worlds within the context of their families.

4.2.4 Self and Family: Effects of family dynamics, identity and coping.



To focus on fathers whilst ignoring the family context would fail to acknowledge the roles these men are balancing on a daily basis. Whilst being a father raising a son with AS participants sought to be good husbands, in some cases good sons to aging parents and supportive family men. Positive and negative relationships, within the extended family, were powerfully expressed.

4.2.4.1 The Role of Husband/Father

Balancing roles of husband and father were rarely straight forward. Unsurprisingly, participants considered their role of husband, both as a supporter and recipient of support within the relationship. Marriage and fatherhood triggered pressures in balancing their needs with those of their wives' and sons (Gray, 2003).

Several fathers reflected as to whether they were good fathers supporting their wives beyond wage-earning. James and Stephen asked themselves, is fatherhood just about love? Are they too nice and need to push more? Both had remote fathers and wondered whether their own experience has confused their role. '*I don't want to try and live my life again through them'* (Stephen: 48). Dave talked about having been a *'good dad to his first two children, but with Nigel and his disability, it is a different journey'* (Dave: 58).

Many integrated the role of husband and father, perceiving their job as supporting their wives to care for their children (Gray, 2003). James described his wife as the mainstay. He relied on her to nurture the children and he felt she took on a lot. He felt his part was to support her in their dual responsibility for parenting the children (James: 98). James cooked and encouraged completion of homework. Emotional support for wives was also important. '*I know Anna can get quite upset, quite naturally upset. You know you have sadness around the disability'* (James: 36). Otto acknowledged Hilary's workload, stress, and need for his support since working from home. He acknowledged that as a man out at work he was able to legitimately 'walk away' with the pretence that he was still playing his part. Once he started working from home he empathised with Hilary that coping alone without backup from a partner was tough and one could feel trapped.

> *Hilary's had an awful time dealing with Morris on her own and that two people dealing with that is much, much easier. That whole thing of being able to get some time out, being able to walk away from it . The other person is actually there to support that rather than just walk away from it. You can't walk away from it if you're on your own* (Otto: 66).

Only Dave felt he had to be the strong one who supported his entire family including his wife, due to her own poor health. There were indications that he had to protect Mary from some of Nigel's difficulties, dealing with them himself. Dave acknowledged that Mary had done a lot of the work, fighting for support. However, he constantly had to worry about and check the situation as, '*she hasn't worked through her own health needs'* (Dave: 112). Dave did not appear to have anyone to turn to for support himself and presented as very contained, perhaps to protect himself and his ability to keep going?

Stephen and Andrew described difficulties sharing their time and energy, mediating between their wives and sons and providing respite from stuck situations (Stephen: 30; Andrew: 76). *'There's always going to be this tension between the attention I give to Mark and the attention I give to Ellen'* (Andrew: 207).

Most participants expressed their reliance on their wives in supporting them emotionally. In fact most of the men were persuaded by their wives to take part in the interviews as an opportunity to come to terms with their feelings. When asked why they volunteered to take part several implied their wives would interview more effectively, '*I am not the one you should be talking to,*' (James: 2). Perhaps this reflected a traditional notion of wives taking care of matters linked with the children? James reflected, throughout the interview, on the roles of self, father and husband. He considered how their experiences with their son and the AS had influenced their development as both individuals and a couple. There appeared to be a sense that marriages break up or are strengthened by the experience of having a son with AS,

> *...because we've had to fight for Len for many things as well, you don't accept things at first times, you er, it gives you perhaps a degree of maturity as well you didn't have. We look back on when we were married, late 20's very young...even at that age we were young. We are different people now, today, than we were then. I'm sure that's true of everyone, but I think our marriage has had to harden, to fight battles* (James: 44).

Wives were mostly described as capable and taking control. Both Otto and James described their wives reading and researching AS (James: 6; Otto: 206). This had been important in helping them to understand their sons. Dave's wife worked hard for the diagnosis, despite her own health issues (Dave: 12) and Andrew described

Ellen taking the major care role (Andrew: 76). Several of the fathers had moved from a traditional breadwinning role to either primary carer or co-parenting the children at home. This was motivated by societal changes as well as personal development and practical solutions within the family.

Otto described the transformation from the comfort of his high status city job to a realisation he had not been supportive during the early years of Morris' life, *'coming home at 11 or 1 o clock, you know, the last train home. When Hilary's been sitting there looking after the children, that must be very galling'* (Otto: 48). He now realised her achievements and equality.

Patrick and John also talked, with admiration, about their wives. Patrick stated that his wife did 80% of the caring for Ned (Patrick: 101) and both John and Otto felt they gained the most support from their wives. Otto referred to his wife as resilient and way ahead in coming to terms with the AS. He was '*always playing catch up*' (Otto: 204).

> *I think one of the things I've found about Hilary is she's, I'd say usually right, often right in ways that catch me out. She's thought things through way before I did. And I catch up, years later in some cases. Asperger's being a case in point you know, it took me years and years to realise there was an actual problem there. Whereas Hilary had cottoned on pretty soon because she was there all the time* (Otto: 196).

The development of the couple was expressed strongly. Each participant had been married for at least ten years. Fathers talked about age and maturity influencing their marital journey and a sense of fatherhood. Andrew felt being a mature dad was an adventure (Andrew: 147) but difficult due to his age and loss of patience. He perceived himself as grumpy (Andrew: 8) and this persona appeared to influence the roles he played within the family. Andrew and Ellen conceived after weighing up potential medical conditions and finances (Andrew: 16). Despite the planning and caution several comments suggested he would have enjoyed Mark more if he were a younger father. Andrew found he lacked the energy of his younger years. Demands on his time as a father and husband could be stressful (Andrew: 10).

It seemed there was never an ideal time to have children. In contrast to Andrew Otto felt he wasn't ready for a son. He and Hilary were too young and he felt ill-

prepared for the responsibility. This resulted in him leaving Hilary to support him and their new son. Morris was a demanding baby. He was unable to *'square what we've got in terms of a child...to look after him or participate in that whole thing'* (Otto: 82). Otto felt '*ill equipped.'* He found Morris' crying hard to cope with and often felt '*guilty'* and '*selfish*' (Otto: 78). He reflected that he did not realise the impact a child would have and felt he was not a good father or husband. Some fathers spoke of growing into the role. The sense of resilience as a couple appeared to develop as new challenges were faced and overcome, '*we have drawn on each other'* (James: 70) in a '*joint struggle,'* (Patrick: 98), *'events galvanised our relationship'* (Patrick: 97). Wives prevented fathers from having to cope alone. They could worry together (James: 6) with a strong sense of mutual sharing.

John felt that couple resilience was crucial. He suggested future research on couples (John: 106). Dan and his difficulties had strained their relationship. Problems were commonly exacerbated by tiredness and worry (John: 76). *'I think our marriage has had to harden...all those little minor disappointments that sort of chip away a little bit. You know, you want the best for him'* (James: 44).

Key factors for maintaining a strong marriage were sharing a vision for their son, putting their son's needs before their own. '*I think we're both as committed... to his wellbeing'* (Stephen: 98). Ongoing communication was crucial in providing mutual and parental support (James: 18, 28). *'If anything, it's, it's sort of made the bond stronger. Because I think we both know that he's going to need more support. And I can envisage him, for example him never leaving home'* (Stephen: 96).

Difficulties occurred when core values created marital disagreement. Some fathers were able to reflect upon how these differences had developed from childhood. Due to the entrenched, deep rooted nature of such issues mutual understanding leading to compromise, was vital. Andrew described differences in values relating to family, work ethic, financial priorities and taking holidays (Andrew: 183). Otto and Hilary had fundamental disagreements regarding whether to use public or private services to gain support.

> *...one of my theories is that you can throw money at problems and get rid of them... it's always been a falling out point for me and Hilary... Why aren't we paying somebody private to do it?...My natural inclination wouldn't be to go to Social Services...I would never think we need a social worker. That's not where I come from, you know, socially I'm middle class* (Otto: 196).

Andrew and Ellen disagreed on how much to pressurise professionals. There was a tension between Stephen and Nina as to how much to push Tim. Coming to terms with the diagnosis at different rates was also difficult for couples. However, these couples appeared to have found ways of compromising. Participants often conceded to their wife's judgement.

Fathers who changed their career plans to fulfil their family duties reflected in a variety of ways. Otto grieved his career dreams (Otto: 56), but in hindsight felt proud of the company he had developed at home. Others felt being at home was a good decision for them and their families, particularly giving wives a chance to fulfil career prospects (Stephen: 30, James: 100). Several fathers spoke about the idea of leaving, '*it could have turned out so much differently if I'd just buggered off. I wouldn't have been there amidst all the difficulties'* (Otto: 100). Participants felt this was an easy option for men which they had resisted. Otto had instead used work and alcohol to escape from his difficult home situation. Leaving would not have been acceptable, resulting in a shameful rejection of family values.

> *Stopping drinking and working from home were two major things that have, you know, made our marriage sustainable...I think a lot of people who have children who are hard to deal with like Morris, er, it's very common to become, never there, just piss off. It's what you do. It's so easy, this is a real horrible place to be, why don't I just leave, you know? I suppose I come from a family where that wouldn't be, I suppose morally would be not how to behave* (Otto: 52).

John felt the quality of the couple's relationship determined the dad staying and working together (John: 108). Dave agreed,

> *It would have been very easy on both sides to walk away from it. But that's not the way it is. You've got these issues and you've got to deal with it. You've got to think of the family. I mean if it's just the husband and a wife, or two people that are partners it's easy like nowadays, you*

can just walk away. But when children are involved you've got to think of the bigger picture (Dave: 118).

Of the many reasons fathers stayed common ones were sticking together through adversity and putting the child first. '*May and myself are very alike, we wanted what was best for Ned'* (Patrick: 22). A shared vision and ongoing communication were crucial. '*I think what's helped is, Anna and I we have quite a strong bond to use. We talk through everything, I just think we're very alike in many respects (pause) and we want the best for Len'* (James: 28). James mentioned several times how Anna almost walked out, '*that's an example of where it's just, it's too much for her. And, you know, you're there trying, trying to support her as well. It's a strain for both of us'* (James: 98). Despite a long marriage this single event had stayed with James. He had relied totally upon her and seen her pushed to the edge. This frightened him and possibly re-activated thoughts of abandonment as a child. There was often an implication that some wives played a joint maternal nurturing role for both their husbands and sons.

This section outlined the marital relationships. The next section considers family units and the varied and complex dynamics within them, including the couple the son with AS and in some cases siblings. The extended family was also extremely influential within the lives of these fathers.

4.2.4.2 Positioning of Family Members: Influencing family life

This section considers the constellations of the family unit represented amongst participants. These dynamics were complex and multi-faceted, they included; the parenting and childhood experiences of the couple, the personalities within the family, gender and positions of the children within the family and unexpected circumstances such as the AS. It considers how raising a son with AS impacted on individuals and family life.

Change is difficult for people with AS. Family life is fluid and dynamic and without a great deal of planning and adapting to maintain a level of consistency, this environment can be much more stressful than school, which is timetabled and highly

organised. Adaptability is important in raising a son with AS, yet this can result in a stuck situation for all family members. Where the challenge of change is so traumatic for the child with AS and those around, it is easier to keep events the same as far as possible. Alverez and Reid (1999) suggested that when a family is caught up in the inflexibility of their Autistic child the whole family system becomes 'autistic.'

Stephen developed an acute awareness of how family members impact on one another. He realised that shouting at Tim just upset his daughter, Holly. (Stephen: 38). As a father he had to think of the needs of each family member which was not easy. John spoke about his misconceived ideals of family life, *'like the Waltons'* (John: 100). Disillusionment followed, when he struggled to meet the needs of Dan and his two younger children.

Family holidays were mentioned by several fathers as times of great stress. '*Getting away is quite difficult... Mark finds going away more difficult' (*Andrew*: 183).*

> *You couldn't just book the standard package holiday and go. Because it wouldn't have been a break for us cos you're worried about what he's doing, what he's getting up to, who he's upsetting and all that because, obviously, people don't understand it, so therefore we had to do something different. So in that respect, financially it's a drain* (Dave, 50).

Underlying such practical difficulties was the sense of problem ownership. Commonly the difficulties caused by the AS were owned by the couple or the family as a whole. Blaming, 'scape-goating' or putting the problem in the son was not apparent. In most cases the focus was the situation not a 'problem child.' This may be pivotal in the families remaining together. Fathers were concerned with providing security for the whole family, balancing their attentions as best they could. Post-diagnosis the AS presented as an ongoing management task. Working with the unknown and unpredictability of the AS forced fathers to focus on the wider implications for the family (Dave: 12).

James spoke about how the family unit had been the best support for him and Len. '*I think we as a family unit have given him a lot of support. It's been a drain at times but we've helped him get to where he is today'* (James: 62). Most fathers described

the family unit as a source of identity (James: 94), for both themselves and their sons. It represented family values (Dave: 48). To a greater or lesser degree their sons were included, with a perceived natural place within the unit, rather than viewed as separate and isolated. It took a lot of work to include sons with AS as they tended to isolate themselves. An easy option would have been to allow their son to sit on the sidelines (Otto: 26).

Although the fathers tended to take responsibility for the well-being of the family unit, family constellations differed. Patrick described Ned as '*in the mix'* although his AS made him different. Ned is one of five children each one unique (Patrick: 16). Dave spoke about personal sacrifice. As the strong one, he put his family first. For him the role of a father was to take responsibility (Dave: 40-44). Otto acknowledged his family as different, yet had done his best with the situation to make it work for him and his family (Otto: 60).

Putting their children, particularly sons with AS at the centre of their lives from the beginning was commonplace, despite the difficulties in meeting their needs (John: 28). Dave felt this had taken a toll on his health but was the right thing to do (Dave: 48). Patrick positioned himself as a co-parent with May, '*I am sure my children will make the best of what me and the wife have got to offer'* (Patrick: 30).

John found that his family had naturally split into two groups. This may have been a way of coping with the practical and emotional pressures of the situation. John found himself supporting Dan's siblings when Dan aligned himself with his mother. '*Ah, just, I don't think I'd ever have a real strong bond with him. Er, I, I just think we'll er tick along really. I think he'd always go to his mum*' (John: 104).

Six of the families had more than one child. Therefore the son with AS was part of a sibling group. The chronological position within the family appeared important, influencing how the father viewed the family unit and related to his son. Ned was the fourth of five children, with older sisters and a younger brother who also had special needs. Patrick tried to give all his children the attention they needed, but found this difficult (Patrick: 105). Nigel was the youngest of three. He was unexpected and very different from his older siblings who posed few difficulties

(Dave: 22). Nigel caused the family to re-adjust their lives both psychologically and practically.

The next section considers the impact of siblings and on siblings in relation to raising a son with AS, from the fathers' point of view, contrasting the experience of two fathers who had only one child.

4.2.4.3 Siblings

The position of the son within the family seemed to affect the fathers' views of their sons' development. The accounts suggested it was hardest when the son with AS was a first child. Generally the more children fathers had, the higher the acceptance of developmental difference.

> *…if he had been a single child, and the only one we had, I think that would have really thrown our whole world upside down...I think we were in a lucky position of having four other children... you know it threw the whole thing into the mix* (Patrick: 48).

The difference in development to siblings and peers brought fathers a sense of disempowerment and uncertainty. Belief that what happened today could affect the future raised the stakes for successful parenting. Some of the sons with AS were firstborn and others had older siblings. Two were lone children. Each position appeared to bring its own strengths and difficulties. Parental identification of developmental issues often came later when there were no older siblings, as there had been no experience upon which to base 'normal' development (Jordon, 2002). Otto's first born Morris has AS, yet his other son Martin has no apparent difficulties. When asked about the significance of the order in which they were born he felt he experienced them in a linear way and could not imagine a situation where Martin had been his firstborn son.

> *That was my introduction to parenting, so you don't know that it can be easier than that until you actually experience it...if Morris had been like Martin, parenting would have been, I would have been a great parent (laugh). The stress would have been so much less. I would have behaved so much better as a result, you know. I would have had lessons to learn* (Otto: 98).

Similarly James had two sons, the first with AS. He spoke of sadness as he witnesses his younger son Rob overtake Len developmentally. This highlighted his worries for the future. '*You know will he have an independent life, will he have a girlfriend....I don't have that concern with Rob'* (James: 108).

Stephen echoed this, '*I've got to be careful that you know that my inner fears don't actually become realised because I don't give him the opportunity to, or help push him in the right directions. Where you see I don't have that with Holly* (older sister)*'* (Stephen: 104*).*

Both James and Stephen compared their heightened anxiety regarding their sons with AS compared to a more relaxed approach to their other children. This emphasised the increased levels of emotional energy needed to raise a son with AS.

James noticed that Rob became increasingly less patient with Len as he developed (James: 102). Like all sibling relationships the dynamic between the brothers constantly changed, yet an additional dimension arose when one child had disordered developmental patterns. Sibling rivalry, emanating from this mismatch, could be difficult for fathers to cope with. Otto attempted *'to make it bearable'* by buying two of everything, '*so there is no fighting... well maybe other parents do that, but you know, to an extreme level. Where you know to avoid him beating up his brother or being horrible or hard to deal with'* (Otto: 152). Fathers commonly expressed fears as to how their other children were affected by growing up with a brother with AS. Whilst impact on siblings is rarely acknowledged by professionals, it could have a profound effect on their development (Axup, 2004).

The fathers were very aware of their responsibilities towards siblings and how they were affected by brothers with AS. Holly, with her strong sense of justice, felt that she was unfairly treated, compared with her brother,

> *I don't think she always understands that we might excuse his behaviour because he's got Asperger syndrome, that doesn't necessarily mean that you know that we condone it. Whereas I think she feels that it does and because he's not receiving what she thinks you know is fitting retribution for something or other, therefore he's getting away with something* (Stephen: 100).

John found his younger children had had to be independent and *'slot in'* with Dan's needs, '*Oh, I think it affects erm, they, they don't get the time that they deserve really. Cos Dan demands a hell of a lot of time and they are pushed to the side sometimes'* (John: 102). Dave also felt his children had to be more independent due to time taken up with Nigel and in fighting the authorities (Dave: 48). Patrick was aware that Ned took a lot of time; there was an issue with trying to spend time with four siblings as well (Patrick: 12).

As a younger brother Rob had struggled with Len's social communication difficulties, '*Len can be very, very single-visioned, very difficult to get him to compromise. For a younger brother, for an older brother that really can inflame a situation quite quickly'* (James: 102).

Otto gave a very powerful account of Martin's life with Morris,

> *Martin's had a really nasty time...in so many ways. The way that Morris' treated him, the difficulty that I've had I suppose being a father to him, because it's so much more pleasant to be away from the whole thing. Erm, and then when I'm with him not being as nice to him as I'd really like to be. Erm, it's cos, you know. I don't know, cos there's so much guilt in all of this that I said in so many ways. Another profound way that Martin has a problem in his life is, it's so easy to sit the two children in front of the television to do whatever they do, and then go away and do something else and be away from them. And so Martin becomes a parent for Morris* (Otto: 152).

Otto felt that Martin was denied a childhood due to his brother's AS. He had not experienced a 'normal' holiday and had been physically abused by Morris. Otto deeply regretted this, particularly having put Martin in the position of carer. Several fathers found that siblings had formed positive role models helping develop appropriate behaviour in sons with AS. Yet, Otto was not the only father with concerns about siblings slipping into a carer role. James stated he wanted Rob to be a sibling not a carer (James: 102). Holly was about to move to high school, leaving Tim in the primary school. Stephen reflected on how Holly monitored Tim's behaviour and well-being in school. Otto defined Martin, as a secondary parent, due to his maturity. Although the youngest child, Otto found Martin was able to deal with Morris, but felt guilty that '*he should be put in that position for our convenience'* (Otto: 208).

For many participants siblings represented *'normality'*; a baseline, reassurance that they were not bad parents (Dave: 12). James implied liberation in producing *'a normal son.*' He no longer felt to blame, '*what helped me, I guess er, was having Rob...nothing wrong with Rob'* (James: 26). Rob changed the father-son dynamic. If Len were the only child, it would have been too intense, '*Rob rubbed the edges off*' (James: 70). Perhaps Rob eased James' pain, '*he's the boy perhaps I wanted as Len'* (James: 26). Rob granted James an image of who Len could have been. This could raise identity issues for both boys (James: 44).

Raising children, prior to the birth of a son with AS, gave fathers the experience of being *'a normal dad.'* This meant social communication issues were quickly identified, often leading to early diagnosis (Stephen: 30).

> *I think I've got a lot more experience because of the circumstances of what you've had to deal with. With two children, you know the older two, normal schooling and friends and issues...Then you get one that's, like is different, which comes under the disability side. And you deal with that. So I'm probably more aware of a lot of things father-wise than a lot of others* (Dave: 58).

Fathers found they were forced to use different parenting methods in dealing with their sons' with AS. It took more thought to understand the meaning behind the behaviours and find strategies which worked. '*If it was one of my other children it'd probably not be an issue'* (John: 58).

Sharing their time and attention was difficult for all six fathers who had more than one child. Patrick talked about how as parents '*we have to balance all their needs as individuals and a family to help siblings cope'* (Patrick: 10). Dave tried to ensure fairness (Dave: 32), yet it was not always appropriate to treat his children the same as their needs differed. Some fathers described how spending time with their sons with AS was both difficult and less enjoyable. This led to guilt. Fathers put themselves under great pressure trying to give equally to their children. Relationships with sons with AS did not come naturally and took a lot of work. As children grew older, and fathers more experienced, fathers realised a different kind of fathering was needed adapting to individual child's, particularly sons with AS.

4.2.4.4 Extended Family

For all the extended family was a powerful concept or reality. It had either positively or negatively influenced family life. All wished for acceptance for themselves, their sons and family unit. Some fathers experienced their extended family normalising their sons in an attempt to deny the AS. It seemed some members found it hard to bear and lacked the capacity to support the family unit. Some fathers experienced their nuclear family isolated by the wider family, who labelled them as 'bad parents,' particularly pre-diagnosis. Fathers sensed a fear of the difficulties being contagious, a social taboo, whereby the family is in some way tarnished by the AS. Practical and emotional support, or lack of it, often depended on the acceptance or rejection of wider family. In some instances this echoed back to the fathers' family backgrounds, early parental attachments and family identity.

Several fathers felt they had given up seeking wider family acceptance for their sons. Patrick found the lack of understanding difficult, '*sometimes you are too close to them to educate them'* (Patrick: 87). John had a mixed experience of wider family acceptance and rejection. He found family rows and splits on his wife's side of the family brought them closer as a couple. He told them, '*get your head around it or on your bike'* (John: 86).

Otto found that his parents accepted his sons, but had never accepted his wife. He was the *'bridge'* between them. Otto's mediation between his parents and wife was crucial in preventing an '*eruption'* (Otto: 172). This tension was increased by paternal grandparents refusing to accept the diagnosis, another way of blaming Hilary for the difficulties. Normalising of the AS was common, Andrew's parents-in-law dismissed the diagnosis, commenting that Ellen was the same at Mark's age and he would grow out of it (Andrew: 171). Patrick found wider family were unable to take the situation on board. They would forget how to treat Ned in five minutes and clearly did not understand (Patrick: 85-7). This normalising was made more likely by the high functioning nature of sons, where difficulties could be masked. Some fathers felt disbelieved and disempowered by extended family.

The accusation of being a bad parent, particularly by extended family, was a painful one. This was experienced by several fathers. Otto claims that his parents' reaction, denying Morris' difficulties was the most difficult thing to deal with. *'It's dealing with my parent's unwillingness to appreciate the difficulty of dealing with Morris. Um, and to change their views... Lack of the sort of support that you need...a part of that is them seeing it as all Hilary's problem'* (Otto: 116-120).

John's parents changed their view of his parenting post-diagnosis but other family members still had difficulty with it, causing rifts within the family and cutting off possible means of support. *'They probably looked down at our parenting....even after we told them what the diagnosis was. Erm, on coming to terms with it and there was a big bust up in the family'* (John: 86).

Dave's parents were supportive but Mary's family had split over judgments made about Nigel and their parenting. Dave felt family members responded out of their own difficulties. However, he felt angry and without sympathy due to the impact it had had on Mary, Nigel and in isolating their part of the family, '*unfortunately it's never going to change'* (Dave: 88). He had given up and resigned himself to coping with the situation, often by opting out of family gatherings. '*Family gatherings, couldn't really be bothered if I went or not because you knew it was pick on Nigel time...other members of the family...they've got issues but they've never really accepted it'* (Dave: 80).

The impact of negative judgements by extended family could be isolating and devastating to relationships. This could result in having difficult choices to make between people who were once close. Otto had not made a choice and remained stuck in a conflict between his parents and wife whilst dealing with his son's difficulties. He was trying to be a good son and a good husband, yet by being one he could not be the other.

Family roles were being played out in all of these narratives. Mary, rejected by her extended family, identified with the rejection her son Nigel felt within the wider family and school. Due to the general rejection and isolation they experienced, the family home was the only place these sons felt safe, putting a big responsibility on the nuclear family to support them. Dave acted as rescuer and container for his entire

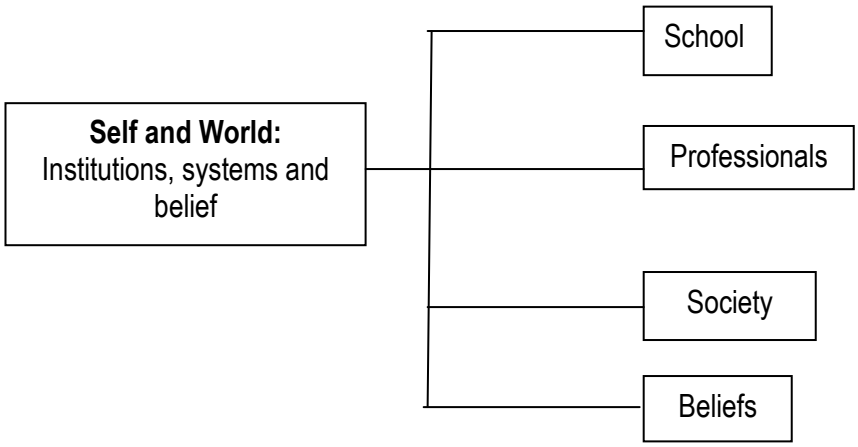
family (Bion, 1984; Berne, 1964). Could maintaining these positions over a period of time form defence mechanisms and polarised roles, where reunification became increasingly impossible? Sometimes identifying unhealthy family patterns with parents can raise questions they need to consider.

Andrew pointed out the importance of family background in understanding the nuclear and wider family. He noticed a diversity of temperament between families, Ellen's, extrovert and critical (Andrew: 175), his own laid back and insular. Andrew appeared to find being with Ellen and her family overwhelming and retreated to his childhood haunts as a coping mechanism (Andrew: 185).

The amount of support available to fathers from extended family was variable within and amongst families. Otto's in-laws occasionally provided respite. However, as grandparents aged, support from this generation lessened. Dave mentioned that, although some family members didn't understand AS, they were still able to offer some respite (Dave: 78), particularly his own parents. James found his wife's siblings very supportive. As an only child he did not have the same resource to draw upon. Several fathers spoke about becoming the carers for elderly parents. The extent and likelihood of this would increase over time forming an additional pressure, caring for both generations simultaneously (Dave: 18; Stephen: 2-4).

The next section moves beyond the family to the wider world of institutions, society and belief systems.

4.2.5 Self and World



This section considers the impact on fathers of social institutions, systems and beliefs about the world in which they raise their sons. It looks at experiences of accessing education and support from professionals, how fathers perceive sons' impact on society and society's influence on their sons. Finally, it assesses the way fathers' existential beliefs play out in the way they cope and perceive life in raising a son with AS.

4.2.5.1 School

School is a large part of a child's life. For many young people with AS the academic arena is where they excel. Yet it is an institution which demands high levels of social communication and can often lack understanding of children with AS. Fathers raised issues regarding sharing the diagnosis with schools, their experience of battles with staff in gaining understanding for their sons and the social challenge of bullying.

> *I just want Ned to be accepted and not pointed at or laughed at. I think as a parent we all want that. Because I believe now what happens to him now will develop him as an adult and are we going to have a well-rounded adult* (Patrick: 22).

They considered how their sons coped with transition to secondary school and the onset of puberty, plus the impact school-life had at home. Anxiety over homework and feelings where mainstream schools failed to meet their sons' needs were

expressed. Experiences of siblings, who attended the same school, were highlighted by fathers as a concern.

The news of diagnosis received mixed responses from schools. Dave commented on how Nigel was treated badly pre-diagnosis (Dave: 46), yet post-diagnosis support became more available. After a lot of thought John finally told the school about Dan's AS. They were unsympathetic and struggled to understand the condition. James and Andrew found that there were so many battles with schools about support related to understanding their sons they had to pick which ones to fight. This created disagreements at home and impacted on their marriages (Andrew: 46). '*At school, you, again with little things that happen, you will talk about them. You might have a battle, you might have to fight with the teacher... So that sort of thing inevitably puts a strain* (on the marriage)' (James: 98).

James commented that he hadn't had to fight for his other son to receive an appropriate education. He learnt how to anticipate problems (James: 100), yet this was made difficult as Len was different in school compared with home. There was *'a typical lack of understanding...what with Asperger's,..the teacher was very intransigent...It was a classic thing really he* (Len) *didn't pick up the cues...yet she was still giving him an after school detention'* (James: 98).

Both Patrick and Stephen found supportive members of staff who made life easier and enabled flexibility (Patrick: 85; Stephen: 74). Parents could trust these staff members to cope during the school day (Stephen: 76). Stephen realised in preparing Tim for high school that primary school staff had improved their management of Tim more than Tim had improved his social communication. This scenario can give parents unrealistic expectations which may impact heavily when it comes to the transition.

Stephen was aware that Tim needed adult support when he was spiralling out of control and was fearful as to whether this would be available in year 7.

> *They certainly seem to understand Tim better now than they did when he first started. But I shall miss that. That's one thing cos you've got to start again with a new set. It will be different, because obviously he won't have the same teachers for the whole day, it will be a different*

> *set. And no doubt there will be ones who are, er what's the word, better able to understand him than others* (Stephen: 74).

Secondary transition was a turning point for Otto and Andrew. For Otto the school's inability to cope meant the family were on their own.

> ...*they made him basically go mad, for want of a better more professional way of describing it. That was probably the most awful experience. Cos that was also a bit of realising this is never going to be a problem that schools can help you adapt to. This is more our problem than we thought it was* (Otto: 98).

Otto realised at this point how reliant both he and Morris had been on the safety and support of the junior school. Once he found the secondary school could not support Morriss and he was no longer able to attend school, Otto and Hilary had to face the prospect of educating Morris as well as parenting him. Otto became aware of Morris' susceptibility to anxiety and possible mental illness. He began to feel isolated, along with Morris, from the community often centred on school events and children's achievements. This formed a bleak picture.

Andrew experienced similar transition trauma with his son, who after completing junior school became very stressed during the 11+ examination '*going to a strange school environment... he came virtually top of his year. I mean they don't say things, you know looking at the marks he got....he then, went back to school and it all fell to bits'* (Andrew: 141). Otto and Andrew described '*awful'* experiences of transition to high school (Otto: 128). Most felt that this should be a time where a great deal of practical and emotional support is available for such children and their families.

People with AS view the world differently. Focus on detail, rather than the big picture, can be both a strength and weakness. Due to the complexities of human communication people with AS tend to prefer the predictability of objects and can simplify and often polarise situations within relationships (Attwood, 1998). Peer relationships are particularly difficult as roles are less clear cut and the negotiation of power confusing. Misinterpretation is common, when there is little understanding of AS.

This was illustrated by Stephen.

> *...well look, he's got Asperger syndrome he doesn't really understand some of the social norms. And you get teachers saying 'well that's not acceptable, you need to speak to him, that this is not how we behave'. Well, I understand that but he doesn't see the world in the way that we do. Er, its that, I think unless you've had experience with people with Asperger's. You really stop and think, how do they see the world? It's very difficult. All you see is a child behaving badly, or behaving in a way that we don't really, we wouldn't do and therefore interpret it as bad* (Stephen: 32).

The fathers spoke not only of their sons' perceptions of the world, but also themselves. How does a young man with AS cope with transition to high school, onset of adolescence, confused relationships due to poor social emotional development, yet average to above average intellect? Increased focus on peer group and developing a sense of self and identity, whilst coming to terms with an AS diagnosis all add to the complexity of problems. According to James Len knew he had AS but didn't like the idea. James felt uncomfortable about Len's self perception and having a label, especially approaching adolescence (James: 6).

The social challenges of school were highlighted by the fathers interviewed (James: 62). Stephen felt that Tim's poor social skills were more evident in the school situation then at home.

> *I've seen him with other people...I go up to see the Head and Tim's been called in...He sits there and he squirms around, and he can't make eye contact. I've never seen him like that cos at home he makes, he's perfectly ok talking to us* (Stephen: 12).

In contrast John had difficulty with staff recognising Dan's anxiety about school, as he stored it up until he got home and was very difficult to cope with. Dan's difficulties in school could be observed in his unusual behaviour, particularly his isolation. In my practice as an EP I have found that non-disruptive boys with AS can be overlooked by staff at the risk of decreasing emotional well-being, as well as vulnerability to bullying (National Autistic Society (NAS), 2009).

Dave described Nigel as different to others in school since nursery. Unlike Dan Nigel expressed his needs by acting out. '*He was quite a lively one compared to others.*

And he sort of liked to explore and he was very strong, even for a little one' (Dave: 32).

Peer isolation was a worry and rendered their sons socially vulnerable. This might also isolate the family within parental circles, where social groups formed around children's activities. These boys tended to opt out of extra-curricular activities (James: 62). Otto described Morris' lack of friendships as tragic (Otto: 22). The boys' social isolation intensified parents' reliance on staff support for their sons, as they were not accessing the usual peer support and protection gained through friendships. High school transition meant parents lost the supportive, trusting relationships they had often built up and relied on with primary school staff. They were anxious whether staff in high school would be able to offer similar support, given the structures of subject based staff and student numbers (Stephen: 74-76). Most described their sons as victims of school bullying. Stephen suggested Tim was 'easy game' (Stephen: 76) and Patrick described how Ned's experience of bullying has developed into depression and suicidal thoughts. The implications for mental health problems as a result of social misinterpretation, communication difficulties and bullying experiences are serious, yet rarely explored or understood.

Careful thought had been given by some fathers about the experience of siblings in school (Axup, 2004). They could feel embarrassed by the behaviour presented by their brother and identified in relation to their sibling with AS, rather than in their own right (James: 102; Stephen: 100). Stephen found that his daughter looked forward to changing to the girl's high school (Stephen: 76). He worried that Holly would no longer by available to watch Tim and communicate his difficulties to them.

Homework caused difficulties. Despite most of these boys being academically able they struggled to adapt between school and home situations, particularly when they felt there was an ambiguity e.g. homework. James and John described their frustration in motivating their sons (John: 44).

> *You might look forward to the weekend but if you know that during the week he's got a project to do for homework and you just know how much, how difficult that's going to be. And I know the pressure that it will put on Anna and, of course, on myself as well* (James: 40).

Participants clearly valued education. There was a sense that if incomplete or sub-standard homework was submitted they, along with their sons, would be judged (Andrew: 80). Pressure in fostering academic development was perhaps greater for this group of parents than others, as academia was seen as their sons' strength.

Four of the fathers had taken their sons out of local mainstream schools, due to their sons' inability to cope with the social setting and achieve their academic potential. Dave felt a specialist residential school was the making of Nigel (Dave: 66-74). This decision involved a great deal of family commitment in making regular long journeys to visit Nigel (Dave: 74). Otto described how home education was an imposition on family life (Otto: 128). He would love Morris to be able to cope with school life.

Due to the difficulties encountered, competent professional support is very important, both within school and from outside agencies. The next section considers fathers experiences of professionals in supporting their sons.

4.2.5.2 Professionals

In referring to professional support, or lack of it, various issues were raised throughout the narratives. The impact of the professionals featured in recounting the birth, diagnostic process and gaining appropriate educational, health and social support. Fathers referred to difficulties asking for help, dealing with the perceived power differential and marital disagreements regarding professional involvement. Throughout the accounts all of the fathers told of both positive and negative experiences of professionals and the services they represented. This information could be drawn upon in improving services for this group.

Birth difficulties were highlighted within some stories. Medical malpractice was alluded to by several of the fathers. This raised issues which could never be resolved and brought previously unexpressed anger to the surface (James: 78; Dave: 30; Simon: 4). The overwhelming experience of diagnostic assessment followed by no support was common. Several felt isolated and left to get on with it. The most common complaint was not being taken seriously by professionals (Dave:

30). Simon described himself as '*seething'* when medical professions didn't appear to know what they were doing (Simon: 6).

In contrast, Patrick found that support became available post-diagnosis. This was a turning point (Patrick: 73). Fathers recalled how sons could appear fine at clinical appointments but presented with odd behaviours at home. As an experienced father Patrick was initially unconcerned about Ned not meeting his milestones, until the screaming started. He felt that parents hold the whole picture, which is constantly changing, thereby difficult to communicate to professionals.

> *I thought my word we are going to have a screaming child for the rest of our lives. It was like until you live the stages you never understand how the child will develop... To be fair to them we probably came to them with you know 'now he is lining up his..,' we never came probably with the whole picture because it was developing all the time and they were probably only hearing maybe one or two things and then all of a sudden it would change to another* (Patrick: 18,63).

Both home and school observations were valued and it was felt by Patrick that this should be part of the diagnostic assessment (Patrick: 20). He described how gaining an assessment was hard work (Patrick: 16). Professionals were under the impression parents didn't want a diagnosis, yet all of the participants found diagnosis helpful.

> *You know we were frustrated Tina because it seemed like years of fighting and obviously you came on the scene and various things helped, but it just seems that nobody ever wanted to talk to you about it* (Patrick: 16).

When professionals disagreed parents lost faith in them and some paid for second opinions (John: 32). The benefits early identification and intervention was stressed (Otto: 14). Being taken seriously was valued by fathers. The effects of not being heard were devastating, '*We did get rebuked a lot of times'* (Patrick: 16). James felt they were '*fortunate*' that Len's difficulties were identified by a health visitor who understood the condition, took it seriously and referred for early diagnosis and support (James: 20).

Some individual professionals were cited as helpful but systems and related bureaucracy were frustrating. Metaphors relating to battles and fighting systems

were recurrent (Dave: 48; James: 44; Patrick: 16). Patrick recalled feeling there was no one person to turn to (Patrick: 16). It seemed as if the system was incongruent with their human situation. The accounts suggested a longing for one sympathetic key professional to whom they could turn, rather than endless letters, phone calls and being passed from one faceless person to another. *'The whole time you're having to fight the authorities generally and do letters to this one, that one, erm with him. So it does take over your life'* (Dave: 48). Patrick felt that, *'if there was a family case worker or someone appointed who could channel all the different departments that were putting effort into the one they could collate everything'* (Patrick: 79).

Dave and James suggest that instead of battling with the authorities, they could have been putting their energy into family life (James: 52; Dave: 7; Patrick: 16).

> *...with lack of support from the schools...and the way they used to treat him. And really we should have taken certain action which we didn't because there's only so much you can do. When you've got a full time job and everything else, you don't want to keep dragging up the past you want what's best for him. But you know, certain things I'd certainly do differently, you know I'd bang on a few more doors, to help others really. So they didn't have to go through what we did* (Dave: 46).

A case worker approach could support families in asking for help. It is assumed that middle-class parents, represented in this study, are able to find their way through the system. In fact, the concept of 'pushy parents,' criticises them for doing so. Otto and Dave spoke about how difficult they had found this, particularly in relation to Social Care (Otto: 200). Dave recounted the two most difficult decisions he had to make, allowing Nigel to go on medication and sending him away to a distant residential school (Dave: 66). He described a point where they knew they had to let the professionals take over.

Most of the fathers interviewed were professionals, as were their wives. Again it is assumed that such people do not experience the power differential between parents and professionals often discussed in relation to those from poor socio-economic backgrounds. However, the majority alluded to feeling victims of *'experts.'* Andrew, now a professional, spoke of looking up to people with qualifications (Andrew: 86) as he left school at an early age to work on the land. Patrick found it very difficult to criticise professionals in telling his story, perhaps worrying about offending them?

The power differential within the interviews had to be born in mind. Patrick blamed himself for his inability to provide professionals with the whole, ever-changing picture of Ned. Following every criticism he made excuses for professionals such as their workload and, '*maybe not enough training'* (Patrick: 16). Patrick found professional continuity was difficult to achieve due to staff changes and the family moving house (Patrick: 18). Perhaps in a small borough cases could be maintained by the same professional despite the families moving across town?

Wives were often the instigators of professional involvement, due to a primary care role. Fathers spoke about disagreement regarding trusting professionals (Andrew: 48). This appeared to be the result of the mothers having more intensive relationships with their sons and potential support systems. Dave stepped in when he felt his wife was not being believed or taken seriously (Dave: 30). Otto found it more difficult than Hilary to come to terms with accepting professional help (Otto: 210) and like many fathers opted out of opportunities to attend meetings. This is made easy by the system which often neglects to include fathers (Page et al., 2008). However, like Dave, he was highly protective of Hilary when professionals criticised her parenting (Otto: 4).

Difficulties over family holidays were raised (see section 4.2.1.1 in this thesis). Similar problems were voiced gaining and accessing respite for the family, as people with AS can find change traumatic. For some sons leaving their mothers would be particularly difficult and parental worry might outweigh the benefits of respite care. Patrick felt that people weren't aware of the help available to families. This needed to be more accessible (Patrick: 73).

Views of people surrounding fathers are all influenced by wider society. These included family, friends and professionals. Society sends out a variety of messages about disability, social behaviour, children and parents. Such messages are constantly delivered via the media and in the street. The next section considers the relationship between the fathers interviewed and wider society.

4.2.5.3 Society

The stories told reflected the participants' perceptions of the nature of society at that time. The issue of labelling people according to their disability, both formally and informally, was broached. The importance of wider society understanding AS was felt strongly by the fathers, in protecting their sons. Several fathers raised the contribution their sons made to society.

Several fathers felt society was about fitting in. Stephen used the metaphor of a '*mould.'* Although Tim didn't 'fit the *mould'* it was important that he found his '*niche'* (Stephen: 62). The '*mould'* seemed to be synonymous with 'normality.' Patrick experienced a lack of societal acceptance, leading to alienation, '*other people would be oh gosh, and step back, you haven't got a child that's normal. And that sort of alienates you'* (Patrick: 22). Most fathers' struggles reflected the experience of moving from an accepted group in society, with an education, job, good income, marriage and children, to this sense of alienation, both in having a son with AS and being forced out of some situations by their sons' behaviour and lack of capacity to engage socially. Otto disassociated himself with the idea of support from Social Care, this was something for other people (Otto: 200).

The fathers' relationship with the concept of society depended upon individual values. Patrick and Andrew presented with traditional socialist values in their downplaying of material wealth (Patrick: 14; Andrew: 89). Otto felt money solved a lot of the problems but he reached a point where he had to ask for help (Otto: 194) and give up his career ambitions for his family (Otto: 56). Patrick spoke of his determination to encourage his children to respect others, regardless of difference (Patrick: 44) and contribute positively to society. Andrew struggled with his feeling of being '*out of kilter with all of society*,' trying to raise a son in a society which had lost its way (Andrew: 89). His beliefs were clearly influenced by his religion, but perhaps also by his age and country upbringing? He felt it would have been easier to have managed AS in the past, where communities were smaller and everyone knew you (Andrew: 101). Despite using the diagnostic label AS, he looked back to a time where personalities weren't medicalised they were just people with their

individual characteristics. By contrast, Patrick looked back to his childhood, where the language and labels of disability were derogatory (Patrick: 22).

Patrick drew attention to how labelling could lead to stereotyping in modern society, with the example of the film 'Rain-Man.' '*Before, I probably would have been like everyone else thinking, just seen – 'Rain-man' the film... look at that, and think every time they pass you think of 'Rain-man' you know that is Autism for you'* (Patrick: 54).

Dave suggested that society has used labelling to opt out.

> *I also think it's gone to the other extreme now, where it's very easy to label them and it's not necessarily that condition. It's just a case of 'oh let's give them a label, then that's alright, that's dealt with'... Bit of an easy cop out, where you go to the other extreme, what in my view would be bad parenting, or lack of parenting* (Dave: 62-64).

Interestingly Dave did not include himself in this view, despite being called a 'bad parent,' yet he might be making a valid point. The label can put young people into categories which are deemed acceptable by society, whilst setting them apart from society. This medical model has its dangers in putting the problem within the child, making them the responsibility of professionals and colluding with systemic avoidance of the painful probing into society's part, which needs to take place. This supports systemic defence mechanisms (Clarkson, 1997; Sinason, 1988), both of families, institutions, political and economic systems.

Fathers grappled with their own experience of the label AS and society's use of labels in conceptualising disability. Simon took this a step further in relation to Keith, although he had the medical diagnosis, he took a social view of disability (Simon: 28) (Oliver, 1990). Wider society is not autistic. Therefore, it is difficult for a person with AS to operate in such a 'foreign place' (NAS, 2010). The emphasis shifts from the label providing access to society in the same way one would guide a foreign visitor. It was as if Simon had stripped away the illusion of society's embellishment of the meaning behind the label, reminiscent of the boy in Aesop's fable of The Emperor's New Clothes.

The social model might be most helpful in emphasising the understanding and support needed by fathers and their sons. However, diagnostic labels create a common language around which to gather and exchange information. All of the

fathers felt that the more information about AS was shared the less vulnerable their sons would be (Andrew: 6). Fathers were keen that others experiencing AS in the future have a more positive experience, through the sharing of their stories (Dave: 8). *'I'm just interested in being able to help people understand erm Asperger. Both it's, you know, diagnosis and the impact that it has on people and family and society in general'* (Stephen: 10).

Many suggested their parenting came under society's microscope, *'what a terrible parent I must look like'* (Otto: 156). Dave and John found that society's assumption that behavioural difficulties are a direct result of bad parenting had made them uneasy in social situations (Dave: 102). *I think my dad and that thought, oh he's just got no respect for him and he kind of probably thinks I should give him a good clout half the time to be honest with you* (John: 34).

Otto took a wider view, recognising that Morris' behaviour affected the people around him. It was not acceptable socially and affected any potential friendships (Otto: 14, 22). Dave raised neighbourhood issues, (Dave: 50) concluding that public perception could be difficult to manage for fathers.

> *You couldn't just book the standard package holiday and go. Because it wouldn't have been a break for us cos you're worried about what he's doing. What he's getting up to, who he's upsetting and all that. Because obviously people don't understand it. So therefore we had to do something different* (Dave: 50).

He implied a sense of powerlessness. Choices beyond the home were limited for his family (Dave: 96). Simon also pointed out that society was not prepared for people with AS (Simon: 18).

Several fathers highlighted their sons' vulnerability within society. They recognised that all adolescents needed protection, e.g., from certain media messages or their peers (Patrick: 22). This was increased due to their sons' lack of understanding of social consequences, *I think he needs a direction, because of the things he can't do. It is hard sometimes that he can't do this, because this would happen. This could happen, or you'll upset someone* (Patrick: 60).

Other fathers gave example of such vulnerabilities. James worried about Len's poor road sense (James: 28) and attempted to balance protection with supporting independence. Stephen wanted societal understanding, ensuring Tim was valued for his contribution to the world and not exploited (Stephen: 62-64).

Fathers' experiences were underpinned by existential beliefs. Why are we here in the world and what purpose do sons with AS have? The next section considers attempts to answer such questions.

4.2.5.4 Existential Beliefs

This section considered beliefs which drove perception, actions and could also serve as psychological coping mechanisms. Fathers' narratives included their thoughts as to their place in the world and that of their sons. Beliefs about chance, fate, blessings, judgement and forgiveness were explored. Most were influenced by Christianity.

Belief systems appeared to empower fathers, particularly those involving a pre-destined framework of events, through which philosophical coping mechanisms developed. Stephen, a Roman Catholic, felt Tim's purpose was to teach society about the value of openness and honesty (Stephen: 60). This echoed the sacrificial Christ story, put on earth to suffer for the greater good. Like Christ, Stephen suggested, Tim's measure of success is different to a boy without AS (Stephen: 64). He found solace in Tim's purpose, yet struggled with the seeming randomness of events. He was clearly worried about the exploitation and symbolic crucifixion, inevitable when one challenged society's norms. Like Stephen several fathers spoke of their unique journey, different to other fathers (Dave: 58).

There was a sharp contrast between the effects of faith between Stephen and Andrew. Stephen's consoled him with the belief that despite the difficulties there was a positive side to Tim's AS, teaching him and others to be more tolerant open and honest in a corrupt world (Stephen: 62-66). Andrew however implied by speaking of others in his congregation that Mark was trapped in a 'self-centred,' 'dark prison,' he

would have to '*decide on God to be the focus of his life'* to save him (Andrew: 32). '*There's a judgement day when* everyone *gets found out'* (Andrew: 62). It seemed that Andrew did worry about Mark not achieving salvation, but couldn't say it directly, referring to the masses, who couldn't put God at the centre of their lives, yet he went as far as referring to Ellen and people with AS as egocentric and selfish (Andrew: 32). Scorgie et al (2004) suggested that parents often felt having a child with needs was either a punishment or blessing from God. How this was framed could influence parental resilience and the ability to cope.

Dave implied that, through his pain, he received the gift of empathy for other families. He could now help others in the same situation (Dave: 46, 60). He referred to his own sacrifice, taking the rough with the smooth, but not opting out (Dave: 44). Perhaps, in practical terms, this gift could allow fathers to support each other? Andrew's experience of AS helped him view himself and others differently (Andrew: 34), corroborating and at times challenging his faith.

The journey from adversity to insight and a better life was stark in John's narrative. He explained how facing the possibility of his son dying had given him new perspective. He lived in gratitude:

> *There's no down side to it exactly, like he's my son. I couldn't, you can't change them you know, so, and er. You know it makes me look at the world a little bit differently. Definitely, there was a couple of times where I thought I was going to lose him* (John: 62).

Whereas John considered his past experience of Dan's illness, many compared their sons with boys at the local support group (Stephen: 64; Andrew: 167; Dave: 24, Simon: 6). All affirmed that it could have been worse, helping them feel more positive about what they had.

'Universality' is a common coping mechanism, where solace is found in the idea of others having similar difficulties (Yalom and Leszcz, 2005) (John: 72; Patrick: 22). Normalising (Lasser and Corley, 2008) was also apparent, *'I'm sure most parents would have those sort of concerns for their children regardless of their condition'* (Stephen, 62). *'He will manage...other people do'* (John: 82). Belief about the world was powerful in influencing fathers' perspectives. Andrew's life was informed by faith

(Andrew: 30), '*God loves you and you know you've got a greater purpose in life than sitting feeling sorry for yourself and worrying about yourself'* (Andrew: 32). Andrew was held by his belief in God, an all-powerful father, who has a plan. This faith enabled him to bear the unknown, a foundation upon which to build resilience and move on. However, the AS challenged his belief about the egocentricity of his son and his theology of sin. He appeared to be seeking a way to integrate the medical model of diagnosis with spiritual teachings of the church.

> *...part of the Christian gospel is a challenge to people. So how much do you challenge people with Asperger's and how much do you accept. Because as well as the Christian faith is also about grace....Where you accept people and forgive them. And er there's always hope for them because there's grace and forgiveness. And so yea, you know, it certainly, certainly I need to reflect on the way I treat people* (Andrew: 32).

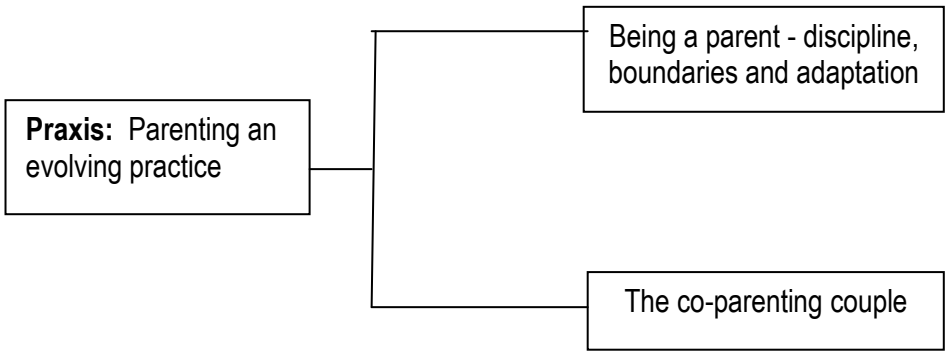
Andrew had a bottom line. Although life was hard, he was world-weary and looked forward to retirement, '*God knows,'* (Andrew: 125). The tonal quality and emphasis suggested that God would not give him anything he couldn't cope with. There was a sense that God would sort things out. He had to contain the contradiction between his faith's core belief in selflessness with the egocentricity characteristic of people with AS (Andrew: 32).

Patrick found perspective and resilience in past experiences of homelessness, unemployment and had to consider all five children. His faith was in his own strength and that of his marriage. *'We have been through the homelessness bit and that sort of thing. Me, I was out of work and I think in some ways it galvanised the family, makes us all look at things differently'* (Patrick: 97).

There was a notion of if they did the right thing, where they had control, they could feel exonerated and all it might turn out well. The next section considers the practice of parenting. This stems from core beliefs often based on one's own childhood experiences. Fathers commonly, grappled with the challenge of changing parental practice in raising sons with AS.

4.2.6 Praxis

Parenting: an evolving practice.



This section considers the fathers' experiences of parenting, an evolving practice which they shared with their partners.

4.2.6.1 Being a Parent: Discipline, boundaries and adaption

Participants spoke about the characteristics of a good father (see section 4.2.3 in this thesis). However, attempts to achieve their ideal were challenged in raising sons with AS. Fathers mentioned frustration, challenges to their patience (James: 52) and the need for a good sense of humour (Dave: 32). A common belief that the role of father evolved through practice was expressed, '*I have got more understanding of the condition and I have had to change with it'* (Patrick: 58). Parenting practice also changed within the context of family relationships. During the interviews practical ways of coping with their sons were shared. Some felt this could help others. They had had to learn the hard way: *'You've just got to deal with it, cos no-one teaches you these things. You learn it the hard way'* (Dave: 38).

As experienced fathers they no longer sought perfection and were relatively comfortable with learning through making mistakes. They reflected on the past when they thought there was a 'right way' to parent. Some worried they may have contributed to their son's difficulties by getting it wrong.

> *When we first had the diagnosis we would work really hard on Len. We knew one of the difficulties for example...giving eye contact. So we*

> *would give him eye contact if he spoke. And I er don't know whether now that's coming back to haunt us a little bit. Because um, he expects to be heard now, when he talks, and he's got quite a loud voice at times" (smile in voice)* (James: 46).

On reflection James worked hard in the early days to prove the diagnosis wrong. He spoke about being in a state of denial for a long time. Later he realised his ability to change Len through parenting strategies was limited. Dave echoed this, '*you always try and put the family first and do what's best in what's your opinion'* (Dave: 44). Similarly Stephen said, '*you know you can't go back and do it again' (smile in voice)* (Stephen: 50). Dave realised his limitations: *'If you've got someone with a problem...there's only so much you can do. And it's acknowledging that'* (Dave: 92). James' narrative suggested a painful process of developing a sense of how much power he actually had to help Len and coming to terms with the inevitable aspects of AS (James: 46).

The emphasis on dealing with frustration, finding patience and becoming a good parent suggested both losing and gaining control was common (see section 4.2.2.5 in this thesis). Balancing their needs with those of their sons was difficult, particularly whilst puzzled as to what kind of fathering their sons needed. Stephen spoke of comparing himself with others in attempting to be a good parent (Stephen: 50). Most found that the diagnosis helped alleviate the worry of being perceived a 'bad parent' by others (Otto: 88) (see section 4.2.3.2 in this thesis). '*They would class it certainly in the early days as bad parenting. Because he wouldn't do what he was told or you know. It was a strain'* (Dave: 92).

Some fathers adopted strategies used by their parents and those tried and tested with their older children. Often these didn't work on sons with AS (Patrick: 58; Dave: 32).

> *It was accepting that you know, shouting at him and trying to sort of punish him in the sort of traditional ways, the way that my father would have done with me didn't work with Tim. It would just escalate everything up... it's just one of those things you modify your behaviour, so yea. So I think that accepting that he needed handling differently er. And I'm glad I did cos it makes me feel better and it makes him better you know and life's a bit quieter in the house as a result* (Stephen: 86).

Stephen found that he had to adapt to Tim and strategies that worked for his own parents, disciplining him as a child, did not work with Tim. One of the most difficult learning experiences of living with a son with AS was learning how people with AS think differently, therefore parenting strategies needed to be learnt anew rather than based on past experiences or intuition.

John was also at a loss as to where to seek specific advice in a culture where only 'normal' parenting advice was readily available.

> *...sometimes you feel lost really...you don't have the answers, you haven't got anything to, you know, all your experience is normal really isn't it and this is abnormal. It's different, and you have to make, like I say there's no one out there to say 'oh this is the way you should do it'. You know you can watch Super-nanny on television like you know you deal this way with children. But it's like it's a different kettle of fish with someone, with a child with Asperger's you know. You hit brick walls and there's no getting round them really... And you have to learn by your mistakes. You think oh, this isn't working* (John: 44).

This sort of experience put John and other fathers under pressure to develop their parenting skills in isolation. Isolation is a theme which reoccurs over and over within the parenting experience of sons with AS.

Several participants found they had to be skilled in both responding in the moment and foreseeing difficulties, implementing plans to avoid problems (John: 44; Dave: 44). Balancing the setting and enforcing parental boundaries, whilst being able to adapt one's response to unpredictable and often unusual behaviours featured within several narratives.

> *With Ned that we need to set down guidelines and boundaries where he can't step over, he obviously pushes and, don't get me wrong, the boundaries are flexible at times. But I think he needs a direction because of the things he can't do* (Patrick: 60).

For Patrick boundaries were partly about protecting Ned, compensating for his difficulties by accurately foreseeing consequences. As a father he provided for Ned's individual needs rather than trying to treat all of his children the same way. Initially Nigel would not accept Dave's boundaries and new strategies to support him, including diversionary tactics, were developed.

> *Once you know what to do and how to defuse it, which in his case was trying to get his mind away from what he'd got his mind focused on, to something else, then that was alright. But it was having that skill* (Dave: 40).

Dave found that he needed to set boundaries in a way Nigel understood. He took account of Nigel's lack of ability to take on board other's perspectives. Issues of fairness between siblings needed to be explicit in explaining and promoting understanding, developing empathy (see section 4.2.4.3 in this thesis), (Jordon, 2002). Dave found he was able to reflect on his mistakes. Being both fair and caring was important to him (Dave: 38, 44). They suggested knowledge of AS improved capacity to meet their sons' needs, both emotionally and practically. Arguably, fathers who left the family home might not have been able to develop an understanding of their sons' needs or have the capacity to adapt. This might particularly relate to fathers' with autistic traits or other factors (Alvarez and Reid, 1999).

For fathers it took time to realise they had to adapt to the developmental needs of their sons. Some developed an understanding of their son's needs. Frustration with others who did not adapt was apparent, particularly school staff (see section 4.2.5.1 in this thesis).

Promoting life-skills was particularly important to fathers. It was difficult to support sons to embrace a wide range of activities whilst restricting isolating pursuits. Andrew felt he was too relaxed and had allowed Mark to pursue a narrow world, '*I tend to be quite soft with him... The thing is Mark wants to be on his computers or on, just sitting watching telly... I mean my natural reaction with Mark is nearly always to give in'* (Andrew: 8, 78, 89).

Widening Mark's world was a challenge for Andrew. This was a theme which featured repeatedly within the narratives. Will my son ever develop the skills to be independent and cope without me (see section 4.2.1.4 in this thesis)?

Some fathers struggled to redefine their paternal role in accommodating their sons' AS, particularly in the public arena. Otto spoke of Morris' '*really weird behaviours'* (Otto: 56). Stephen worried about the impact on Tim when other adults did not know

how to cope. '*The thing I feared most...would be that other parents would react to Tim's behaviour, in certain circumstances'* (Stephen: 86). Patrick acknowledged that Ned hadn't developed social skills naturally. '*It is hard sometimes that he (Ned) can't do this because this would happen or you'll upset someone* (Patrick: 60). He felt explicitly embedding his values through discipline helped the parenting process.

This group of fathers were all involved in co-parenting to some extent with their wives. The next section will consider the benefits and the difficulties of sharing the parenting role.

4.2.6.2 The Couple: Parenting/co-parenting

The fathers interviewed were all part of established married couples. Despite different parenting styles the partnership aspect was important to most. Recent research suggests that the child benefits from the different parenting styles of mothers and fathers from toddlers to teenagers (BBC4, 2010; Bowlby, 2007). This study included only those fathers who had remained married and were living with their wives. It was hoped that insight could be gained as to how this was achieved given the emotional pressure of a son with AS.

Co-parenting was emphasised by many. John felt the decision to stay in the family was more difficult where there were health problems. It was not simply the father's decision, however, but it involved the quality of the couple's relationship.

> *...it is a lot more stressful with a kid with Asperger's...I think maybe you need to look at, erm um the couple. I think it's not just the dad who decides to stay. It's how couples work together. Why they stay together. That's probably like any relationship really. When you think about it, it's not one or the other it's how you work together. It's a partnership* (John: 108).

This highlighting of cooperation and co-parenting is echoed by others. Simon stated that '*the effect of both parents'* is important in raising a son with AS (Simon: 28). Difficulties had '*galvanised*' some relationships (Patrick: 97) as couples became isolated from the extended family (see section 4.2.4.4 in this thesis).

Negotiation, compromise and mutual respect for wives featured within most of the men's accounts,

> *It's not just about the way I've parented. Draw on that, you know cos you're in a partnership. So it's what, you know you do it together. So like I will probably sort of chastise my children like more but my wife is dead set against that. So it hasn't really happened like that you know. So you know I respect her views in that. Erm, so it's not just all down to me is it really. Er and it's not just me, father, it's me mother as well isn't it* (John: 36)?

John clearly illustrated the dynamics of negotiation and compromise within a couple. Although John's tone was positive it is easy to see how such compromise could have a negative effect on the partnership.

A good illustration of the mutial respect held for partners was given by Patrick.

> *I always say that and we had to split it up obviously May's been 80% the carer for Ned and I have been the other 20%. You know so I look at it as total respect for her. And I suppose that is what has changed, that makes our relationship even better, that I have total respect for what she has done with the kids particularly Ned* (Patrick: 101).

This actually shows how a virtual circle could be acheived by the marriage impacting on the parenting and the parenting on the marriage.

'*We*' was used widely in discussing parenting. There was a sense of journeying together as couples

> *Yes, we are really close anyway and we have always been, but I think it galvanised us as well cos we have been through the homelessness bit and that sort of thing. Me, I was out of work and I think in some ways it galvanised the family, makes us all look at things differently* (Patrick: 97).

Within the partnerships there were clearly identified roles. Fathers often operated, supportively, in the background, *so I think both, Anna and I we're supportive of each other. I think I like to cook, so perhaps that's a bit different for a father as well* (James: 34). Couples at times could form a good balance, as well as experience tensions (Gray, 2003). Andrew and Ellen's hopes for Mark's future differed. *'My*

philosophy is well he needs to look towards getting a job. Ellen's is well he ought to get a degree' (Andrew: 97). Differences reflected family backgrounds and value systems. However, in most cases, there appeared to be similar hopes and expectations with an underlying vision of wanting what was best for their sons.

4.2.7 Summary

Chapter 4 has considered the themes and discussed issues raised in the interviews and subsequent analysis. It illustrated six super-ordinate themes with underpinning sub-themes, which were interwoven as a reflection of human complexity. Every aspect of self identity across time appeared relevant to fathers' 'lived experiences.' My participants played various roles within the family and the wider world. Many different dynamics were important in raising sons with AS - the couple, the family unit, the extended family and previous generations, as well as friends, colleagues and children's service professionals. The following chapter summarises these thematic findings, and concludes the study outlining research strengths and limitations, my reflexive journey, implications for practice and further research possibilities.

Chapter 5: Conclusions, Summary and Limitations

5.1 Introduction

This chapter concludes the thesis. It reminds the reader of the research area and, within this context, discusses limitations of the methodology and research process. This is followed by a reflexivity section, where the researcher's personal journey and concerns are developed. The findings and discussion points are briefly summarised, providing an overview of subsequent implications for practice and further research.

5.2 The Research Area

My initial motivation was to explore fathers' experiences in families who have a child diagnosed with AS. In previous research of parents' experiences I demonstrated that it was difficult to access fathers; mothers had indicated fathers often left the family home in such circumstances (Axup, 2003). EP home visits usually took place with the mother; fathers often left the room, indicating they did not feel involved. My literature search revealed little substantive work on fathers raising sons with disabilities, particularly with AS (Chapter 2). This suggested a gap in the literature to which this study makes a distinct contribution in exploring fathers' experiences raising a son with AS, and particularly factors that have contributed to their remaining in the family home. The findings have both theoretical and practical implications for EPs and wider Children's Services professionals.

5.3 Summary of Research Findings

This section provides an overview of the research findings. It summarises key issues and fathers' experiences in relation to each theme.

5.3.1 Self in Time – Autobiographical time continuum.

Fathers' reflected upon and re-evaluated constantly, their childhoods, perceptions of their parents and personal timeline in light of their experiences raising a son with AS. The possible genetic factors, thought to be linked with male members of families, brought additional searching across time. The developmental aspect of fathers, their sons and manifestations of the AS were recognised in hindsight, emphasising both hopes and fears for the future. This raised the importance of fathers' perceptions of their own developmental history in understanding the father-son dynamic.

5.3.2 Self and Identity

This theme raised the interconnectedness of fathers and sons. Their perception of their sons profoundly affected their identity, leading to reassessment of self. This could be painful. Balancing responsibilities of fatherhood, work and partners was difficult. The AS brought the additional strain of how to be with their sons and how to meet their own 'masculine' needs and societal expectations whilst avoiding isolation and disempowerment.

5.3.3 Selfhood and Syndrome

In considering their relationship with their sons' syndrome and in some cases their own, fathers grappled with potential causes and recognised unanswered questions were difficult to live with. The diagnosis was an artificial milestone. There was a sense that the AS had always been there but now had a name. Their son was still the same person.

5.3.4 Self and Family

Despite the commonality of a marital relationship and nuclear family, fathers spoke of their family's unique ways of coping with raising a child with AS. As husband and father, there could be feelings of isolation, influenced by mothers' enmeshed relationships with their sons. Coping techniques included more involvement with siblings and providing back up for their wives. Awareness of how siblings embodied a representation of 'normality' and influenced perceptions of sons with AS was common. Fathers worried about the impact on siblings, who were sometimes neglected and forced in to a position of providing a carer role. Extended families

were a lot more influential than anticipated. They brought support in some cases, but isolation and conflict in others.

5.3.5 Self and World

Fathers considered their core beliefs and values through which they saw their world. These were both sustaining and challenged by raising a son with AS. In addition to family adaptation fathers struggled to deal with perceptions of themselves and their sons in society at large. There were mixed experiences of professionals. Some individual workers had been supportive, although the system was criticised as confusing and seemingly inhuman. Fathers longed for a key worker with whom they could build a trusting relationship over a period of time. Experiences of school were mixed, depending on individuals and their understanding of AS. Primary schools were most successful in supporting fathers and their sons. Secondary transfer brought varying degrees of trauma. Fathers felt transition for sons with AS needed to improve together with schools' understanding of AS. This could foster adaptability in developing a school life accessible to their sons.

5.3.6 Parenting an Evolving Practice

Little parenting support and advice was available to fathers, who struggled with the image of being a 'bad parent' when challenging behaviour was exhibited in public. Over time fathers had learnt alternative strategies in preparing sons for the outside world, whilst they adapted to developmental needs and supported mental wellbeing. The couple played a vital part within the stories. Fathers developed a shared vision with their wife for their sons and discussed their worries. Wives were admired for providing childcare, research into AS and battling with school and other agencies to support their son's needs.

There were several reasons why these fathers had stayed within the family home. The relationship with their wives was crucial, as was their commitment to their children. There was an added societal, and in some cases, wider family pressure. Leaving was not viewed as an option. It was irresponsible. Fathers felt guilty where they had escaped family life through alternative means, e.g., work. Both the luxury of enough money and, conversely, adversity appeared to support fathers in remaining with their wives and living at home.

5.4 Limitations and Strengths of the Research Process

As anticipated, the small sample size and idiographic interview process generated a great deal of detail which had to be reported selectively. Such findings will be difficult to generalise in terms of the wider population of fathers of sons with AS. However, there is a likelihood of commonalities between participants and others in similar situations. Some of the research literature and researcher's anecdotal experiences bore this out.

In hindsight a more unstructured interview may have gained richer data. There was a pressure to cover the areas on the schedule. This may have meant less space was given to explore each concern of the participants as deeply as possible. To some extent the themes were led by the questions which worked against the spirit of IPA. On a positive note all of the question areas were relevant and made sense to participants. In this particular participant group many areas might have remained closed had the scene not been set. Despite the hesitancy of some participants in volunteering most talked for an extensive time and with emotional depth about their experiences. This was important in developing my own and wider professional interest in the implications for practice within applied psychology. As such certain areas of experience e.g. schools and professionals, needed to be broached. This appeared a common tension between methodological, human and pragmatic needs.

The poster to attract participants did not specify clearly enough that they had to live in the family home with partners and children. Criteria three i.e., 'Do you live with your son within the family home?' was not obvious to volunteers, therefore one failed to meet this. His interview became a pilot, giving an opportunity to trial the interview schedule. Criteria one, the DSM (IV) classification, might be at odds with the exploration of lived experience as it uses a medical model more in keeping with positivist principles. The issue of diagnostic criteria is discussed at length both in the literature review and in the findings. Many researchers questioned the use of DSM (IV) in isolating samples as diagnostic practice varies. However, as a tool for common language it was the best option available.

The volunteer sample was limited to a white, mainly middle-class group. Historically some had come from working class backgrounds, which is reflected in the data where they talked about their own childhoods and how this influenced their parenting. Although this had disadvantages for generalisability, it had advantages for homogeneity. From a wider perspective all research exists within a specific culture, point in time and space. Given the epistemological position of the researcher this meant replication was not considered a viable proposition.

The act of audio recording may have restricted the data provided. This was an issue for some participants. One completed most of his interview unrecorded. In order to compensate for the lack of visual cues immediate notes were made post-interview.

The interview dynamics were complex. Participants were mostly professionally secure, male and in physical terms larger than me. This might have given them an image of a more powerful position. I had previously met all but one participant within my role as an EP, which may have equalised the power dynamic. I conducted the interviews in my home office creating an organising role which might have given participants a perception of my power position. I was very aware of the potential danger of participants trying to please me, worrying about offending me as a person or professional and being 'the good interviewee.' For one participant (Simon) I felt I represented the professionals he despised. He was able to vent his anger, yet remain pleasant, by framing me as an exception. I wondered whether he acted out his anger and need to be in control of the situation by insisting the tape be turned off five minutes into the hour long interview. This may have been symbolic of the control he had wanted to take in previous situations where he had felt disrespected and patronised by professionals. The data on the tape was used, but the remaining unrecorded data was not as Simon clearly wanted to conduct the rest of the interview in private.

IPA is a co-construction process with both participant and researcher contributing the findings, therefore respondent validation was not felt to be appropriate. It was felt that the personal nature of the inquiry may have made individual feedback too intense for participants. Overall findings will be presented in a variety of forms, namely to individuals, conferences and group meetings. A written summary will be shared and a presentation at the local support group (SAFE) offered.

5.5 Reflexivity

This section is about my research journey focusing on my integral part in the process, as opposed to a role of 'objective' observer. This research experience has been personal as well as professional, whereby I connected with my participants as a fellow human being. As such the research has '*empathetic validity*,' '*the potential of practitioner research in its processes and outcomes to transform the emotional dispositions of people towards each other, such that greater empathy and regard are created,'* (Dadds, 2008, p.279).

I have worked with children and families for over 20 years, many involving AS. The participants' disclosures were both humbling and informative. They have given me a deeper understanding of the implications of their experience within which to continue my work as an SEP. I interviewed participants, co-constructing a narrative, which belonged to them, yet was influenced by me (see section 3.8 in this thesis). My thinking, feelings and beliefs have evolved throughout the study and clearly influenced my analysis, discussion and practice. The depth of our human engagement enriched my research role in knowledge terms, in analysis and implications. It added both richness and complexity as I felt a heavy responsibility to re-present their 'life-worlds.'

Moving beyond the individual stories was difficult, as I felt great responsibility to preserve each individual narrative. Constructing themes meant telling a thematic story rather than the individual fathers' stories. I found solace in the idea that this study's findings could support many fathers, their families and children once completed. The thematic process itself caused tensions. I had 15 initial themes, (see appendix L) requiring that I produce some structure. In doing so there was a constant balancing act between staying true to the particular in the text and summarising the results for the writing up of the research. This was an epistemological tension for me (Shaw, 2010). As a counsellor I am used to working in-depth at a case study level rather than group analysis. However, as an SEP and researcher, I am required to identity trends and patterns within groups. There were pressures given my EPS has an investment in my research outcomes.

Dual role complications existed as researcher and SEP practitioner. My precise role for the participants may have been muddled. However, clearly I stated the current researcher role, our long term relationship within the EPS may have been stronger in their perception. They were aware of my prior knowledge of their family life so we were not starting from a neutral position. This may have restricted or encouraged disclosure. Some things may have been left unsaid as they assumed I was knowledgeable. Both pre and post knowledge muddied the whole research process, particularly as my EP work continued during the analysis and interpretation. However, we might have gone to a deeper level more quickly given an existing rapport. They may not have volunteered if they had not had a positive view of our relationship. In fact only one unfamiliar participant came forward as a result of advertising.

Confidentiality was an issue throughout. Although I followed the usual procedures of anonymity some of the more sensitive quotations were left out, just in case the thesis was read by family members who were able to identify participants. The original transcripts were made available to examiners only.

I learnt that research is a more complex process than envisaged. Mine and the participants lives constantly moved on, in some cases profoundly. This has encouraged me to have a more open and dynamic way of being whilst working with families. I gained a greater appreciation of the pervasiveness of an AS diagnosis in all areas and relationships within family life. On a deeply personal level I added a strand to my understanding of being childless. I would not trade my 'life world' for those like my participants struggling with the implications of AS in their sons.

I was shocked by the lack in professionals of what I see as common sense from my EP experience. This research raised the profile of my foreknowledge and assumptions. The participants' stories gave me a window into how other professionals perceive and respond to issues of AS. Sometimes small actions such as active listening, remembering details and providing ongoing contact details to answer further questions can give reassurance, but this rests on understanding. I am strongly motivated to find increasing means to share my understanding to better support fathers of sons with AS and their families.

As my study has moved to completion the wider research community has continued to raise new issues and insights in understanding AS and those who live and work with it. I have been sensitised to ideas, information and findings which have thrown new light on my work and study. Advances in neuro-science and its links with attachment theory have continued to inform practice as well as understanding. Work regarding the genetic aspects of AS with its social implications for marriage patterns are being discussed within the psychology community and popular press (Warner, 2011). Just recently the social isolation and interest in computers of those with social communication difficulties have been raised in the light of involvement in cyber crime (BBC Radio 4, 2011). Social isolation does not mean people with AS do not have an impact on society. Young people with AS are vulnerable to being victims of, and /or unwittingly perpetrators of, cyber crimes without moving from their bedrooms (The Guardian, 2009). They are very susceptible to mental illness with a higher than average rate of suicide (Howlin, Goode, Hutton and Rutter, 2004).

5.6 Implications for Professional Practice

Despite my concerns and the common assumption that fathers would be reluctant to contribute they had a lot to say. The implications for professional practice and policy below were either suggested by fathers or implied through their stories.

5.6.1 Fatherhood

The literature and my data clearly suggested there is a need to re consider the role of the father within our society. Increased training and awareness of the psychological aspects of fatherhood are needed from pregnancy onwards in supporting and valuing fathers and their role. Such a change may encourage fathers to stay within the family. Services for fathers should include support systems, actual or virtual. Male 'fathers' workers' could be statutory within LAs. They could provide advice, opportunities for contact with other fathers, someone to talk to about parenting issues and ways of developing relationships and involvement in their child's life.

A cultural message that fathers are important and capable is needed. This could be communicated at various levels, from the media to local service delivery. For example administrative teams sending letters to fathers as well as to mothers. This could contribute to a fathers' inclusion in their child's life even if they no longer live with their child. Ongoing reminders that they are fathers throughout their child's life could make a difference and have positive implications for a range of societal issues, particularly relating to sons.

5.6.2 Assessment and Diagnosis of Asperger Syndrome

The data suggested that early identification supports families. There is a continued role for EPs in working with parents and staff to identify children's needs, moving towards formal assessment if necessary.

In terms of diagnosis fathers expressed a range of feelings related to the medical model and diagnostic labelling. A multi-agency approach to assessment, diagnosis and support could provide a better understanding of children with AS and the diagnostic label (NICE, 2011). Fathers and some professionals feel the medical model is restrictive, ignoring the social/familial context. EPs are well place to balance the assessment and intervention process using a 'social model' whereby children are assessed within a familiar social setting, e.g. at school with their peers. As a result of this research and recent NICE Guidelines a local working group within my LA has been created to address this.

5.6.3 Beyond Diagnosis

Fathers complained of a lack of post-diagnostic information and support. Parents could feel better supported if the diagnosis were given in person rather than by letter. The data suggested that parents needed time to adjust to a new way of seeing their child. It would be useful if literature about AS, including contact details of a key professional, were given to parents at the time of diagnosis. They could then access support when they are ready. Post-diagnosis, fathers needed to ask questions

regarding possible causes, behavioural characteristics and to explore implications of the diagnosis.

5.6.4 Therapeutic Support

The data reflected intense emotions felt by fathers, suggesting that there is a place for therapeutic support, as an individual, couple or whole family. This does not fall within the brief of the EPS, but could be accomadated within multi-agency locality teams. For example our EP service has attached voluntary counsellors to support parents of children with difficulties. The data illustrated fathers' difficulties coming to terms with the diagnosis. Some needed to explore AS within the context of their own lives and wider family as well as working through difficulties accepting their sons. A continuous bereavement cycle meant struggling with a loss of the taken-for-granted, e.g. playing football. Therapy would recognise the emotional aspects to e.g. building relationships with sons, not knowing the future, family stressors and balancing hope and realism.

5.6.5 The Educational Psychology Service

The data suggested that fathers experienced difficulties beyond those identified 'within child.' EPs can play an important role in promoting systemic orientated change at familial and institutional levels, e.g. schools. This would aim to shift the focus from a hopeless view of the child who is percieved as the problem. Such views engender feelings of powerlessness in profssionals and families alike. The move would be towards one where those significant to the child begin to own solutions and focus on the strengths and developmental aspects of the child and the AS. This would involve making changes to the environment, the culture and the behaviour of others based on increased knowledge and understanding.

EPs can support fathers offering an alternative or complementary view to the medical model, whereby difficulties are acknowledged, but strengths and the sons' alternative ways of thinking are also valued (Warner, 2011). EPs could encourage individual support packages within LAs, whereby the allocation of resources are

according to need rather than medical diagnostic category. This could give parents more of a choice as to whether they want to go down the diagnostic route or not.

5.6.6 Professional Support

The literature and data expressed fathers' need for ongoing support via a key professional who is easily accessible and remains, as far as possible, throughout the child's life. This professional could support fathers during their sons' transitions, e.g. to high school, and help them access resources, rather than expecting parents to spend valuable time struggling through unfamiliar bureaucratic processes.

Access to a range of professionals working together to deliver a package of support via a key worker was important to fathers interviewed in this study. It seemed to be important that professionals were honest, empathic and able to be in the space of 'not knowing' alongside the fathers. Listening and taking fathers seriously rather than blaming and judging was important within the narratives.

There appeared to be a role for professionals in helping fathers understand their sons' behaviour as a form of communication and to consider defence mechanisms employed by themselves and other family members.

5.6.7 Parenting support

Locally there is access to 'Good Beginnings,' a course for parents of pre- school children with social communication difficulties (Essex County Council, 2004). However, the data suggested that those with older children or whose children had been indentified at a later stage had few opportunities for AS specific parenting support. One parent made the point that mainstream TV shows such as 'Super Nanny' were not relevant to him, there was nowhere for him to go. The benefit of a parenting programme designed for those raising children with AS would include opportunities to gain strategies from professionals working within the field, other parents and a forum to express concerns and share coping techniques where they felt understood and taken seriously. A balance between behavioural management

strategies commonly successful with those with AS and those tailored to the individual child's strengths, needs, thinking styles and interests in relation to home and school are important.

5.6.8 Wider family support

It was clear from the narratives that support needs to be flexible, bearing in mind various family constellations, e.g. individuals, couples, siblings, nuclear and extended families. Involvement of the relevant family members could be crucial in creating a strong support network. This might include giving parents opportunities to invite other key family members along to meetings and/or professions responding to requests from parents to speak with significant family members about AS.

Fathers raised their inability to access respite as sons with AS struggle to cope with any changes in their environment. It was clear from the data that breaks for couples and siblings were important. Perhaps a creative solution might be AS friendly breaks where there is provision made for the child with AS giving other members a break whilst on holiday with their child? Direct payments have come some way to giving families more flexibility, but professional advice is often needed as to where to gain appropriate AS friendly support to meet families' needs.

Supporting couples to support each other was clearly an important issue within the data which helped fathers remain in the family home. This time together might be achieved with parents of children with AS supporting each other in sharing the childcare and bringing the children together. Mothers are often in most need for time away from the child with AS whereas fathers reported a need to engage more with their sons. Professionals may be able to support families in rebalancing parenting roles, by working with the father and the son, e.g. Dads and Lads Clubs.

5.6.9 Community Awareness

Fathers expressed a longing for wider community understanding of their sons and the nature of AS. The Autism Act (2009) makes provision for meeting the needs of

adults on the AC. As a result Autism Awareness Training is to be implemented across workplaces and the wider community (NAS, 2011). This could be extended to understanding the needs of children on the AC and their families extending opportunities to feel welcomed into youth groups and clubs etc. Voluntary organisations, as well as statutory institutions, i.e. schools and LA services could be supported, through awareness, to encourage inclusion within the community. The Autism Bill could support parental employment situations if the Autism Awareness Training made links to employees raising children on the AC and how this can affect families and a work/life balance. Such a bill should raise the profile and understanding of AS. This could affect working parents of children with AS and possibly working opportunities for such children in the future.

Fathers spoke about difficulties going out in public and coping with their sons' unusual behaviour and people's reactions. Sharing insight in the public arena could include parents having small information cards to give out e.g. to the dentist. These would give a brief outline of the diagnosis, (Office for Advice Assistance Support and Information on Special needs, OAASIS, 2011). As with the Autism Bill this practice widens people's understanding of the social difficulties. Such cards could be given to parents at a post-diagnosis meeting. Further public awareness promoted by a range of people could support the breakdown of stereo-tying, and fear of people on the AC.

5.6.10 Education

Fathers expressed a need for shared understanding and responsibility between themselves, school staff and other agencies. Entrusting others with their son's welfare was difficult due to sons' poor resilience and social vulnerability. Being different and lacking friendships often led to their son's becoming outcasts and victims of bullying.

A robust approach to bullying is needed, where staff work consistently with the bullies and victims using an agreed approach, e.g. 'The No Blame Approach to Bullying' (Robinson and Maines, 2008). Within my own practice in high schools peer

mentoring has also proved successful. A nurturing, inclusive ethos throughout schools is crucial for the success of any programme.

Trust and communication between significant adults ensuring their children are physically and psychologically safe was a priority for the fathers studied. They felt that schools needed a better understanding of AS and their sons, leading to specific and generalised support, e.g. developing friendships.

Schools are in a good position to support fathers and sons e.g. via 'Lads and Dads' clubs, where fathers and sons are encouraged to develop their relationship by engaging together in activities. This could be a forum for developing parenting skills, sharing strategies between fathers and accessing support from professionals.

Fathers often found school staff did not listen to them and felt subjected to professional jargon they didn't understand and/or couldn't relate to. This situation could be improved by all professionals receiving training in and practicing active listening. This could support empathic parent/professional relationships, whereby staff can notice the language and metaphors used about their experiences and respond to them.

Professionals often use jargon to detach themselves from difficult emotional conversations. Supervision ensuring their emotional support could improve practice particularly in recognising and understanding their own defence mechanisms.

Awareness amongst staff that many children with AS 'survive' school, but 'act out' pent up anxiety at home where they feel safe, is needed. Father's expressed how they are disbelieved and blamed for their sons' behaviour, because it is only expressed at home. Fathers struggled to support their sons with homework, due to a literal understanding that work is something that takes place at school not at home. Home work clubs in school can help ease child and parental stress in this area.

Transition and social skills work need to be thought about and carefully managed in schools, particularly moving to year 7. Fathers made powerful statements about how their sons suffered during this time. A proposal for a local multi-agency resource

base in a local high school providing transition support and outreach for children with AS was proposed as a result of my research (Appendix S).

School awareness of sibling needs is important. Siblings are often young carers and can become labelled in relation to their brother or sister with AS, restricting their independence and identity. It is common for siblings to develop psychological problems. Professionals need to be aware of their family context.

These were common issues raised in the literature, my professional practice and the findings from this study, along with tried and tested strategies this can be communicated through staff INSET and EP advice.

5.6.11 Local Authority Support

In terms of LA professional support, fathers spoke of extremes, being overwhelmed by the amount of professionals involved to no one being there for them. There was confusion as to which department professionals were from and the role they played. This could be increased through the recent partial amalgamation of social care, health and education into children's services. However the team around the child and family approach could bring parents and professionals together in producing comprehensive, multi-agency support packages (DfES and DoH, 2004b). This could create more clarity as to who is responsible for which part of the package orchestrated by a key worker or lead professional. Pathways for easy access to support and information tailored to the individual needs of the family based on a relationship, rather than assumptions were called for by the fathers.

Ways of helping fathers meet together needs to be investigated. This should not be based on stereo-typical assumptions or replication of the needs of mothers. A regular survey might be useful to ascertain their needs and expectations. This could be part of the post diagnosis follow up and collated on an annual basis influencing service planning.

Relevant information for a variety of professionals regarding their practice has emerged from this study (Appendix R) suggesting news ways of working together.

This has been taken forward locally with the commissioning of a task/finish group involving health, education and social care to look at improving pathways for multi-agency diagnosis and post diagnostic support. My research and the new NICE, 2011 guidelines coincided as a catalyst moving away from a purely medical model, focusing on within child factors of AS, but also the psycho-social model whereby the family and school systems are viewed as important. The proposed new pathway is more holistic theoretically and in promoting practice whereby the family, including the father has increased significant. The EP role and perspective will be central in supporting families through the assessment process and beyond, something all of the fathers felt would be beneficial (Appendix T).

5.7 Further Research

Overall the focus of this study was on fathers remaining in the family, which, whilst critically informative did not address the issues for those who have left. Further research is suggested in this area. It would also be useful to address the challenge of accessing the 'life-worlds' of fathers from non-middle class socio-economic groups and investigate the experiences of fathers from non-white British groups. Research on the couple, siblings and grandparents of such children would also be valuable in deepening understanding and improving services. The pros and cons of a longitudinal study were considered and I feel further research in this area would benefit from collecting data at various points in time from the participants. This could reflect the dynamic of change and the developmental aspect of fatherhood, their sons and the AS.

During this study I have developed a passion for IPA. I feel that the educational psychology service would benefit from such research with various groups who seem complex and perplexing in our work. This could include children as well as adults. Similar work with fathers could include: Fathers whose sons are involved in criminal activity or prison; fathers who have become unemployed and are trying to support families on welfare. IPA could support our understanding of the care system, what is the 'life-world' for a young person leaving care? A young person who is adopted, or who has relinquished her child?

The challenge of using IPA with couples or groups would be interesting. For example,

- Groups of siblings who are growing up in the same family but have differing experiences, due to differences such as age, family position, personality and gender.
- Couples, where one of the partners has AS, or who are coming to terms with a child with a disability or infertility?
- Groups of teachers and other professionals working jointly and within their multi-agency teams.
- Young people diagnosed with AS and their sibling groups.

The list is endless with IPA providing so much potential for change in both the participants, researchers and the wider community.

5.8 Concluding Comment

It is difficult to conclude such an intense research process. Research does not end with the thesis, the wide ranging learning and practical implications flow into mine and others' futures. The aim was to explore the life-worlds of a group of local fathers who are raising a son with AS. There were two objectives in gathering the meanings of the life-worlds through the fathers' narratives. Firstly, to provide a forum for a rarely heard group; this appeared powerful for this group, according to participant feedback and the richness of the data. Secondly, to enhance evidence based practice. This has occurred on multiple levels, my professional empathy and practice, dissemination to other professionals, LA policy and the wider research community. The themes which arose are rich in their depth, diversity and usefulness. There is debate as to whether story telling is valid research, (Koch, 1998); the wealth of information gained from fathers suggested that it was. The power of listening to others' stories is like entering a foreign land, challenging our 'taken-for-granted' and emphasising the value of listening, not only within research, but in daily professional practice.

People live stories, and in their telling of them, reaffirm them, modify them, and create new ones. Constructions of experience are always on the move. Stories, when well crafted, are spurs to the imagination, and through our imaginative participation in the created worlds, empathic forms of understanding are advanced (Koch, 1998, p.1183).

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Appendix A: Overview of Important Research Literature

Author(s), Date, Location	Design	Sample	Methodology	Main Findings/Limitations
1.Axup, T.E.J (2003). England	Qualitative / Epistemology: social constructivist	10 mothers of children with Asperger Syndrome	Thematic analysis – questionnaires and semi-structured interviews	1.Support systems confusing and complex: A key worker system preferred. 2.Early identification important to optimise intervention. 3.Post diagnosis information lacking. 4.Mother emotionally contained family - loss of self. 5.Life cycle theory of bereavement relevant Limitation: sample size, single gender.
2.Baron-Cohen, S. & Hammer, J. (1997). England	Quantitative – experimental Epistemology: Positivist	Study 30 parents of children with Asperger Syndrome/autism - 15 of each sex. Mixed socio economic status normal intelligence. Control group similar in age and education.	One of two cognitive tests given to each parent, in both groups. Reading the mind in the eyes test and embedded figures test.	1. Parents of children with Asperger Syndrome faster on embedded figures test and slightly impaired at mind reading relative to sex matched control group. 2. First – degree relatives show a milder variant of the cognitive profile of Autism. 3. Fathers showed significant discrepancy between social and object related skills, compared with male control group. 4. Suggests a genetic link and reason why Autism gene persists in its mild form there is a cognitive advantage. Limitation: Need for more neuro-imaging studies to clarify brain basis of cognitive phenotype
3.Baron- Cohen, S. (2000). England	Review of theoretical models Epistemology: Social constructivist	76 articles (two models summarised) to develop the discussion regarding how we perceive Asperger Syndrome.	A review of the literature and discussion regarding the central coherence and the folk psychology models.	Argument that Asperger Syndrome / High functioning autism can be framed not a disability but a different cognitive style. This perception can be related to outcomes. Challenges medicalisation of AS/HFA and likely social results, consideration of public perception. Notes implications for resourcing. Limitations: The power the medical model within our culture could have been further explored.

4. Baxter, C., Cummins, R.A., & Yiolitis, L. (2000). Australia	Quantitative: Longitudinal over 7 years Epistemology: social constructivist/family systemic implied	131 parents of children from 6 special schools – with Moderate/Severe Learning Difficulties (aged: 3-5, 10-12, 17-19). Recovered sample – some of the same parents (93) Range of socio-economic groups.	Structured Interviews (Scaling) Factor Analysis	Stress attributed to child with disability – double that of youngest sibling without disability. Stress attributed to any family member may be an indicator of more general family stress. Stress decreased over period of time, but pattern and focus of the worry didn't change. Limitations: Australian study – cultural bias unavoidable. Acknowledges cause and effect cannot be assumed and there are limitations to the measures and statistical analysis.
5.Blatt, J. (2007). Scotland	Case study over 2 years. Epistemology: Psycho-dynamic implied.	A baby and his father.	Observations over the first two years of the baby's life.	Importance of early paternal containment with the capacity to give baby space to explore a range of feelings. The importance of play and reciprocity in developing self-containment, curiosity and empathy. Limitations: case study (small sample) – generalisation problematic, this is not explored.
6.Boyce, P. Condon, J. Barton, J. Corkindale, C. (2007). Australia	Quantitative Longitudinal study over 12 months. Epistemology: not stated but implied social constructivist with use of positivist diagnostic framing of psychological states	312 men who's partners were pregnant and then gave birth -took place in hospital where child born	General Health Questionnaire – 28 was completed when 20 wks pregnant, then when baby was 3,6, 12 months old to measure stress - statistical analysis of results.	Psychological stress amongst expectant fathers associated with poor marital relationships and poor social networks. Increased risk of distress for those with little information re pregnancy, child birth and child care. Limitations: Australian not UK, different cultural bias. All standardised measures have limitations - how were the measures standardised what sample, where (not stated). Funded by Government Health (was there a political agenda?)

7.Brandth, B. & Kvande, E. (2001). Norway	Compilation of 3 pieces of research all quantitative Epistemology: socio/political emphasis implied	National sample of men	Large numbers of questionnaires issued to fathers, interviews with 30 couples relating to how fathers used their paternity quota.	74% unused paternity quota. 97% of those who used leave did so because they wanted to be at home with child and give priority to family. Most who didn't use it or only used a part of it did so for employment/economic reasons. A small number objected to the quota. Limitations: reporting 3 studies within Norwegian context – difficult to generalise within UK re cultural difference. Questionnaires can be leading, were they open or closed questions? How structured were the interviews?
8.Dellve, L. Samuelsson, L, Tallborn, A. Fasth, A. & Hallberg, L R -M.(2006). Sweden	Quantitative – baseline data and two follow ups. Epistemology: Positivist implied	Mothers 136 and fathers 108 parenting a child with a rare disease.	Questionnaires re stress, Before and after Intervention: Intensive family competence programme.	High parental stress in general. Mothers: physical and emotional (esp single mums) Fathers: stress related to incompetence, which decreased after intervention. Decreased strain amongst full time working mothers and fathers post-intervention. Conclusion: parents esp fathers and full time working parents would benefit from the programme Limitations: Swedish study – not UK, cultural bias re generalisation potential. Limitations of questionnaire/quantitative approach acknowledged – suggested qualitative data would give different and additional information.
9.Draper, J. (2003). England	Qualitative Study and Theoretical Analysis Epistemology: Socio-cultural /ethnographic	Review of literature charting historical development of transition or ritual theory. Number interviewed unclear.	Theoretical analysis and longitudinal ethno-graphic interviews related to men's experiences of pregnancy birth and early fatherhood.	Three phases, identified from pregnancy announced: separation from old status, liminality (limbo), incorporation of new status. Traditional rituals lost, new ones needed to mark stages of transition for men. Limitations: Although a theoretic framework can be useful it can also have limitations. The phenomena could be understood in a variety of ways, perspective/frames. The sample was not widely representative of fathers, mainly white, middle class tertiary educated and in stable relationships.

10.Fatherhood Institute (2007). World wide	Systemic Literature Review Epistemology: Various studies but implied social constructivist bias by selection of literature and way it is discussed.	49 pieces of literature 1980-2006	Systemic Literature Review – re fathers and disabled children gathered from different sources – controlled for maternal involvement.	Positive father involvement equated with a range of desirable outcomes for children: 1.better peer relationships 2.less behaviour problems 3.less criminality or substance abuse 4.better educational/career achievement 5.higher capacity for empathy 6.flexibilty regarding childcare and earning 7. more satisfying sexual relationships 8.higher self esteem/life satisfaction Parental involvement through choice important and agreement between parents regarding the nature/degree of involvement. Limitations: Not mentioned but selection of literature could be biased due to the interests of the Institute and their interest in promoting fatherhood positively.
11.Ghaziuddin, M. (2005). USA	Quantitative study Epistemology: Positivist based on clinical diagnostic history.	39 participants with Asperger Syndrome	Looking at possible family links between developmental history/Asperger syndrome: HFA diagnosis, IQ and sibling potential to be on the AC.	Asperger Syndrome clusters in families. Prevalence with other psychiatric disorders, depression and schizophrenia in families of those with Asperger Syndrome, 4 -5.8% Need for more studies on sibling potential to have Asperger Syndrome Limited support to findings suggesting Asperger Syndrome more strongly genetic than Autism. Limitations: small sample size and method of recruitment. Not a random controlled trial, links made, but care should be taken in making assumptions re cause and effects of correlations.
12.Gillberg, C. & Cederlund, M. (2005). Sweden/Scotland	Quantitative Analy Epistemology: Positivist implied	100 boys with AS and their families.	Reviewing patient records.	About 50% of all boys with Asperger Syndrome have a paternal family history of autistic spectrum disorder. Pre and peri-natal risks important in 25% of cases. Limitations: Acknowledged that sampling relied on previous diagnostic practice where the same criteria may not have been strictly adhered to. Difficulty with finding appropriate control group– e.g. re IQ.

13.Gray, E.G. (2003) Australia	Qualitative Analysis Epistemology: implied social constructivist	32 Mothers and 21 fathers of children with high functioning Autism/Asperger syndrome	Discovery of meaning and strategy via semi-structured interviews.	Impact on mothers and fathers differ. Impact on mothers more direct and personal, on fathers indirectly through the mother's stress. Fathers worried about child's future. Limitations: Australian sample – cultural bias unavoidable. No limitations mentioned. Interviews have limitations regarding consistency of interviewer and context particularly with multiple interviewers.
14.Habib, C. & Lancaster, S. (2006) Australia	Quantitative Analysis using Identity Theory Epistemology: not stated, but mix of social constructivist thinking with positivist measures cautiously employed.	115 first time Australian expectant fathers in 1st trimester of pregnancy. High socio-economical status	Standard Measures/ scaling / questionnaires.	Spousal and father status most central to who they are. Foetal bonding could be a prediction of status prominence and content. Limitations: Australian sample –cultural bias issues. Limitations of standardised measures recognised culturally and in simplification (quantifying). Snap shot in time. Cause and effect cannot be assumed.
15.Hastings, R.P, Kovshoff, H. Ward, N.J. Espinosa, F.d. Brown, T & Remmington, B. (2005) England and Wales	Quantitative Epistemology: positivist implied.	Parents of 48 pre-school children with autism	6 measures: behavioural scales and screening questionnaires. Interviews – 297 items.	Mother's positive perceptions not related to partner's well being. Father's positive perceptions negatively correlated with partner's stress and depression. Mother's stress ratings were positively correlated with partner's depression scores Father's stress was positively correlated with maternal anxiety and maternal depression. Limitations: recognition of the need for more systemic analysis. All standardised measures have limitations although measures explained the limitations of each were not mentioned.

16.Hinckley, C. Ferreira, R & Maree, J.G. (2007) S. Africa	Mixed methods Epistemology: not stated, but implies overall social constructivist with positivist slant in processing of the data	65 fathers telephone survey 4 of these in-depth interviews	Telephone survey and face to face in depth interviews.	Expectant fathers experience a need for information to prepare them for fatherhood, particularly on fatherhood, pregnancy, basic childcare skills. Perceive TV the best means of gaining that information. Limitations: Cultural bias (S. African sample) perceptions of manhood likely to be different to UK sample. Telephone interviews would not pick up non verbal cues.
17.Huws, J., Roberts, S.P. & Ingledrew, D.K. (2001). Wales	Qualitative Epistemology: symbolic interactionalism	Email group of parents of children with Autism – 6142 messages over 3 month period in 1998 from 374 email addresses	Grounded Theory / email messages.	Parents use the email group to:- 1.search for meaning 2.adapt to change 3.provide / gain support and encouragement 4.narrate/share experiences Limitations: Recognised it is a snap shot in time and may change over time. Email data may be more honest due to the anonymity, but could be limited due to the lack of relationship between researcher and participant, the verbal, non verbal and contextual cues.
18.Johnson, M.P. & Baker, S. (2004). Australia	Quantitative Epistemology: Social constructivist implied	384 expectant/ fathers	Standardised measures of stress, anxiety, depression, and coping during partner's pregnancy, childbirth or miscarriage. Repeated 1 year later.	Childbirth or miscarriage increased measures in comparison with pregnancy. These dropped after 1 year. Coping responses varied and were situational specific. Findings suggest implications for support needed to be offered. Limitations: Cultural bias (Australian sample) Usual limitations of standardised measures, this was outlined and acknowledged.

19.Lasser, J. & Corley, K. (2008). USA.	Qualitative Study:Grounded Theory Epistemology: Social constructivist	20 parents of children with Asperger Disorder	Semi-Structured Interviews	Found central phenomena 'constructing normalcy,' meaning-making and adapting the environment for their children important. Limitations: generic term 'parenting' doesn't mention how many fathers involved or whether there is a difference between fathering and mothering.
20.Little, L. (2002). US	Quantitative: Part of a larger study. Epistemology: Positivist implied	411 parents of children with Asperger Syndrome and non-verbal learning disorders	Internet questionnaires on stress and family issues.	Mothers reported more stress than fathers. Mother more likely to seek professional help. 45% mothers and 26% fathers were taking medication for depression. Likely that numbers with depression higher, but not seeking help. Nature of children difficult: easily frustrated but chronically inflexible. Coping strategies differed across genders. Limitations: acknowledged that explanations remain speculative – unable to assume cause and effect. Limitations of individual standardised measures and statistical analysis not mentioned.
21.Page, J., & Whitting, G., Mclean, C. (2008). UK	Mixed Methods Epistemology: not stated – many reports, socio political stance	Review of 99 policy documents2002-07 Survey 150 LAs Interviews 26 LA staff Fieldwork and interviews various levels of staff in 8 LAs	Various.	Recognition of fathers partial and uneven in policy documents. 9 policies full recognition of fathers. Policy and practice for including fathers needs developing, via breaking down barriers to services and improving engagement. An Every Father Matters document would be useful. Limitations: selection of documents and reason for government commissioned report may cause implicit bias.
22.Rohner, R.P. and Veneziano, R.A. (2001). USA	Literature Review Epistemology: Social constuctivist/ psycho-social	189 articles/ literature related to father-love showing changes in father role through 19th-21st centuries.	A Review of literature over a period of time showing the change of father role and influence of 'father-love'/involvement on children.	Father love powerful in child development Nurturing and warmth from both parents important for psychological and cognitive development Need to consider the triadic relationship of mother/father/child rather than mother/child. Limitations: fatherhood seen as a cultural conception – therefore because based on the US experience may be limited in relation to the UK.

23.Roll-Pettersson, L. (2001). Sweden	Qualitative Study Epistemology: Social constructivist implied	46 parents of 38 children with a cognitive disability. aged seven to 16 years	Semi-structured interviews	The data revealed that parental responses vary, some pass through phases (the adaptation-mourning model). The majority report from time to time experiencing incidents and events which they perceive as critical and difficult. Insufficient evidence to support professionals continuing to adhere to the adaptation-mourning model, together with its associated pathological-dysfunctional paradigm. More encompassing models are needed to better support the families throughout their lifespan. Limitations: Based on Swedish experiences – cultural bias unavoidable. Use of models to frame human experiences can be useful and limiting.
24.Simmerman, S., Blatcher, J., & Baker, B.L. (2001). USA	Mixed Method Epistemology: Implied Positivist with some relational aspects.	60 families with a child with severe intellectual disability. 88% intact marriages other actively involved with child.	Surveys, interviews at two points in time 1.5 yr gap. Measures: Father Help and Satisfaction Scale: Regression Analysis	High agreement between mothers and fathers re fathers help Fathers mainly engaged with playing, nurturing, discipline and deciding on services. Most mothers satisfied with amount of help. Satisfaction related more to indicators of family well being than extent of help. Marital adjustment and implications for counselling were considered. Limitations: not UK (California, US) cultural bias likely. Generalisation (even within US): predominantly white middle class. Surveys and measures all have their own limitations these are not explored.

25.Taanila, A., Kokkonen,J., & Jarvelin, M.R. (1996). Finland	Quantitative Statistical Analysis: follow up study Epistemology: Social constructivist implied, but with positivist measures.	89 families, 88 mothers, 74 fathers of children with Mental retardation (MR), Motor Handicap (MH), Diabetes Mellitus (DM). Born between 1976-1980 (Oulu University Hospital)	Interviews and questionnaires	1. Child's disability affects most parents on a personal level. 2. Regardless of disability family concerns are:- health, wellbeing and future. 3. mothers felt impact more than fathers 4. Did not always affect marriage and family life negatively. 5. Most had remained with biological parents 6. Marriages remained unchanged or stronger. 7. Marriages suffered relating to time spent caring for child. Information, realistic expectations and practical advice important in supporting couple. Limitations: not UK (Finland) cultural bias likely. Generalisation difficulties recognised as higher refusal rate amongst one of the groups of parents sampled.
26.Wilgosh, L. & Scorgie, K. (2006). USA	Qualitative Method Epistemology: Social constuctivist/ interactionist (implied)	18 parents of children with a disability (5 fathers), 15 American, 3 Mexican. 8 African American, 7 Hispanic descent,	In depth interviews	Coming to terms with diagnosis not a linear process, critical questions reappear at child/family markers, requiring reworking of images and meanings. The family life cycle model seems the most appropriate theoretical framework. Limitations: US study – cultural bias unavoidable. Acknowledged that can only capture the moment data is collected, human experience not linear. Framing data within a model can be illuminating and limiting.
27.Woodgate, R.L., Ateah, C and Secco, L. (2008). Canada	Qualitative Method Epistemology: Phenomenological, Hermeneutic Stated	16 families with children with Autism residing in a Western Canadian Province.	Qualitative interviews with parents	The essence of the study was isolation. 3 themes emerged: a) vigilant parenting, b) sustaining self and family, c) fighting all the way. Findings suggest that knowledge about parenting children with disabilities and chronic illness has not been transferred to those parenting child with Autism. Limitations: Canadian study – cultural bias unavoidable. Acknowledged that experiences change over time – this is only 'true' for that moment. May not generalise to single parents.

Appendix B: Letter granting ethical approval

Dr Martin cook

School of Psychology
Stratford
ETH/10/65
5/06/2009

Dear Martin,

Application to the Research Ethics Committee: Exploring the experiences of fathers of sons with Asperger Syndrome (T Axup)

I advise that the University Research Ethics Committee has now approved the above application on the terms previously advised to you. The Research Ethics Committee should be informed of any significant changes that take place after approval has been given. Examples of such changes include any change to the scope, methodology or composition of investigative team. These examples are not exclusive and the person responsible for the programme must exercise proper judgement in determining what should be brought to the attention of the Committee.

In accepting the terms previously advised to you I would be grateful if you could return the declaration form below, duly signed and dated, confirming that you will inform the committee of any changes to your approved programme.

Yours sincerely

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02082232976

Research Ethics Committee: ETH/10/65/0

I hereby agree to inform the Research Ethics Committee of any changes to be made to the above approved programme and any adverse incidents that arise during the conduct of the programme.

Signed: .Date: 05/06/2009

Please Print Name: Dr Martin Cook

Appendix C: Participant Information Sheet

You are invited to take part in a study carried out by Tina Axup, a Senior Educational Psychologist in Southend-on-Sea on Sea and doctoral student at the University of East London. The aim of the study is to improve services for young people with Asperger Syndrome in understanding the issues facing fathers and hence improving understanding and professional practice.

The Purpose of the Study

The purpose of the study is to explore the lived experiences of fathers of sons with Asperger Syndrome, investigating how they feel the diagnosis has impacted on their relationship both with their sons and other important people in their lives. In order to gain this information I will be conducting interviews with several interested fathers who choose to volunteer.

Why have I been invited?

I have discovered in my work with young people with Asperger Syndrome and through previous research with parents, that fathers often leave the family home. This research will focus on fathers who:

Live with their sons within the family home.

Are raising sons diagnosed with Asperger Syndrome who are at least 11 years old.

What will it involve?

Taking part in the study will involve arranging a convenient time for you to take part in a face to face interview. The interviews are expected to last an hour and will take place in a private office in Westcliff on Sea, within the next few months. The interviews will be taped, but your personal information will remain confidential, any identifiers e.g., names and places will be deleted or replaced by pseudonyms. You will be able to withdraw from the study at any time. Although the experience is intended to be an enriching one for participants, it is acknowledged that sensitive issues may arise. Debriefing will be offered immediately after the interview and if requested a follow up appointment to discuss any issues raised with myself or another trained professional. Only information given which could result in serious harm to yourself or another person will be passed on, in this instance this would be discussed with you first.

What will happen to my information?

The tapes will be transcribed and anonymised. All personal information will be kept strictly confidential in line with the Data Protection Act (1998) and the researcher will work within the ethical codes of the British Psychological Society and University of East London. All personal data will be stored in a locked place and destroyed when the study is complete. The transcripts will be analysed to identify any common themes shared by participants. The findings will be written up and recommendations made to support young people and their families in the future more effectively. The findings may also be published in an academic journal, yet no identifiable information will be used.

The project will be supervised by:

Dr. Martin Cook, Principle Educational Psychologist / Tutor:
You can contact him at:
The University of East London,
University House,
Stratford Campus,
Romford Road ,
London E15 4LZ
M.Cook@uel.ac.uk

For any further questions please contact:

Tina Axup,
Southend-on-Sea on Sea Borough Council
Department for Children and Learning
7th Floor, Civic Centre,
Victoria Avenue,
Southend-on-Sea on Sea,
Essex, SS2 6ER
tinaaxup@Southend-on-Sea.gov.uk Tel: 01702 215195

Appendix D: Recruitment Poster in Schools

ARE YOU A FATHER RAISING A SON WITH ASPERGER SYNDROME?

DO YOU LIVE WITH YOUR SON WITHIN THE FAMILY HOME? IS YOUR SON 11 YEARS OLD OR OVER?

IF YOUR ANSWER IS YES
TO THESE QUESTIONS
I WOULD BE INTERESTED IN INTERVIEWING YOU
ABOUT YOUR EXPERIENCES.

TINA AXUP
SENIOR EDUCATIONAL PSYCHOLOGIST.

For further details contact:

tinaaxup@Southend-on-Sea.gov.uk

Appendix E: Extract from Newsletter

Supporting Asperger Families in Essex

Charity No. 1095075

SAFE ESSEX NEWSLETTER

Issue 42(April/May 2009) www.aspergers.org.uk

Are you a father raising a son with Asperger Syndrome?

Do you live with your son within the family home?

Is your son 11 – 18 years old?

If your answer is **yes** to these questions

Tina Axup, Senior Educational Psychologist in Southend-on-Sea would be interested in interviewing you about your experiences.

For further details contact on: tinaaxup@Southend-on-Sea.gov.uk

Appendix F: Letter sent to potential participants

Letter headed paper

Dear Mr ....

You are invited to take part in a study exploring the experiences of fathers raising sons with Asperger Syndrome. I am a senior educational psychologist with an interest in Asperger Syndrome. I work for the Local Authority in the Children's Services Department and have spent for several years supporting young people with Asperger Syndrome. The purpose of the research is to capture the lived experiences of fathers, improving professional practice and sharing with other parents who can identify with these experiences. The research will form part of a Doctoral Thesis under the supervision of the University of East London. If you would like to take part please read the enclosed information sheet and return the slip below via email or post.

Best Wishes

Tina Axup

Senior Educational Psychologist.

I .....would like to take part in the above study and can be contacted at:

---------- (email address or telephone number)

Signed ----------

Appendix G: Demographic Questionnaire

Questionnaire

Please state a fictitious name to be used in the context of the research:

Age

Nationality

Highest Educational Qualification

Employment

Age of son with Asperger Syndrome

Age of son at the time of diagnosis

Time with partner

Age of partner

Partner's Employment

Other children, age, gender and any diagnosed disabilities.

Appendix H: Pilot interview schedule

Tell me why you volunteered to take part in this research?

Can we start from the very beginning?

1. Tell me about the time when you knew you were to become a father?
2. Can you continue the story of how it was raising X.
3. Did you draw from your own childhood experiences in any way?
4. Has the experience of raising X affected you?
5. Do you view yourself differently?
6. Do you feel others view you differently?
7. Has your experience of fatherhood changed over time?
8. What about your relationship with your partner?
9. What about other children and extended family?
10. Where have you found support?
11. What has been the most positive aspect of raising X.
12. The most difficult?
13. How would you describe yourself as a father?
14. How do you see the future for you and your son?

Appendix I: Interview Schedule

Interview Schedule:

Tell me why you volunteered to take part in this research?

Tell me about X.

What activities do you do with X?

Can we start from the very beginning?

1. Tell me about the time when you knew you were to become a father?
2. Can you continue the story of how it was raising X.
3. Did you draw from your own childhood experiences in any way?
4. How would you describe yourself as a father?
5. Has the experience of raising X affected you.
6. Do you view yourself differently?
7. Has your experience of fatherhood changed over time?
8. What has been the most positive aspect of raising X.
9. The most difficult?
10. Where have you found support?
11. Do you feel others view you differently?
12. What about your relationship with your partner?
13. What about other children and extended family?
14. How do you see the future for you and your son?

Appendix J: Informed consent form

UNIVERSITY OF EAST LONDON

Stratford Campus, Romford Road, Stratford,
London.E15 4LZ
University Research Ethics Committee

If you have any queries regarding the conduct of the programme in which you are being asked to participate please contact the Secretary of the University Research Ethics Committee: Ms D Dada, Administrative Officer for Research, Graduate School, University of East London, Docklands Campus. London E16 2RD (telephone 0208 223 2976 e-mail d.dada@uel.ac.uk)

The Principal Investigator

Tina Axup (Senior Educational Psychologist)
Southend-on-Sea on Sea Borough Council
Educational Psychology Service
7th Floor, Civic Centre,
Victoria Avenue,
Southend-on-Sea on Sea,
Essex, SS2 6ER
Email: tinaaxup@Southend-on-Sea.gov.uk
Tel: 07767664042

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.

Project Title

Exploring the Experiences of Fathers Raising Sons with Asperger Syndrome: An Interpretative Phenomenological Analysis

Project Description

The purpose of the study aims to explore the lived experiences of fathers raising sons with Asperger Syndrome. It aims to investigate how they feel the diagnosis has impacted on their relationships both with their sons and other important people in their lives. In order to gain this information I will be conducting interviews with several interested fathers who choose to volunteer.

Taking part in the study will involve arranging a convenient time for you to take part in a face to face interview. The interviews are expected to last an hour and will take place in a private office in Westcliff on Sea, within the next few months. The interviews will be taped, but your personal information will remain confidential, any identifiers e.g. names and places will be deleted or replaced by pseudonyms. You will be able to withdraw from the study at any time. Although the experience is intended to be an enriching one for participants, it is acknowledged that sensitive issues may arise. Debriefing will be offered immediately after the interview and if requested a follow up appointment to discuss any issues raised with myself or another trained professional. Only information given which could result in serious harm to yourself or another person will be passed on, in this instance this would be discussed with you first.

Confidentiality of the Data

The tapes will be transcribed and anonymised. All personal information will be kept strictly confidential in line with the Data Protection Act (1998) and the researcher will work within the ethical codes of the British Psychological Society and University of East London. All personal data will be stored in a locked place and destroyed when the study is complete. The transcripts will be analysed to identify any common themes shared by participants. The findings will be written up and recommendations made to support young people and their families in the future more effectively. The findings may also be published in an academic journal, yet no identifiable information will be used.

Disclaimer

You are not obliged to take part in this study, and are free to withdraw at any time during the tests. Should you choose to withdraw from the programme you may do so without disadvantage to yourself and without any obligation to give a reason. You will be given a copy of this Consent Form to keep and look back at any time.

I understand that my interview will be taped recorded and I am aware the recordings will be typed up onto a computer and stored carefully until after the project is over, when they will be deleted.

I understand that if I decide at any other time during the research that I no longer wish to take part in this project, I can notify the researchers involved and be stop being in it straight away.

I consent to my personal information being used for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Participant's Statement

I …….....

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed: Date:

Researcher's Statement

I ……..

confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed: Date:

Appendix K: Follow up email to participants

Wednesday, 22 July, 2009 8:58

Hi .....,

Thanks for coming over for an interview, I really appreciate you making the time in your busy schedule. I would be really interested in any thoughts you have regarding the experience/process of being interviewed, if you have any reflections please email me them. Also as I said a counselling colleague has offered 4-6 free sessions if you would like to explore any issues the interview raised for you ..... can be contacted via email at .....

I will be creating opportunities when the research is over to relay the results to you and other participants and hopefully using the results to support parents and dads in particular better. Best wishes Tina

Appendix L: Initial emergent theme list

Diagnosis

Cause

Genetic

Behavioural traits

Wife/marital relationship

Perception of Asperger syndrome/disability

Hopes, fears, future

Experience of professionals

Feelings expressed

Metaphors and powerful language

Psychological frames/language

Identity, perception of self/roles

Own parents /extended family

Siblings

Why volunteered?

Appendix M: Initial Mind Maps

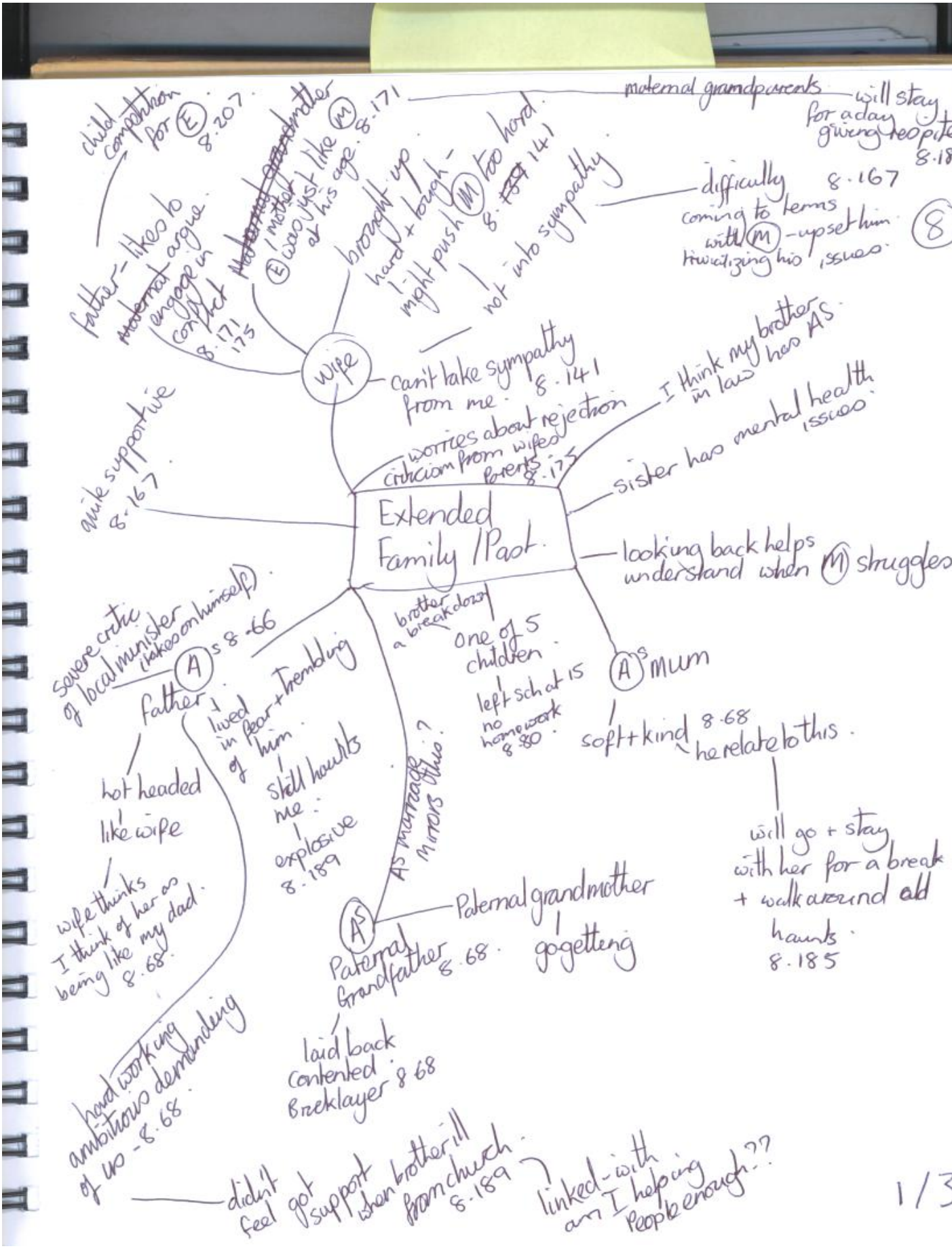
Examples of mind-maps: for one participant/one theme

James' mind-map (sibling).

Andrew's mind-map (extended family).

Otto's mind-map (diagnosis, the experience of father).

Patrick's mind-map (Role/identity of father).

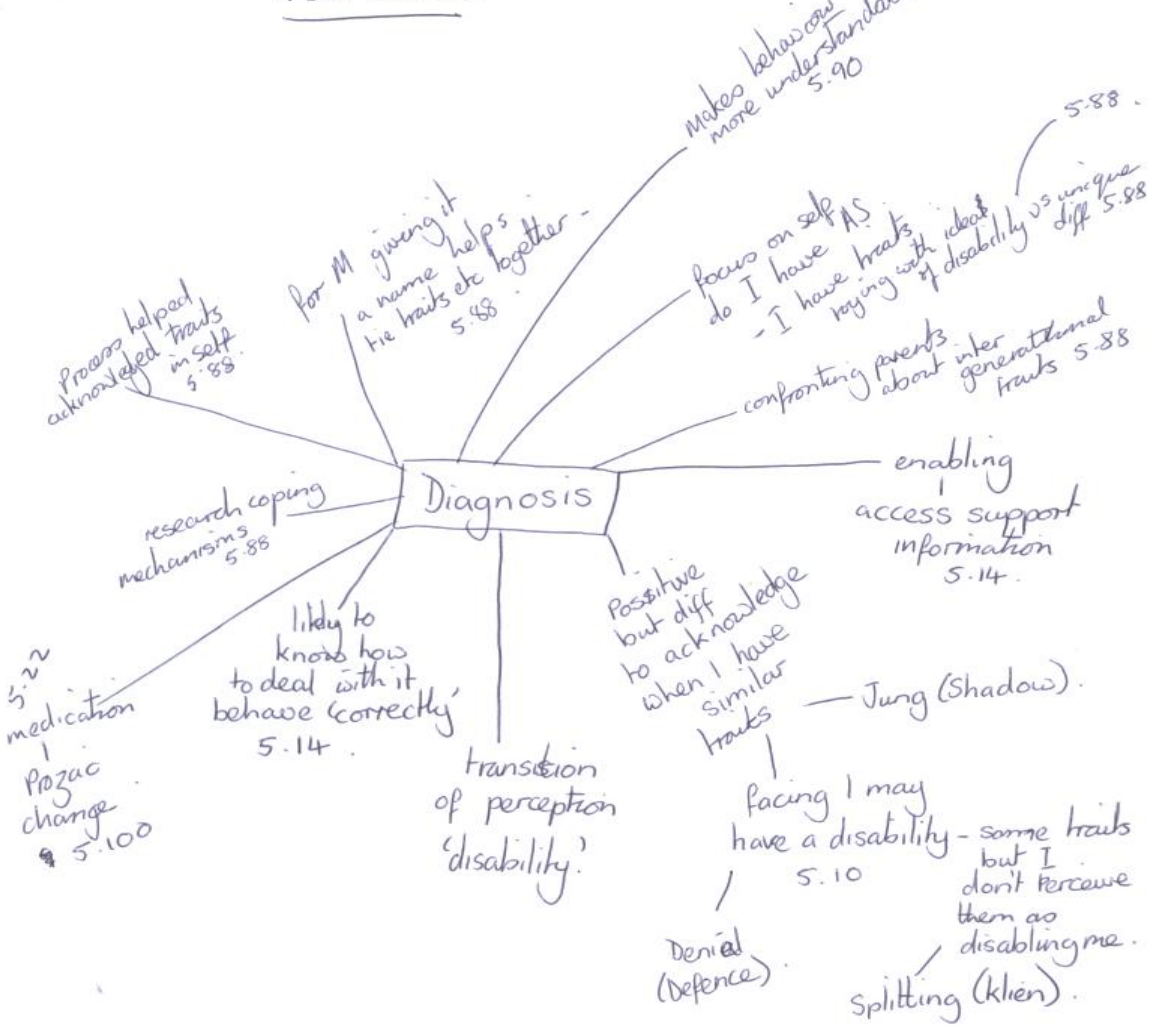

Extended Family / Past
wife
can't take sympathy from me. 8.141
worries about rejection criticism from wifes parents 8.175
I think my brother in law has AS
sister has mental health issues
looking back helps understand when (M) struggles
A^s mum
soft + kind 8.68
he relate to this
will go + stay with her for a break + walk around old haunts. 8.185
brother a breakdown
one of 5 children
left sch at 15 no homework 8.80
AS marriage mirrors this?
A^s
Paternal grandmother
gogetting
Paternal Grandfather 8.68
laid back contented Bricklayer 8.68
A^s 8.66
father
lived in fear + trembling of him
still haunts me
explosive 8.189
severe critic of local minister (takes on himself)
hot headed like wife
wife thinks I think of her as being like my dad 8.68
hard working ambitious demanding of us - 8.68
didn't feel got support when brother ill from church 8.189
linked - with am I helping people enough??
child competition for (E) 8.207
father - likes to ~~maternal~~ argue engage in conflict 8.171 175
~~maternal grandmother~~ mother
(E) was just like (M) at his age 8.171
brought up hard + tough - might push (M) too hard 8.~~139~~ 141
not into sympathy
maternal grandparents
will stay for a day giving respite 8.18
difficulty 8.167 coming to terms with (M) - upset him trivializing his issues
quite supportive 8.167
1/3

Analysis: Themes. Otto - Interview 5.

The Diagnosis / The experience of father.

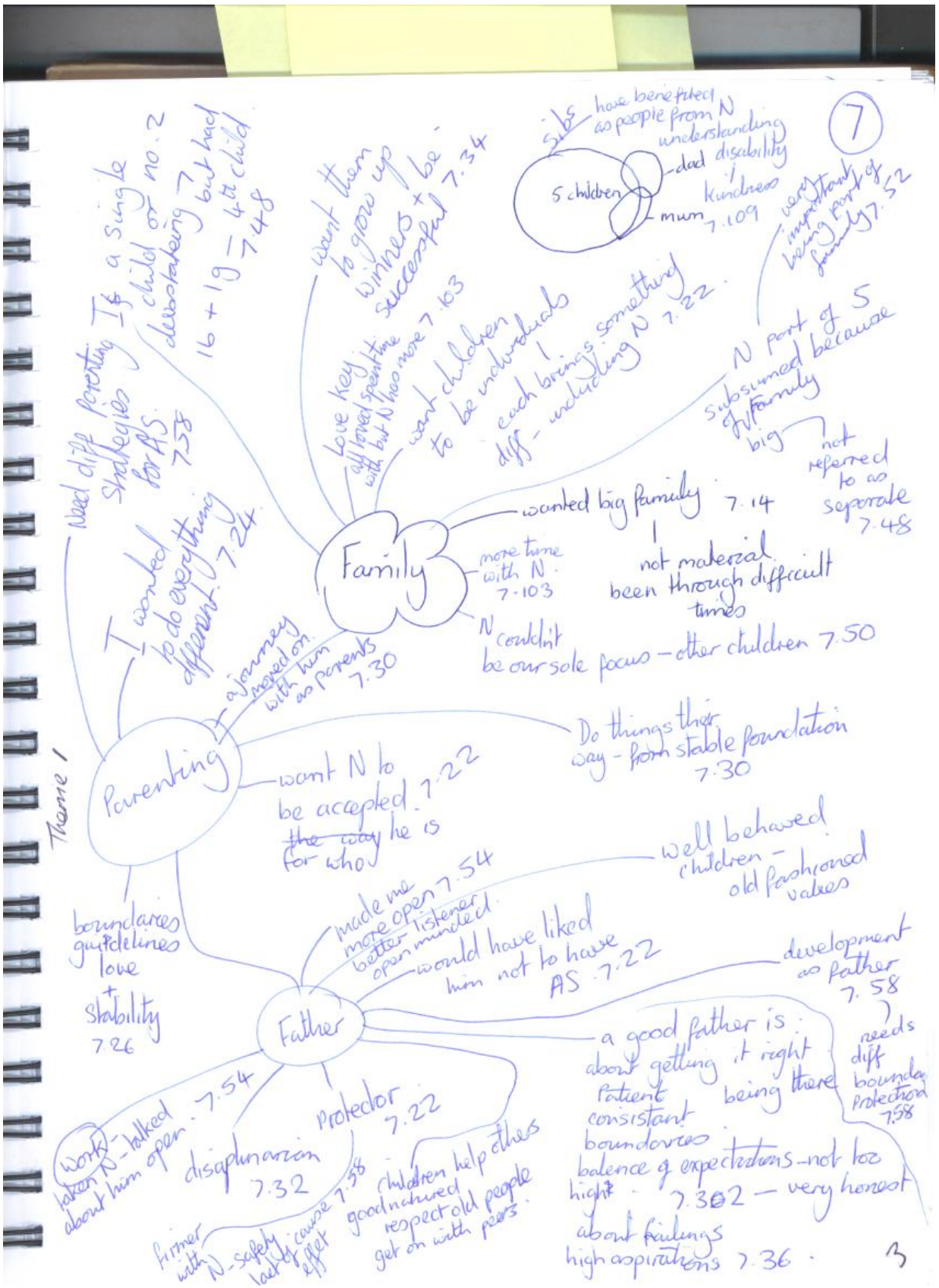
(main themes)

(5)



Theme 4.

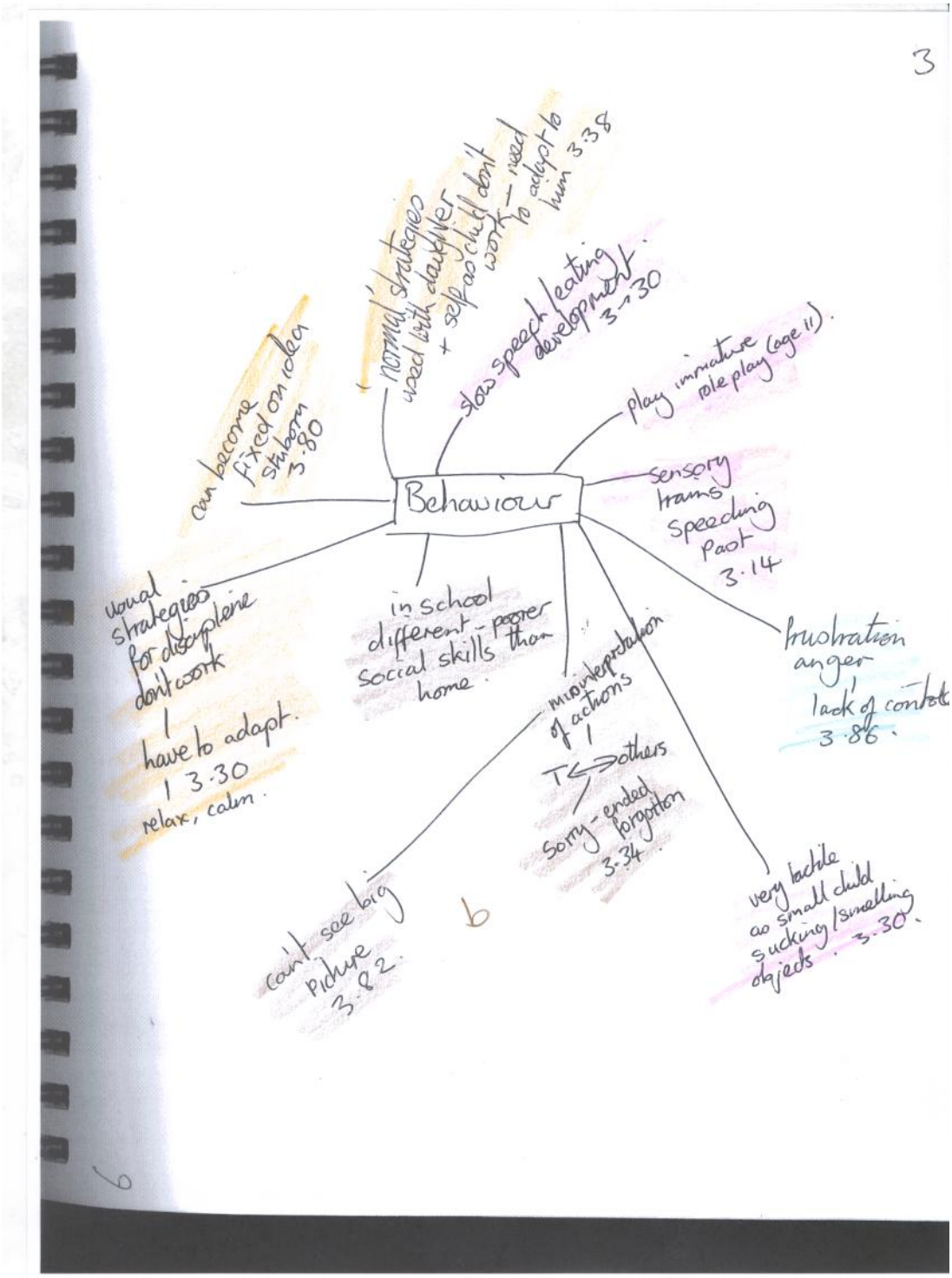
13


7
Theme 1
Family
Parenting
Father
5 children
dad
mum
sibs have benefited as people from N understanding disability / kindness 7.109
want them to grow up winners + be successful 7.34
Love key all loved spent time with but N has more 7.103
want children to be individuals
each brings something diff - including N 7.22
very important being part of family 7.52
N part of 5 subsumed because of family big
not referred to as separate 7.48
wanted big family 7.14
not material been through difficult times
more time with N 7.103
N couldn't be our sole focus - other children 7.50
Need diff parenting strategies for AS 7.58
I wanted to do everything different 7.24
a journey moved on with him as parents 7.30
Do things their way - from stable foundation 7.30
want N to be accepted 7.22 ~~the way~~ he is for who
boundaries guidelines love + stability 7.26
made me more open 7.54 better listener open minded
well behaved children - old fashioned values
would have liked him not to have AS 7.22
development as father 7.58
needs diff boundary protection 7.58
a good father is about getting it right being there
Patient consistant boundaries
balance of expectations - not too high 7.302 - very honest about failings high aspirations 7.36
Work - taken N - talked about him open 7.54
disciplinarian 7.32
Protector 7.22
firmer with N - safety lack of cause 7.58 effect
children help others good natured respect old people get on with peers
3

Appendix N: Colour Coded Mind-Maps

Fine tuning themes with colour-coding

Stephen (participant 3)– fine tuning themes on 'behaviour' map.



Colour Coding – Temporal **Self and Identity** **Selfhood and Syndrome** **Self and Family** **Self and World** **Praxis**

Appendix O: Examples of charts

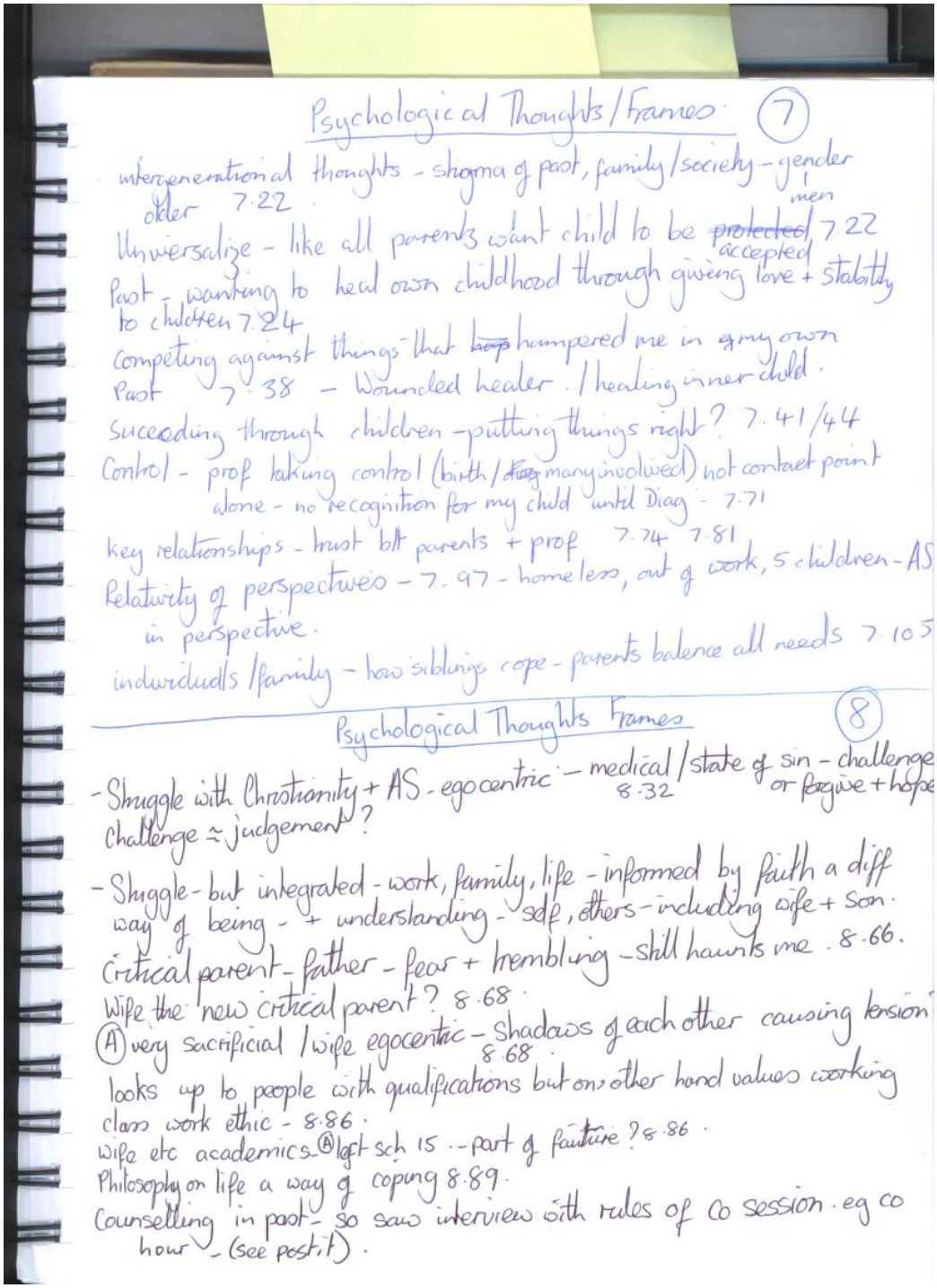
noting :

Psychological Frames

Psychological Frames (colour coded – fine tuning themes)

Feeling Vocabulary

Metaphors and interesting use of language



Psychological Thoughts / Frames (7)

intergenerational thoughts - shame of past, family/society - gender men older 7.22

Universalize - like all parents want child to be ~~protected~~ accepted 7.22

Past - wanting to heal own childhood through giving love + stability to children 7.24

Competing against things that ~~keep~~ hampered me in ~~g~~ my own

Past 7.38 - Wounded healer / healing inner child.

Succeeding through children - putting things right? 7.41/44

Control - prof taking control (birth / ~~diag~~ many involved) not contact point alone - no recognition for my child until Diag - 7.71

key relationships - trust b/t parents + prof 7.74 7.81

Relativity of perspectives - 7.97 - homeless, out of work, 5 children - AS in perspective.

individuals / family - how siblings cope - parents balance all needs 7.105

Psychological Thoughts Frames (8)

- Struggle with Christianity + AS - egocentric - medical / state of sin - challenge or forgive + hope 8.32

challenge ≈ judgement?

- Struggle - but integrated - work, family, life - informed by faith a diff way of being - + understanding - self, others - including wife + son.

Critical parent - father - fear + trembling - still haunts me . 8.66.

Wife the new critical parent? 8.68.

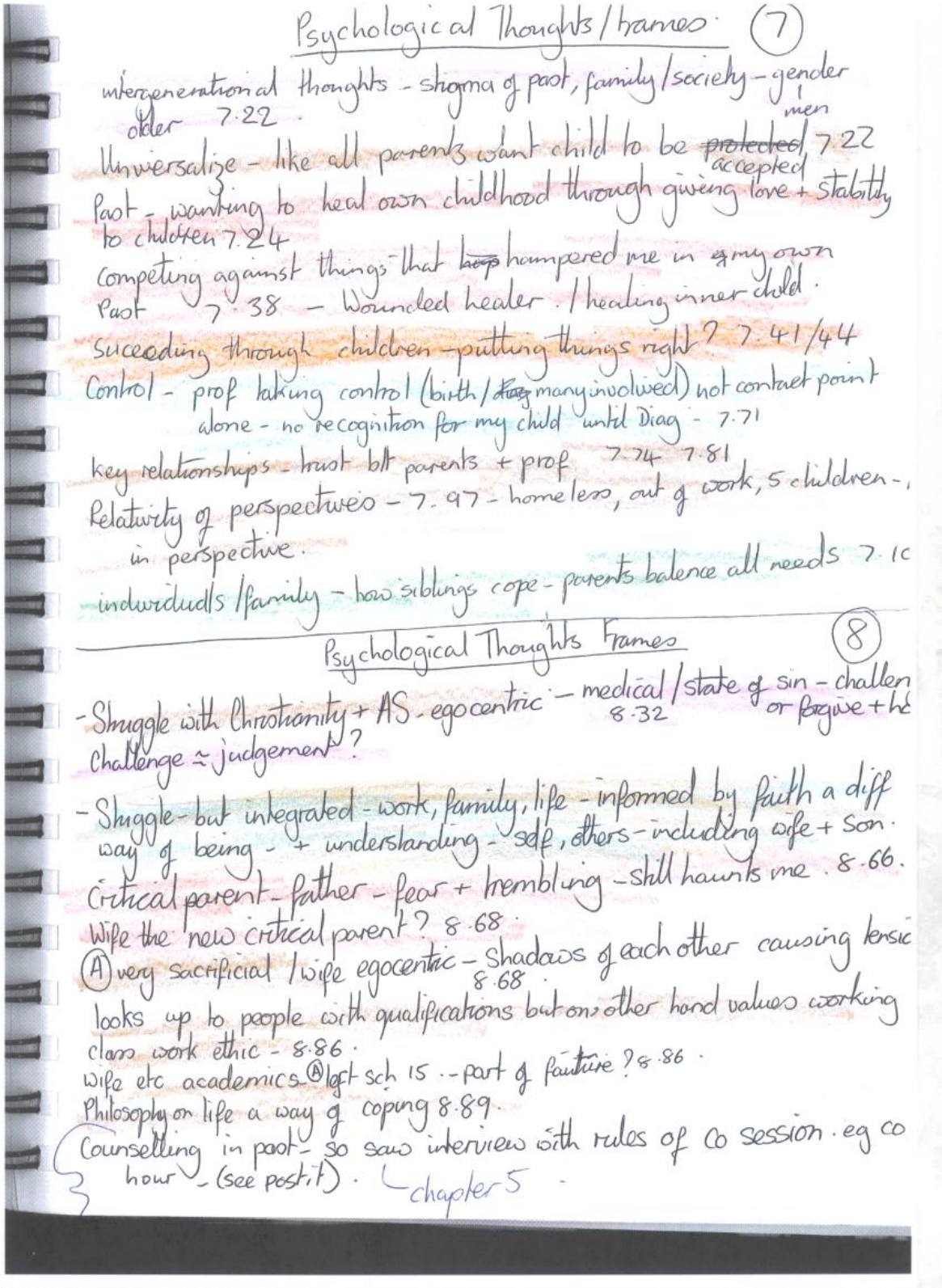
(A) very sacrificial / wife egocentric - shadows of each other causing tension 8.68

looks up to people with qualifications but on other hand values working class work ethic - 8.86.

wife etc academics - (A) left sch 15 - part of failure? 8.86.

Philosophy on life a way of coping 8.89.

Counselling in past - so saw interview with rules of co session . eg co hour - (see post it).



Psychological Thoughts / frames (7)

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Universalize - like all parents want child to be ~~protected~~ accepted 7.22
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Control - prof taking control (birth / ~~diag~~ many involved) not contact point alone - no recognition for my child until Diag - 7.71
key relationships - trust b/t parents + prof 7.74 7.81
Relativity of perspectives - 7.97 - homeless, out of work, 5 children - in perspective.
individuals / family - how siblings cope - parents balance all needs 7.10

Psychological Thoughts Frames (8)

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challenge ≠ judgement?
- Struggle - but integrated - work, family, life - informed by faith a diff way of being - + understanding - self, others - including wife + son.
Critical parent - father - fear + trembling - still haunts me. 8.66.
Wife the new critical parent? 8.68.
(A) very sacrificial / wife egocentric - shadows of each other causing tensic 8.68.
looks up to people with qualifications but on other hand values working class work ethic - 8.86.
wife etc academics (A) left sch 15 - part of failure? 8.86.
Philosophy on life a way of coping 8.89.
Counselling in past - so saw interview with rules of 60 session. eg 60 hour - (see post it). → chapter 5.

Colour Coding – Temporal **Self and Identity** **Selfhood and Syndrome** **Self and Family** **Self and World** **Praxis**

Feelings 5

Guilt.
Fear
loss.
hated - Ms company.
Regret - past behavioural
time lost - where couldn't enjoy being with M 5.104

Hope - he will be less AS as grows older - like me 5.106 /108.
adapt disability to be a strength + succeed.

Feeling (2)

Guilt - must be doing something with boys - offering what he can? - strong need not to be distant like own father - away of putting right?

sadness - around the disability 2.36.
Regret - if only he didn't have it 2.36.
Dread - things will be diff or L 2.38.
Disappointments - chipp away at you 2.44
Wonder - about future 2.44
Frustration
upright 2.52.
⊕ feelings eg proud were hinted at but feeling words not used 2.62.
'he did well'
Worries - what is going to happen in the future? 2.106

---

(3) fear - the weird kid - isolated 3.86. - worry about getting it wrong (fatherhood)
worry - will he ever start talking? 3.30 3.50
eating
distressing - not eating 3.30 hard to understand.
crying.
forget - as difficulties come + go 3.30
Proud 3.78.
hope - makes people more forgiving 3.66. disappointed 3.98
Guilt feeling

Powerful Use of Lang.

(6) to be honest repeated throughout - put in tentative informat then gave more with 'to be honest' when felt safer.

- answers for your son - big wise man - passing it down - intergenerational - +
- Hit a brick wall - trying to give advice.
- Pregnancy + birth - over the moon, he was the centre of our life high - floating (out of body?).
- Parenting Dan - different kettle of fish - hit brick walls - no getting around them 6.44.

Suck it and see strategy 6.44.

but ~~Lord~~ can't just roll with it - go down blind alleys. 6.44.

- can shake him - can't control AS - lost in him - can't separate.

Label to hook it on (bad behaviour) - different label - but his personality 6.52 6.58

Cuts you down - ~~Dad's~~ Dan has superior air - perhaps - Dad feels it because of own schooling / social status.

I'm only human - try to keep a lid on it (behaviour screaming shouting). 6.64

fluid experience UC - then AS 6.68.

get your head around it or on your bike 6.86 (AS + extended family father - expect to be a 'big beacon of wisdom'.

(7) tag - label / Diagnosis for N 7.16. - very important.

fighting - System.

~~Upset = talking about~~

Galvanized relationship with wife AS/children homeless. 7.97

in the mix - of 5 children 5.89-91 Joint Struggle 7.98.

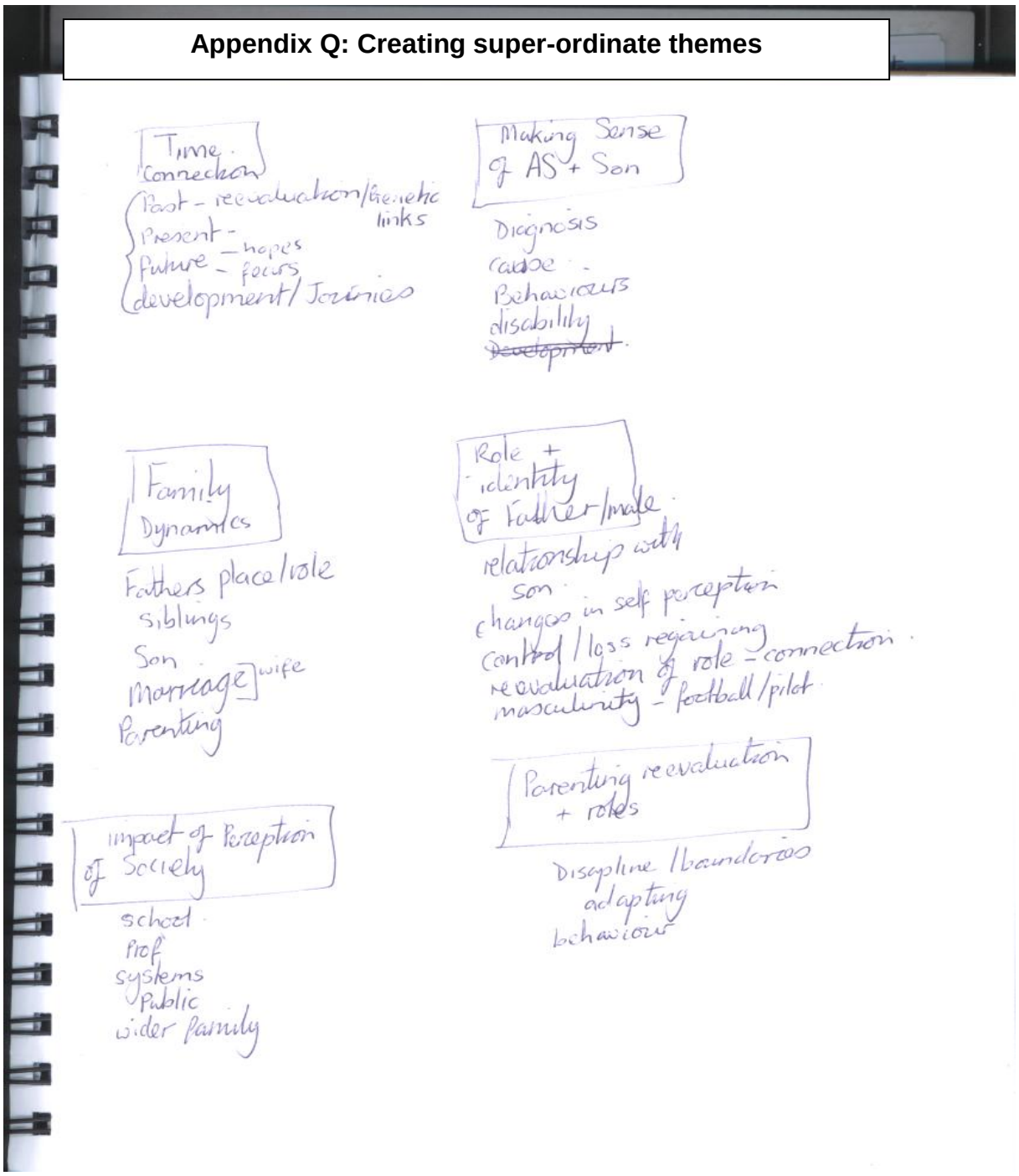
Appendix P: Theme Chart

Participants

	1	2	3	4	5	6	7	8	9
T	pilot	identity / perception of self roles	family	siblings	diagnosis	dad's perception of son	activities ways of connecting	father/son relationship	professionals
H		father/son relationship	school	school	genetics	Diagnosis	family, parenting, role of father: work/siblings	school/ professionals	Diagnosis: AS or personality?
E		professionals	behaviour traits	diagnosis	cause	identity / perception of self roles	wife	diagnosis, co-existent illness, AS	future
M		diagnosis	Wife	wife	behaviour traits	fatherhood: father/son relationship	cause /diagnosis, AS	genetic/ family traits	school
E		wife/marriage	AS condition	family unit/ extended family	wife	wife, couple, co-parenting	behaviour traits/development	wife, parental relationship, parenting, marriage	parents
S		hopes, fears and future	hopes, fears and future	role of father	perception of disability	Parenting	professionals, system - control	work/ faith	
		activities	Siblings	AS/behaviour	hopes, fears and future	behaviour traits	school	extended family past	
		sibling	Society	hopes, fears and future	professionals	perceptions of AS/other illness	society	society	
		school	role of father/ father son relationship	society	father/son relationship	thoughts about the future	extended family	hopes, fears and future	
		perception of AS, disability, development		professionals	identity / perception of self roles	family dynamics	hopes, fears and future		
		genetic cause		work	sibling	extended family			
		behaviour traits			own parents	own parents and parenting			
		own parents			family members	Professionals			
		extended family				Siblings			

(January 2010)

Appendix Q: Creating super-ordinate themes



Appendix R: Comments from Professionals who read the thesis draft.

Thank you for sharing this interesting and purposeful work with me, WELL DONE!!! It brought up emotional issues for me .....
Maybe there's another study: children of parents with Asperger Syndrome – the long term effects on their lives. Can I have a copy when it's finished as a good learning tool?

Dear Tina

I read with interest your thesis. As a Speech and Language Therapist I read and discussed, frequently, material relating to the perspectives of mothers and 'motherese', i.e. the way in which mothers respond to their children in infancy. However, I cannot recall a time in my professional life when I gained easy access to that relating to fathers such as in journals or in study periods. I consider this to be quite a loophole!

In practice now, as a Psychotherapist, I can see the place of forums for fathers. I am aware of the need for an empathic and well-informed key case-worker who acts as a constant source of support to families, tracking the vital paths of their child's journey through the maze of life. I recall how often I have been asked "And how long will you be here to offer help and support?"

I thank you for bringing such concerns to public awareness. I was relieved on retirement to think that you would be there for people in Southend-on-Sea who had children with Aspergers and that confidence is well founded.

Let me know when you have your Doctorate. I want a copy. It was educative for me.

All good wishes

Dear Tina

I have followed your research with interest and have found the information helpful for me in my work as a counsellor for the education system. I have a parent who has a son with Aspergers and although I knew what it was I did not fully understand the implications for him as a father until I read the literature you survey and the words of your interviewees. I have gained a depth of understanding which I feel I bring to our session work as a consequence of this.

Regards

Appendix S: **Vision for a Local Resource Base**

VISION FOR A RESOURCE BASE

Tina Axup (Senior Educational Psychologist) and Jim Stait (Social Worker)

It is our suggestion to set up a Resource Base within a secondary school in Southend-on-Sea that supports children and young people with social communication difficulties (SCD) including those with an Asperger Syndrome (AS) or High Functioning Autism (HFA) diagnoses. Such a resource would fill an important gap within Southend-on-Sea that is increasingly evident in our day to day work with these children and family.

Such a Resource Base would support our vision that all staff within children's services will recognise and understand the special needs of this vulnerable and often hidden group of young people enabling them to be fully included within their school and community. We wish to see a holistic approach that not only incorporates the young person's educational needs but also their social emotional needs. The vision is one which recognises the systemic nature of the school, family and community, whereby all those significant in the young person's life can receive relevant support and a safe space in which to explore issues arising for them.

It is envisaged that this resource base will not only act as are source to the host school, their young people and families but a valuable outreach base for the growing number of people with social communication difficulties, their families and provide consultancy to other professionals in the Borough.

Whilst the paramount issue is that children and young people's lives will be greatly improved by identifying and providing the correct resources, in this current economic climate we believe that there will be considerable long term savings to prevent services from having to address the presenting problem and crisis intervention.

BACKGROUND INFORMATION

Research shows that the number of children diagnosed with disorders related to social communication difficulties, such as AS has doubled over the last 5 years. This may not reflect a greater prevalence of the condition but highlights the growth in identification. Our findings suggest that an increased awareness of the condition has not meant that service providers have necessarily gained an increased knowledge of the condition, leading to inclusive practice.

Our own experiences show that there remains a general lack of understanding of these young people's needs and even less of how to meet them in mainstream schools. Having been involved with and spoken to young people and their parents/carers, professionals from health, education and social care we have become increasingly aware of their views. Their general feedback is unanimous that the current services are not meeting the needs of many children with social communication difficulties who attend mainstream schools. Often the experience of school generates extreme stresses and anxiety that are released at home, putting undue pressure on families and in some cases contributing to family breakdown. There is also an increasing incidence of these young people suffering from mental health problems often indentified during secondary transition and throughout adolescence.

SAFE (Southend-on-Sea Asperger Families in Essex) have provided a letter expressing their full support for the suggested resource base. Young people with AS expressed their need for those around them to understand their strengths and difficulties and to recognise their needs, *"trained people who understand the issue", "teachers who understand AS."*

Asperger Syndrome

AS is the medical name for young people with social communication difficulties, who unlike those with classical Autism have average to above average intelligence and whose speech has developed normally. AS is categorised as on the Autism Continuum. Like classical Autism it is a lifelong disability that

affects how a person makes sense of the world, processes information and relates to other people.

People with the condition have what is known as the ‘Triad of Impairments:’

- social communication
- social interaction
- social imagination

AS has been described as a 'hidden disability'. This means that you can't tell that someone has the condition from their outward physical appearance.

People with SCD/AS suffer from highly anxious states within social situations and when they experience change, this is often expressed through strange, odd and repetitive, ritualistic behaviours. The fear and terror of an unpredictable social world can result, in them becoming trapped in their own homes, or even their bedrooms where things are safe and predictable. Most often they have developed an unhealthy dependency on parents/carers, restricting the lives of their parents and families to the extent they have been referred to as ‘Autistic Families’ mirroring the rigidity of their child in order to survive.

EDUCATION

‘Inclusion’ can sound hollow when applied to education provision for people with AS. Inclusion should not just mean being under the same roof as others but being fully integrated within the school community. Increasingly we are attending meetings where we hear heart rendering stories of these young people who are deeply unhappy in school. Often these young people are academically very able but socially struggle to fit into a main stream setting. Conversely the specialist schools can sometimes meet their social needs but are not able to meet their academic needs, thereby failing to acknowledge their main strength and depriving them of a peer group where academic concepts can be discussed and developed.

The emphasis is on academic targets which these young people are intellectually able to achieve but ignores their fundamental need to interact in a world where they are unable to undertake basic tasks such as going in a shop

or walking in a crowd. Depression and low self esteem may arise from social isolation, loneliness, and feeling like the odd one out. The current system merely perpetuates this.

Primary schools appear to cope better with these young people than secondary school. This is for a range of reasons including the onset of adolescence, emphasis on peer relationships and mismatch between academic ability and social maturity. They have come from a relatively small junior school where they have most lessons in one room with the same teacher. They have been with the same group of pupils from the age of 5 who have come to accept their 'quirky' behaviour. They then enter a large senior school where they encounter many new children and bullying is a common theme. They have up to a dozen different teachers who expect them to become independent not understanding the tight structure in which such young people rely on to cope with the daily unpredictability of people and systems.

Imagine if a wheelchair user was not able to access their class because it was on the first floor with no lift available. It is easy to firstly see the disability and to then understand the 'concrete/physical' barriers they face. It is easy to recognise the adaptations that would be needed to support the wheelchair user to access the class. Now let's consider the barriers people with social communication difficulties face. There is no concrete visual prompt, there may be no obvious trigger for the young person's anxiety (if they are able to express this at all) and no straight forward solution. These young people need a great deal of time and empathy over a long period of time in which to be understood and where they can trust the adults. Parents are a great resource in finding out the young person's strengths and needs, yet can be dismissed as being a nuisance.

Our experiences of the education system is that whilst some staff at school have been given the training, very few still do not really "get it". The young person SCD/AS do not necessarily exhibit behaviours within the school that shows their level of distress but they have the ability to hold onto it until they get home which negatively impacts on the whole family. Containing the anxiety will frequently prove a barrier to learning and the young people will not achieve their

full potential which in certain circumstances has led to them becoming school refusers.

Research shows that:

- 40% of children on the autism continuum have been bullied at school.
- 43% of children on the autism continuum were officially excluded from school between 2007-2008.
- Pupils with special educational needs are over eight times more likely to be permanently excluded from school.

'These challenges arise because of a lack of understanding of autism, and the distinction between disability and disobedience.' (Ambitious about Autism, 2010 Parliamentary Briefing)

Due to their cognitive, speech and language skills children with AS are more likely to participate in mainstream life than those with classical Autism, who tend to belong to more 'protective institutions' e.g. special schools. Therefore mainstream school can give these young people good opportunities to socialise with positive role models or expose them to bullying and peer isolation. In our experience student experience depends on the mediation of competent staff who understand the nature of Asperger Syndrome.

- 51% of Britain's school teachers have never received specialist training to help them support children with autism.
- 44% of teachers do not feel confident teaching children with autism.
- Only 10 %have received such training in the past 12 months.

What bald statistics can never show are the anxieties and stresses caused often inadvertently to the individual within the school. One young man in Southend-on-Sea was recently left traumatised with suicidal thoughts because he was the only pupil on the last day of school that came home with nobody having signed his school shirt which is now a tradition for school leavers. As a result he received emergency counselling from the Child and Family Consultation Service. This evidences the additional costs associated with a lack

of understanding of the condition but the emotional cost of such an experience to this young man is certainly immeasurable.

In Southend-on-Sea there have been preventable breakdowns in mainstream schools which result in children switching to specialist provisions both in and out of county.

Education resource bases are slowly beginning to be set up over the country although they specifically address the educational aspect and are not holistic as we are suggesting.

FAMILY SUPPORT

We have become increasingly aware that some parents find it difficult to fully understand how their child thinks and are stuck with the notion that given the right services their child will be 'normalised.' They continue to set them goals and send them to clubs/activities against the child's wishes. There are very few services for children with Social communication difficulties and their families. We have found that the level of input required is minimal to make a major difference. The work is often helping a parent see the world through the eyes of their child to help them understand.

SERVICE PROVISION

As a result of their experiences in mainstream school children are suffering episodes of mental health problems and mental health services are acknowledging a vast increase in referrals for this particular group.

At present health, education and social care have to find resources to address the 'presenting' problem such as young people becoming socially isolated and reacting with violent outbursts. Addressing the 'underlying' anxiety and fear at an early stage is essential. School can be a key player in acknowledging these feelings and supporting young people's communication and social skills on a daily basis whilst celebrating their talents. Young people's lives will be greatly improved by identifying and providing the correct resources. In this current

economic climate we believe that there will be considerable long term savings to specialist and acute services by addressing needs at a universal and targeted level, rather than crisis management.

These young people fall in between mainstream and specialist services within education, health and social care. They do not meet the criteria of the CWD team but there is a lack of understanding from the mainstream staff to assist the families.

Southend-on-Sea's Children with Disabilities (CWD) Team is regularly addressing crises in the family home as a result of the anxieties and violent outbursts from children whose needs have not been recognised or understood in their schools which could have been easily preventable. People are born on the Autism Continuum and there is no cure but with the correct management and adaptation to their environment they can lead to fulfilling lives. It should be recognised that the violence often exhibited within the home affects the whole family especially the young person's siblings who are unable to have friends around to play or have sleepovers as would normally be expected.

FINANCE

We envisage this resource base to be an investment for the future whereby if the correct support and identification of needs is met then this will have considerable savings for other services such as health, education and social care of having to deal with reactive crisis management.

An inclusive educational resource base in Swindon estimated a 5 fold financial saving from money spent on out of county placements. We can cite many young people in Southend-on-Sea on Sea who have required specialist, expensive services, which may have been avoided through a base providing support at the earliest stage. It is very common for parents to be sent a letter informing them of a diagnosis with no follow up support.

From our discussions with professionals in education, health and social care we have becoming aware of the increasing demands both time and financially

placed on the various services and it is our belief that it is possible to provide a quality service that also remains cost effective.

SOUTHEND-ON-SEA CHILDREN'S PARTNERSHIP CHILDREN AND YOUNG PEOPLE'S PLAN 2010-2013

Our suggestions are entirely in keeping with the goals and visions as set out in the CYPP Plan 2010-2013. The plan 'Vision and Introduction' sets out its goals for the children and young people of Southend-on-Sea:

■ Helping children and young people to raise their aspiration and achievement
■ Ensuring they have the opportunities they need for inclusion
■ Facilitating their participation in decision-making that affects their lives
■ Providing them with excellent services and excellent outcomes

Our suggestions have been based upon years of working with young people and their families and listening to the problems they have been encountering. We kept hearing the same message from individuals and families and went to the local SAFE group to facilitate their collective participation and listening to their views. They have produced a letter that fully supports our suggestions which is in keeping with the plans wish to enable children, young people and their families to "influence the shape of provision"

Children and young people's aspirations are to be giving the recognition of their different needs and to receive quality services according to these needs that enable them to feel included and to support them to achieve excellent outcomes. In keeping with the CYPP 2010-2013 "priorities for improving outcomes" we believe that such a resource base would

PRIORITIES FOR IMPROVING OUTCOMES ARE PRIORITIES FOR IMPROVING OUTCOMES ARE:

'Reduce the need for children and young people to be looked after'
'Reduce the number of children and young people who have experienced bullying, including face to face, text or internet'

‘Ensure that every child has access to high quality school places that meet their needs.’

Most importantly in section 4.1 governance arrangements sets out that we should be “*Always acting to put the children’s needs before organisational structures”.* At present we believe that these young people are being expected to fit into a system that does not recognise their collective needs.

Southend-on-Sea’s aspiration is for all children to be successful and to achieve their full potential. It is therefore essential that those professionals who are expected to provide such high standards themselves fully understand the different needs of children with SCD / AS.

Young people, families and professionals are clearly identifying that the existing services are not meeting the needs of this client group. Improving the proportion of these young people accessing higher education is vital. Research shows that universities are beginning to look at the needs of young people and adapt their teaching to meet their needs. All too often in secondary schools the young person is expected to fit into a system that is, ironically, inflexible and rigid. Too often young people are ill prepared and put off from learning due to their experiences in secondary school education and will have given up any aspiration to attend further education.

CONCLUSION

In years to come it will be inconceivable that so few services/resources were in place for this group in society and I would like to see Southend-on-Sea on Sea as pioneers of such a service. Research shows that whilst resources/services are slowly developing in schools, these mainly address the educational aspect of the child and there does not appear to be projects that are fully holistic that incorporate not only the educational provision but also the social aspect of the young people and their families.

These young people are too often trapped in their homes for fear of an uncertain world outside. They are not drinking, taking drugs or causing criminal

damage and are therefore not seen as a problem in society but an ‘out of sight out of mind’ mentality is not something we should be prepared to tolerate. These young people’s lives are important and they should be given the opportunity to fulfil their potential.

A recent discussion with the OFSTED inspectors acknowledged that the problems associated with meeting the needs of young people with AS is a nationwide problem and not something just encountered in Southend-on-Sea.
We have identified an area of unmet need in the Borough and through discussion/consultation with the young people and their families, professionals from health, education and social care we have developed a suggestion that not only meets the needs of the young people, allowing them a far greater opportunity to achieve excellent outcomes but is also cost effective. It will produce savings in specialist school services both in and out of county and will reduce the demands currently placed on health and social care including the emotional upheaval of a child having to be accommodated in the event of family breakdown.

We want Southend-on-Sea Children's Trust to show a shift in their paradigm of thinking and take the step to become PIONEERS in Britain in their pursuit of EXCELLENCE to help meet the needs of all its children and young people to show a commitment to ensuring and valuing the diversity of this particular client group.

“Strengthening the responsiveness of services by further involving children, young people and their families and enabling them to influence the shape of provision.”
Southend-on-Sea children’s partnership children and young people’s plan 2010-2013.

Appendix T: Draft ASD Policy

Southend-on-Sea-on-Sea Educational Psychology Service Involvement in the Identification, Assessment and Follow Up of students with Autistic Spectrum Disorder (2011)

Background

NICE has recently developed clinical guidelines regarding the pathways of identification and assessment of children and young people on the Autistic Spectrum (Sept 2011). Southend-on-Sea Emotional Health and Wellbeing Subgroup have commissioned a Task and Finish Group to explore the development of local pathways. The Educational Psychology Service has been represented on both groups together with a range of professionals from health, education and social care. Advice has also been taken from parents of young people on the Autistic Spectrum.

Work with children who may have ASD is a key part of the casework of Educational Psychologists. It would increase the effectiveness of the work if children were identified at the earliest opportunity, prior to diagnosis. The Educational Psychologist has a role in bringing a social constructivist perspective to the assessment and support of such children and young people.

NICE Guidelines and Local Plan

NICE recognises the Educational Psychologist as key in the multi-agency assessment/core diagnostic team. Clinical and Educational Psychologists are both mentioned in the guide, yet it is recognised that each offers different skills and perspectives. There is acknowledgement within the group that the social context is an area where the Educational Psychologist can provide an important part to the picture of the child.

Although there are specific assessment tools for diagnosing autistic spectrum disorder, it is agreed that the educational psychologists' role continues to be related to supporting the child's access to education.

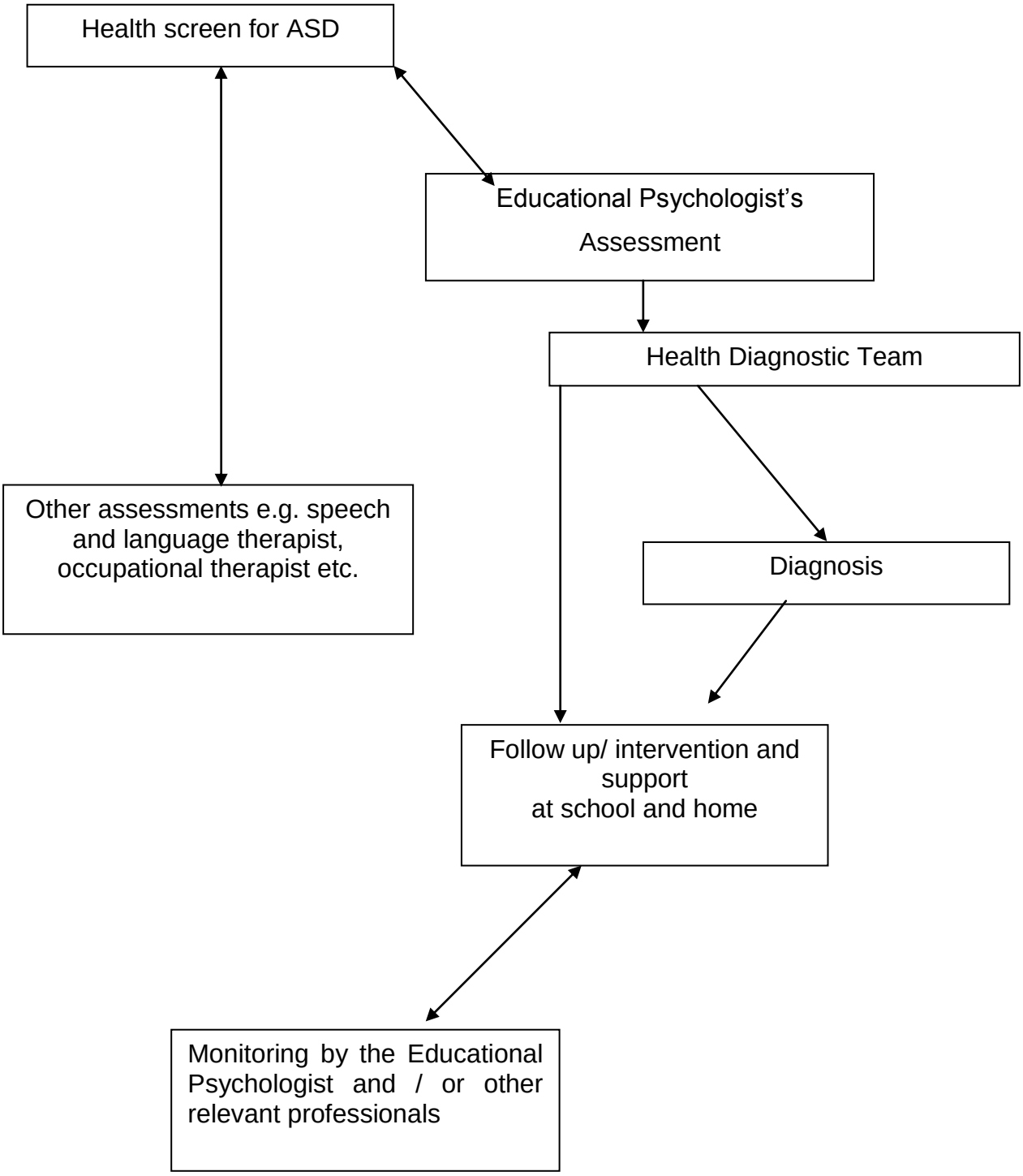
Assessments/recommendations will primarily aim to support the child/young person, school staff and parents/carers in accessing a broad, balanced and relevant curriculum. However, it is believed that this information will also support the diagnostic process.

The group has proposed that an assessment is carried out by an Educational Psychologist prior to diagnosis, as this information is crucial to developing a holistic picture of the child's social communication skills and social / learning context.

It is proposed that the assessment by the Educational Psychologist will take the form of:

- A consultation with school staff and, if possible, parents;
- Observations of the child/young person in a relevant social setting e.g. school.

The Educational Psychologist may also conduct an individual assessment, e.g. a cognitive assessment, projective work, if that is what is considered to be appropriate.

The paediatrician will refer the child/young person to the Educational Psychology Service once the child has been identified with the likelihood of autistic spectrum disorder using a screening assessment e.g. the CASTE. An assessment will be carried out by an Educational Psychologist in negotiation with the child's school and parents. The school will be asked to complete a CAF prior to the Educational Psychologist seeing the child (in accordance with the usual procedure for bringing a child to the attention of the Educational Psychologist). The Educational Psychologist's assessment will then be shared with the paediatrician or other professionals involved in making the diagnosis. The child can then be raised by the school and parents with the Educational Psychologist when support is needed. It is understood that if the Educational Psychologist identifies the child prior to the health professional, the health professional will accept the Educational Psychologist's referrals through the

CAF and screen the child in order to decide whether or not a diagnostic assessment is appropriate.