

**THE UNIVERSITY OF EAST ANGLIA AND NORFOLK AND WAVENEY MENTAL  
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**AN EXPLORATION OF THE  
EXPERIENCES OF PARENTS AND  
THEIR CHILDREN WHO HAVE  
UNDERTAKEN THE PARENT CHILD  
GAME WHEREIN THE CHILDREN HAVE  
ASPERGER'S SYNDROME**

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## **ABSTRACT**

**Christine P. Lawson, MSc by Research, Submitted June 2011**

### **An Exploration of the Experiences of Parents and Their Children Who Have Undertaken the Parent/Child Game Wherein the Children Have Asperger's Syndrome**

The number of children with a diagnosis of Asperger's Syndrome (AS) is growing. There are many non-medical treatments exclusively designed to help children with AS or High Functioning Autism (HFA). Experts agree that such treatments should involve the family.

The Parent/Child Game (PCG), a treatment to aid with parental management and family relationships, has been well-used (and well-researched) with regard to neuro-typical children. Prior to my research, I had made an adaptation to the PCG to accommodate the needs of children with AS or HFA in my role as a nurse specialist within a Child and Adolescent Mental Health Service (CAMHS). This study used semi-structured interviews to elicit the experiences of three parents and two children who took part in the adapted PCG. Five Key Informants—professionals with expertise in children and families with ASD, but not from CAMHS—were also interviewed to add context and to broaden the knowledge and perspective on family life with an ASD child.

The study used a narrative methodology with purposive sampling to elicit the core themes of the experiences of the ten participants. These themes were: desire for a quicker, smoother pathway to diagnosis, issues within family life (parental stresses, living with a hidden disability, and need for respite care) and the struggles with the educational system. Families wanted more support and training for themselves and for professionals in all fields; they also wanted society to be more understanding.

The findings. Parents and children reported that the adapted PCG was effective in the following areas: parental management (especially increased confidence), improved family communication and consequently an enhanced parent/child relationship.

296 Words

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What we cannot reach by flying,

We must reach by limping.

*(Beyond The Pleasure Principle, Freud)*

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# **CHAPTER ONE**



# **CHAPTER ONE**

## **INTRODUCTION**

The government defines mental health problems in children and young people as:

*“Abnormalities of emotions, behaviour or social relationships sufficiently marked or prolonged to cause suffering or risk to optimal development in the child or distress or disturbance in the family or community,”* (NSF DH 2004).

Child and Adolescent Mental Health Services (CAMHS) are multidisciplinary teams set up to diagnose and treat mental health difficulties in children including the agenda above. According to the Office of National Statistics in 2004 one in ten children aged between 5-16 years has a clinically recognisable mental disorder; 1% has a less common disorder, including Autism; 2% had more than one type of disorder (ONS 2004). I have worked in this area for 20 years, with the last ten years as a clinical nurse specialist. Sometimes this work warrants intensive input focussing on the parent and child relationship. One intervention that I have used for many years is the ‘parent/child game’ (PCG), which was originally developed by Forehand and McMahon (1981). The parent is guided on positive interactions with their child whilst they play together; via video link up, by the therapist who is observing from another room. This technique is used when the parent is finding the child difficult to manage; the principles can be used with all adult/child relationships (Jenner 1999). Some of the families that are referred to CAMHS have a child with an Autistic Spectrum Disorder (ASD). Although the PCG has been well-researched with behaviourally difficult children (Jenner 1999:5), children on the autistic spectrum have not featured.

### **How this thesis is structured**

The thesis presents the study, process, findings and claims over four chapters.

Chapter One introduces the research. I also examine the literature around the key areas of Autistic Spectrum Disorder (ASD) and the PCG, by way of understanding the main concepts and to set the scene for the reason for the research. Also, from the literature we gain a picture of the prevalence of ASD, and the issues around lack of clarity of diagnosis. I also examine the literature pertaining to the struggles that parents have in trying to meet the needs of their children with ASD. I have not examined all interventions available but do mention other interventions where relevant to this study.

Chapter Two looks at the methodological approach taken in the study. Following the retrospective semi-structured interviews of three mothers, two children and five Key Informants, I analysed the transcripts using a narrative approach. Narrative inquiry is a growing method for exploring experiences, particularly in the field of health sciences and, in this case, specialist nursing. For this work I have particularly drawn on the works of Riessman (1993), Clandinin and Connelly (1994), Holloway and Freshwater (2007) and Speedy (2008).

Chapter Three offers my interpretations of the personal narratives. Using a narrative approach, I draw out the themes from each of the interviews and then initially compare the themes across the family interviews, followed by comparisons across the Key Informants' themes. The narratives offer an important and moving insight into the pains of parenting a child that needs special understanding. The families share their stresses and their strengths of family life, education and society at large.

Chapter Four discusses the findings alongside the literature.

## **BACKGROUND LITERATURE REVIEW**

### Process

An initial literature search explored Asperger's Syndrome and High Functioning Autism: issues around diagnosis, relevant treatments, parenting and family life. MetaLib search engine was used with 10 databases such as: CINAHL (EbscoH), Medline (Ovid), Zetoc (Brit. Lib), as well as a trawl of the references of articles chosen. Search words used were: parenting and Asperger Syndrome or High Functioning Autism. These terms covered the scope of my study; there was no intention to cover everything about ASD. This initial search amounted to thousands of articles dealing with issues across the autistic spectrum, including many neurobiological studies. I therefore narrowed the search by adding 'without' to terms, like neuropsychological, neuroscience, serum, phenotypes and brain chemistry.

Articles were chosen if it was clear in the abstract that the study covered High Functioning Autism or Asperger's syndrome and family life or parenting and the articles were not older than ten years (unless they were significant to the understanding of the development of ASD). The vast majority of the articles came from specialist journals in the field of Autism and developmental disorders, as well as psychological and psychiatric journals. Originally I was not planning to cover the diagnostic process;

however there were numerous studies and articles discussing the lack of clarity and different criterion used, therefore it was too significant to omit.

I conducted a second search before beginning the write-up in order to capture any new articles and any new information that may have emerged.

### **AUTISTIC SPECTRUM DISORDER**

Edward Ritvo wrote that managing ASD is; *'like sailing.....not straight into the wind'* (Ritvo E. 2006: 102).

Currently Autism is classified as a Pervasive Developmental Disorder (PDD). PDD is the umbrella term given to lifelong difficulties in social and communication skills over and above general delay (Lord and Rutter 2004). This includes: Autistic Spectrum, Asperger's Syndrome (AS), Rett's Syndrome, Childhood Disintegrative Disorder and PDD-NOS (**N**ot **O**therwise **S**pecified), including Atypical Autism<sup>1</sup> (DSM IV 2000).

At times I will use the term ASD when referring to an article that has used this term and includes AS and/or High Functioning Autism (HFA). My study focuses on AS and HFA and, as the difference between the two terms is still under discussion, I will use them interchangeably (discussion follows).

#### **Asperger Syndrome: Where did it begin?**

In 1911 a Psychiatrist named Bleuler (who was studying schizophrenia), coined the term autism ('selfism') to describe the symptoms that his patients displayed: social withdrawal and a detachment from others (NAS 2008). Leo Kanner was the first person to document his findings about children who are now termed Autistic. He was born in Austria and qualified as a doctor in 1921. He immigrated to the USA in 1924 and became the first child psychiatrist in the USA, developing the first child and adolescent psychiatry department located at Johns Hopkins Hospital, Baltimore. In 1943 Professor Kanner documented his observations on a group of boys that shared similar features. The boys gave the impression of having normal intelligence yet they had a general lack of awareness of other people's existence or feelings (Lord and Rutter 1994). Kanner gave the first clinical description of Autism. The particular

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<sup>1</sup> Atypical Autism = presentations that do not meet the criteria for an Autistic Disorder because of late age at onset, atypical symptomatology, or sub-threshold symptomatology, or all of these (DSM IV 2000).

behaviours he documented were: wanting things to remain the same, repetitive behaviours, and a lack of imaginative play with other children, as early as age 1 year (Lord and Rutter 1994).

Hans Asperger, a Viennese paediatrician (also in the 1940s), described boys who had features similar to the autistic group that Kanner was studying. He used the term '*autistic psychopathy*' (Attwood 2004:14). Asperger's work was initially only known about in Austria and Germany; it was not until the 1980s, and when his work had been translated into English, that child psychiatrist, Lorna Wing, used the term Asperger's Syndrome (Attwood, 2004). Although Leo Kanner and Hans Asperger described children with similar features, Kanner described children with more severe autism, whilst Asperger described more able children (Attwood 2004).

During the 1990s Asperger's Syndrome was placed on the autistic spectrum and was classified as a sub-group of Pervasive Developmental Disorder (PDD) (Attwood, 2004).

#### What does AS look like?

Children with Asperger's Syndrome are usually of average to above-average ability. They often have a wide vocabulary, yet do not always understand the words they use (NAS 2008). Children with AS can present as intelligent because their language is often advanced and sophisticated (Ozonoff 2002). This can cause problems when people expect more from them than they are actually capable of. There can be difficulties with social communication, interaction and imagination. Children with ASD may have difficulty understanding non-verbal cues and the two-way reciprocity of conversation; they are also very literal, which gives rise to difficulty understanding instructions, jokes, metaphor and sarcasm (NAS 2008; Attwood, 2004). Difficulties with social interaction include: making and keeping friends, not wanting to be touched—but standing too close to others, not liking eye contact—yet sometimes staring through a person, often talking over others or interrupting with their own agenda or topic (Attwood 2004, NAS 2008). Another difficulty arises with social imagination, for example: AS sufferers have difficulty transferring social skills from one situation to another and understanding others' subtle non-verbal messages. They are often inflexible about the manner in which something is done and have limited interests and activities (NAS 2008). AS people do have feelings, but it is sometimes difficult for them to identify and express their feelings, as they prefer to use logic to intellectualise emotional situations (Wing 2002). There are now many personal accounts of living with AS from the inside. Nita Jackson has written of her experiences as a teenage girl with Asperger's

Syndrome, explaining how volatile her relationships had been—particularly those with her family (Jackson 2002).

### Diagnosis

It had not been my intention to cover the diagnostic criteria in any detail; however, there is still such disagreement surrounding it, that I could not let it pass. Discussions are still taking place over the classification of PDD and its sub-groups (Szatmari 2000, Ehlers and Gillberg 1993, Ghaziuddin 1992). These will be examined later. The primary focus of this study will be on HFA and AS. The diagnostic criteria for each one varies according to the classification used. *The American Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, 2000)* and the World Health Organization's *International Classification of Diseases (ICD 10, 1993)* are almost identical (see appendix 1) and have a strict set of criteria, mainly: 1. Difficulties in social interaction and, 2. Restricted, repetitive and stereotyped patterns of behaviour, interests and activities, with an absence of significant language delay or cognitive development for AS, but not for HFA. However, language delay as a diagnostic distinction between AS and HFA is not agreeable to all. Prior et al (1998) found no difference in language delay between children with a diagnosis of Autism, AS or Pervasive Development Disorder- Not Otherwise Specified (PDD-NOS). They studied the behavioural differences in clusters of children in those three diagnostic subgroups. One-hundred and thirty-five children from Britain and Australia were studied. Clinicians had already diagnosed the children using *DSM III*, which was current at the time. Notable differences were found among the children in levels of social communication development and theory of mind<sup>2</sup>. Ozonoff et al had similar findings in (1991). Prior et al concluded that the term 'spectrum' was appropriate and that the primary difference was a matter of *degree* in the areas of social and cognitive impairments (Prior et al 1998).

Diagnosis requires the taking of a detailed developmental history of the child, including language development. The clinician is therefore dependent upon retrospective commentary, which can potentially be unreliable (Prior et al 1998). Szatmari et al (2000) tested 42 autistic children and 20 AS children between the ages of 4-6 yrs. At a 2 yr follow-up they found that the children diagnosed with Autism who had developed

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<sup>2</sup> Theory of Mind= 'Mind Blindness' first coined by Baron-Cohen in 1990 as a distinguishing feature of Autism, suggests that there is a basic dysfunction in the systems serving mentalising functions. That is, 'being aware of physical things but blind to the existence of mental things, e.g. blind to thoughts, beliefs, knowledge, desires and intentions' (Baron-Cohen 1997).

fluent language were very similar to the children with AS children at enrolment. Consequently Szatmari suggests that rather than distinguishing between the two diagnoses by language; rather that HFA and AS represent parallel but possibly overlapping developmental pathways (Szatmari 2000).

According to Howlin (2003), diagnosis may well be a matter of timing. She noted that a number of children with HFA and early language delay catch up with their AS peers later on. She suggests that the only true way to compare the groups is to match the two groups for intellectual level (Howlin 2003), which few studies have done. Bennett et al (2008) conducted a longitudinal study exploring language development in children from ages 4 to 17 yrs who had a diagnosis of AS or HFA. They specifically focussed on the deficits of grammar and syntax, rather than the semantic and pragmatic deficits that would be common across AS and HFA. This has the effect of placing the children in different groups, but with some of the groups overlapping. Bennett et al suggest that consideration be given to specific language impairment rather than the global diagnosis of '*language delay*' which offers an ambiguous differentiation between AS and HFA (Bennett et al 2008:624). AS children may develop language at the normal developmental stage, and sometimes earlier; however most often their vocabulary is more in line with that of adults, but without full understanding (Frith 2004). Language development/ability can be assessed at any age and is potentially more reliable than recalling past events (Bennett et al 2008).

Gillberg and Gillberg (1989) offered the first operationalised diagnostic criteria using Hans Asperger's four case studies. These broad criteria include six areas of impairment or difficulty (see appendix 1). Szatmari (also in 1989) offered four criteria which were very close to those of the Gillberg's, with all criteria having to be met. According to the National Autistic Society (NAS) definition, there are three main areas of impairment. This 'triad' includes: social interaction, social communication and social imagination (NAS 2008). Each area of the triad varies with individuals due to age and ability, and these three components impact on all relationships (Bogdashina, 2006). DSM-IV-TR, ICD 10, Gillberg and Szatmari and NAS criteria are all still in use. Depending upon which criteria the professional uses to make the diagnosis determines whether or not a child would receive a diagnosis. This variety of criteria offers challenges for families, professionals and researchers; and raises questions not only about the validity of diagnosis but also about the differentiations between the sub-groups as well. As a result, debates still ensue.

Szatmari (1992, 2000) discusses this dilemma in its broader terms, including PDD and Atypical Autism. Clarity of diagnosis is essential both for parents to understand and help their child, as well as for practitioners and researchers. Javaloyes (2006) suggests using a new set of criteria under the heading: '*Disorders of communication and socialization.*' Javaloyes proposes that this would separate the more able and leave the 'Autism' label for those with very particular problems who fit the diagnosis for the more severe end of the spectrum. However, it is not quite as simple as that, for the time being when discussing ASD, professionals need to hold in mind that all the PDD and ASD subtypes have yet to be clarified and consensus achieved (Prior et al. 1998).

Malloy and Vasil (2010) offer a social model of ASD preferring to see it as a difference and not a disability. With contention over the diagnostic criteria and the very positive aspects of ASD, they suggest that as a disability it is socially constructed and not necessary at all. They aver that professionals and parents are Pathologising difference.

Research for clear diagnostic criteria continues along two main avenues: symptoms/behaviours and aetiology. *DSM IV* instructs that if the criterion is met for Autism, then that should be used over the diagnosis of Asperger Syndrome (*DSM-IV-TR* 2000). Ozonoff et al (2002) suggest that both groups of children need the same treatment, therefore the focus should not be on differentiation but on helping the child and the family. Frith (2004), in her review paper, offers the suggestion that HFA and AS are interchangeable labels and that Lorna Wing proposed the term Asperger's Syndrome in order to raise its profile as a form of Autism. Only time will tell whether both names persist. As consensus has not yet been agreed on the sub-categories of AS and HFA, for the purpose of my study I have used them interchangeably as Frith suggests.

### Prevalence

It is estimated that 1 in 100 of the child population of the UK has ASD (Green et al, 2005). Asperger East Anglia suggests that, '*1 school child in every 70 is now diagnosed with a form of Autism; this includes children with average or higher than average intelligence who have no obvious difficulties learning to speak*' (Asperger East Anglia, 2008). Baird et al (2006) looked at the child population of South Thames, focussing on 9-10 yr olds with a diagnosis of ASD (n=255). They found the prevalence to be 38.9% per 10,000 for childhood autism and 77.21% for other ASDs, suggesting

1% of the child population could be ASD. The National Autism Plan suggests ‘an ASD prevalence rate of at least 60 per 10,000’ (Le Couteur et al 2003:1 NIASA).

As discussed above, there is no consensus of diagnostic criteria; therefore prevalence will be difficult to quantify. The majority of prevalence studies looked at the younger age range. However AS is rarely diagnosed before the 5<sup>th</sup> birthday—and often not until well into school life—as symptoms can often be very subtle and allowances made in case of developmental delay (Gillberg 2002). The first study of an ASD population took place in 1993 by Ehlers and Gillberg. Using the Gillberg criteria—in which 5,000 children born in Göteborg were assessed—the minimum rate of 26 per 10,000 was found. Further studies have been undertaken, but are often not comparable with Ehlers and Gillberg due to the age of the children when studied and the criteria used. A range of 11-85 per 10,000 has been found (Kadesjö, Gillberg, Hagberg 1999; Lesinskiene, Puras 2001; Chakrabati, Fombonne 2001). Asperger’s Syndrome is currently diagnosed on average at around 10 years of age in boys (Rutter, Taylor, and Hersov, 1995). According to Asperger East Anglia, there are about 6 times as many boys as girls with AS (Asperger East Anglia 2008). Baird et al showed similar results in gender difference (Baird et al 2006). According to Gillberg, girls and women can have a somewhat different group of symptoms than is usual with males, and therefore can be missed (Gillberg 2002). In practice this does seem to be the case, however with ambiguity over criteria, clarity on the issue of gender presentation may be harder to justify? Research into any area of ASD needs to be understood within the context of the difficulties that surround the lack of clarity in diagnosis.

### Mental health issues

Undoubtedly, as members of a CAMH service, we are seeing many children with AS, HFA and the related co-morbid psychiatric disorders. It is this group of children and families that are the core of my study.

Research shows that ASD, PDD and all the sub-groups suffer with higher rates of psychiatric disorders than the general population. About 35% of the ASD population will experience a severe manic or manic depressive illness; 15% will suffer from depression, anxiety or obsessive compulsive disorder (OCD); there is also a higher than average suicide rate—particularly among young adults (Asperger East Anglia 2008).

Ghaziuddin (2005) states that children with Autism and AS suffer a wide spectrum of psychiatric disorders. Clinical samples of AS and HFA suggest that the prevalence



rates are higher than for Autism. In a study he conducted in 1998 he found that '23 of 35 children with AS (66%) had psychiatric co-morbidity, the most common were ADHD<sup>3</sup> and Depression' (Ghaziuddin 2005:99). He continues to say that children with AS, PDD, PDD-NOS and Atypical Autism present with more psychiatric disorders than do Autistic children (Ghaziuddin 2005:100). This maybe for a number of reasons, complications with the initial diagnostic criteria may be a factor but also this group are more verbal than the Autistic group and can talk about some of their feelings (ibid).

Gadow et al (2004) looked at preschool children with PDD; this included children with AS. They found that half of the children met the criteria for ADHD. Gadow et al and Ghaziuddin appear to agree that psychiatric symptoms are common in children with PDD and ASD (Gadow et al 2004).

As far back as 1999, high rates of co-morbid psychiatric diagnoses were found in children with AS and HFA. In Australia, Tonge et al (1999) studied seventy-five children with HFA and AS between the ages of 4-18 years. Both groups scored significantly high for behavioural and emotional disturbance, with the AS (85%) children scoring higher than the HFA (65%) children, (*the child mental health population in the UK of roughly the same age is 10-15 %* ONS 2004:8). In Canada, Kim et al (2000) also found significantly greater anxiety and depression problems in AS and Autistic children than the general population; however, they did not find a marked difference between these two groups (Kim et al 2000). Other more recent studies have similar findings: MacNeil et al in Canada (2009) and Kuusikko et al in Finland (2008).

In the UK, Learning Disability Services and Mental Health Services are typically very separate services, as have been Paediatric Services. Children have fallen between these services due to some professionals not acknowledging that children with Autism/LD could have a psychiatric diagnosis as well. Therefore children have generally been seen by one service or another, but not more than one (Ghaziuddin 2004).

Fortunately, this situation is beginning to change; but it will take time for services to adjust—including training staff in dual professions. Access to a CAMHS service locally is still difficult if the child has a learning disability.

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<sup>3</sup> ADHD=Attention Deficit Hyperactivity Disorder; ADD = Attention Deficit Disorder; or Hyperkinetic Syndrome, main features are inattention, lack of concentration, impulsivity, and hyperactivity (Ghaziuddin 2005:109).

### Family life and parenting a child with AS.

AS has a profound impact on individuals and their families. This has been well documented: Attwood, 2004, Ozonoff, Dawson, McPartland, 2002, Rutter, Taylor, Hersov, 1995. The research consistently shows high levels of parental stress (Gray 2003).

Gray's (1997) study interviewed fifty-three parents of AS and HFA children about family life. Most of the parents reported trying to achieve '*normal family life*'. This was based on their understanding that normal family life was related to the ability to socialise, the emotional quality of interactions and rituals, and routines. The strongest threat to this was described as the presence of the child's aggressive tendencies or even threat of them, and few families felt they had accomplished normal family life (Gray 1997:1105).

Epstein et al (2008) explain that children with AS and HFA have unique and less obvious difficulties than children with a diagnosis of Autism; these are often masked by the usually average to above average abilities in language and intellectual development. This can give the impression that the child is non-compliant, rather than having impaired functioning in specific areas—for instance sensory areas or social interaction.

Behavioural problems of one type or another are common referrals to CAMHS. The professionals' job is to search out—through questioning and history taking—the source of the behavioural difficulty and, if identified, to provide a diagnosis. At the point of referral, parents are often highly stressed, believing that there is something wrong with their child and/or their parenting. Some children who presented with behavioural problems might have had undiagnosed ASD. Typically, the difficulties may be around executive functioning difficulties, such as routine tasks like getting up in the morning, getting dressed; and skills such as planning, switching (from one task to another), as well as working memory (Epstein et. al, 2008). Epstein emphasises why it is important to get the diagnosis right in the first place—so that we know what difficulty we are dealing with and how best to help (ibid).

### What is on offer for AS families?

The communication abilities of ASD children are quite different from that of a typical child. Managing their behaviour can be particularly challenging and needs careful thought and handling (Ozonoff 2002).

Generally the availability of support is patchy across the country. As I mentioned earlier, children can fall between statutory services. Each service is specialised and has its own criteria for referrals. For instance, a referral to CAMHS requires a mental health issue, and not simply a problem that is a result of having AS. If the child has average or above IQ, he or she would not fit the Learning Disability (LD) service because AS is not an LD issue. That leaves the family with only the support of various charitable organisations, such as National Autistic Society (NAS). Some counties have their own Asperger groups. Locally, we have Asperger East Anglia.

A number of training programmes have been developed in order to try to help the AS person to interact in a more typical way. Bogdashina explains that parent-training programmes are essential as '*1) the child and parent are together for a long time, and 2) parents need an understanding of their child in order to communicate and teach him/her*' (Bogdashina, 2006:218). In the USA, Steven Gutstein has developed a programme named 'Relationship Development Intervention' (RDI), aimed at working intensively with the parent and mainly Autistic child (although his programme is suitable for AS as well). Gutstein breaks social skills into two main areas: instrumental skills and relationship skills. His programme focuses intensively on relationship skills (Gutstein 2005, 2000). Gutstein states that parents and professionals can use this programme with children of all ages. He believes that during the first year of life something goes wrong, '*interrupting the natural joyful dances of parent and child that form the base for all future development*' (Gutstein, 2000: xi). He has worked with more than 200 children over many years. However, the programme is intensive and lengthy and, as it stands, would be difficult to fund in an NHS community setting.

Great emphasis has been placed on teaching social skills to AS children using behavioural strategies (Attwood 2004). One example of a behavioural support programme aimed at schools and parents has been developed by Rebecca Moyes. This is individually structured, with contracts and a format that sets out what the child, parent and school need to do in order to help the child to make the most of his/her education (Moyes 2002).

Another programme in use is 'Social Stories'. These are helpful in assisting the child to function in particular social situations. Stories are created often in cartoon form, for a given social situation. The story helps the child to learn a new skill or to have an understanding of a social situation. The child may then learn an appropriate response for that situation (Gray 1994).

Identifying emotions in others is one of the key deficits of children with AS. Attwood has developed a programme for AS children, to help them to identify emotions by using photographs or pictures of facial expressions (Attwood 2004). Whilst behavioural programmes are helpful with learning appropriate behaviour, they do not with help communication that requires feeling (Gutstein 2000). *'For AS children and their families, relationships are not the fun interactions that most of us encounter, but are stressful and confusing situations'* (Gutstein 2000: xi). *'The social world of children with Autism too often becomes an overly scripted or chaotically mystifying setting'* (ibid).

### What do AS children and families want?

In the documents *Every Child Matters* (2004) and the *Children Act* (2004), the government has set out a framework focussing on five key outcomes for all children in the UK. These state that *'every child should have the opportunity to be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being'* (DoH 2004). 3137 children and young people responded to the Every Child Matters document and amongst many things they said *'they agreed that the Government should help families at difficult times. They said practical support, counselling and guidance was needed to aid families who struggled'* (DofE 2004).

Beresford et al (2008) set out to talk to children who had ASD and their parents, to find out what they wanted. Beresford et al (2008) interviewed 25 families, including 28 children from 3-19 yrs. wherein the child was on the autistic spectrum. The interviews enquired about desired outcomes for the children's lives. Areas of worries highlighted by the parents were: communication difficulties, mental health concerns, social skills needed for everyday life, low levels of emotional and behavioural maturity, and—without exception—all parents prioritised improved friendships, as this was the basis to a good and happy social life. The common theme for the children was making and deepening friendships (Beresford et al 2007). From these findings Beresford et al suggest that, *'in order to reach these goals, a 'whole family' approach is needed, with interventions or support for the child and the parents'* (Beresford et al 2007:14). The National Autism Plan for Children also states,

*'That involvement of families in any therapeutic intervention is crucial. Helping them to develop social communication and teaching parents and where possible other family members, to understand and communicate with their child,*

*improves the parental and family self-esteem and their ability to cope'* (NAS 2003).

Beresford et al explain that children on the autistic spectrum were the least included in the research that contributed to the outcomes framework and may not have been included at all (Beresford et al 2007). The European Parliament's Declaration on the Rights of People with Autism says that people with Autism, '*have the right to be involved in all decisions affecting their future,*' and also '*as far as possible, in the development and management of services provided for their well being*' (Charter of Rights for Persons with Autism 2006). In his research, Preece (2002) concludes that consulting with children with autistic spectrum disorders is vital if the care services are to be successful. Including the children in my study was an important factor without which a vital voice would be missing.

### **THE PARENT- CHILD GAME**

Most parents do not receive training in child-rearing and usually base their parenting skills on their own experiences of being parented. For the vast majority this works reasonably well. However, when a problem arises with the management of difficult behaviour or, in more severe cases, when the courts are involved with delinquent behaviour, then help with parenting strategies is necessary (Jenner 1999). The PCG was developed from many parenting strategies with the common focus on catching the problem early (Jenner 1999). In 1968, the American psychiatrists Rex Forehand and Robert McMahon began putting their findings into a structured programme (Forehand and McMahon 1981). This eventually resulted in the development of the "parent/child game," a technique to enable parents to manage the behaviour of their young children with behavioural problems. The technique aims at fostering a good relationship between parent and child (Forehand 1981, Forehand and McMahon 1981, Forehand and Long 2002). In 1982, Jenner and Wolkind, and a team at the Maudsley hospital, developed the game in the UK (Jenner 1999).

Sue Jenner explains that the theoretical foundations for the PCG are in three areas. The first of these is social learning theory; which suggests that our thinking can be shaped by our experiences, in the same way that our behaviour has consequences (Jenner 1999). Children observe the models that they have around them and adapt their own behaviour to imitate those models (Newman, Newman 1999). Secondly, child development theory: explaining what an individual child is able to do (Jenner

1999) and what can be expected at a particular age and stage. This puts the child's behaviour and parents' expectations into an appropriate context of ability (Newman, Newman 1999). Thirdly, attachment theory: illuminating how experience of early relationships influences the way individuals function in society (Jenner 1999). A secure attachment to the main caregiver gives the child a feeling of security and confidence that sets the foundation for all future relationships (Murray-Parkes 1999).

### The technique

The PCG is structured to be flexible in its application. Following a referral, the family are invited for an assessment. The initial assessment includes: the family history, the development of the child and a detailed history of the most difficult behaviour. An individual plan will then be agreed between the parents and the therapist, taking into account that every family is different. The PCG sessions then take place in a family therapy suite, equipped with video recording equipment, as well as a viewing room with a one-way mirror and microphone link-up between parent and therapist.

The sessions are conducted in two parts. In the first part, the parent is asked to encourage the child to play with him/her for ten minutes. This is a free play session with a range of appropriate toys. The parent will have already been given instructions on how to interact with the child, using, praises, 'attends'<sup>4</sup>, smiles and warm touches. Within the literature about the PCG, this is termed as being 'child-centred' (Jenner, 1999:13). The parent is asked not to be directive or to try to teach the child during this part. The second part of the game is 'child-directive' and begins when the child is asked to tidy up. The focus now turns to put in place appropriate boundaries for the child's behaviour and sanctions for the parent to use. These may include 'time out' (to cool down) or warnings about making good choices. The programme usually runs for 6-12 sessions, one session per week. As part of the treatment programme, the parents are expected to commit to practising the technique at home every day for 10 minutes between treatment sessions.

With parental consent and a signed agreement to that effect, the sessions are video-recorded. The recordings are available for subsequent analysis by the team, as well as for use with the parent and/or child as a learning tool. If parents do not agree to video recording of the sessions, then therapy continues without the use of this equipment. If sessions are video-taped then the videos/DVDs are stored with the child's file and

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<sup>4</sup> An approving statement, 'Describing out loud to your child, with warmth and enthusiasm, what they are doing' (Jenner 1999:14)

treated as a record of therapy, in the same manner as with written files. *'By means of the free play sessions; the parent is encouraged to build a positive relationship with the child with guidance and encouragement from the therapist'* (Jenner 1999:13).

As I mentioned earlier the PCG has been well researched with children with behavioural problems; however I could not find any evidence of it being studied with children with ASD. There is evidence that the PCG helps the quality of the parent/child relationship, with a significant by-product being the positive improvement in other family relationships (Forehand and McMahon 1981).

### The adaptation

The PCG is one intervention that I offer at the local CAMHS team. In my experience, it works well when families are motivated and committed to change. However, over time I noticed that it was not having the good effects within the rising referral population of ASD children. It was at this same period of time that my young step-son was diagnosed with Asperger's Syndrome. My husband and I also realised that the usual way of parenting that had worked with our other children was not working in his case. Thus I began to explore ways of working with and understanding the ASD spectrum of children.

I decided to make a small adaptation to the PCG to increase the playfulness of the parent/child interaction and to facilitate facial contact in a fun way. Seach (2007) discusses the importance of play as interaction and specialises in children with Autism. Gutstein (2005) talks about 'spicing up communication' and 'amplifying facial expressions'. Because AS people often *'do not understand facial expressions they tend to avoid visual facial contact'* (Ozonoff et al 2002:62). Adults, when wanting a child's attention, will tend to say 'look at me'; this can cause distress in a child with AS and it becomes the occasion for a battle (Attwood 2004:54). Nonetheless, facial contact—and particularly eye contact—is crucial in normal communication. During the PCG, whenever I noticed that the relationship between the parent and child was strained (whether or not the child had AS); it was usually the case that the parent and child had stopped looking at each other—even when there was a good level of verbal communication. The lack of eye contact clearly led to a gap in the level and quality of their interaction. Using Seach and Gutstein's, ideas I set about thinking up a few very simple games that would encourage facial and eye contact that could be fun and could be incorporated into the PCG. This exploration sometimes involved lovely, long play sessions with my grandchildren who were a wealth of information and creativity.

One game that all the children enjoyed was a form of a game I played as a child: 'hide the thimble'. This involved one person going out of the room whilst the other person hid a thimble. Once the thimble was hidden, the person outside came in and searched for it, with clues being given by the hider as to whether the seeker was getting warmer or colder as regarded the location of the hidden thimble. I decided to exclude verbal communication in the PCG, when the child had AS, in order to encourage facial contact and use expression in a non-threatening and fun way. The child chose the facial expression to let the parent know whether they were warmer or colder; usually they chose a smile for warmer and a frown for colder. All of the parents and children seemed to enjoy this game although some took time to really catch on.

### **AIMS OF THE RESEARCH**

The aim of the study was to explore parents' and children's experiences of the adapted PCG wherein the child has ASD; and more specifically, those with High Functioning Autism or Asperger's Syndrome. The study aimed to gather parents' and children's personal experiences of the game and their personal perceptions of its efficacy.

My research questions therefore were: What are parents' and children's thoughts, feelings and perceptions with regards to their experience of the PCG? Do parents and children who have undertaken the PCG perceive it to be effective? If so, in what way(s)?

#### **Summary**

In Chapter One I have briefly introduced the context of Child and Adolescent Mental Health as a service. I then set out the structure of this thesis.

The background literature search highlighted the difficulties around the lack of definitive diagnostic criteria. There are still five different sets of criteria in use, all with slightly different requirements. This makes obtaining a diagnosis variable, to say the least. The ripple effects from this are that professionals and parents are often left with uncertainty. Research results have to bear in mind that their populations may vary according to the diagnostic criteria used, therefore making both generalisation and comparison with other studies difficult. The literature also showed that many of the diagnoses seem to overlap, thus adding to the lack of clarity in making a diagnosis.

It was clear from the literature that family stress—particularly maternal stress—was common with ASD children. There was also an obvious lack of support in many areas:



at home there was little respite and in school there was little understanding shown by the school staff. Although there appeared to be many interventions available for ASD children and their parents, they were very specific, limited in access and time-consuming. It was illustrated by the literature that many interventions had not been evaluated and there was little evidence that they were efficacious. The literature about the PCG showed that it had been well researched with a population of children that had behavioural difficulties, but not those with an ASD diagnosis. Through this research I hoped to close the gap and clarify whether an adaptation to the PCG could render it more helpful for children with ASD and their parents.

In Chapter Two I develop my reasoning for using a narrative methodology and subsequent analysis.

# **CHAPTER TWO**

## CHAPTER TWO

### METHODOLOGICAL CONSIDERATIONS

The purpose of the research was to explore the experiences and perceptions of parents and their children who have completed the adapted PCG. The study's aims were to gather parents' and children's personal experiences of the game and their perceptions of its efficacy. Therefore my research questions were: What are parents' and children's experiences of the PCG? Do parents and children who have undertaken the PCG perceive it to be effective? And, if so, in what way(s)?

A narrative method was used to collect the data through retrospective, semi-structured interviews with parents and their children with AS. Purposive sampling was used to generate the sample for the study. Parents and children were specifically identified if they had undertaken the PCG and the child had Asperger's Syndrome; these were a small and unique group. However, all families from that group were invited to participate in the study once they had finished the game; this was through the year 2009. Purposive sampling was also used to select five Key Informants, who again were interviewed using a semi-structured approach in order to elicit their experiences of working with similar families. I chose the Key Informants from professionals who worked with ASD children and their families, but not within the mental health setting—in order to reflect a wider perspective. The Key Informants came from a diverse range of professional backgrounds. Key Informants can add useful insights about the study group (Creswell 1998). Schensul et al (1999) explain that Key Informants offer a deeper or broader knowledge on a particular topic. They have gained their knowledge from a specific position and can offer insights and information that few others can provide. Schensul et al go on to suggest that '*it is good practice to interview a number of Key Informants from different standpoints, allowing for cross checking, which can add to the validity and reliability of the study*' (Schensul et al 1999:84).

#### Qualitative research

Narrative inquiry emerged from the broader field of qualitative research. As Pinnegar and Daynes (2007:4, 30) explain, qualitative research is characterised first, '*by forming assumptions about interpretations of human action, and secondly, by its focus on understanding, rather than prediction and control*'. This distinguishes qualitative research from quantitative research. Denzin and Lincoln (2003:3) assert that '*qualitative research cuts across disciplines, fields and subject matters*'. They go on to say that although it is a field of inquiry in its own right; it is very complex, with

interconnected terms, concepts and assumptions. Qualitative research is also recognised as having its own history in a number of disciplines such as: *'education, social work, communications, psychology, history, medical science, anthropology and sociology'* (Denzin and Lincoln 2003:39). Narrative form is used across and within the qualitative research traditions: biography, phenomenology, grounded theory, ethnography and case studies, to name only a few (Creswell 1998:65 table 4.1).

Pinnegar and Danes illustrate their ideas about how qualitative research evolved from the previously accepted modes of quantitative methods. They explain their ideas of this evolution as a series of turns (Pinnegar and Daynes 2007). The turns are points along the way where researchers have changed their thinking and made a significant shift in their perspective. The shifts were challenges to the positivist assumption that there is a truth "out there" to be found, based on the ideas of standardisation, neutrality, linear causality and objective truth (Lincoln and Guba 1985:28). Denzin and Lincoln cover the same developments by using the term 'moments' (Denzin and Lincoln 2008).

Researchers began to accept that their role of being *'objective and in control'* was not, in fact, born out in practice, as had been previously assumed. The idea of the objective researcher seeing the human person as an object of study was being eroded, and so began the move towards a relational interaction wherein both parties learned from the particular experience (Pinnegar and Daynes 2007). Lincoln and Guba (1985) compared the positivistic or scientific research method (ibid: 1985:19)—*'in which the knower and the known are independent—with the naturalistic method, in which the knower and known are inseparable'*. Lincoln and Guba (1985), as well as others, suggest that it is not possible to be completely independent/objective, nor can the effects of the investigator/respondent interaction be eliminated from the research equation, even if researchers so desired.

Lincoln and Guba (1985) assert that generalisations do not apply to the particular. Qualitative research is not about prediction and control. Clandinin and Connolly (2000) also suggest that there can be many interpretations of a single event; yet all are equally valid. This move is away from the scientific conception of validity, which suggests there is only one valid way of knowing (Pinnegar and Daynes 2007).

### Qualitative Methodologies

Strauss's and Corbin's methodology is known as *'Grounded Theory'* and seeks to discover or generate a theory. It employs interviews which continue until 'saturation' is

reached; that is, until no new themes or ideas are emerging. This could take up to 20 or 30 separate interviews (Creswell 1998). The transcripts from the interviews are analysed using various levels of coding. The codes are labelled and the process continues re-coding until selective coding is decided upon. The key to Grounded Theory are the theoretical insights that are developed (Green and Thorogood 2005). They go on to say that the process of reaching saturation point is time consuming and is difficult to attain within the time constraints of health research. Grounded Theory seeks to find a theory based upon people's experiences at a specific time; whereas the narrative method looks at the experience based in its context and from past to future experiences.

Ethnographers often immerse themselves in a particular culture and may also observe or live with the ethnic group for extensive periods (Creswell 1998). The information sought in ethnographic studies is often societal or cultural experiences, rather than personal. It takes time for the researcher to become sufficiently immersed in the culture in order to understand the experiences gathered (ibid 1998). Ethnography looks at how people in everyday life make sense of what others do and say (Green and Thorogood 2005). Exploring and analysing experience per se is not the focus of ethnography.

Phenomenology is another qualitative method that may use interviews to elicit information. According to Lester (1999:1), phenomenological research is '*powerful for understanding subjective experiences, gaining insights into people's motivations and actions*'. According to Starks and Brown Trinidad (2007), the phenomenological approach focuses on the meaning that people make of their experiences. Although both narrative inquiry and the phenomenological method examine experiences, in my study I focussed on people's experiences in themselves, rather than the meaning they made of those experiences, as phenomenological research does.

Personal experiences are often represented in story form, and narrative inquiry seems to be the best way to capture and represent those experiences. Allen and Cloyes (2007:100) say that to '*study experience language should be looked through to the private minds of the participants*'. That is not to focus on the language itself but to look beyond and through it to the experience behind that is being portrayed. The language itself then is not the focus of narrative analysis.

## Narrative inquiry

Since the 1960s, narrative inquiry has permeated into every discipline and profession (Riessman and Speedy 2007).

*‘Contemporary narrative inquiry can be characterized as an amalgam of interdisciplinary lenses, diverse disciplinary approaches, and both traditional and innovative methods—all revolving around an interest in biographical particulars as narrated by the one who lives them’* (Chase 2008:58).

Narrative inquiry, however it is conducted, seeks to interpret and understand a particular *experience*, whether it is that of an individual, a group, a society or a culture. Because the main focus of this study is on individual personal experience, I consider narrative inquiry as an appropriate method for the research.

Over time, *‘narrative inquiry has emerged as a distinct methodology, at the centre of which is the ‘story’—the most essential element that accounts for human experience’* (Pinnegar and Daynes 2007:4). Individual stories, biographies, auto-biographies, diaries, letters, memoirs and interviews have a great deal to teach us about human experience.

As with the narrative method as a whole, Riessman (1993) avers that there is a great difference of opinion as to what narrative inquiry actually is. Narrative inquiry can take many forms, such as poetry, story, or conversation. The type of enquiry will determine the type of analysis and therefore the type of interpretation. Narrative inquiry *‘embraces narratives as both the method and the phenomena of study’* (Pinnegar and Daynes 2007:5).

In its simplest form, narratives are personal stories created from particular periods of time past, re-presented and with a link to the future. Narratives are person-centred and allow *‘the study of the experiences of people in context’* (Holloway and Freshwater, 2007:15).

I have chosen a narrative approach because in the health profession it is particularly important to hear the client’s/patient’s voice, to give space to hear their lived experience of a service or treatment (Holloway and Freshwater 2007). Through narrative inquiry, health professionals can gain a deeper understanding of clients’ perspectives and insights, leading to more appropriate treatment and care pathways. Through listening to their experiences we gain the patients’ perspectives and an

awareness of their needs, rather than the specialists' ideas of needs (Holloway and Freshwater, 2007).

Narrative Inquiry offers a framework that can focus on a particular area of study, but with enough freedom to allow the participant to *tell it as it is*, enabling their voice to be heard. This corresponds with my way of working in my role as a nurse therapist. I am guided by clients telling their stories and by accompanying them on a journey of exploration to new insights and possible change.

### Can experience be studied or understood?

Denzin and Lincoln (2000) examined claims that personal experience cannot be truly represented or evaluated. They suggest that ultimately the experience is evaluated and written by researchers, therefore transforming it into the researcher's representation, rather than the narrator's own story. The impact of this has led researchers to scrutinise and further develop their methods. They have also begun to question previous assumptions about participants' experiences, the telling of their stories and the researcher's role in gathering and analysing the findings. This throws new light onto concepts such as: validity, generalizability and reliability (Denzin and Lincoln *ibid* 2000).

Denzin and Lincoln (2000) suggest that once an experience has happened, in order for it to be told, words have to be chosen to describe it. Therefore it becomes a representation. They propose that autoethnography (the study of one's own experiences) may be the only way to study experience. This method uses reflexivity as a key element in order to capture one's own experiences. Lincoln and Guba (2000) state that human unconsciousness is not accessible to science and thus not truly knowable. Gubruim and Holstein (2000) imply that the processes in the unconscious are so enmeshed, we are not aware they are being generated. Does this then suggest that we cannot even study our own experiences? Clandinin and Connelly (2000), along with many others, believe that personal experience can be studied. Dewey (1916) believed that experience could be studied and, in fact, states that an event *only* becomes experience once it has been processed. He goes onto to say that if an event happens that is not consciously processed, then it is not an experience; it is in the processing that it becomes an experience. The *Oxford English Dictionary* also describes 'experience' as requiring conscious processing in order to be an experience:

1. *'An action of putting to the test, to make experience of, to make trial of.'*

4. *'The fact of being consciously the subject of a state or condition, or of being consciously affected by an event. A state or condition viewed subjectively: an event by which one is affected.'*

(*The Compact Edition of the Oxford English Dictionary* 1971:930).

Bochner (2001:154) puts it in plain words: *'The call of stories thus inspires us to find language that is adequate to the darkness and obscurity of experience. We narrate to make sense of ourselves and our experiences over the course of time.'*

Mankind has been sharing experiences for thousands of years—be it in picture, oral, or written form. An example of one of the earliest written epics from ancient Mesopotamia in which the hero, Gilgamesh, relates his experience of the death of his friend Enkidu (translated by George 1999:81).

Clandinin and Connelly (2000) consider that the best way to study experience is through narrative, and that narrative is central to thinking about and understanding experience. Clandinin and Connelly's work expands Dewey's original ideas in the field of education on narrative inquiry and experience. According to Dewey (1973), the term 'experience' has much more meaning than is found in its everyday usage. Dewey understands human experience to be not simply on an individual (internal) level, but also on a social (external) level, and that both happen simultaneously. He also describes human experience as being a continuum: an experience evolves from a previous experience, to the present, and will again move to a future experience. This underlying concept necessitates that the inquirer hold in mind the fact that whatever is being considered has not occurred in isolation, nor is it static. Studying experience becomes a complex and multi-layered task. Dewey believed that *'experience is a fundamental ontological category from which all inquiry, narrative or otherwise proceeds'* (Dewey 1973: 43).

Clandinin and Connelly (2000:50) conceptualised Dewey's original theory by using the term *'three dimensional inquiry space'*. This incorporates the notion of time, place and interaction of the experience under inquiry.

Individuals may perceive different things from the same experience. This does not take away from any one experience. Clandinin (2007:42) talks about beginning inquiry with respect for an ordinary lived experience; that *'narrative inquiry is an exploration of the social, cultural, and institutional narratives within which individuals' experiences were constituted, shaped, expressed, and enacted'*.



There are many examples of perspective, for instance: the way in which we view a globe. Whatever perspective we choose to view it determines which landscape is in view and therefore whether we see ice, green fields or desert. However, it is still the same globe. Every experience, as it is described, emerges from a particular perspective loaded with previously lived experiences.

### Interviews in Narrative Inquiry

As humans, we have conversations as part of everyday life (Riessman 1993). It is in and through the telling that we create our unique view of an experience. Narrative inquiry draws on this natural phenomenon in order to hear and understand participants' perceived experiences. Therefore conversation, in the form of an interview, is often used in narrative inquiry in order to hear peoples' stories (Riessman 1993).

Interviews may be structured in different ways, often dependent upon what the interviewer would like to know. A semi-structured interview provides a framework for the focus of a topic of inquiry, yet gives space and freedom for participants to elaborate on their experiences. This differs from a structured interview, which would generally adhere to a list of oral questions or a written questionnaire, and in which the participant's answers are restricted to the given questions—without further elaboration (Fontana and Frey 2000). Alternatively, there are unstructured interviews wherein the participant is given an opening question, with the interviewer then following the participant's lead wherever the topic may go (Fontana and Frey 2000). Interviews can be between individuals or within groups and can include face-to-face, telephone conversations and even written correspondence (Fontana and Frey 2000). Clandinin and Connelly (1994: 417) suggest that it is the '*researcher's goal which determines the beginning and end of an interview*'. This, in turn, is determined by the information sought and the methodology employed.

Mishler (1986), like Riessman (1993), emphasizes that the narrative interview should evolve in the form of a conversation. This then becomes a collaborative encounter between the narrator (participant) and listener/questioner (interviewer), in which together they produce and make meaning of the experiences and events of the narrator.

Clandinin and Connelly (2000) also discuss the impact the interview has on participants. As they think through and talk about their experiences, new insights might emerge in the re-telling which, in turn, may motivate change. Therefore the experience will again be 're-storied'.

The Department of Health (February 2009) set out strategies for children's and young people's health, emphasising the importance of hearing the voices—not just of the commissioners and clinicians—but also of the children, young people and their families. Service user involvement has grown, not just in research circles, but also in advising and influencing services. A National Advisory Group was set up to conduct a national CAMHS review (2008) and utilised a high level of user involvement in their research, thus giving the services a vital perspective that had been previously missing.

As my work involves working with and listening to adults and children, it was important that my research included both adults and children. The narrative inquiry method offers a mode of exploration of experiences that is amenable to individuals, whatever their age.

### Reflexivity and insiderness

Reflexivity, according to Horsburgh (2003:308), refers to *'the acknowledgement by the researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience'*. One method of demonstrating reflexivity is for the researcher to use the first person at points in the research where he/she has personal input (Horsburgh *ibid*). In order to attain the rigour required for good qualitative research, researchers need to be aware of their own thoughts, feelings, culture, gender, environment and personal history, as well as and their subsequent impact on the researched. This is necessary throughout each stage of the study (Etherington 2004). Reflexivity can also help to balance the power in the relationship, helping it to become more collaborative. Speedy, in her discussion of good and real reflexivity, likens it to *'being held in a hall of mirrors'* (2008:30). She goes on to explain that *'everything we do and everything we write is reflexive'*. For me, this analogy encompasses the complexity of the task, not just a mirror, but a *hall* of mirrors—giving and receiving feedback between researchers and researched (a circular exchange of information) from every angle and level. Etherington (2004) goes on to suggest that interpretations are better understood by the readers if they are informed about the researcher's position within the research process.

Being completely objective is clearly unachievable; however researchers need to work towards identifying the factors that influence the research process. Peshkin (1988) discusses how he interrogates his own subjectivity continually throughout his investigations and suggests that it needs to be identified during the process of the study, not retrospectively. Lincoln and Guba (2000) agree with Peshkin that we must be thorough in questioning each of the roles or 'selves' we bring to the study.

I have trained in child mental health, as well as in psychotherapy with children and adolescents. A part of my role has been working with parents and children around attachment and relationship problems. This requires a high level of ability to empower parents and children to reflect on their relationship difficulties and successes. From my experience of clinical practice, it is these reflective skills that make narrative inquiry the most natural way for me to conduct research. Etherington describes it as, '*to be transparent in their relationships "letting slip the cloak of authority" with clients as a way of addressing the imbalance of power in therapeutic relationships*' (Etherington 2004:30).

During the interviews and the analysis, I was aware that there were times when I had moved between *researcher* and *therapist*. Holding the tension between these two positions proved to be a more difficult task than I had anticipated. Regular discussions and reflections with my supervisors helped me to identify some of my biases and role conflicts. In retrospect, it was at those particular times that I became aware of the process described by McIntosh (2010): of becoming a practitioner-researcher. My role as the therapist with each of the mothers and children clearly played a part in the interview process. At one point in an interview, Susan asked me if I thought her son was schizophrenic. I was very aware that I struggled to respond as a researcher and not as a therapist. Each mother and child interviewed had previously known me as the therapist, and I was aware that they might have continued to relate to me in that role. I not only brought my roles as therapist and researcher to the encounter, but my many 'selves' as well: mother, step-mother of a child with Asperger's Syndrome, grandmother, daughter and lecturer, to name a few. Thus the issues that the participants talked about—particularly the diagnostic process—were also personal to me.

Breen (2007:165) discussed her '*middle ground position*' when interviewing families who had experienced loss through traumatic motor accidents. Breen described herself as neither an insider nor an outsider. She had some experience of loss, but not in the same way as had the participants in her study. Breen, along with others, preferred to see the situation as on a continuum. Weston (1996) agreed with Breen and discussed her struggle of feeling that she was neither an insider nor an outsider, and yet both. To be reflexive, we must identify, examine and challenge our own thoughts, feelings and biases—whether they are cultural, personal, or societal—in order to be transparent in the research process (Hardy et al. 2009).

As with Breen and Weston above, I found myself an insider, and yet, not quite, as I was not a birth parent of an AS child and was not the main carer. Nevertheless I was a step-mother and had lived with a child with AS. As the therapist, I also had detailed knowledge regarding certain aspects of the participants' lives, as they had shared their struggles and worries during the sessions when we had previously met.

The hall of mirrors that Speedy (2008) described, and my experience of interviewing, led me to create the flow diagram in Figure 1.

**Figure 1** offers a representation of the transfer of information between two people: in this case, a one-to-one interview situation.

The bold colour in each individual case represents the initial encounter; this does not suggest that individuals come to the meeting without previous influences or experience. In fact, each brings to the encounter all of their prior knowledge and experiences. Each would bring, whether known or unknown: values, beliefs and perceptions about themselves and their experiences, and about the person they are due to meet and their expectations of the encounter.

The interaction is therefore *ready loaded* with information that will influence how each person hears, observes and responds to the interaction.

It is within this context that I, as the therapist/researcher interviewer, attempted to elicit the experiences of parents and their children.

As the researcher interviewer, I brought to the interview, information, perceptions and experiences—as did each interviewee. I had the research questions in my mind, as well as previous information about each individual derived from being their therapist. When an interviewee answered a question, their response was taken by me and filtered through all of the knowledge already held by me. Some of that knowledge and filtering I would have been aware of; some of it I would not. As the response was processed in my thinking, my conscious mind chose what to focus on in response to them. And so it goes on: the process of taking, filtering, adding to or dropping information and then responding to them. The diagram may go some way to show the multi-layered complexity of an interaction.

FIG 1

## THE STUDY

### The sample

Purposeful sampling seemed appropriate due to the limited population that could take part in the PCG. As Green and Thorogood (2005:102) explain, '*purposeful sampling consists of explicitly selecting participants who will produce data on a specific topic*'. Also, the Key Informants were chosen from among diverse professions, each having direct working experience of children with AS, but not working in child mental health, as I was.

Given the small population who had undertaken and finished the PCG within the time-frame of the study (during this time seven families had taken part in the PCG). It seemed that four parents and four children made an optimal sample size. The inclusion criteria were parents and children who had taken part in the PCG—specifically wherein the child had a diagnosis of AS and no more than two other diagnoses. Because the children were clients of a CAMH service, they would have had at least another diagnosis. Children accepted into a CAMH service require a mental or emotional problem and not solely a developmental disorder such as AS. I decided to limit the number of diagnoses for each child to no more than two in order to reduce the complexity of the picture for each child. *All* families who met those criteria within the time frame of the study were invited to take part.

Initially, as a pilot, I invited for interview the last parent that took part in the PCG before I made the adaptation. I have included that interview in the study. The rest of the families were invited as soon as they had completed the PCG, and were sent a letter of invitation for interview from me (appendix 4). They were also sent an information sheet for adults (appendix 5) and one for children (appendix 6), a consent form for adults (appendix 7), and one for the child (appendix 8).

In all, seven families were invited. Three families did not respond. One mother initially responded, but after three cancellations on her part, I decided to forego the interview. Three other mothers responded and were interviewed; and two mothers gave permission for their children to be interviewed. Two children, one aged nine years and one aged ten years, were interviewed. No fathers took part in the study. Once a family had responded by returning their consent forms—including a contact telephone number—I called them to arrange the interview. The families were given a choice of venue for the interviews: either a room at the centre (not where the PCG had taken

place) or at home. One mother chose to be interviewed the centre and two chose to be interviewed in their homes. Of the two children, one mother chose for her son to be interviewed at the centre and the other chose her home.

Ten Key Informants were invited for interview by letter (appendix 9); they were also sent an information sheet (appendix 10) and a consent form (appendix 11). Four Key Informants initially responded. I was later contacted by a fifth, as she had heard about the study and requested to be interviewed. In fact, she had been one of the ten who had been initially invited, but had not received my letter. I therefore interviewed five Key Informants. The Key Informants' expertise was to add context to the findings and to broaden the perspective and knowledge on family life with an AS child, relationships and the wider issues. The Key Informants had not necessarily worked with the same families and would not be questioned about specific families (who would remain anonymous). The Key Informants were invited for interview as soon as ethical approval was given. Once a Key Informant had agreed to be interviewed (by returning the signed consent form along with a contact telephone number), I telephoned him/her to arrange a time and place that was convenient. As with the families, Key Informants were asked where they would prefer to meet.

### Participants

All names have been changed in the interest of confidentiality.

**Participant 1:** Susan was a single mother with one child at home: a boy, Billy, aged eight years old. Susan also had an older son who was grown and living independently. Billy had a diagnosis of HFA, ADHD (Attention Deficit Hyperactivity Disorder) and Pica (the desire to eat unusual things). Susan was interviewed at the centre but declined her son being interviewed. Susan and her son had attended the PCG before I made the adaptation.

**Participant 2:** Sharon was a mother of two boys: Peter, aged ten years old with diagnoses of AS and ADHD (participant), and Jack, two years old with a diagnosis of Autism. Sharon's partner Bill, the father of both boys, attended the PCG sessions, but declined to be interviewed. Sharon chose her interview to be at home and Peter's interview to be at the centre, on different days.

**Participant 3:** Jane was the mother of three children. The eldest was Ellis, aged nine years, with a diagnosis of AS. Jane and her husband Mark had three children: Ellis

aged nine years, Alex, aged eight years, and Olivia, aged three years. Jane chose for her and Ellis's interviews to take place at home and on the same day.

**Child 1:** Peter was 9 years of age and the oldest son of Sharon and Bills two boys. Peter had a diagnosis of Asperger's Syndrome and ADHD. Peter's interview took place at the centre, in a room different from the PCG. Peter was given the option to be alone with me or to have one of his parents present; he chose to bring his mother Sharon. Peter brought two toys with him but did not use them. I offered a number of activities; he chose the play dough, which he used whilst we talked.

**Child 2:** Ellis is the oldest son of Jane he was nine years old and had a diagnosis of Asperger's Syndrome. At their request, I interviewed Ellis upstairs in his bedroom and then interviewed Jane downstairs in the sitting room. They were not present for each other's interview and the other children were not in the house.

### Key Informants

**Key informant 1** was a Speech and Language Therapist, specialising in ASD. She opted to come to the centre to be interviewed.

**Key informant 2** was a support worker for a charitable, special needs organisation. She opted to come to the centre to be interviewed.

**Key Informant 3** was a manager of a service offering a specialist music and movement activity for children with ASD; she opted to be interviewed at her place of work on a day when there were no activities.

**Key Informant 4** was a specialist behavioural support worker in education; she chose the centre for her interview.

**Key Informant 5** was an Educational Psychologist; the interview was conducted at her office building in a room booked for this occasion.

### Data collection

Semi-structured interviews were the major research tool used for eliciting the data. Interviews give a context to the gathering of people's experiences of a particular event. The semi-structured interview gave some form to the interview session, yet allowed for the participants to tell their stories using their own words. This structure allowed space for the participant to give as much depth of information as he or she wished. *'In order*



*to get the depth of understanding the design must remain flexible*' (Rubin and Rubin 2005:35). A list of possible questions were prepared, but I remained flexible about whether they would all be used or in what order (appendices 12 and 13).

I found semi-structured interviewing appropriate for the narrative method. Participants had the opportunity to talk about their experiences on a specific topic (e.g. the PCG), and could include family and life influences that were salient at that particular time.

Open questions were also used to aid the participants in the process of describing their personal stories. Open questioning can help reduce possible influences that direct questioning may bring about (Holloway and Freshwater 2007). *'Open questions have the following characteristics: They ask the respondent to think and reflect; they will give you opinions and feelings, they hand control of the conversation to the respondent'* (Straker 2008).

There could be disadvantages to the semi-structured approach, for example: the potential loss of control of the interview.

Interviewing children may present challenges as well as opportunities. I work with children daily and they never cease to amaze me with their responses and personal insights. The power imbalance in the research interview relationship is one that needs consideration and sensitive handling. This is especially true with the child-adult dynamic. Eder and Fingerson (2003) discuss a range of modes to facilitate child interviews. One way they consider, and one which I used for my study, was for the child to be engaged in an activity that they enjoy. This way the child is relaxed and the interview can feel informal. Eder and Fingerson (2003) also discuss using open ended questions with less focus on getting the research questions answered, but to let the process flow naturally. In my study, I interviewed Ellis in his own bedroom. He was relaxed, surrounded by his own things and spent a good deal of the time showing me his fossil and dinosaur collection—as well as his special teddy bear. Peter, on the other hand, came to the centre, with which he was familiar, and used the play-dough while we talked. Eder and Fingerson (2003 *ibid*) also suggest one way to address the power dynamic, is to enhance the reciprocity in the relationship. In my study, I tried to make the interaction as natural as possible—more like a conversation (reciprocal) than an interview—and to take a genuine interest in the child and what he had to say. I recorded all of the interviews, but found it difficult to make notes at the time as I was focussed on the interaction between us.

## ETHICS

The National Research NHS Ethics Service gave ethical approval in October 2008 (appendix 2) and the East Norfolk and Waveney Research and Governance Committee gave approval in November 2008 (appendix 3). The study took place between November 2008 and February 2010, in a coastal town in Norfolk, although one Key Informant was from a more central location in the county.

Narrative research, by its nature, encourages people to share their stories and experiences—and therefore some element of themselves. '*Narrative research has components of research and therapy*' (Holloway and Freshwater *ibid* 2007:56). In narrative telling, new insights can occur and a change in thinking or re-construction of the story/experience may take place. In research, as in therapy, this may need sensitive handling. During my interview with Susan, she began to reason that perhaps she should have allowed her son to play more freely during the PCG, rather than having tried to keep him calm. It was through the process of the interview that she realised there may have been benefits for allowing a more natural dynamic to occur.

What researchers do with people's personal and private information during the analysis is also important. To be mindful of personal information and how it is used—not just for research purposes—but with regard to the impact on participants when their stories are interpreted by another, requires sensitivity (Holloway and Freshwater *ibid* 2007).

I adhered to the practices of confidentiality: all names were changed from the point of transcription and identifying information has either been changed or omitted.

### Informed consent

When conducting research with human beings, it is key to ethical practice that there be informed consent (Holloway and Freshwater 2007). The concept of informed consent is underpinned by the notion that taking part in any research is completely voluntary. Informed consent requires that the participant has all the information necessary to understand what will happen throughout the process. This includes the right to withdraw at any time, without giving a reason (Green and Thorogood 2005).

Researchers of all disciplines have a duty to 'do good' in research (beneficence) and 'not to do any harm' (non-maleficence) (Green and Thorogood *ibid* 2005). The code of ethics was drawn up by the World Medical Association in 2000 and has become known as the Declaration of Helsinki (Green and Thorogood *ibid* 2005).

I feel that I applied these ethical practices in a number of ways. My initial contact was by letter, along with an information sheet. The parents were then in control as to whether they wanted to take part or not. I requested that they return their signed consent forms to me and include a contact phone number. The latter was so that I could call them to arrange an interview at a place and time that was most convenient to them. Thus the control remained with them. The letter also explained that they could stop the interview process at anytime without having to give an explanation. The parents also had control over whether or not they involved their child. They also explained to their child, in their own words, the nature of the research and what would happen. It was in this manner that the parents gained assent from their child. Signed consent was obtained from each adult as well as consent from the parents for their child to be interviewed; the child signed (assent) an agreement to take part (World Medical Association 2004).

The parent had the choice of time and venue for their child and I gave the child the option to be interviewed alone or with someone else present. I anonymised all participants and their information.

### Research with children

Research with children has further potential difficulties, in that they are a particularly vulnerable group of the population. The National Children's Bureau (2001) has set out in their research guidelines the values and principles to be used when conducting research with children. According to the Declaration of Helsinki (World Medical Association 2004), in the case of children who are not legally able to give informed consent, '*researchers must then gain informed assent*' (Greig et al 2007:174). '*The adult with parental responsibility should give consent as well as obtain the child's assent*' (Greig et al ibid 2007:174). The Family Law Reform Act 1969 gave young people between 16 and 17 years of age the right to consent to treatment. This can also include younger children, if they understand the consequences of their decision (Greig et al 2007). In such cases, the child is what is commonly referred to as being 'Gillick competent'<sup>5</sup>—or that the— 'Fraser Guidelines' have been applied (NSPCC 2009).

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<sup>5</sup> **Gillick competency and Fraser guidelines** refer to a legal case which looked specifically at whether doctors should be able to give contraceptive advice or treatment to under 16-year-olds without parental consent. But since then, they have been more widely used to help assess whether a child has the maturity to make his or her own decisions and to understand the implications of those decisions (NSPCC 2009).

*'Whether or not a child is capable of giving the necessary consent will depend on the child's maturity and understanding and the nature of the consent required. The child must be capable of making a reasonable assessment of the advantages and disadvantages of the treatment proposed, so the consent, if given, can be properly and fairly described as true consent'* (Taylor, R. 2007).

## ANALYSIS

Narratives, as Riessman (1993:4) puts it, *'[are] meaning-making structures, narratives must be preserved, not fractured by investigators, who must respect the respondent's way of constructing meaning'*. This is respectful both of people as well as the experiences they are willing to share. The training I undertook in mental health and psychotherapy incorporated the greatest respect for an individual's personal/sensitive information. It stressed the need to avoid over-interpretation or dissection of a person's story. This aspect of my clinical training, coupled with Riessman's statement above, helped me to focus what I wanted to achieve in this study.

Reissman states *'that there is no canonical approach in interpretive work, no recipes and formulas'* (Reissman 2007:69). Peräkylä (2008) states that there is no pre-defined protocol for narrative analysis. However, by reading and re-reading the material, the key themes do come to light, thereby illuminating the meaning of the transcript. Peräkylä goes on to say that this process may be the method of choice, for instances wherein text analyses are not the core of the research (Peräkylä 2008). Clandinin and Connolly (1994:417) use the descriptor *'personal experience method'*. They later suggest (2000) that the most beneficial starting point for analysis is the exploration of the experience itself. This is achieved by reading and re-reading the text, and is the process of understanding and making an interpretation of the narratives. In the early stages of analysis, interim texts are formed—preliminary thoughts and interpretations that will be changed as new insights and new depths are exposed in the re-reading. Keats (2009:191) describes the need to look for relationships *between* the texts, not just the similarities, *'but also the differences and contradictions'*. Keats uses the term *'inter-textual'* readings, which is reading across the different participants' stories in order to find the related themes (Keats 2009:191). With Keats' methodology in mind, in

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combination with those of Clandinin and Connolly (2000), Riessman (1993), Crossley (2000) and Speedy (2008), I attempted my analysis of the interview stories.

### The process

As stated above, I transcribed the first three interviews, and the rest were completed by a medical secretary. In the cases in which I had not transcribed the interviews, I listened to the audio-tapes and made corrections as necessary. The transcriptions were then sent to each participant for verification. I did not hear from anyone concerning their transcripts.

I read each transcript a number of times so that I immersed myself in the data. I often did this along with listening to the audio-tapes and making some initial notes in the margins of the transcript—using the ‘review’ facility on the computer program. In this way, the themes and topics began to emerge. This is in keeping with Keats (2009), who explains that following the generalised readings of the texts, specific readings follow; this deepens the focus on the relevant aspects of the participants’ experiences, with regard to the research questions (Keats 2009). Themes stood out whenever a number of the participants brought up the same issues. If one participant gave a different perspective from the majority of the others then I highlighted it, with a possible interpretation as to why that person might have seen it differently. Discussions were held with my supervisors, who offered their possible insights, interpretations and explanations. Eventually the main themes were identified for each individual interview; I then followed the main/common themes across the family interviews. I decided to group the two mothers and their respective children together, because they talked about the same times and events of the PCG.

I carried out the same process with the Key Informant transcripts; first identifying themes in individual interviews and then across the five interviews. The identification of inter-textual relationships can help in understanding how the texts are related (Keats 2009). *‘Patterns and themes can arise by noting such things as phrases, words or perspectives that are used frequently’* (Keats 2009:191). The major themes across all the interviews were then mapped (Fig 2).

Clandinin and Connolly (2000) talk about the transition from field text to research text and how this is not a smooth, linear shift. Rather, it is one of complex layers of emerging threads, patterns and themes that are revisited again and again. In this

process my supervisors provided ‘fresh eyes’ on the text, by offering insights into my reading and interpretation.

Clandinin and Connolly (1994:417) go on to explain that personal experience methods ‘need to look in four directions at the same time: 1) ‘inward conditions’ (for example: feelings), 2) ‘outward’ (i.e. the surroundings), 3) ‘forwards’ and 4) ‘backwards’, i.e. the past, present and future’. They maintain that an experience happens on all levels at the same time. These four elements did appear to emerge from the experiences of the people I interviewed. Parents talked about their feelings (inwards), including joy, disappointment, guilt (backwards) and frustration in life with an AS child, along with their hopes, dreams and fears (future). They talked about their feelings concerning the equipment, e.g. cameras and one-way mirror, and how it felt to be observed. They spoke regarding life before, during and after the game.

## **MEASURES OF RIGOUR**

### Validity

‘The “traditional” criteria for research are validity and reliability’ (Holloway and Freshwater 2007:111). These traditional, positivistic criteria were based on the understanding that there was a “truth” to be found. These criteria cannot be applied in the same way to qualitative research (Holloway and Freshwater 2007). Issues such as validity, bias and trustworthiness need to be examined within the context of the study (Olesen 2000).

Emden and Sandelowski (1998:209) discuss a number of criteria offered for evaluating validity in qualitative research. However, they add that it is a ‘*profoundly human endeavour, imbued with multiple meanings and interpretations in which sensitivity to the values and contexts of both the researcher, the researched and the audience is acknowledged*’—they suggest that a set of criteria does not guarantee good research. In the second part of their paper (1999: 5), they add that, whatever criteria one may use, one should also use the ‘*criteria of uncertainty*’. I imagine that this proposes being transparent in the processes of conducting research as Polkinghorne (1995) and Silverman (2005) suggest. Thorne (2000:70) appears to concur with these ideas when she states that, ‘*in looking for good qualitative research, you should be able to see that the findings have been identified by a logical process; that the relationship between the*

*actual data and conclusions are precise and the assertions are credible and believable'.*

In this study, I have attempted to be as transparent as possible about the people, context and the process. All participants were sent a copy of their transcripts for correction. I have utilised the critical eyes of my supervisors and peers throughout the study. Further, I have included verbatim quotes to support my interpretations, whilst keeping in mind that there could be many interpretations of a given text. I have presented each stage of the process throughout the study, and hope this offers the reader an opportunity to examine the interpretations presented. Shared themes across the texts may offer some support to the authenticity of the data, as well as offering deeper insight and understanding. For instance, one theme that emerged across all participants, except one, was the lack of understanding in schools about AS. This may suggest that what participants had to say about their experiences was corroborated by other parents and professionals.

#### Negative instances

Seale (2007:78) and Silverman (2005: 239) explain that *'to look for negative instances/deviant cases or differences could provide: a) additional support, b) they require a rethink of the researchers original ideas and c) may be seen as exceptional for good reasons'.*

In my study, the first parent to be interviewed was Susan. Susan and her son had attended the PCG before I had made the adaptation. Susan's story gives a contrasting experience to the other two mothers in the study who experienced the game after the adaptation, and I believe it adds additional support. It appears to highlight the fact that the change was necessary, albeit from only one experience of the PCG before the change.

#### Summary

In chapter two I have discussed my choice of narrative methodology, setting it within the historical and developmental stage of qualitative research methods. I have discussed issues such as reflexivity and insiderness in research. The study is detailed and a brief first introduction to the participants and reasons why they were chosen. Data collection and ethics are also covered. The second part of chapter two looked at

the analysis used, offering details of the process that I took and the matters of rigour that were inherent.

In Chapter three I will present the findings giving the core themes with my representations and some illustrative verbatim texts to support my thinking.



# **CHAPTER THREE**

## **CHAPTER THREE**

### **RESULTS AND FINDINGS**

This chapter offers my “representations” of the experiences of three parents and two children who undertook the parent/child game (PCG). I also offer representations of the five Key Informants’ interviews.

It would be naive to think that there could be only one way to represent the material gathered in this study. I have chosen a narrative based analysis and, in keeping with that paradigm, I have attempted to allow the participants’ voices to be heard. My interpretations evolve from my hearing, reading, re-reading of the text and then grouping of the emerging themes. My previous therapeutic relationship with each of the families is also acknowledged.

I have chosen to group the families into mother-child dyads, of which there are two, along with one mother whose child was not interviewed. I considered that to represent the mother and child as a dyad gave a natural feel to their *telling* and a sense of their *shared* experience of the game, having been *‘in it’* together. Each representation begins with a brief description of the family members, diagnoses of the referred child, along with the context of the interviews. *‘Context is important, a) when weighing up the influences that may impact upon the interview process and b) when trying to understand the experience in its fullness’* (Riessman 1993:61). The two children interviewed were both boys with AS; one of them also had ADHD. Because AS children are known to understand the world in very literal, black and white terms, (Attwood 2004) their answers, on the whole, were short and direct.

My representations of the families are grouped into three sections, broadly based around the research questions: ‘What are parents’ and children’s thoughts, feelings and perceptions with regards to their experiences of the parent/child game?’ and ‘Do parents and children perceive it to be effective?’ ‘If so, in what ways?’ The interview questions were grouped broadly around the following areas: Family life before attending the PCG, Experiences of the PCG, and Family life after the PCG. “Other issues” are topics that the families chose to talk about during their interview, which I felt were evocative illustrations of their experiences of life with a child with AS, as well as influences that may have impacted upon their parenting. Each section is further subdivided into the themes that became prominent through the reading and re-reading of the transcriptions of the interviews (McLeod and Lynch 2000, Riessman 1993).

Although each parent and child has a unique experience to share, there were also common themes that emerged with regards to the PCG and the struggles in parenting a child with AS.

A following section groups the themes of the five Key Informants whom I interviewed. The themes are defined by the similarity of the responses given by the majority of the Key Informants. Again, these were identified by the successive readings of the transcripts from their interviews; wherever one person stood out with a different view, I have also made mention of that.

All participants' names have been changed in order to maintain anonymity and confidentiality. Any identifying personal information has also been omitted in order to protect individuals. Fictionalising was considered as a means towards anonymity; however, I felt that certain pieces of information were essential to understanding family life and the struggles of parenting a child with AS. Verbatim quotes have been added to give the reader a sense of the conversations and to attempt to give the participant a real voice within the representation.

## **MAPPING THE THEMES**

Using a narrative analysis, through reading and re-reading the stories as told by the mothers and children, I identified the major themes that began to emerge. Initially I worked on each individual mother and then their children, trying to identify the main features of their stories. Once the main themes were identified I then moved to the Key Informants narratives and continued reading and re-reading again until their main themes were identifiable. I was then able to look across each of the individuals highlighting the common and disparate themes. Eventually I then moved to the main two groups of 1) parent/child to 2) Key Informants themes.

### Figure 2 Description

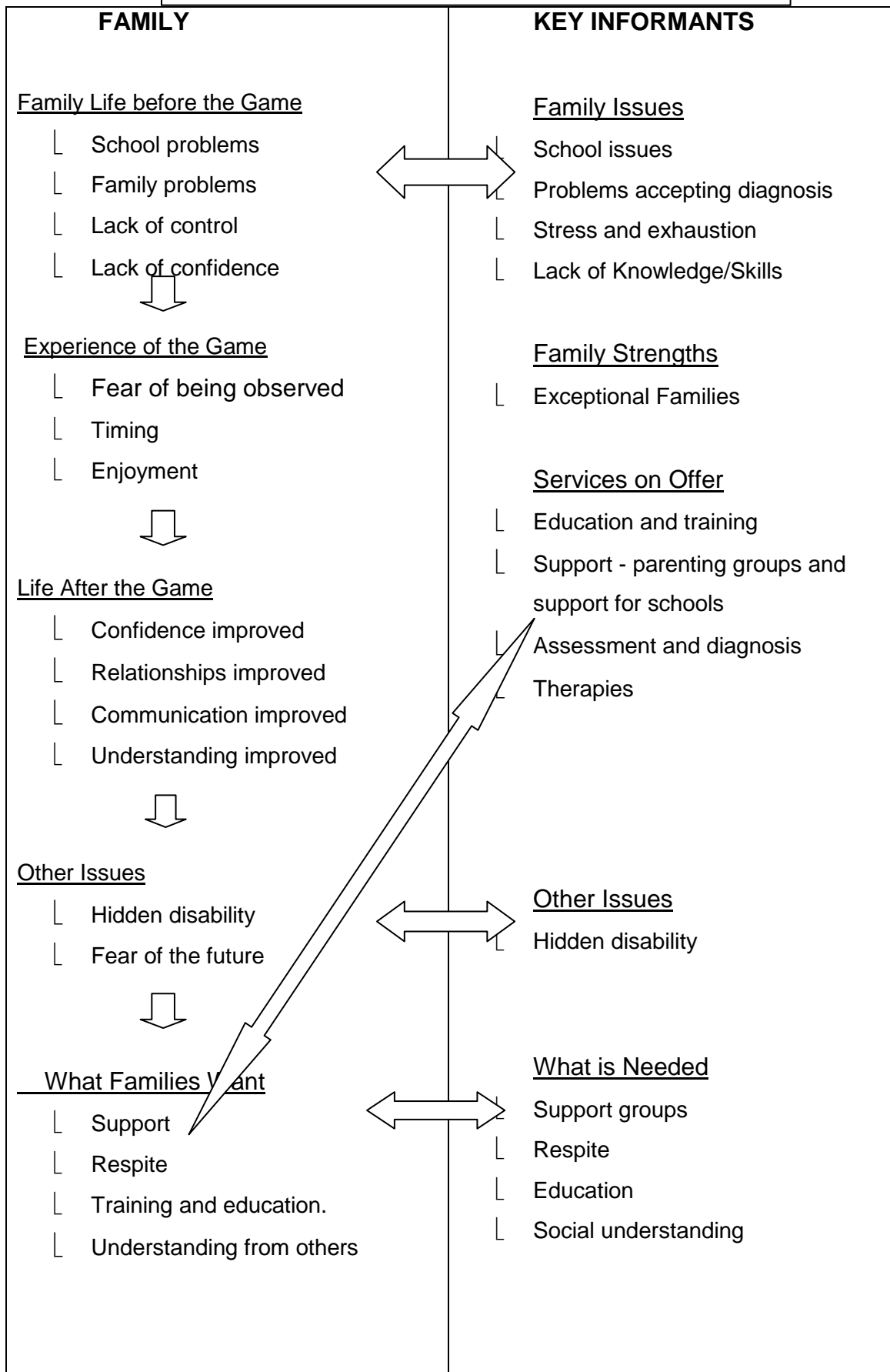
Figure 2 maps the core themes shared by the families and by the Key Informants, as well as across these two groups.

The families' core themes are grouped around the interview questions, as stated above. During the interviews the families talked about other matters that were important to them and I have added these under: 'Other Issues' and 'What the Families

Want.’ The interviews were semi-structured, which offered scope for the participants to talk about other salient topics, as well as to discuss their experiences of the game. The

Key Informants’ themes again were organised around the interview questions. As with the families, the interviews were semi-structured and often gave rise to discussion of the Key Informants’ noteworthy issues. I have added these under ‘Other Issues’ and ‘What is needed.’ There was indeed a great deal of similarity within and across the groups, but also noticeable differences.

Figure 2. MAPPING THE CORE THEMES



## **Susan's Story**

### **Family make-up**

Susan was a single mother whose first son was grown and living independently. Susan came to the PCG with her eight year old son Billy, who had diagnoses of ADHD and AS. Susan and Billy attended three sessions of the PCG, this was before I had adapted it to accommodate the needs of children with AS. Susan had a few extended family members living nearby who could offer some support. Billy was referred due to very difficult behaviour at home and at school. He was enrolled in a mainstream school.

Susan agreed to be interviewed and chose the centre as the venue; she declined having Billy interviewed.

## **FAMILY LIFE BEFORE THE GAME**

### **Lack of control**<sup>6</sup>

Susan told me that she felt that she was not in control of Billy any longer. Life for Susan revolved around Billy and managing his behaviour. He would get into a temper and slam things around; even when he was not in a bad mood, he was clumsy and noisy. When getting toys out of a box, he would simply turn the box over and tip them out. He was equally noisy when putting things away; he would throw them or slam them into the box or drawer. Susan was finding this behaviour distressing, as they lived in a flat and she knew the neighbour downstairs could hear the commotion. Susan tried to explain her concerns to Billy, who appeared to listen at the time; but five minutes later he would have forgotten and would do the same thing again. Susan worried about Billy's behaviour, yet she also worried about not giving him enough freedom. If she tried to give him a little bit of a free rein, his behaviour would escalate and then she felt she had lost control again. When they were out in public, Billy was hard to manage. He tended to run off. Susan could only travel on the bus if she had her hands free for her son. This meant she could carry no shopping as she had to hold

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<sup>6</sup> Lack of control in this context indicates the parental sense of their lack of control over the children's challenging behaviour. Parents described situations where their children had been uncontrollable and unsociable, at home or in public.

onto Billy. Without restraint, Billy would run up and down the bus whilst it was in motion. If Billy was not handled correctly, then Susan had to battle with him all day. She was constantly trying to avoid conflict. Susan described how she felt at such times:

*'Because it was getting to a point that I felt that I couldn't, I wasn't in control any more and I had run out of ideas to get life back in control again' (L 7-8).*

*'In social situations I can't control him very well; things do go out of control, he's always the one that will be leaping across all the chairs and making the kids go into a wild frenzy, even if they are all sitting there playing, he can get them all up onto their feet, you know just playing war games, flying all round everywhere' (L 393-397).*

*'He sees no danger, he won't sit still, and he's just flying up and down the bus' (L 424).*

Billy's multi-diagnoses made him particularly difficult to manage. His ADHD meant that he lacked concentration, was impulsive, hyperactive and was unaware of danger (Kutscher 2005). Having AS meant that he saw the world in a very literal way; communication would be based on his needs alone, lacking empathy for others, (Ozonoff et al 2002).

School was a difficult place for Billy, as his concentration was poor and staying on task was hard. School staff also struggled to manage him. Clearly, under these conditions his education was suffering. Life for Susan was hard and few people understood Billy's behaviour. The school did struggle to keep him on task and Susan told me what she had witnessed:

*'Well at school they can't get his concentration for three minutes at a time before having to turn round and go back to him again' (L 263-264).*

Susan was hoping for strategies to help her to manage Billy better. She wanted to be able to help him to play, as well as to extend his attention and co-operation.

Billy manifested a number of sensory issues and the most difficult one was food. Extreme fussiness about food is common (ibid). This meant that Billy's diet was very restricted and also that he would not take tablets or medicine. Therefore medication for his ADHD was not an option, although Susan did try.

### Preparation for the PCG and perceptions brought to the sessions

Although Susan had attended the preparation session with me, it seemed that she had not really understood what the aims of the game were. Susan said she had spoken to a friend who related her experience of an intervention at another clinic; however that had turned out to be something quite different than the PCG. Thus Susan's expectations were very different from what the game could, in fact, offer.

Susan had not prepared Billy for the PCG; she had wanted him to act normally and not know what was going on, at least for the first session. She felt that if he had known he was being watched he would act differently or not comply at all. Susan explained:

*'I had information because a friend had done something similar' (L 17).*

*'I hadn't discussed it in front of him; I hadn't told him anything. I didn't want him to know what was happening' (L 42).*

## **EXPERIENCE OF THE GAME**

### Fear of being observed

Part of the PCG involves the parent and child being observed playing together. This was usually carried out by the therapist behind a one-way screen and if permission is given it is also videoed. The vast majority of parents initially feel uncomfortable with this; in fact I don't really like being observed/videoed. Some parents speak of having a fear of being observed/videoed and struggle a great deal with this part of the game.

Although Susan had told me that she was comfortable with the idea of a one-way screen and cameras recording the sessions, her responses were somewhat contradictory. For instance, she used descriptions of the experience such as, 'secret agentie,' '20 pairs of eyes looking at us' and 'uncomfortable.' Susan thought that there might have been more going on, such as being watched by lots of people in a secretive way. Although her fears were about being watched and how this would make her feel, Susan often said 'it was fine.'

*'I thought it was going to be a lot worse than how I felt' (L 37).*



*'I thought it was going to be more secret 'agentie' being studied....[laugh]... behind a glass screen and..I was in a big reflective mirror and knew you were on the other side' (39-41).*

*'Yea, that there were 20 sets of eyes all staring but that was fine, it was just a part of the room really, you couldn't even notice that it was there. As I say I thought it was going to be like tin foil...[laugh]... the other side of it looking through it, but looking through at us' (L 53-56).*

Despite Susan's efforts to prevent Billy's knowing what was happening, she felt that Billy had guessed he was being watched from behind the mirror. Susan had not thought that Billy was bothered about being watched.

### The game

Susan felt that she worked hard during the PCG to stay calm and to keep Billy calm. However, during the interview she reflected that it may have been better not to have done that, and to have allowed things to evolve as they normally would have done. Had this been the case, then I would have seen a more typical picture of Billy and his mother. Susan related to me what she was trying to do during the session:

*'So I was a bit more aware that I was trying to keep him... so that you could actually watch him at play, but really that was sort of not what I should have been doing I should have let you have a more truer glance of what does go on (L 64-66).*

*'I have just had the idea, thinking about it in retrospect, of how he did get on' (L 83).*

*'I shouldn't have tried to stay so calm myself and let him do it and let you get a more proper picture' (L 85-86).*

Susan said that Billy thought the PCG was boring and that she thought he became over-familiar with the toys in the room, but she also told me that she thought Billy liked the toys.

In the event, Susan felt that Billy did not include her in his play; she had felt ignored by Billy whenever she had tried to make a suggestion and he hadn't responded. As stated above, Susan and Billy attended the PCG before I made the small adaptation. What

Susan described was also my observation and reason for changing the game: children with ASD would not necessarily involve the parent in their game.

*'I felt a bit redundant in the playing situation; he was quite merrily building his bricks alone' (L338). 'But at home he does tend to slam things around more once he has finished what he is doing, whereas here I was asking him to put the things away and he was putting them away, he was alright about it he didn't mind' (L 76-78).*

### **LIFE AFTER THE GAME**

Susan talked about how she was coping since the PCG had finished. She did not say that the PCG had been helpful and I did not ask her directly if she thought it had been helpful. Susan had attended a few specialist support groups and found that she had learnt a lot from discussions with other parents and using 'common sense.' She was also learning through experience what Billy could cope with—within the confines of his disabilities. Susan referred little to the PCG and did not say whether she thought it was helpful or not.

*'You just, using own common sense and hearing other parents talk. It's all the parents talking amongst themselves' (L 354).*

#### **Bearing witness/on the record**

'Bearing witness' or 'on the record' are terms that are given in this case to parents feeling the need for professionals to observe the child when they display the most difficult behaviour. *'Bearing witness, to acknowledge, to be present with, and to testify to the authenticity of another's experience, to demonstrate respect for another's truth'* (Cody 2001:97).

At one point Susan had said that she felt uncomfortable about being videoed, yet she also said that she thought being videoed was a good idea and would have liked more observations in different settings. Susan thought that if Billy were observed in most areas of his life, I would have gained a fuller picture of how he was, and only then would I really be able to understand and assess him. It was as if she were saying I needed to be there for entire days in order to understand what she had to deal with. As

she voiced this she began to rationalize that this would not be possible for every child I saw.

## OTHER ISSUES

### Fear of the future

Susan worried about Billy's behaviour and as a consequence began to think that maybe she tried to keep too tight a rein on him. Susan tried to balance her need to keep Billy within her control, against letting him release some energy and thereby risk losing control of him. Some of Billy's behaviour could be dangerous and life-threatening, for example: running across the road without looking. As with many parents, she had constantly to assess and make a judgement on her child's abilities and the dangers around him.

*'I do worry too much about his behaviour and it does seem really unacceptable to me sometimes and I do, I worry too much basically, perhaps I should let him be a bit more of a kid, but I know how it can escalate if I let him go a little bit, should I say lose it and just go crazy, so I do worry too much' (L 97-100).*

Susan was very worried that Billy could be schizophrenic, as he told her that his head would often tell him to engage in his difficult behaviours. Susan clearly had grave concerns about her son's mental health and his future life. Susan coped with her concerns by dealing with life on a daily or short term basis, not looking too far ahead.

*'Sometimes you try to get him to logic it through with you, why, but he can't, he can't you know, he's really upset afterwards, I wondered if he could be schizophrenic, I don't know if he is to you but he was saying about his head just tells him to do it and I thought "oh god, you know"' (L 112-115). 'When he gets older I don't know what will happen, but I forget about all of this and I don't look to the future' (L 420).*

## SHARON AND PETER'S STORY

### Family make-up

Sharon and Bill had two boys, Peter and Jack, ten and two years old, respectively. Peter had dual diagnoses of ADHD and Asperger's Syndrome. Jack had been

diagnosed with Autism at the same period they were attending the PCG. The family were referred to me for the PCG because Peter's behaviour had become very difficult to manage. Peter attended a main stream school, as many Asperger children do. However, Peter's education was suffering and he was under threat of permanent exclusion. They attended eleven sessions of PCG. Both parents attended most sessions and fully participated in the activities with great enthusiasm and a positive sense of humour.

### **FAMILY LIFE BEFORE THE GAME**

#### Lack of control and lack of confidence

As Sharon described life with Peter, the first three years were the most difficult. She was a young mum and she didn't know what was wrong: She doubted herself and her abilities to parent her son. Sharon also felt that she was seen by others as a young woman who could not cope. Sharon felt that she was doing a bad job as a parent, because her son was difficult to manage. Sharon did not know if she was parenting correctly or managing Peter appropriately.

*'This makes you feel bad about yourself; this might be where some of my insecurities come from' (L 528).*

*'You just feel that you're doing a bad job and that as a parent you are letting them down' (L 14).*

Sharon made the assumption that she must be getting it wrong due to Peter's very difficult behaviour and the negative feedback she received from other people. When Sharon took Peter out, the public, including neighbours would shout at her.

*'Sort your kid out, get him under control, he shouldn't have done that, he is horrible - it knocks you as a parent and it does make you feel that you are doing a bad job' (L 35-40).*

Sharon felt that Peter was out of her control when she first came to the PCG. Sharon's confidence was very low, battered by her situation; she thought people were against her. Sharon described a desperate situation wherein Peter was very hard to control in all areas of life. Life was very stressful and exhausting.

*'When we came to you he was on the verge of getting expelled from the smallest school in the County. His behaviour was atrocious' (L 197). 'It was every week where he would run out of class, run off, not come in, being rude to the teacher, hitting, fighting, it was weekly' (L 206-208). 'He was horrendous to live with, horrible, I dreaded it, it was like walking on eggshells just wondering what he was going to hit me with next, I was battered and bruised most of the time' (L 341-349).*

*'I just think that my confidence has been battered that much and that's how it made me feel. It would have been a bit more reassuring before I met you to know that it wasn't a personal vendetta against me' (L 86-89).*

Sharon relayed to me the lengthy road to obtaining a diagnosis for Peter. She described having consultations with professionals who would not give a clear diagnosis and did not explain anything to her. Research shows that a lengthy diagnostic process adds to the stress levels of parents (Goin-Kochel 2006, NAPC 2003). It was only after a crisis, when Peter was seven years old, that he got the right help and a diagnosis of ASD. Sharon then felt let down because it seemed to her that she had simply been left to get on with managing Peter's situation herself. Because Sharon had only limited information about Autism, she became even more distressed.

*'I kept immediately thinking, well I have watched "Rain Man" and a few documentaries on the TV and that's all I know. I would have liked to have known a bit more, when we were out the triggers, the iceberg, what I learnt far, far later, I could have done with learning that a lot, lot earlier' (L 616-620).*

#### Preparation for the PCG

Sharon and Bill attended the preparation session before the PCG began. [I will address the preparation issues in the discussion section.]

#### Perceptions brought to the sessions

Sharon expected to be told off and to be told that it was her fault that her son behaved the way he did. However, she had decided that she would manage her embarrassment about that for the sake of her son and that she would be told the right thing to do. Sharon and Bill sacrificed their own feelings of guilt and inadequacies for their son's well-being. Both Sharon and Bill had experiences of being in care as children. Consequently Bill thought that their children would be taken away as that had

been his experience as a child. Sharon had known that this would not happen without going through certain procedures and had tried to reassure Bill. Despite all of these worries they still attended and were willing to learn for the love of their son.

*'He said we will probably have the SS on our back now, is what he said, but again through his own experiences he said that, and not knowing the Centre and SS are all completely different agencies. I said to him that there's a whole procedure that you have to go through anyway; they are not just going to turn up with a load of people and go right bang, that's not going to happen. There is a procedure that people have to follow' (L 111-116).*

## **EXPERIENCE OF THE GAME**

### Fear of being observed

Sharon admitted to not liking the camera, but rationalized her worries by telling herself it was only one therapist and that she was doing it for the good of her child. After her initial concerns she managed to relax and could then ignore the cameras. Again Sharon sacrificed her own feelings in order to help her son.

*'At first I was like "oh my god"; as I don't like the camera, but then I just thought this is for Peter, you've got to ignore the camera, ignore all that just forget because it's only you seeing it, it weren't loads of people. But once you got past the initial I'm being filmed, it was fine and I could just ignore it' (L 4-7).*

Peter said he did not worry about the cameras; he just got on and took part in the fun.

*'Didn't notice the cameras, didn't worry about them, just played' (119-132).*

### Bearing witness/on the record

Sharon was hoping that Peter would show his worst behaviour in the PCG sessions. Sharon wanted to be told 'live' how to manage Peter when this situation occurred. However this did not happen, Sharon managed Peter better without that ever happening.

*'I said, the first time I met you, I hope Peter does kick off in there and you can tell me in my ear (through the earpiece) what it is that I should be doing,*

*because when you're out there and he's doing it, you don't know what to do for the best as he is putting himself in dangerous situations, running off, jumping off, hitting and whacking people, and at the time you just act on impulse I suppose. You just do what comes into your head at the moment, whip him away, chase after him you know whatever. So I was hoping that he would kick off in there, so that you could tell me the best thing to do there and then what to do, like another person's view on it, what should be done now' (L 124-132).*

### Timing

Sharon had completed the locally run Early Bird course, which helps parents to understand their ASD child's behaviour. Peter had also moved to a more understanding school with fewer pupils. In addition, Peter had begun a course of medication for his ADHD. Sharon felt the timing was just right for her family. She had gained knowledge from the parenting group. Also, Peter's medication was having a good effect and the school was working with her. Sharon was aware that all of these things impacted on each other and on her. She was becoming knowledgeable and skilled.

*'Since doing the Early Bird and coming to you he's had a much better year this year. A complete change around from last year' (L 189-191).*

*'You have to do it when the family really need it' (L197).*

### Enjoyment

Sharon thought that the protected time that Peter had with both of his parents whilst participating in the game was valuable to him, as well as having time off school. Sharon believed that Peter loved playing the games and seeing his mum and dad being silly. While playing the game, they laughed a lot and, without realising it, their communication improved. This, in turn, helped their relationships. Peter expressed his pleasure about the special time they all had. Peter said that he had enjoyed playing the games with his mum *and* dad. The two games that Peter mentioned ('Hot and cold', 'Hide and seek') were physical and interactive.

*'All of it, it was fun, mum and dad hid a crayon and a sheep' (L 41). 'It helped having fun with both mum **and** dad' (L 80).*

*'I liked the other thing where you tell people what to do' (L 58). [Simon Says]*

Sharon described the enjoyment the family had in the games—especially Peter.

*'He enjoyed getting an afternoon off school but he did definitely loved coming and having me and dad to himself with no phone, telly, brother, neighbours in and out, it was pure him and us' (L 271-273).*

*'He loved mum and dad being silly all at once; he went on about it for weeks. It meant that much to him, it did that much for him that he felt the need to keep telling everyone 50 times how great it was and it was great, and he still says do you remember that time and we say yeah!' (L 307-311).*

*'I never wanted to miss a week because I knew how much it meant to Peter, to have his mum and his dad to himself being silly and playing games' (L 712).*

## **LIFE AFTER THE GAME**

Sharon and Peter both relayed to me their pleasure with each other's company since attending the game. Sharon gave many examples wherein she had managed situations better than prior to the game. She talked about thinking things through and planning in advance the strategies that would be helpful in managing Peter's difficult behaviour and outbursts.

### Confidence improved

Sharon talked about the positive feelings that she experienced during and after the game. Her confidence improved and she was affirmed for the positive parenting that she was already doing. Once Sharon felt more confident in the game, this spread to other areas and she became more confident at home and when out with Peter. Sharon was able to manage Peter's behaviour in a controlled and thoughtful way. The stress and the worry fell away and she was able to think more clearly, and to be thoughtful about her management of Peter.

*'We were told we were doing a good job. That for me really boosted me big time' (L 99). 'It boosted my confidence and then slowly with that— It was nice and that boosted my confidence massively, massively' (L 71).*

*'I felt more confident with him and wasn't afraid to challenge him, like I was and really worked with it' (L 25).*



Once Sharon felt more confident about herself and her management as a parent, she could challenge Peter's difficult behaviour with a new self-assurance that she was doing the right thing. Sharon began to think through incidents and management strategies before they happened and was prepared, rather than responding impulsively. Sharon took the skills acquired in the PCG sessions, along with her new confidence, and generalised them to many situations. Sharon talked about many incidents where she was managing better, this included de-escalating potential outbursts. Sharon talked about a bedtime when she managed a potentially difficult situation very well, with a positive outcome.

*'So like last night when he was getting hyper, instead of, don't be getting hyper get to bed, work with it and have some banter with him and kind of getting him up to bed without me directly saying go to bed, I was doing it in a playful way and he got to bed eventually, after we'd discussed whatever it was that was making him feel very unhappy' (L 25-32).*

#### Relationships and communication improved.

Sharon described feeling warmth and love towards her son again and was able to tell him so. Prior to the game they had lost these positive expressions of love as the relationship had deteriorated. Through the PCG the quality of the family relationships improved, as did the communication. Sharon was extremely open and shared very intimate feelings that she had experienced towards her son. She described how she was able to tell him that she loved him and that he was very special to her. These feelings had been buried under the stress and negativity that had built up over years. The following extracts describe, in Sharon's words, how difficult their relationship had become and how communication between them had broken down.

*'When you have a problem child you don't say those things. How can you say nice things to someone who is smashing you in the face? When we came out of the PCG I could just drop it out that I loved him and he was special to me' (L 332- 227).*

*'It made me to be able to say Peter, to say how much I love him and how special he is, as often when you have a child out of control as he was before we started, you never say things like that to them (L 330).*

Sharon also described how Peter's communication had improved.

*'It's the communication, not that he was worried to say "can you play with me?". He would just never think to say, "Can you play with me?"' (L 235).*

Peter thought he got on better with his mum and dad after the PCG, but couldn't say why. He then thought it had helped because they had enjoyed playing together.

*'I think I get on better with mum and dad but I don't know why' (L 176-179).*

*'It helped having fun with both mum **and** dad' (L 80).*

Peter described how he had special times with each of his parents. He had special time to play with his dad in the evening; this was introduced from the PCG. Also they had re-instated outings with dad; this had been lost before as life was too chaotic. Peter said he thought the outings and special play times helped him to get on better with his dad.

*'I've been going up in my room and like we have been going on Mario go-Kart and that, on my Nintendo Wii' (L 99). 'There's Lego and that' (L 89).*

*'I am going to Hollywood cinema with dad, but will miss casualty that I watch with mum' (L 238) 'will you record it?' [To mum] (L 225).*

*'I think doing things like that with dad helps us to get on better' (L 244).*

## OTHER ISSUES

### Hidden disability

Sharon talked about how few people really understood Asperger's Syndrome. Because Asperger children *look normal* and appear to be functioning adequately, their lack of understanding in social communication is often misunderstood. Sharon described many situations in which people expected Peter to behave in a particular way and, when he didn't, they just thought he was being naughty or difficult. Sharon found it both frustrating and embarrassing because it was impossible to stop to explain his condition to every passerby. Sharon tried to explain to Peter, as he did not understand what he was doing was wrong or why people didn't understand him.

*'Sometimes I wish Peter were not so bright, he would probably get the help he needs, I had to change his school to a smaller one and one that understands,*

*so that he could cope but now he will be sent to a high school where there will be 10 times more children' (L 590).*

### What they didn't like

Peter didn't like the session when his mum broke down and cried and talked about the stresses of her life. Quite a lot of the problems Sharon discussed were about Peter and his difficult behaviour, but not all, and he did not like to hear how much he upset his mum. Also he didn't get to play that day and, for him, the session was not as much fun.

## **JANE AND ELLIS'S STORY**

### Family make-up

Jane and Mark had three children: two boys, Ellis and Alex, 10 and 8 years old respectively; and one girl, Olivia, 3 years old.

Ellis had a diagnosis of ASD and was referred to me because Jane was struggling to manage Ellis's behaviour at home and he was regularly in trouble in school. Jane was worried about the school's negative attitude and management of Ellis; and Ellis was showing symptoms of high anxiety.

They attended six sessions of the PCG.

## **FAMILY LIFE BEFORE ATTENDING THE PCG**

### Lack of control and lack of confidence

Jane's initial worry was that Ellis used to 'change into a character' when they went shopping. Jane could not help Ellis simply to be himself. In discussions, we felt that this was due to his high anxiety, particularly when lots of people were around. This was exacerbated due to sensory over-stimulation such as sights, sounds and smells in the supermarket.

Jane was also worried about Ellis's inability to play. She felt that he used electronic games too much, and that he didn't know what else to do. Jane told me about situations when she tried to take Ellis out to broaden his experiences.

*'He just cannot play. I think there is only so much collecting fossils I can do' (L 204-205).*

*'He wants to go to the park but when he is there he doesn't go on the play equipment, he climbs a tree or wanders and it is the wandering you can't have. So really unless you tell him what to play with, he will not play, he will just sit there' (L 180-183).*

Although Jane got frustrated, tired and stressed in managing Ellis at home, the school was an additional source of stress for her. Jane related a situation in which she felt the school had over-reacted.

*'The thing is, like they said when he got banned from the school...that was when he went around school and they was worried about him smashing windows, and whether or not he would hurt them, I seriously don't think he would have hurt them, but they said "how would you have known?"' (L 317-320).*

Jane had organised her day and all of her routines in order to manage her three children—especially Ellis. She even had to have her shower when all the children were in school.

*'I know I can't watch him 24 hours a day. I didn't have my shower and I need to have a shower in the morning' (L 335-336).*

Managing Ellis in public was also difficult and tiring a family day out could be very stressful as Jane explains.

*'You need to come up with answers you don't want another mum or father coming up and having a go. Three weeks we have been there and three weeks we have had somebody come up and say he has done something to their child' (L 489-492).*

Other parents seem to give themselves permission to speak their minds and Jane was told by one parent she spoils her children by taking them out so much.

*'We've already been told by other mums that we are stupid because we go to Colchester (Zoo) on a regular basis' (L 518-519).*

### Perceptions brought to the sessions

Jane had attended speech and language therapy with Ellis when he was younger, in which a one-way mirror was used. Jane felt that had been a good experience. However, she had been behind the mirror, and not in the room with the Ellis. This was very different from the PCG experience.

*'He never, never knew we was on the other side because it would spoil it, he thought I went home or I had to go speak to somebody else in the building because I never saw him again, I think they let me go back in at the very end but they gave you so long in there and he would come back and join them and they monitor so you can see what they are like without you' (L 14-18).*

## **EXPERIENCE OF THE GAME**

### Fear of being observed

Jane said she thought it felt weird being watched and wearing the earpiece. She also used the word 'weird' when talking about trying not to instruct Ellis during the PCG, because she had always taught him. Free play was unfamiliar to Jane. She also thought Ellis was unusual because he could shut himself off to the cameras.

*'It felt weird, and he (Ellis) can shut off. He can shut off to the fact people are watching' (L 86-87).*

Jane told me she felt she was being closely studied, but after a few sessions she relaxed more.

*'You feel like you are under scrutiny' (L 126). 'Well after the first couple of sessions I got used to it' (L 169).*

Ellis told me that he had been a bit shy about the cameras to begin with, but he managed to forget about them and said they didn't change his behaviour.

*'The video made me feel a bit shy' (L 177). 'It didn't change me though; I just forgot about it' (L 188).*

### Bearing witness/on the record

In comparison to Susan and Sharon (above), Jane did not mention that she would have wanted me to see Ellis at his most difficult. However, she did describe examples of his behaviour in very great detail.

### Timing

Jane did not mention the timing of the PCG as having been important; however, she did talk about many other courses that she had attended prior to the PCG. This may have given some grounding for the PCG work, as Sharon had described in the previous interview.

### Enjoyment

Ellis said that the PCG was fun. He enjoyed it because he got to play with his mother. He liked the 'hide and seek' game; he couldn't resist helping his mother whenever she couldn't find the toy. Ellis's description of seeing his mother struggle and his wanting to help her, showed that even with ASD he could empathise, particularly with regard to the main attachment figure.

*'It was fun (L 7); I played with the toys and Lego, I get to play with mummy (L 11-15-21); I had to show mummy I couldn't resist helping her, she was near the clock and I did a big smile' (L 55). [A smile indicates if the seeking person is getting nearer to the hidden object.]*

Ellis thought it had been beneficial to be able to tell his mother how he was feeling. He seemed to appreciate the improved communication between himself and his mother.

*'It has been helpful to mummy because she can find out how I think' (L 92).*

Ellis clearly valued the special time that he had with his mother during the PCG. Jane was pleased with their time together and Jane told me how nice it had been to see Ellis happy again.

*'It was nice to see him smiley and happy because a lot of the time you don't see him like it; he looks depressed or anxious' (L 405-406).*

## LIFE AFTER THE GAME

The PCG includes discussions about behaviour management, we talked about how shopping was usually a difficult time. From this discussion, Jane changed their shopping time to evenings, when it was quieter. Jane was happy to see that this had worked and Ellis had not changed in character as much.

*'Remember that time I told you he used to be a character (star trek). Since we've done the late night shopping he's not in character half as much as he used to be, so whether or not what link was there he doesn't seem to be in character as much' (L 124-126).*

However Jane was very keen to help Ellis to lead as normal a life as possible and wanted to help him to overcome his social worries, so she did not want late night shopping to become the norm.

*'But I don't want them not to go to shopping to know how things are meant to be done because he's got to learn' (L 148-149).*

### Confidence improved

Jane did talk about how things had improved and that, as a result, she had put in place new strategies that worked for her and Ellis.

### Relationships and communication improved.

Ellis felt that the PCG helped him and his mother to get on better and not to argue so much. Communication is usually the key to better relationships and the PCG aims to improve the quality of the relationship through better communication.

*'It really helped us to get on, because we used to argue a lot of the time' (L 287).*

Jane felt that the game had helped her to find out what Ellis liked; and she was better able to predict the difficult times.

*'Just finding out what he likes' (L 305).*

Jane told me that she thought Ellis got a lot out of the time alone with her in the PCG. She had also included more play time at home.

*He got a lot out of it (L 266) Time with me, (L 270)*

## **OTHER ISSUES**

### Hidden disability

Jane talked about how the school did not understand Ellis. The school saw a 'normal' boy with average to above-average learning abilities; and these did not fit with his behaviour, thus they dealt with him as a naughty/difficult boy.

### Fear of the future

Jane worried about money, although her husband, Mark, worked. They still had debts. Jane wanted to be able to work, but the school was constantly ringing her about problems with Ellis. Jane had to be almost 'on call'; this meant she could not commit to a job. Jane also worried about Ellis remaining dependent into his adult life. Jane had two brothers who still lived at home and needed support—thus her worries about the future for Ellis.

*'I can't totally see him, I can see him being independent in some respect but I don't know how far' (L 278-279).*

*'My fear is if they can't make him happy at school, they are going to return him to home every single time' (L 720).*

### What they didn't like.

Ellis talked about one occasion when his mother got upset. Ellis empathised with his mother's upset and also felt sad. Ellis also knew that his behaviour had often upset his mother and he wanted, on this occasion, to make her happy.

*'Mummy was with you and she ended up in tears and I felt sad. I thought I should try to make her happy, but I didn't know how' (L 246).*



## KEY INFORMANTS

Key Informants were chosen to provide an additional source of data, thereby giving a fuller picture of the issues facing families with ASD children. The Key Informants all had involvement with families with ASD children and, due to their differing professional lives, offered their own unique perspectives (Heyrman, Goedhuys, 2001). Therefore the five Key Informants were specifically selected for their professional skills and training, and were from a range of services other than mental health. Involving Key Informants from other areas would potentially give varying perspectives (Marshall 1996).

Three of the Key Informants were from statutory organisations: a Speech and Language Therapist, an Educational Psychologist and a Specialist ASD Advisor to schools. Two other Key Informants were from charitable organisations: a Support Worker for special needs and a Manager of an organisation for special needs children and their families.

Three Key Informants chose to be interviewed in the Centre and two chose their own places of work. Although each professional had individual perspectives on the families and their struggles with ASD children, the Key Informants also presented a number of similarities. The core themes were made up of their similarities. The few diverse responses I have highlighted with some interpretation as to the reasons for the difference. Usually it occurred where most said one thing but one person said something different.

The Key informants are represented here as a group, rather than individually as with the families. The rationale for this is that the study was looking at the families' experiences of the PCG, whereas the Key Informants were chosen to add context and to broaden the knowledge and understanding about life for families with an ASD child.

*KI 3 'A lot of families I know they try as much as possible to, lead as normal life as possible and therefore they will sort of go about society trying to achieve that, so they are constantly up against disapproving, so they are constantly being looked at, and so to a certain extent they've constantly got to have broad shoulders and so I think that's... ah... almost a complete requirement of people who are prepared to go out with their children, in that way, but at the same time there is no reason why they shouldn't do, and in a way it's just society that has got to change' (L 129-138).*

## CORE THEMES

### Diagnosis

Four of the five Informants had some input to the diagnostic process. Locally a multi-professional forum gives the final diagnoses on children with ASD. The Key Informants are in favour of a forum approach to diagnosis, because it is more holistic and involves a number of professions and opinions in order to arrive at the correct diagnosis. Key Informant 5 had a number of comments to make and discussed the multi-professional forum in detail.

*KI 5 'In this area we have a very good system in terms of health and the Autistic Forum there, of which all of us attend at different times' (L 38-40).*

*KI 5 'You've got a whole range of professionals there including speech & language therapists, as well as people from the Child Mental Health and also from other sections of health' (L 46-48).*

For some families, accepting the diagnosis can be difficult. This was mentioned by all those involved in the diagnostic process, and three of those said that fathers find it more difficult to come to terms with. Key Informant 1 explains why she thinks that is so:

*KI 1 'Dads often have much more problems accepting the diagnosis, definitely what we see, I think it is often because they haven't seen their child with its peers, they see their child in isolation and think "Oh yeah everything is going fine. It's only when they see the difference [with their peers]'" (L 157-160)*

### Services they offer

Early Bird and Early Bird Plus are training groups for parents who have ASD children; and three of the Key Informants said they were involved in these groups.

*'Early Bird is for parents whose child has received a diagnosis of an autism spectrum disorder (ASD) and is of pre-school age (not yet of statutory school age)' (NAS 2010).* The programme seeks to support parents from the point of their child's diagnosis to the child's entry into school.

*'Early Bird Plus is for parents whose child has received a late diagnosis of ASD and is aged between 4-8 years. The programme looks at home and school settings training*

the parent and professional together' (NAS 2010). Key Informant 1 spoke highly of the benefits to parents.

*KI 1 'The whole session is very interactive in a small group and you can see the parents building relationships with each other and it is thrilling actually and also the parents will say they like meeting other parents then they know they are not the only ones going through this' (L140-143).*

As professionals, the Key Informants offered various services, for example: assessments for the diagnostic process, feeding clinics, and support groups, education and training for parents and school staff, and helping ASD children to problem-solve.

Key Informant 4 explains that a part of her role and the service she offered was to train school staff about ASD issues. It seemed from her statement that schools can choose not to have the training. According to three of the Key Informants, and many parents, schools were not the most understanding or skilled in matters to do with ASD. The reason may be because schools have the option whether or not to train their staff in ASD, thus potentially perpetuating the gaps in knowledge and understanding.

*KI 4 'Usually, beginning of school term, we do training for all the whole school and then individual staff working with children, class teachers, assistants and SENCO (Special Educational Needs Coordinators), so it's individual work as well as whole school training because we feel that there is no point just working with the teacher or child because the child will move on in the school and staff need to be aware. We encourage schools to have the whole school training. Some do, some don't' (L 31-43).*

### School Issues

A number of Key Informants talked about school-based problems: mainly lack of staff training or understanding of ASD. There was a general sense of frustration that schools are not keeping up with what is known about ASD children and their difficulties. They also had experience of teachers who were already overworked and could not cope with 'another thing to do.' Key Informants 1 and 2 talked about their frustrations with some schools.

*KI 1 'It is quite frightening actually when you hear some of the things that go on in schools, now we know about autism, "because we have had a child with it" and they don't realise that every child is a bit different and it is really frustrating*

*because you can really see them making things worse by not identifying why a child has got a behaviour and they react to the behaviour according to their behaviour policy, which don't suit ASD children' (L 297-303).*

*KI 2 'The bulk of the work is going into schools to try to get schools to understand' (L75-76).*

*KI 2 'They don't seem to grasp that there is not enough training for autism and the fact that they are all so different' (L 82-83).*

Key Informant 5 gave a very positive picture and felt that schools were changing and taking on board the challenges of having an ASD child in their school. She felt that teachers were receiving training and implementing the necessary strategies. It may have been that this Key informant had a catchment area where the schools were more proactive and working with ASD issues. It could also have been that this key informant engaged them well in her input within the school.

*KI 5 'I think schools are doing enormously well; there's lots of resources in this area. There are the advisories, support teachers run groups with the SENCO's<sup>7</sup> every term, there's a lot of support in that way. There's lots of generalised learning around in the schools in the early years. As long as you keep the TA<sup>8</sup> staff and even if they go to other schools, they are building up a huge amount of knowledge, information and understanding of the children and they are very skilled' (L 325-331).*

It seemed to be a mixed picture, where some schools were doing well and others were not taking on board the implications for their ASD children.

#### Strengths of families

Every Key Informant talked about and highlighted the strengths of many of the families they saw. They used words such as: 'admire', 'managing stress, and "strong bonds', 'sense of humour', 'broad shoulders', and 'amazing.' It was clear that all the professionals felt that the majority of parents were exceptional at trying to support their

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<sup>7</sup> Special Educational Needs Advisor.

<sup>8</sup> Teaching Assistant

children with ASD. Examples of four of the Key Informants' statements are given below.

*KI 1 'Their commitment to their children, that can be real a strength, that we do regularly see. Um... Their commitment and their love for their child and wanting to get it right' (367-369).*

*KI 3 'I think one of the strengths that they have is the total belief that they have in their young people, yes, and the total belief that they deserve a real life and normal a life as possible they are determined that they are going to get it' (L 416-419).*

*KI 5 'I think it's amazing how they cope and I know that some of them have extreme difficulties with coping' (L 143-145).*

*KI 4 'It's quite amazing how they tend to, you know, the whole family life, they modify(their lives) without even sort of, giving it much thought, to help support the child who has some needs' (L 497-499).*

Key Informant 3 recounted how the family members whom she had seen in her specialist groups had developed close bonds through the activities; and although the child's autism would never go away, they had certainly increased the quality of their attachments.

*KI 3 'I see a terrific closeness building up and it's almost completely contrary to what you expect to when you see or hear about autism, it's that sort of malfunction of social interaction and so many cases is just not true, I mean, it's that, you know, there's a bond between parent and child it's amazing and equally so can be very much so with the siblings well, very, very supportive, very defensive of their sibling, and that sort of thing, so yes, I have seen that and witnessed that' (L 432- 438) .*

#### Difficulties families face

The Key Informants saw many of the families struggling with high levels of stress, which is a major problem, ultimately leading to some families breaking down. Initially families can feel isolated and many are exhausted.

*KI 3 'We do see the frustrations we do see the stress, we do see the tears and that's all very much part of it, life goes on so you know you get a family there that is stressed' (L 481-483).*

*KI 3 'There are lots, not so rosy and I'm sure also that, you know, no matter how stressed you are the majority of occasions, you put on a brave face and you go home and that's when, times when you really let rip, you know, you have a really good sob but all you can say is that, you know and 1½ hour of that day has been alleviated by a little bit of social interaction' (L 495-500).*

*KI 4 'That's where you can see the anxiety, very anxious and very stressed themselves, that's often the case' (L 491-492).*

Key Informants talked about the families' problems of going out in public, as their children may want to do something that seems inappropriate—for their age, gender or place. A simple visit to the shops can become an emotional battle for an already stressed and exhausted parent. Some of the experiences of the Key Informants were personal, as they disclosed they also had a child with special needs. Key informant 2, although a professional, told of experiences about outings with her child which was similar to those of the parents I interviewed.

*KI 2 'Yeah, especially things like shopping, you know, going out for days, you know people look at us, people glare at us make comments, it's not fair, but you usually get comments' (L 313-315). 'I was in the supermarket and I just turned round and said "He's autistic. Why are you so rude?" Then they shut up' (L 318-319).*

*KI 2 'I've had comments of "That boy is a baby because he's holding his mum's hand"' (330-331).*

### Hidden Disability

All Key Informants made comment with regards to AS being a hidden disability. The child does not have an outward sign that he or she has a difficulty understanding the world. Therefore when the behaviour does not match society's expectations, people assume the ASD child is being wilfully naughty.

*KI 2 'I think that the other difficulty that they face is the fact that parents know he looks normal, you don't get that, yeah nobody realises that they have a got a problem' (L 307-309).*

*KI 4 'In all our training, this invisible disability thing, is not a cliché, it's a fact' (L 566).*

Children with AS, despite having the same core difficulties, can have very different presentations. Key Informants expressed their frustration that others (in this case a teacher) did not understand the very real differences between children with AS and wanted to treat *all* of them in the same way. Could it be the case that people begin to see the diagnosis or label and not the unique child?

*KI 4 'And if there is one thing that I would want people to understand [it] is just because they have seen one child on the spectrum, that that's it!' (L 706-717).*

Key Informant 5 worked directly with children in the school setting and found them amazing. She delighted in their differences. She enjoyed working one-to-one with children as this helped them to understand themselves.

*KI 5 'I certainly find the children amazingly different, it's just amazing the differences. You can still have the defining features, the children are also so different and of course on a one to one setting, a lot the children appreciate that very much and feel much more understood' (L121-124).*

#### What is needed?

The Key Informants identified many needs. They suggested groups of all kinds for parents, such as education and support. For the children they recommended groups on social skills and befriending, as well as advice and help on sexual matters and careers. A 'drop-in' was suggested or perhaps someone at the end of the phone for help and support. They identified that there is a desperate need for respite and holiday arrangements so that parents can either get help or have a break.

Greater understanding was a need unanimously voiced by all Key Informants. This included society as a whole, as well as acceptability in mainstream activities. They were also aware of the need for teachers and school staff to be more understanding.

*KI 2 'One simple word understanding' (L 375).*

*KI 3 'If pigs might fly, a society was more accepting, yes, I think that's, that's certainly got, because it, it is hurtful, it is hurtful' (L 521-523).*

*KI 5 'Also, one of the things we need to do much more is about the positive aspects of Asperger's. There's the book with famous people who are supposed to have had Asperger's, or who have it still and I think that's really important and we don't do enough of that. They should all have a book' (L 286-290).*

*KI 5 'I think there are loads of gaps in terms of support for parents and ultimately support for children through that, but I think we need much more earlier support for parents really' (L 258-260).*

*KI 4 'I think for others to understand' (L160). KI 4 'but I really, really would just increase their understanding' (L 537).*

*KI 4 'It would make such a difference because we do not need major changes, we need people to just think things through rather than take it for granted and what I often find in high schools, things just don't work because staff just don't have the time, they say like we can't be bothered, you know, because 10 different subjects and 10 different teachers and yes, they have 30 children but if they could just have that understanding I know I keep saying just, but I don't think it's asking for much' (L 540-547).*

### Other Factors

Three of the Key Informants disclosed that they have children with either ASD or special needs. They felt that this could be helpful when working with families, in that the appropriate use of disclosure could help to engage families. In those instances, the families seemed to feel that the professional really did know what he or she was talking about.

*KI 1 'Sometimes I will say things that my son has done or situations, and people will take what you are saying if they know you have walked in their shoes a little bit' (L 48-50).*

*KI 2 'I do tend to use him as an example and I find that the families accept me more, possibly, believe me more because, not that I know what they are going*



*through, because everybody is different, but I can understand a lot of it' (L 290-292).*

*KI 3 'Personally I have had a child with special needs, so I know what it's like going out with a child who is not likely to behave normally, so I can see it from both sides' (L 138-139).*

*KI 3 'I always say, take pride in the fact that my older son has got no inhibitions at all about, you know, disabled people, they are just people and that's he has been brought up with a family and his brother has special needs and it's normal life and he when his brother has been excluded from something he just says "weird people", you know, so I think that to me I think that says it all, yes' (L 646-651).*

### Summary

In Chapter Three I introduced you to the families that took part in the research, along with summaries of their narratives. This was followed by an introduction to the Key Informants and a summary of their core themes. I also gave my representations of the narratives within the context of the core themes that emerged; in some instances using verbatim quotes from the transcripts for my illustrations. The core themes were mapped within participant groups and across the groups.

In Chapter Four I offer a discussion of my findings, implications for practice, limitations of the study, as well as some reflections.

# **CHAPTER FOUR**

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### **DISCUSSION**

In this chapter I will explore the main themes that have emerged from the study in relation to the current research and evidence that are available. The main themes were: 1) Life before the game: problems getting a diagnosis, family stresses, school problems, lack of confidence in parental control; 2) Experiences of the game: fear of being observed, timing of the game and enjoyment of the game; 3) Life after the game: improvements in confidence, relationships, communication and understanding; 4) Other themes to emerge were: hidden disability, fear of the future. 5) What families want: support, respite, training and education for themselves and for professionals along with understanding from society.

I will also evaluate the findings and their implications for future practice.

#### **Introduction**

In the previous chapter, through the use of a narrative approach, I analysed the experiences of ten people: three mothers and two of their sons, who were diagnosed with Asperger's Syndrome, along with five Key Informants—professionals who work with families with AS-HFA.

Although the study's main focus was the families' experiences of the PCG, in order to place it in context, I felt it was also important to include a wider understanding of family life—the successes and the struggles—as well as what brought them for help to the CAMH service.

The mothers gave a moving picture of the difficulties and struggles they had faced since their children were small. The two children added their personal feelings about relationships, particularly with their parents. Through their narratives, this study presents personal experiences of the PCG and offers important insights into the lives of families with a child with Asperger's Syndrome.

## **FAMILY LIFE BEFORE THE GAME**

### Lack of parental control and confidence lead to high levels of stress

All three parents talked about feeling that they had lost control of their child's behaviour; they therefore lacked confidence in their parenting abilities. This, in turn, contributed to their high levels of stress.

This theme came through very strongly. All three parents talked about their feelings around the loss of control over their child's behaviour. As a consequence they felt a lack of confidence about their parenting ability. The mothers talked about their difficulties in managing their children's challenging behaviour, it was so severe that they needed a referral to CAMHS. They described extremely problematic behaviour, e.g. that they felt they had 'lost control'. This not only had an immense impact on the mothers and their sense of self, but also on how they experienced family life. What came across in these narratives was the mothers' sense of isolation, and feeling blamed by others—particularly pre-diagnosis. They talked about having no-one to whom they could turn who could understand their situation. Others—including professionals—often saw their children as simply naughty and difficult. These stressors were also identified by Chell's (2006) study who found that parents with Asperger children often felt guilt, stigma, and isolation, along with a lack of understanding and support from the public and professionals. I will expand on this later in the chapter under the heading of Family Stress.

### Diagnosis

Another key theme to emerge was the families' experience of the diagnostic process as both lengthy and stressful. The mothers described their frustrations of being passed to many different professionals before a decision about a diagnosis was made. Sharon particularly talked about how long it took and how many professionals they had to see before a diagnosis was given. This experience is contrary to the recommendations of the National Autism Plan for Children (NAPC) which advocates early identification and diagnosis through a multi-agency assessment, with a response to parents within seventeen weeks (NAPC 2003). The multi-agency aspect—working as a co-ordinated team—would alleviate the necessity for parents to see so many professionals separately (NAPC 2003).

An early diagnosis, as recommended by NAPC, may also have helped to alleviate some of the stress experienced by participants in this study. The parents I interviewed related to me the consequences of delayed diagnosis: the child often suffered negative experiences and repeated failure in his or her relational interactions. Sharon and Jane talked about how, prior to diagnosis, both the general population and professionals saw their children as naughty, and gave a great deal of negative feedback. This began to set a pattern with certain people and situations. Goin-Kochel (2006) explains that an early diagnosis could reduce the stresses the child and family have to endure. In a cross-cultural study, Goin-Kochel et al (2006) found that a diagnosis of autism was given at a mean age of 3.3 years in males and 3.7 years in females. For AS, it was a mean age of 7 years in males and 8.9 years in females (Goin-Kochel et al 2006). They used two age groups at the time of the study: one for those under 11 years of age and another for those over 11 years of age—with the oldest being 22 years. This web-based study received responses from parents in five different countries, but mainly the US. The study showed that age at the point of diagnosis was reducing (Goin-Kochel et al 2006). However, Goin-Kochel add that the slow diagnostic process contributes to: *'1) Parental distress and difficulties coping and, 2) 'They miss out on being eligible for early intervention services, which in turn may affect the child's long term outcomes'* (Goin-Kochel et al 2006:441). Mandell et al (2005) in the US had similar findings; they also added that children who presented with physical symptoms, e.g. walking on tip toes, hand-flapping or odd play, were diagnosed earlier than children whose symptoms were less obvious, such as oversensitivity to pain or hearing impairment (2005). This was certainly confirmed by the parents and the Key Informants in my study: the less obvious symptoms of HFA and AS were often missed. The mothers and Key Informants in my study talked about AS being a hidden disability and this also seems to be the case in the diagnostic process. They talked about having to see many different professionals, some of whom knew nothing about AS-HFA; and even those that did know were often not confident enough to make a diagnosis. Sharon told me about many appointments she attended with her son with a senior professional, who talked about a possible ASD diagnosis but would not make a decision; this went on for a number of years. It was only in a crisis situation that a different professional saw her son and referred him to our services that he finally got a diagnosis. NAPC recommends that there should be awareness training across all professions, *'as well as specific training and updating for those specialist professionals working with children and families with ASD'* (NAPC 2003:27).

In my study, I found that children with clear autistic traits were generally diagnosed early; yet those with Asperger's Syndrome—who were bright and articulate—were often seen by untrained professionals and as a consequence were often not recognised, even though there may have been great difficulties for the child, both in the family and school. In her narrative, Sharon compared the vast difference between her two experiences of specific support during the diagnostic process for Peter and Jack. These findings have to be balanced against necessary caution in diagnosing young children, bearing in mind the possible differential diagnoses.

Although Goin-Kochel et al (2006) explained parents' feelings about the length of time to diagnosis; their study did not include those families whose children were *not* diagnosed with ASD. It may be that the time/caution undertaken by the professional was correct and in some cases a diagnosis of ASD was not given. Clinicians have to be cautious due to the potential harm of a wrong diagnosis. Stoner (2005) found that parents wanted the professionals to be proactive and '*assist them in obtaining a diagnosis by listening to their concerns and to avoid using the "wait and see" method, as parents have a greater understanding and sense of their child's condition*' (Stoner et al 2005:48). She goes on to argue that early screening would not do any harm, nor would sending them on an early training programme. '*There is nothing to lose and everything to gain*' (Stoner 2005:48).

### Family stress

One of the key findings from this study was the mothers' stress and frustrations of life with a child who has AS-HFA. The Key Informants also noted the high level of stress in the families that they had met.

In her study, Schall (2000) reported that parents of children with autism told how exhausted they became. Only part of the stress and exhaustion came from the 'daily grind' of parenting an autistic child—'*a great deal came from constantly fighting battles with professionals and others*' (Schall 2000:416).

All three mothers in my study described the many stresses that impacted upon their lives and those of their family. They experienced low self-esteem; they felt they lacked the parenting skills required; they doubted their own judgements about their children; family routines took longer; outings—if attempted—were extremely difficult; parents were exhausted and relationships were strained or broken. Sharon described how she had stopped saying loving things to her son.

*When you have a problem child you don't say those things. How can you say nice things to someone who is smashing you in the face? When we came out of the PCG I could just drop it out that I loved him and he was special to me' (L 332- 227).*

She described how going out was a 'nightmare'—even to the shops or the park. Ordinary family routines were demanding; bedtime and morning routines were particularly taxing. Much of the current research confirms that parenting an AS-HFA child produces significant levels of parenting stress (Epstein 2007, Kelly 2008, Lee 2009, and Schall 2000).

Epstein et al (2007) demonstrate that the '*levels of stress are positively correlated to the child's levels of impairment*' (Epstein 2007: 503). Gray (2003) looked at gender and parental coping with an Asperger, or high functioning Autistic child. He found that mothers were generally the main carers and that they experienced greater amounts of stress when caring for an ASD child. Gray found that high levels of stress for the mothers and subsequent lower levels of stress for the fathers caused considerable strain on the marriage (partnership). However, fathers did report concerns about their child's future. In Gray's study, the mothers generally reported that their emotional well-being was severely affected by their child's autism. With some mothers, this was so severe that they had needed psychotherapy and/or medication (Gray 2003). A study by Allik et al (2006) showed that mothers, but not fathers, reported impaired health-related quality of life; they also found '*maternal mental health was related to the extent of symptoms of hyperactivity and conduct problems in the child*' (Allik et al 2006:6). The three mothers that took part in my study were the main carers for their children, managing their appointments, etc. Susan was a single mother, so parenting naturally fell to her. Jane's husband worked full time and did not attend the sessions. Jane did say that it was her job to manage the children and any attendant problems. Sharon and her partner, Bill, both attended the sessions, but it did fall to Sharon to manage the children and their difficulties most of the time. Sharon and Jane both broke down in their PCG sessions and talked about the huge burden they were trying to manage. It is clear how much time parents have to be available to their children even when they are in school. Many parents like Jane feel that they have to put their lives on hold. Having a career is almost impossible and even doing the regular things in life, like having a shower when you want one, becomes a timetabled activity.

The Key Informants also talked about mothers being the main carers and bearing the greater proportion of stress. Some of the Key Informants also talked about the fathers finding it more difficult to accept the diagnosis. It was suggested by one Key Informant that this might be the case as many fathers worked and thus did not have to manage their child's behaviour on a daily basis or deal with professionals and peer relationships.

Sivberg (2002) examined 37 parents of children with ASD and 37 parents of children without ASD who were matched for: children living at home, age, sex and background. Sivberg assessed for levels of strain on the families and levels of coping, and stated that results illustrated that there were significantly higher levels of stress on the families with ASD children. The ASD families also scored significantly higher for non-constructive coping strategies, such as distancing and avoiding (Sivberg 2003). All three parents in my study talked about feeling that they could not relate to or understand their child, and that a distance had grown between them. Parents had to learn a new way of relating to their autistic child and, although my study was small in number, it seems that the PCG helped with this.

Stuart and McGrew (2008) looked at the factors impacting on the main caregiver six months after diagnosis. Caregiver stress levels were directly linked to the severity of the child's autistic symptoms, additional life demands, social support and coping strategies. Most families reported high levels on all parameters consistent with a high level of burden, including passive avoidant coping strategies; Stuart and McGrew also add that, *'having a negative diagnostic experience can profoundly affect the families' feeling of burden across several dimensions'* (Stuart and McGrew 2008:10,11). In my study Sharon particularly talked about avoiding close contact with her son Peter as his difficult behaviour had caused a strain on the relationship. The relationship had broken down to the point that she couldn't even say nice things to him or want to do pleasant things with him. Avoidant behaviour was common in the parents in my study.

Lee (2009) examined caregivers' psychosocial adjustment (depression, anxiety and marital adjustment) between mothers and fathers of HFA children, and parents of children without a disability. Lee found that HFA parents had higher stress levels and poorer mental health, along with lower marital adjustment, than the parents whose children had no disability. She also noted that parents of HFA children tended to be *'less optimistic had lower self-esteem and less psychological stability'* (Lee 2009: 107-108). Higgins et al (2005) explored the factors associated with family functioning



wherein there was a child with ASD. In their study, a large proportion of the children (59%) were diagnosed with HFA. They found, as the above studies show, that parents reported lower marital happiness, family adaptability and family cohesion; however, there were no reports of low self-esteem (Higgins et al 2005).

One mother in my study was single. However, we do not know the details of the break-up and whether this was due to the child's behaviour. The two other mothers did talk about the stress on their marriages/partnerships.

Mori et al (2009) found, after studying 193 families in Japan, that families with children with AS suffered significantly higher levels of stress than families with autistic children. Mori also found that the stress levels could be triggered by factors associated with the child's behaviour and parental perceptions (Mori et al 2009). They concluded that parents of AS children showed significantly greater stress levels and linked it to the child's behaviour and parental perceptions (ibid). They also add that AS has lifelong, high levels of dependency, despite relatively normal cognitive abilities (ibid). Certainly my parents bore all of this out in their narratives.

Benson and Karlof (2009) studied parents of children with ASD and found that they reported significantly higher levels of both anger and depression (Benson and Karlof 2009). In addition, other family issues have been explored: Rivers and Stoneman (2003) examined the sibling relationships, (one with ASD and one not) along with the parental marital relationship. Their study suggests that when the parents were experiencing marital problems, it not only had a negative impact on the children, but that the sibling relationship was negatively affected as well (Rivers and Stoneman 2003). Two families in my study had more than one child, and both discussed the difficult rivalry between the siblings, at this point I do not know if the marital relationship had any impact or not.

However the impact of stress in one area of life seemed to have far reaching effects in many other areas of family life. Clearly there is a great deal of research looking at parental stress and family instability for children with ASD. The experiences of the parents in my study bear out the findings of the research literature.

### Family Strengths

Despite the families' describing their high levels of stress, exhaustion and strain, they also demonstrated a great deal of resilience and adaptability. They continued to work

with and for their children to help them to be the best they could be. Although the Key Informants also described the high levels of stress within the families with whom they worked; they too related their very high regard for the families' resilience and hard work. Pakenham et al (2004) found that *'integral to coping with raising a child with Asperger's Syndrome (parental adaptation), parents made sense of their situation and sought the benefits from Asperger traits (meaning making)'* (Pakenham et al 2004:261). Their research highlights the resilience some families employ in order to manage the difficulties that they face (Pakenham 2004). Certainly, the families and the Key informants in my study reported that most families were working hard to find positives within their situation and to turn their lives around to a more satisfying experience. All of the parents wanted their children to have happy fulfilled lives.

Bayat (2007) also looked at family resilience and found that a substantial number of families with ASD children displayed a family connectedness marked by *'closeness, positive meaning making of the disability, and spiritual and personal growth'* (Bayat 2007:702). Bayat's study emphasised that families reported becoming stronger as a consequence of the disability (Bayat 2007). One Key Informant spoke of the families she saw who had both high levels of warmth within the family, as well as the determination to work through all of the difficulties they faced.

Pakenham (2004) and Ozonoff et al (2002) assert that 'reframing' is a positive coping strategy and a healthy one: i.e. focussing on the child's strengths as opposed to focussing on the child's difficulties (Ozonoff et al 2002). All of the parents and Key Informants in my study talked about the positive qualities of the children they knew and their areas of great strength and ability. A number of them said that society and professionals should be highlighting the positive, unique abilities of people with AS, rather than focussing on the negative aspects of AS. This is in keeping with the findings of Ozonoff et al (2002).

### Problems in the school setting

Difficulties with the child's education constituted a major theme that emerged from the narratives. Only one Key Informant felt that the schools with whom she had contact were meeting the needs of ASD children. The other four Key Informants emphasised significant problems in the school environment. Gable (2006) explains that parents *'often find themselves in a position with a school in which they have little control, influence or trust, and must fight for services'* (Gable 2006:131). The picture seems to

be that some schools do undertake training and are well-informed, consequently working well with ASD children. These same schools work well with the parents and other professionals to help the child to reach his/her potential.

Sharon told a compelling story of the two schools her son attended. The first was not helpful or supportive and her son was failing in all aspects. The second school was very understanding and supportive, and worked with both Sharon and her son. Consequently, his behaviour and learning improved dramatically. Unfortunately, Jane's son Ellis remained in his school where she felt they did not understand ASD, although they assumed they did understand and thought they were putting everything in place for him. Ellis continued to struggle and his mother Jane continued to be desperately worried about his emotional well-being and educational future. Gable (2006) also drew attention to what can happen when schools do not work with the parents: '*An unresponsive educational environment has very real consequences for the life trajectory of a child with AS—in this respect schools have the potential to become more or less disabling for the child with AS*' (Gable 2006:131). The Key Informants talked about the schools being able to opt out of ASD training sessions. The frustration experienced by the Key Informants was high, and at times they were shocked by the comments of some of the teachers. Some Key Informants told me that they had been into schools to offer training, but it was clear that a number of staff members were not interested and did not change their practice.

There are a number of school-specific interventions that could be adopted; however, adapting the PCG may also be a possibility. According to Freeman (1997), there is one form of approach in schools that is suitable for autistic and typical children: '*that is structured educational programs geared to the person's developmental level of functioning*' (Freeman 1997:646). Whilst I agree in essence that it is good for everyone, few educators could assess and implement such an individualised programme with classrooms of twenty-five to thirty-five pupils.

There is clear guidance for educators within Parts One and Two of *Autistic Spectrum Disorders: Good Practice Guidance* (2002). It gives comprehensive advice and guidance on managing and understanding ASD within the educational setting:

*'All those who plan or provide for children with ASD should have some knowledge and understanding of autism. Education staff training programmes help to spread knowledge and understanding of the disorder and should be open to all relevant staff, not just teachers. If staff are not aware of the way a*

*child is affected, then the child might be seen as naughty, lazy or non-compliant'* (Autism Working Group 2002:15).

Part Two of the *Autistic Spectrum Disorders: Good Practice Guidance* (2002) looks in detail at the school environment and offers guidance on all aspects, saying there should be

*'Effective communication between home and school about individuals' behaviour plans. Parents are always consulted when there is a significant change to the behaviour plan'* (Autism Working Group 2002:88).

Despite the advice above, it was clear from the experiences of parents and professionals in my study, that few of the schools they attend have a real understanding of children with AS and their difficulties. Parents told me that the schools were not informed or helpful. At times they were seen as unhelpful and, in one case, the mother described it as abusive.

Although my study focussed on a very small number of participants, other studies show that schooling is a common problem for children with AS. Whitaker (2007) explored the views of 173 parents' questionnaires (49% response rate) of all the children with a diagnosis of ASD attending mainstream school in Northamptonshire. The most important issue for parents was that *'educational staff should have some sense of what lay beneath the challenges and difficulties both presented and experienced by the child'* (Whitaker 2007:175). Other issues identified were: *'the child's progress in social skills, the capacity of staff to manage the child's behaviour, the level of structure offered and the child's happiness'* (Whitaker 2007:174). In the USA, Stoner et al (2005) interviewed parents whose Autistic children were attending special schools; they found difficulties similar to those in my research. Parents in the Stoner et al study wanted open communication with schools. Parental lack of trust in educational staff emerged as a problem, and one recommendation from the study was for staff to *'enhance trust with parents and recognise that every interaction has the potential to either enhance or reduce trust'* (Stoner et al 2005:49).

In my study, Sharon's narrative brought to light that some schools can get the support level right, as the second school her son attended made a great difference to his educational experience. Only one Key Informant gave a positive view when talking about schools.

The picture which has emerged from the narratives clearly indicates that some schools are well-informed regarding ASD, and that this shapes their day-to-day practice as well as their understanding of parents/families. Sadly, other schools were seen as severely lacking in this regard.

This general problem is reflected in the literature. Ozonoff (2002) discusses school-based problems, explaining that teachers might have general knowledge about learning difficulties, but this is very different from specific knowledge as regards AS or HFA, particularly because these children are generally above average and may not have a difficulty with *learning* at all. Ozonoff echoes what the parents in my study have expressed, which is that teachers see the child as able or bright, but unable to manage the work. Teachers then make the assumption that the child is lazy, defiant or stubborn (Ozonoff et al 2002). Jordan (2008), a specialist in child development and ASD, gives the same message when she discusses the difficulty with 'educational inclusion' as it stands today. She explains that inclusion was based on a model of typical development, which in itself has been discriminatory (2008). She goes on to suggest that inclusion is not actually inclusion but *integration*, as the content and teaching of the National Curriculum in mainstream schools were not adapted to accommodate children with ASD. Adaptation of mainstream curriculum for learning difficulties usually means breaking down information into smaller steps. This is not suitable for children with ASD as they actually think differently (Jordan 2008). In her article, Jordan gives a strong message that ASD children need to be understood with regards to ASD and their individual needs. She says: '*it is not enough for an educator to note a child's behaviour without some understanding of what it might mean in a particular case*' (Jordan 2008:13). Batten et al (2006), in their report for the National Autistic Society, *Make Schools Make Sense*, also recommend that there should be ASD-specific approaches for children in schools and also acknowledge that families have a wide spectrum of experiences with schools (Batten et al 2006). They also say that the '*education system is failing too many children with Autism*' (Batten et al 2006:44).

One of the mothers in my study had considered home-schooling her son. However, she was well aware of the many difficulties this would involve. In Batten et al's report (2006), a number of people were interviewed who had successfully home-schooled their children in preference to sending their child to fail in the state system. Of those parents who opted for home-schooling, few had received any outside support and were simply left to get on with it (Batten et al 2006).

School settings that stimulate sensory and emotional overload result in highly anxious children who are unable to learn (Gable 2006). In my study, Ellis certainly displayed symptoms of high anxiety over school issues. His protective/defensive behaviour in school was seen by the teachers as defiant and manipulative at best, and as aggressive and threatening at worst. However, ASD children who are home-schooled are at risk of missing out on opportunities to develop the social interaction that the school setting can offer.

It is within this stressful context that the families came to CAMHS for help. Some children came with an ASD diagnosis; some did not, and were diagnosed following an assessment in the CAMH service. All were suffering mental, emotional or behavioural difficulties severe enough to be referred to a tier three CAMH service. The PCG is one behavioural programme that was on offer. If the PCG can help parents and children towards better communication and relationships, this should help the child to have improved relationships in other settings, providing that the adults have an understanding of the child and their specific issues. The Early Bird programme offers the opportunity for a professional that is working with the child, usually the teacher or the classroom assistant to join the group and learn alongside the parents. The learning can then be cascaded through home and school as required. If parents and children are willing, then a professional could have attended the PCG with them in order to be involved in, and learn from, the experiences with the family.

There are also a number of programmes that schools could employ if they were willing, for example: social stories<sup>9</sup>, TEACCH<sup>10</sup>, or simple planned programmes (Autism Working Group 2002, Batten et al 2006 and Jordan 2008).

There is little else on offer locally for ASD families, and parents usually have to travel some distance to attend what is available. Two of the mothers, Sharon and Jane, did not drive; a factor which limited their options.

Goin-Kochel et al (2007) discuss the many treatments and therapies tried by parents and their children with ASD. Of the 479 parents that responded to a web-based

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<sup>9</sup> 'By creating a short story, the situation is described in terms of relevant social cues, anticipated actions and information on what is occurring and why' (Attwood 2004:33).

<sup>10</sup> 'Treatment and Education of Autistic and related Communication-handicapped Children. Mainly used at school with home supplementation techniques easily generalised to work environment' (Ozonoff 2002:78).

survey, they and their children had tried between seven and nine therapies, and were using between four and six. These therapies included pharmacological, behavioural, educational and alternative therapies. *'Many of these interventions required significant training, education and management on the part of the parent'* (Goin-Kochel et al 2007:195). In addition, a number of the therapies had little or no data to support efficacy; yet parents continued to try them and professionals to deliver them (Goin-Kochel et al 2007). Ozonoff et al (2002) draw attention to the lack of evidence-based research for treatments specifically designed for AS and HFA children.

By contrast, the PCG needed only a slight adaptation in order to be appropriate for ASD and, in particular, AS-HFA children. It does seem to me that professionals either try to offer the typical treatments (which often do not work) or develop a whole new batch of therapies that are overly specific. In essence, what I have experienced is that each person is an individual and, in order to work with that person, we need to try to see the world through his or her eyes (i.e. be person centred). With a little effort, we can adapt our practice to suit each person's specific needs. The skills that we have can be applied with precision in particularized treatment. The PCG appears to offer this solution, in that it begins with the family's difficulties, and then works together on the areas we have collectively identified in a way that is acceptable and appropriate for that particular family.

## **EXPERIENCE OF THE GAME**

A number of themes emerged from the participants' narratives with regards to their experience of the PCG. Two linked but separate themes were fears of being observed or scrutinized by the therapist and/or being videoed. Timing was a third theme: i.e. whether it was the right time for the family to embark on the PCG or not. A fourth theme was the enjoyment that the families experienced during the game.

### Fear of being observed

It emerged through the parents' narratives that, although there had been a preparation session prior to starting the PCG, the parents had had many worries and misconceptions about the PCG. Susan appeared to be very fearful of the video suite, although she kept saying she was fine. She also thought she was coming to take part in something that a friend had told her about, which, in fact, had been quite different from the PCG.

All of the mothers and children initially had fears about being observed, as well as about being videoed. These were readily acknowledged at the time of the therapy. However, once the PCG had begun, most relaxed and entered into the game. Susan seemed to be the least relaxed, and, in her narrative did talk about 'secret agents' and being watched by many eyes from behind the screen. The two children explained that they relaxed very quickly into the game and described forgetting about the cameras altogether soon after starting the PCG.

### Timing

Two of the mothers felt that the timing of the PCG had been right for them, as it followed on from theory-based courses that they had recently completed. Sharon and Jane mentioned a number of other groups and training sessions that they had attended. This seems to have helped them both as the PCG felt like a natural progression for them from theory to practice.

More research is needed into treatments that are appropriate for ASD children and their families and at an optimum time for them, making it most effective. I could not find any literature that discussed the timing of the PCG or any other talking therapy. This study offers new insights into the timing of any therapy. The parents in my study clearly thought that the timing of therapy was an important aspect of their experience.

### Enjoyment

Another theme that emerged was that two of the mothers and both children spoke about enjoying the games. These two families had attended after the adaptation. They found the games fun and they laughed a lot together. It seemed to facilitate the positive aspects of their relationships. Forehand and Long (2002) as well as Jenner (2002) talk about the need to have fun with your children in order to have a good relationship and to learn together. They have not extended that to discuss the merits of it in the PCG.

The mothers also spoke about feeling supported through having time to tell someone how bad their situations were for them and then to discuss some strategies about how to manage the most difficult behaviour. Sometimes the mothers spontaneously broke down and became tearful. They spoke of this positively, in that they simply needed to let out their feelings. However, both of the children found these 'emotional' sessions not to their liking—unsurprising for children with ASD. The PCG literature does not



report on the support that parents may gain from taking part in the PCG. Although the efficacy of the PCG has been researched with children with behavioural difficulties; I did not find any studies that included the support the parents experienced. My study suggests that the whole experience was helpful to parents in different ways, not just the time in the room with the child.

The children's willingness to contribute to the study gave the whole process added meaning for me. The children showed insight about their own feelings and that of their families. It was clear that, although the boys presented with very difficult and challenging behaviour at times, they both were sensitive towards their parents' feelings and needs. Both children said that they enjoyed the games in the PCG and were delighted in the time they had with their parents. The children also felt that it helped them to get on better with their parents. As a result of the PCG, parents began to include special time for the children at home. Sharon and Jane both talked about how their children did not want to miss the sessions and looked forward to coming and playing the games.

Susan's experience of the PCG was different. She felt that she was just marking time with Billy and that he did not really want to come. Susan had misunderstood what the game was about and tried hard to keep Billy calm. Susan and Billy had attended the game before I had made the adaptation for ASD. Billy chose construction games that he could complete alone; thus Susan felt redundant. It was exactly this type of observation that led to my making an adaptation to the PCG. Billy's not spontaneously involving his mother in his game is very typical of ASD children. Comparing this with the two families that experienced the adapted game shows what different results can be obtained. I would suggest that this gives an indication that the adaptation was necessary wherein the child has ASD.

## **LIFE AFTER THE GAME**

### Improved confidence, relationships, communication and understanding

The PCG aims to encourage a good quality relationship with mutual respect; this, in turn, facilitates effective management.

The PCG has heretofore been researched with typical children and families: e.g. Forehand and McMahon 1981, Forehand and Long 2002. Their research, however,

focussed on 1) improvements in behaviours as reported by the parents in therapy, and 2) observations by the professionals both during and at the end of therapy—with follow-up, in some cases, through to fifteen years of age (Forehand and Long 2002).

Forehand and Long's research does suggest good results, with improvements in all family relationships—including communication and understanding, along with parents feeling more confident in their parenting skills (Jenner 1999). However in my search of the literature I could not find any articles researching the parents' or child's *experiences* of the PCG. Also, my study specifically focussed on children with ASD, which previous research on the PCG had not.

I found a study reported by Solomon et al (2008) with a trial of Parent Child Interaction Therapy (PCIT). PCIT is very similar to the PCG as it uses a one way mirror and ear-bug to communicate between coach (therapist) and parent. '*It is a behavioural-based manualized parent coaching intervention*' (Solomon et al 2008:1767). Their study focussed on parents with children with ASD and behavioural problems. They modified PCIT slightly in two ways: first, by prohibiting the child from talking excessively about his or her own interest; and second, they encouraged parents to be more directive, rather than let the child play in isolation. The research method they employed used a battery of rating scales and inventory measures<sup>11</sup>. They found, amongst a number of things, that there was a reduction in parent perceptions of child problem behaviours, although there was no significant reduction in actual behaviour. There was, however, an improvement of the child's adaptive functioning<sup>12</sup>. They report a significant increase in the shared positive affect<sup>13</sup> of parent child dyads (Solomon et al 2008). Although they reported some anecdotal evidence, they did not interview the participants about their experiences.

A key theme that came through from Sharon, Jane and their children was improvement in terms of family relationships and parenting. They shared that their family relationships, understanding and communication had shown marked improvement,

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<sup>11</sup> E.G. The Eyberg Child Inventory (ECBI), Behaviour Assessment System for Children Parent Rating Scales (BASC), the Parenting Stress Index-Short Form (PSI-SF), Shared Positive Affect Coding Adapted from Kochanska and Aksan (Solomon 2008:1770).

<sup>12</sup> 'Adaptive Functioning: increased willingness to share, to shift between activities, to adjust to new situations and try new things' (Solomon 2008:1773).

<sup>13</sup> 'Positive Affect: occurs where there is laughing, joking playfully, singing happily, smiling, saying I love you or an affectionate touch' (Solomon 2008:1775).

along with their having gained a new confidence in managing their children. Sharon explained that she could manage Peter in a more considered way; she had learnt to anticipate situations and to be organised for the activity. As a result, Sharon was therefore prepared and did not respond impulsively. Once Sharon had attained a better quality relationship with Peter, she could hear his specific needs and struggles, this not only helped Sharon to understand Peter, but also to help Peter to understand himself and those around him. Sharon described this well when she talked about building in quiet time for Peter to play alone in his room—which he liked. He then learnt that he could ask his parents to play with him once they had free time, after his younger brother went to bed. Asperger children do not realise that they have to say what is going on inside them; rather they assume that because they know it, everyone else must know it (Attwood 2004). The adaptation I have made to the PCG is to facilitate games that do not require verbal interaction, but rather visual interaction—and in a pleasurable way. This helps the child to learn to communicate his or her needs through the interaction.

Peter and his parents had not *really* been listening to each other prior to the PCG. Improved communication was evident in the family's relationships once they really began to hear one another. Peter felt the special play times and the PCG had helped him to get on better with his dad because they were doing things together.

Jane too thought that she got on better with Ellis and, as a result of the PCG, put in strategies at home that worked better. Jane felt that she and Ellis had better communication and therefore an improved relationship. Jane said that, through the PCG, she found out what Ellis liked and was better able to predict difficult situations. Ellis told me that the PCG helped him to get on better with his mother and that they did not argue so much. Ellis said that it helped that he could tell his mother what he was thinking and feeling. The improved communication enriched the quality of the relationship. Jane had said she was pleased to see Ellis happy again.

Sharon and Jane talked about feeling less stressed, feeling in control again and enjoying more of life than before. Once they had tried and tested the new strategies, their confidence improved and they all relaxed. However in Solomon's et al study (2008) he found that despite improvement in parent positive affect, parental stress did not reduce.

## OTHER ISSUES THAT EMERGED

### A hidden disability

Many of our social norms are founded upon unspoken rules. ASD people struggle to understand what is acceptable with whom, when and where—particularly as so many rules are unspoken or subtle (Ozonoff 2002). *'Society appraises an individual by the way they look, behave and talk. The person with AS has no distinguishing physical features'* (Attwood 2004:28). Add to this their unusually advanced and sophisticated language (Ozonoff 2002) we can see why people might have normal/high expectations of the child and are shocked when they get something different. Professor of Linguistics at Tel Aviv University, Shlomo Izre'el, states that, *'in the mythology of ancient Mesopotamia, language symbolises intelligence'* (Izre'el 2001:135). He goes further to suggest that *'we hold the same perception today... that we evaluate the intelligence of people (notably of children) by their linguistic capabilities: the more eloquent a person's language, the more intelligent we consider him to be'* (ibid). Izre'el (2001) highlights how the opposite has also happened when he cites (Sacks 1990:8-9) *'It was for this reason that the congenitally deaf, or "deaf and dumb," were considered "dumb" (stupid) for thousands of years and were regarded by an unenlightened law as "incompetent"—to inherit property, to marry, to receive education, to have adequately challenging work—and were denied fundamental human rights.'*

All three parents and most of the Key Informants explained their experiences of professionals and the public as that of not accepting that a child has problems because they 'look normal'.

Lasser and Corley (2008) interviewed twenty parents of children with AS. One of their findings was the issue of a 'hidden disability'—related by many parents. The parents explained the difficulties they faced in public when their children acted outside of what was expected to be normal for their age or the context. Lasser and Corley termed this *'the normalcy incongruity'* (Lasser and Corley (2008:343). This type of situation was extremely disturbing to parents and children interviewed in my study, as not only did people notice, but they often reacted in a verbally abusive, and/or aggressive way. Often the child's behaviour did not directly affect anyone else, e.g. an older child holding hands with the parent. During family outings, when parents and children had this type of experience, it only added to their stress, emotional upset and isolation. Gray (2002) interviewed 53 parents of children with AS or HFA about the stigma that

they experienced as a result of their child's behaviour. He found that mothers, more often than fathers, encountered avoidance, hostile staring and rude comments from others (Gray 2002). Indeed, the parents were more likely to experience stigma if their child was displaying aggressive symptoms, than if the child was passive (Gray 2002). Gray also found, as my parents described, that as the disability is less evident with AS and HFA, people are more likely to react in a '*negative fashion*' (Gray 2002:742).

### Fear of the future

Fear of what life will be like in the future was a key theme in the parents' stories. All the parents worried about their children's futures: will they achieve anything in education; will they be able to get a job and keep it; will they be able to be independent; will they have good relationships and will they be happy? These were the many worries that parents expressed. Susan particularly voiced her worries about Billy's mental health. In the past, it is the case that ASD was thought of as childhood schizophrenia (Lord and Rutter 1994:569). Jane worried that Ellis would always be dependent on someone—probably her. She could not see that he could ever live independently. My study highlighted the fear that families experience about the long term prospects for their children. As I could find no literature exploring this topic my study has offered some new insights and could be an area for future studies.

## **WHAT FAMILIES WANT**

### Support and respite

Support and respite were both emergent themes in relation to what families were asking for, as was also recognised by the Key informants as something that parents could benefit from. Parents said they would like more support: someone to ring in a crisis who could help or a group where they could explore issues. Key Informants also felt that parents really needed support; they felt that the parental groups which they knew about had helped those who attended. Parents were desperate for a break—but in different forms. Some wanted a family that would take their AS child for a few days, to give themselves and the AS child's siblings a break. Others wanted someone to accompany them so that they could manage a family outing or holiday much better. In 2006, MENCAP published a report called 'Breaking Point'. This report identified the very difficult situations of the majority of families caring for a child with severe or

profound difficulties. It states that 'seven out of ten families have reached or come close to breaking point because of lack of short break services' (MENCAP 2006). The National Autistic Society's position statement holds 'that over half of children with Asperger's Syndrome who are not currently receiving a short break service require constant supervision' (NAS, not dated). The Shared Care Network Survey (2008) said that '92% of parents said getting short breaks had helped their child develop social skills and 100% of parents said getting short breaks helped their families to cope' (SCN Survey 2008). Clearly parents see respite as an essential requirement to surviving their parental roles in highly demanding circumstances.

### Training and education

The mothers and the Key Informants drew attention to the need for parental training and education. The mothers felt that such training would enable them to manage difficulties and, in fact, they often attended as much training as they could find. As Gable (2006) describes: '*behaviours are frequently combative, non-compliant and often misinterpreted as emotional and manipulative*' (Gable 2006:131). '*Subsequently, parental responses have the potential to be reactive and unintentionally damaging, with far reaching consequences for the child*' (ibid). The NAPC also suggests that training for parents and carers is essential and should be offered in every area (NAPC 2003).

In Stoner's (2005) study, the parents said they would like good quality training on ASD, as well as training to aid them to attend their child's IEP (Individual Education Plan) meetings in school. Parents know their children best and want to be involved to give them the best chance.

It was unanimous in my study that parents and Key Informants felt that training for parents would benefit everyone. Parents and children in my study expressed that they saw the PCG as 'live' training in interacting with their child, and moreover experienced it as a fun activity. My main research aim was to explore the parent and child experiences of the PCG; however the influencing factors with which families were living and struggling could not be ignored. I have therefore tried to hear those experiences of the families with whom I spoke and to illuminate those events within the context of their lived experiences.

### Understanding

Another unanimous message from my research was the need for more understanding about the condition. Parents and Key Informants brought up the need for society at

large, as well as for professionals—GPs, teachers, etc.—to have more understanding. One Key Informant, who also had a disabled son, felt that society was not tolerant of disabilities—even when they are recognizable disabilities. Therefore, when people act a little differently, it is not tolerated. All of the participants had observed this and expressed the need for change.

It seems that awareness of Autism having a wide spectrum has not permeated society as yet and, as a consequence, there is a general lack of knowledge and understanding. However, in our society, stigma concerning disability is still alive and well. This is an entire topic in itself, but the impact on families is immense—something that came through strongly in my study.

### **IMPLICATIONS OF FINDINGS FOR FUTURE PRACTICE**

This study has highlighted a number of areas of professional practice that require consideration. When a child is exhibiting behaviours that are proving hard to manage, the diagnostic process is only the beginning of the professional process for parents and children with regard to identifying what is going on and what might help. Lack of clarity around diagnosis only adds to this challenging procedure. I would identify this as a fundamental area for further research.

#### Diagnosis

From my study and the literature search, I would suggest that the first important step would be to have more accuracy of the diagnostic criteria. Once clear diagnostic criteria have been agreed, professionals may feel more confident in making a diagnosis; this could also assist in the process of earlier screening. To achieve this would require much greater research and training on all aspects of ASD.

Goin-Kochel et al (2000) suggest that all physicians should be well-informed about ASD through both their initial and continuing development training (Goin-Kochel et al 2006). The National Autism Plan for Children recommends that '*regular ASD specific training of all professionals working in assessment and provision of services, and a national ASD training committee and network be set up to agree and monitor standards for multi-agency programmes for all these levels of training*' (NAPC 2003).

## Services

Services for ASD children and their families are minimal and patchy. It leads me to think that a standardised, multi-agency approach would be more helpful to all concerned. Currently, this not only varies around the country, but even within counties. Within Norfolk, referral pathways vary, and therefore the professionals involved will also vary. AS and HFA children continue to slip into a gap in service provision. They do not fit the low IQ required for the learning disability service and they would not be seen in CAMHS unless there is a mental or emotional problem over and above the ASD. As ASD is a developmental disorder, community paediatrics is usually the place to gain a diagnosis. However, this could be a single-professional or a multi-disciplinary team, depending upon the area. In Norfolk, services do not extend to ongoing support or education, except for a few specific programmes such as speech and language therapy or Early Bird programmes. Otherwise support is generally left to two charitable organisations: Asperger East Anglia and the Norfolk Autistic Society. They both offer some support and training courses for parents and young people with ASD, but both depend on individual donations or financial help from government. The parents in my study spoke about not being able to access some of the few services offered by the charitable organisations as they were too far away. This was acutely felt by two of the mothers who did not drive.

My study would suggest that it would benefit families and professionals if there was a clear single point of access to which front-line workers could refer. Research shows that it should comprise of a specialised multi-agency team, with ongoing support and training for ASD children, their families, carers and professionals who are involved with them (NAPC 2003). This would be a service to which families could return at different stages of development or whenever new challenges arose. It would continue into adulthood for those vulnerable adults who will always require some kind of ongoing support.

## The game

The PCG only required a small adjustment to facilitate its use with ASD children, by way of introducing games that facilitated interactions. This appears to have been successful in that the parents and children enjoyed the interactive aspect of the game and thereby engaged well. Their relationships also showed marked improvement as a result of the game. Susan, however, did not talk of enjoying the PCG (as I had not yet



made the adjustment), but that she felt redundant and that her son had played alone as usual.

What also stood out from the narratives were the initial misunderstandings about the PCG and its aims, along with the worries and stresses that parents brought with them and which influenced their perceptions and expectations of the PCG. I think that future practice should include more preparatory sessions for the PCG. These sessions should help the parents to understand—as fully as possible—the game and its objectives; along with assisting the parents to discuss worries and previous experiences that might influence their thoughts and feelings with regards to working with us. The parents' narratives indicated that one introductory session was not sufficient to prepare them adequately. I had not known this before I conducted this study.

As I mentioned earlier Ozonoff et al (2002) discussed the lack of evidence-based research for treatments for AS and HFA. Further specific research on interventions for this population may help parents and professionals to focus their efforts, as opposed to the patchy ad hoc availability at the moment.

### Education

My parents' views would support the findings of the Autism Working Group that, at the very least, all staff in schools should be trained at an appropriate level in the fundamentals of ASD and management (Autism Working Group 2002). This should include: that each ASD child's special requirements be conveyed to each member of staff, that there should be good communication between home and school, and also that parents be involved in planning the IEP (Individual Education Plan) (2002).

Based on my parents' narratives, I would concur with Stoner's summary of her study (2005): *'It is vital that education professionals understand the perspectives of parents of the children whom they serve. The key to this understanding is open communication, effective intervention practices, and service delivery that meet the needs of the child'* (Stoner et al 2005:49).

Haringey Autism (2005) produced a report based on a survey of ASD parents in which the same issues were raised. Their recommendations included: *'appropriate support by specifically trained staff; specialist units with experience and expertise, a home based programme or combination of them all'* (2005:3).

In the USA, Dymond et al (2007) conducted a survey of 783 parents of ASD children in the Commonwealth of Virginia about what needs to change in school and community-based services. Twenty-eight recommendations came out of the study, many of which mirrored those of the studies cited above, as well as the responses of the participants in my study. The main themes were: appropriate schooling and educational programmes, education and training for people working with ASD children, and *'improve the quality, quantity, accessibility and availability of services'* (Drymond et al 2007:138).

### A hidden disability

All of the parents and three of the Key Informants highlighted situations wherein the public or professionals did not realise/accept that a child had difficulties because he/she *'looked normal'*. The National Autistic Society has been working hard to put ASD on the map through their campaigns. However, it is clear that more education and understanding in the public domain are needed. From diagnosis to treatment, as well as educational settings and the general public, there seems to be a lack of knowledge and understanding of the specific and unique needs of AS and HFA populations. My findings suggest that gaps in training and knowledge need to be addressed.

When I asked the question 'What is needed?' most parents and Key Informants replied: *'Understanding'*.

Key Informant 4: *'In all our training, this invisible disability thing, is not a cliché, it's a fact'. 'Work with the child [and] the child can reach their potential; just understand, a bit more'*.

## **LIMITATIONS OF THE STUDY**

Being a qualitative study, with a very small specific group of participants, the focus was on personal experiences, and not generalizability. The small number is a serious limitation. However, the richness of the narratives does offer a powerful insight into the struggles and joys of life with a child who has AS.

A larger sample would have added further valuable data. However, this was not possible with the population available to me, as every family with an AS child, who took part in the PCG and within the time-frame of the study, was invited to participate. The sample was representative of the local population that had taken part in the PCG,

although lacking diversity as regards to gender, culture and ethnicity. Norfolk generally remains 'White British', although there are a few pockets of gathered immigrant populations. The children were both boys. No girls with AS took part in the PCG within the time-frame of the study. No fathers agreed to be interviewed, although a few did attend the PCG sessions.

As mentioned above, although the study was very small, it nevertheless revealed a more in-depth portrayal of the families' experiences of the PCG. The families' stories appear to be representative of the findings in the literature I researched regarding AS families' lived experiences. No previous research was found with regards to the PCG with ASD children.

One of the strengths of the study was the inclusion of children. Their narratives contributed a great deal to the richness of the findings. Not only did it provide an opportunity for the children to have a voice, but also illustrated that, although AS children struggle with social relationships, they can be very thoughtful, sensitive and caring about their family members and relationships. The two children I interviewed demonstrated that relationships were very important to them. Children's voices are often overlooked: *'too often, the participation of children, even when designed by well-meaning adults, amounts to non-participation if children are manipulated, used as decoration or as tokens'* (UNICEF 2003:5).

This study centred on the families' experiences of the PCG with the small adaptation for AS children; it does not offer a new treatment specifically for AS, but does offer an innovative treatment for AS. Conversely it demonstrates that the AS population may not need their own specific treatment in a completely different way, but rather, an adaptation from an understanding of what works for them.

## REFLECTIONS

My research journey has been a cumulative process which began a number of years ago, through a series of events in both the personal and professional aspects of my life.

Having had two children, who were grown and living independently with little in the way of developmental or behavioural problems, becoming a stepmother in a new marriage didn't seem too daunting! How wrong could I be? As soon as my stepson (aged 8 years) came to live with us full-time, I recognised that he probably had Asperger's Syndrome. I was already a specialist in CAMHS (Child and Adolescent Mental Health

Services) and knew something of Asperger's Syndrome, although it was still in its infancy as far as CAMH services were concerned. It was during my stepson's two-year journey to diagnosis, that I gained more expertise and firsthand insight into living with ASD. Despite being a specialist in the service, my family and I still had to struggle through the systems that knew little about ASD: health, education, and child mental health services, to name but a few. This gave me an insider's perspective of daily living and managing a stepchild with Asperger's Syndrome. My personal experiences and struggles clearly influenced my professional life: already I had become a client/professional, insider/outsider.

My experience of the positions of insider/outsider did not have rigid boundaries but were interwoven. Gallais (2008), for instance, suggests that the insider/outsider researcher is a fluid spectrum within the research process. Although I had a personal perspective of living with a child with ASD, I feel that it was qualitatively different from the experiences of the families whom I interviewed—in that my stepson was not my birth child. However, the parents I interviewed had to come to terms with having given birth to a child with ASD. For them, this was an immensely personal experience with which they were still struggling. I clearly did not share the same struggles. When, at age 16, my stepson went to live with his mother, my position moved more towards that of an outsider as far as daily living was concerned, although I still carried those experiences within me.

My roles as therapist and researcher had their own agenda and outcomes—and yet each was closely interlinked with the other. As a practitioner/researcher I felt that I already had a familiar relationship with the children and families. This aided my research, in that we were familiar and comfortable with each other. I already had a lot of information and understanding about their lives and struggles. From my personal experiences I felt that I approached the families with somewhat of a shared history—with an empathy that an outsider might not have. On that level I was both comfortable and confident. As a researcher, however, I approached them as a newcomer—as this was a role in which I felt a novice and less confident.

When it came to the analysis and interpretation, I initially found it difficult to extrapolate information that was not about relationships, dynamics or motivations—as I would for therapy. I had to try to put the therapeutic experience and knowledge aside in order to see the research material in a new way. As I mentioned in the study, my supervisors were essential in helping me to do this. Being the practitioner/insider in this position

was hard and took time for me to make the shift to researcher. Because of my familiarity in the relationships, I was liable to skip over important comments and insights—as I took for granted what I knew about them. Thus I found it valuable not only to re-read the transcripts, but also to step back from them, in order to allow thoughts to assimilate. Then, when I re-read and re-examined the transcripts, I could do so with a fresh eye.

It was first and foremost having the families' well-being in mind (which was why I adapted the therapy) that led me to begin this research journey. From the beginning I wanted the families, including the children, to have a real voice—not a tokenistic one as can sometimes happen (page 108). My choice of research method was aimed at giving the families the opportunity for their experiences to be heard. The questions were designed to help them give voice to their struggles—which were of such severity that they warranted a CAMHS referral. The wider experiences the families had prior to coming to the CAMH service were crucial in understanding their perspective of living with an ASD child and of the PCG.

In my analysis and interpretation, I tried to stay as close as possible to the families' own words—without betraying their identity. As mentioned on page 34, being completely objective is unachievable. However, adhering as closely as possible to the families' own words helped to keep me grounded in, and focussed upon, the reality of their words and experiences. I did consider fictionalising the stories, but I felt that in doing so, something of the 'real' stories would be lost.

In retrospect, I should have negotiated more protected time away from my full-time job to focus upon the research—this would have diminished some of my frustrations. I would have benefited from more immersion in the studies, reading, reflection, pondering and thinking. Unfortunately, this was not practical within a part-time study programme with the pressure of mounting waiting lists and the ebb and flow of a live case load and all that goes with that. I think that had there been more time to reflect, I would have liked to have written a story from a parent's perspective as a way of encompassing the themes that emerged from the research. I intend to do this for publication?

I would have given more time to planning, allowing for things such as interviews cancelled, finding the best equipment before I began, rather than struggling with what I

thought would work. This is the wisdom of hindsight and what has been for me a new experience.

However, even the 'deficits' in my research will certainly inform my future practice, as I will build in more introductory sessions before using the PCG. This will provide more time for families to ask questions and for me to explore—and hopefully allay—their anxieties and worries. I would also help clarify their understanding about what they are expecting from the PCG. Until I conducted this research, I had no idea that the parents had such diverse ideas about what they were expecting.

Perhaps also it is an encouragement to other practitioners that, with appropriate adjustment, the PCG can provide a useful development experience for parents and their children with Asperger's Syndrome.

Word count 40,317 including the references.

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# APPENDICES



copy



**National Research Ethics Service**  
**Norfolk Research Ethics Committee**

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23 October 2008

Christine Lawson  
Silverwood Child and Family Centre  
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GREAT YARMOUTH  
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NR30 1BL

Dear Ms Lawson

**Full title of study:** An Exploration of The Experiences of Parents and Children Who Have Undergone the Parent/Child Game, Wherein the Children have Asperger's Syndrome.  
**REC reference number:** 08/H0310/149

The Research Ethics Committee reviewed the above application at the meeting held on 13 October 2008. Members would wish to thank you and Dr Robinson for attending to discuss the study.

**Ethical opinion**

Members considered this to be a well written and thought through application.

Through the discussion at the meeting the following concerns were addressed:

- The role of the key informants.
- Reassurance that the recruitment numbers are achievable. It was clarified that the study will not require child / parent dyads to be recruited.
- It was noted that whilst the Participant Information Sheet [PIS] did not inform potential participants that the interview would be audio taped a specific clause had been included on the consent form to inform participants. No further action was requested.

Members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

**Ethical review of research sites**

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority  
*The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England*

East Norfolk and Waveney Research  
Governance Committee



Mrs Christine P Lawson  
Norfolk & Waveney Mental Health NHS  
Foundation Trust  
Silverwood Child and Family Centre  
Northgate Street  
Great Yarmouth  
NR30 1BL

Please reply to: Research Governance Committee Office  
Research and Development Department  
Level 3, East Block, Room 032  
Norfolk & Norwich University Hospitals NHS Foundation Trust  
Colney Lane  
Norwich  
NR4 7UY  
Direct Dial: 01603 287408  
Internal: 3408  
Direct Fax: 01603 289800

17 November 2008

e-mail: [rdoffice@nnuh.nhs.uk](mailto:rdoffice@nnuh.nhs.uk)  
Website: [www.norfolkhealthresearch.nhs.uk](http://www.norfolkhealthresearch.nhs.uk)

Dear Mrs Lawson

**Re: 2008MH06S (128-09-08) An Exploration of The Experiences of Parents and Children Who Have Undergone the Parent/Child Game, Wherein the Children have Asperger's Syndrome.**

Following confirmation of a favourable Ethical opinion I am pleased to confirm that your project has been given full approval from the East Norfolk and Waveney Research Governance Committee and Research Management Team and you may start your research.

Please note that this approval applies to the following sites:

- Norfolk & Waveney Mental Health NHS Foundation Trust

I have enclosed two copies of the Standard Terms and Conditions of Approval. Please sign and return one copy to the Research Governance Committee office. Failure to return the standard terms and conditions may affect the conditions of approval.

**Please note, under the agreed standard terms and conditions of approval you must inform this Committee of any proposed changes to this study and to keep the Committee updated on progress.**

If you have any queries regarding this or any other study please contact Julie Dawson, Research Governance Administrator, at the above address. Please note, your reference number is **2008MH06S (128-09-08)** and this should be quoted on all correspondence.

The Committee would like to take this opportunity to wish you every success with this project.

Yours sincerely

Dr Richard Reading  
Chair  
Consultant Paediatrician – NHS Norfolk

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East Norfolk & Waveney Research Governance Committee – a partnership between:  
Norfolk & Norwich University Hospitals NHS Foundation Trust. NHS Norfolk  
Norfolk & Waveney Mental Health NHS Foundation Trust. James Paget University Hospitals NHS Foundation Trust.

Appendix 4  
Edith Cavell Building  
University of East Anglia  
Norwich NR4 7TJ  
Tel 01603 / 591021  
Fax 01603 / 597019

Sample letter to parents

**Your experience of the Parent/Child Game**

Dear ?

My name is Christine Lawson and I work at the Silverwood Child and Family Centre and you would have met me when you attended for the parent/child game.

I am writing to you to tell you about the research that I am undertaking at UEA on the parent/child game and to ask if you and your child would be willing to be interviewed by me regarding your experiences of taking part in the game. It is part of a Master's degree by research programme that I am currently undertaking, at the University of East Anglia.

Participation would involve attending one interview session for you, the parent (about 1 to 1&1/2 hours), and one for your child (about 1 hour). All information would be anonymized and completely confidential. There is no obligation to take part and once begun you can stop at any time without giving a reason. If you choose not to take part and do not respond to this letter you will not hear any more from me.

Enclosed are information sheets (one for you and one for your child), which give you more details about the study. If you would like to know more before you make a decision, do please contact me at the number below and I will call you back to answer your questions. If you think you would like to take part and you would be willing for your child to take part, I would ask that you speak to your child about it to explain it to him/her. If however you would like to take part, but would not like your child to take part, then you can choose not to speak to your child about it.

If you do wish to take part, would you please complete the consent form enclosed and return in the stamped addressed envelope. I will then telephone you to arrange a convenient time and venue for us to meet.

Yours,

Christine Lawson

Tel: 01493 337601



University of East Anglia  
Faculty of Health  
School of Nursing & Midwifery

Edith Cavell Building  
University of East Anglia  
Norwich NR4 7TJ  
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Appendix 5

## **Parent Information Sheet**

### **The Parent/Child Game**

I would like to invite you and your child to take part in a study about the parent/child game. Please take time to read this information and decide whether you would like to take part. If you have any questions or need further information, please ring me on the number at the end of this letter. Thank you for taking the time to read this.

#### **What is the study about?**

The study is about finding out how parents and children felt whilst taking part in the parent/child game.

#### **Why have you been chosen?**

You are being invited to take part as you have recently finished sessions using the parent/child game.

#### **What do you have to do?**

I would like to interview you and your child once each, at a time that is convenient to you both, either at home or at the centre.

#### **Are there any risks?**

There are minimal risks, but you or your child may get anxious about answering questions, there are no right or wrong answers; rather, it is about your experience of the parent/child game. One or both of you can choose to stop at any point. This will not affect any service that you might need in the future.

#### **Are there any benefits?**

There may not be any direct benefit to you, but it will help us decide about the best services in the future. However, you may find it useful to have the opportunity to tell me about the experience.

#### **Will you or your child be identified?**

No. All information will be treated under the Data Protection Act. However, there are times when some information has to be disclosed to protect you or your child. The raw data will be stored in a locked cabinet on the Trust's premises. All personal information will be anonymized. The results will be published; but neither you nor your child will be identifiable. If you or your child chooses to opt out at any point, your information collected to that date will be destroyed. Otherwise the data will be stored for ten years after the study has finished.

The Norfolk Research Ethics Committee, and the Norfolk and Waveney Mental Health Foundation NHS Trust, have reviewed and approved the project. All clinical research in the UK must be approved before it can begin.



The results will be published; but neither you nor your child will be identifiable. If you or your child chooses to opt out at any point, your information collected to that date will be destroyed. Otherwise the data will be stored for ten years after the study has finished.

The Norfolk Research Ethics Committee, and the Norfolk and Waveney Mental Health Foundation NHS Trust, have reviewed and approved the project. All clinical research in the UK must be approved before it can begin.

**What if there is a problem?**

At the time of the study there will be staff available at the centre should you or your child need to talk about something that has come up during the interview. After the study, you can talk to me by calling me at the number below:

Christine Lawson  
Silverwood Child and Family Centre  
Northgate Street  
Great Yarmouth  
NR30 1BL  
Tel: 01493 337601

**Or if you prefer someone else:**

My Clinical Supervisor is:  
Karen Palmer, Psychologist.  
Silverwood Child and Family Centre  
Northgate Street  
Great Yarmouth  
NR30 IBL  
Tel: 01493 337601

My research supervisor is:  
Dr Jill Robinson  
Director of Teaching/Learning  
School of Nursing and Midwifery  
Edith Cavell Building  
Norwich  
NR4 7TL  
Tel: 01603 597075

Edith Cavell Building  
University of East Anglia  
Norwich NR4 7TJ  
Tel 01603 / 591021  
Fax 01603 / 597019

## Child Information Sheet

### The Parent/Child Game

What is research? 

Research is a way we try to find out what people think about things. I would like to know what you think about the parent/child game.



I am asking you because you have taken part in the parent/child game.



Do you have to take part?

No, you do not; you only take part if you decide to.

Nobody will make you take part.



that you want

AND

You can stop at anytime if you do begin, just let me know.

What will happen in the research?

I would like to talk to you about the parent/child game so that I can know what you thought about it. I will record what we say on a tape-recorder so that I can write it out later. It will only take one time to do this. There will be some things to do, like colouring, if you want to do that at the same time.

What if you get upset?

I do not expect that you will get upset, but if you do, you can tell me, or if you would like to talk to someone else then I can arrange that.

If you would like to know more then ask your mum or dad; if they cannot answer your question then you could ask them to ring me.

Appendix 7  
Participant ID.....

**PARENT CONSENT FORM**

**Title of Project:** An Exploration of The Experiences of Parents and Children Who Have Undergone the Parent/Child Game, Wherein the Children have Asperger's Syndrome.

**Researchers Name:** Christine Lawson

1. I confirm that I have read and understood the information sheet for the above study.
2. I understand that my participation and that of my child is voluntary and that one or both of us are free to withdraw at any time, without giving any reason.
3. I consent to the interview being audio-taped and transcribed.
4. I voluntarily agree to take part.
5. I have discussed the study with my child.
6. I give permission for my child to take part, if they choose to.
7. I agree to the findings being published.

----- Name of Parent	----- Signature	----- Date
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----- Name of Researcher	----- Signature	----- Date
-----------------------------	--------------------	---------------

Contact Telephone Number-----

Thank you for taking part  
Please return this form in the envelope provided.

When completed, 1 for patient, 1 for researcher, 1 for file.

Appendix 8



University of East Anglia  
Faculty of Health  
School of Nursing & Midwifery

Participant ID number.....

**CHILD ASSENT FORM**

**Title of Project:** An Exploration of The Experiences of Parents and Children Who Have Undergone the Parent/Child Game, Wherein the Children have Asperger's Syndrome.


**Researcher's Name:** Christine Lawson


Please tick the smiley face if you agree ✓

1. The study has been explained to me and I have been able to ask questions.



2. I am choosing freely to take part. 

3. I agree to the interviews being tape-recorded and written up. 

4. I can pull out of the study at anytime, without giving a reason. 

Name	Signature	Date
-----	-----	-----
Parent's Name	Signature	Date
-----	-----	-----
Researcher	Signature	Date
-----	-----	-----

When completed, 1 for participant, 1 for researcher, 1 for the file.



University of East Anglia  
Faculty of Health  
School of Nursing & Midwifery

Edith Cavell Building  
University of East Anglia  
Norwich NR4 7TJ  
Tel 01603 / 591021  
Fax 01603 / 597019

Appendix 9  
Participant ID.....

### **Sample letter to Informants**

#### **The Parent/Child Game**

Dear ?

My name is Christine Lawson and I work at the Silverwood Child and Family Centre.

I am writing to you to tell you about the research that I am undertaking at the University of East Anglia on the parent/child game and to ask if you would like to take part. The research is part of a Master's degree by research programme that I am currently undertaking at UEA. The Title of the research is: "An Exploration of the Experiences of Parents and Children Who Have Undergone the Parent/Child Game, Wherein the Children Have Asperger's Syndrome".

Participation would involve attending one interview session with me at a time and place that is convenient to you. All information would be anonymized and completely confidential. There is no obligation to take part and once begun you can stop at any time without giving a reason. If you choose not to take part and do not respond to this letter; you will not hear any more from me.

Enclosed is an information sheet, which gives you more details about the study. If you would like to know more before you make a decision, do please contact me at the number below and I will call you back to answer your questions.

If you do wish to take part, would you please complete the consent form enclosed and return in the stamped addressed envelope. I will then telephone you to arrange a convenient time and venue for us to meet.

Yours,

Christine Lawson  
Tel: 01493 337601

## Appendix 10



Edith Cavell Building  
University of East Anglia  
Norwich NR4 7TJ  
Tel 01603 / 591021  
Fax 01603 / 597019

### **Information for Informants**

#### **The Parent/Child Game**

Title: An Exploration of the Experiences of Parents and Children Who Have Undergone the Parent/Child Game, Wherein the Children Have Asperger's Syndrome.

Your participation would be one interview undertaken by me, at a time and place that is convenient for you. I would be asking you to talk generally about families wherein one of the children has Asperger's Syndrome or High Functioning Autism (ASD). Your input is to add context and to give a broader view of life with, and particularly, parenting a child with ASD.

As part of my work in CAMHS I see families wherein the child has ASD and use the parent/child game with some of them. I will be seeking participation from the families that I see, to tell me about their experiences of the parent/child game.

You will not be identified in the research and all information will be anonymized. All data will be stored in a locked cabinet on Trust property. In addition, all information will be treated under the Data Protection Act. Further, any information will be stored for two years after the study has finished and will then be destroyed.

If you choose to take part, you can withdraw from the study at any time without giving a reason.

I would expect the interviews to last for about 1 to 1&1/2 hours and with your permission will be audio-taped. I will send you a copy of the transcript for your clarification.

The Norfolk Research Ethics Committee, and the Norfolk and Waveney Mental Health Foundation NHS Trust, have reviewed and approved the project. All clinical research in the UK must be approved before it can begin.

Included is a consent form, if you would like to take part please sign it and return it to me in the stamped addressed envelope provided. Please provide a contact telephone number and I will call you to make a time to meet.

If you require further information or have questions before you make your decision, please contact me on the number at the bottom of this letter. This will not commit you to taking part.

If you do not want to take part, then do nothing. I will not contact you again.

Thank you for your time in reading this letter.

Yours,

Christine Lawson

Christine Lawson  
Silverwood Child and Family Centre  
Northgate Street  
Great Yarmouth  
Norfolk  
NR 30 1BL  
01493 337601

My Clinical Supervisor is:  
Karen Palmer Clinical Psychologist  
Silverwood Child and Family Centre  
Northgate Street  
Great Yarmouth  
NR30 1BL  
01493 337601

My research supervisor is:  
Dr Jill Robinson  
Director of Teaching/Learning  
School of Nursing and Midwifery  
Edith Cavell Building  
Norwich  
NR4 7TL  
Tel: 01603 597075

Appendix 11  
Participant ID.....

**KEY INFORMANT CONSENT FORM**

**Title of Project:** An Exploration of The Experiences of Parents and Children Who Have Undergone the Parent/Child Game, Wherein the Children have Asperger’s Syndrome.

**Researchers Name:** Christine Lawson

- 1. I confirm that I have read and understood the information sheet for the above study.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
- 3. I voluntarily agree to take part.
- 4. I agree to the findings being published.

-----  
Name of Informant                      Signature                      Date

-----  
Name of Researcher                      Signature                      Date

Your Contact Telephone Number -----

Thank you for taking part  
Please return this form in the envelope provided.  
When completed, 1 for informant; 1 for researcher site file;



## Appendix 12

### Interview Questions/Prompts with parents or child

Questions will have a broad focus concerning: before, during and after attending the parent/child game.

#### **Experiences before attending for the parent/child game**

- What was life at home like before you took part in the game?
- How did you get on with your child/parent?

#### **Experiences during the parent/child game**

I would offer prompts about what was it like to attend the centre.

- What was it like to play with your (mum or dad) parent or child?
- Did he or she enjoy the play?
- What was it like to be video-taped? Or watched?
- How did you feel?
- In the case of parents: “What was it like to wear the earpiece and be spoken to through it?”

#### **Experiences after attending for the parent/child game**

I would use prompts such as:

- What was the best thing about the sessions?
- What was the worst thing about the sessions?
- Do you think that the parent/child game has helped at all?
- If ‘yes’: in what way?

This would include prompts throughout to help in identifying the word, phrase or metaphor that fits their experience. There might also be questions asking for clarification and further depth, e.g. “That’s interesting; can you tell me more?”

## Appendix 13

### Interview Questions/Prompts with Key Informants

Tell me about your involvement with parents and children with ASD.

What do you spend most of your time doing with these families?

Do you notice anything in particular about the interaction between parent and child?

I am particularly interested in family life and parent child relationships.

What sort of things do parents ask for help with?

What about the children? Do they ask for help?

In what areas do the children ask for help?

What help do **you** think they need?

What are the strengths in families that you have noticed?

If there were something that could help daily life for these families what would you suggest?

Anything else you would like to tell me?

## GLOSSARY OF TERMS

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
AS	Asperger's Syndrome
ASD	Autistic Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Services
HFA	High Functioning Autistic
PCG	Parent Child Game
PDD	Pervasive Developmental Disorder
PPD-NOS	Not Specified