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FACULTY OF MEDICINE, HEALTH & LIFE SCIENCES

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Parents' Responses to their Child's Diagnosis of Autism Spectrum Disorder (ASD)

by

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Section 1: Literature Review

Why is Parenting a Child with Autism a Uniquely Difficult Challenge?

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ABSTRACT

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WHY IS PARENTING A CHILD WITH AUTISM A UNIQUELY DIFFICULT CHALLENGE?

By Amber Jennifer Evans

1.1 Abstract

Parenting is widely acknowledged as a challenging role and can be punctuated with moments of acute stress. For parents of children diagnosed with a disability, raising a child is further complicated by the nature of the child's condition. However, research has revealed that raising a child with autism spectrum disorder (ASD) presents a unique challenge for parents (Lobato, Faust & Spirito, 1988).

The diagnostic process is complex and uncertain for parents, as autism is difficult to define due to the range of the spectrum, thus increasing the risk of misdiagnosis (Mandell, Ittenbach, Levy & Pinto-Marvin, 2007). Diagnosis is usually made comparatively late, especially for those children with more subtle difficulties (Howlin & Asgharian, 1999), and there is often a delay between parents' first suspicions and the final diagnosis (Howlin & Moore, 1997).

Children with autism can have a high degree of functional impairment and extreme maladaptive behaviours, which make everyday management a challenge and contribute significantly to parental stress (Tobing & Glenwick, 2002). Furthermore, although there are many treatments and interventions available there remains a lack of clarity about the most effective options (Howlin, 1998), and predictors of prognosis are uncertain (Szatmari, 2003). Controversy regarding the cause of autism also adds to the challenges facing parents of children with autism (Dale, Jahoda & Knott, 2006). These factors all contribute to higher levels of stress in parents of children with autism than in families of children with other disabilities (Koegel, 2000).

Public awareness of autism is still in its infancy, with research and professional discourse continuing to unearth crucial findings. The debate and controversy surrounding autism spectrum disorders create a climate of uncertainty for parents of children with autism.

1.2 Introduction

Parenting, by general consensus, is a rewarding but difficult challenge. In today's climate parenting is increasingly complicated by many factors, such as the reduction of community support, less contact with extended families and the rising number of single parent families. For parents of children with a disability the challenge is considerably increased. Not only must these parents come to terms with their child's disability, but they also face daily challenges related to their child's condition, such as finding appropriate care or managing complex behaviours. Parents raising a child with autism face an even more complex and demanding task and this review will attempt to highlight the features that make parenting a child with autism a uniquely difficult challenge.

1.2.1 Working Definitions

Autism is defined as a pervasive developmental disorder that is characterised by abnormal development in social interaction, communication impairments and the manifestation of restricted and repetitive interests (American Psychiatric Association, 2000). Wing (1988) coined the term 'Autism Spectrum Disorder' (ASD) which encompasses both autism and Asperger syndrome. Thus, the terms autism, Asperger syndrome and ASDs will be used interchangeably throughout this paper unless stated otherwise.

Although the clinical picture varies across or within individuals, dependent on intellectual ability and age (Happé, 1994), ASDs are characterised by a triad of impairments (Wing & Gould, 1979) regarded as specific and universal to autism. The triad identifies core impairments in socialisation, communication and imagination which form the basis for the diagnosis (Rutter & Schopler, 1987). According to Wing (1988), individuals with autism demonstrate a fundamental lack of social understanding, although this may be manifest in different ways, such as passivity in social situations, avoiding social approaches or pestering others. Individuals with autism usually have difficulty with communication; they may have no speech at all, be echolaic, or be fluent but use language oddly. Beyond the triad of impairments there are other characteristics which are typically associated with autism; non-verbal ability far exceeding verbal skills (Lockyer & Rutter, 1970); possible savant abilities (Rimland & Hill, 1984); and a desire for the preservation of sameness (Kanner, 1943).

Whilst the central features of autism and Asperger syndrome remain consistent, there are differences which allow for distinctions to be made and help to conceptualise the continuum associated with ASD. As well as significant social impairment, repetitive behaviour and preoccupation with idiosyncratic topics; individuals with autism typically present with language delays, whereas children with Asperger syndrome tend to have limited interests without language impairments (Scahill & Bearss, 2009). Autism is a disorder that can manifest in a multitude of forms across the spectrum making it difficult to identify, manage and treat.

Autism is more likely in boys than girls and occurs at a ratio of 4:1 (Kanner, 1943). The onset of autism usually occurs prior to 30 months of age, but is only easily detectable when failure to develop language becomes apparent (Richman, 2001). In contrast, the absence of language delays makes Asperger syndrome more difficult to recognise. Consequently the mean age for a diagnosis of Asperger syndrome is eight years of age although this can vary from very young children to adults (Eisenmajer et al., 1996). Behaviours associated with autism are often undesirable and exigent (Randall & Parker, 1999) and the occurrence of emotional and behavioural disruption within the ASD population is significantly higher than within the intellectually disabled population as a whole (Brereton, Tonge, & Einfeld, 2006). Furthermore, the behavioural presentations of autism can be particularly distressing for parents as their children may fail to develop speech, may appear unloving or be socially isolated. The difficulties associated with diagnosis and the complex nature of the disorder creates an environment for parents which cultivates worry and uncertainty.

1.2.2 Issues of Epidemiology and Prevalence

Historically, autism was once considered to be a rare disorder which did not permeate public consciousness. However, since the publication of Kanner’s (1943) paper, which identified the unique features of this disorder, the prevalence among the population appears to have risen dramatically. Prior to 1980, the incidence of autism was estimated at five cases per 10,000 individuals (APA, 2000). More recently better survey methods and broader diagnostic criteria suggest that this figure has risen exponentially and the prevalence is approximately one in 160 children (when combined with the incidence of Asperger syndrome and other pervasive developmental disorders – not otherwise specified, PDD-NOS; Fombonne, 2005).

Consequently autism now occurs in higher frequencies amongst children than spina bifida, cancer or Down syndrome (Muhle, Trentacoste & Rapin, 2004).

According to Cook (2006) the increase in prevalence is baffling to parents, researchers and educationalists, and longitudinal research is scarce. Advocacy groups, alarmed by the explosion in the number of cases of children diagnosed with ASD, are driving more research into both the causes and potential educational treatments.

If the increase in prevalence over time reflects a true rise in the frequency of autism there would be a valid reason for alarm and exploring causality would be a public health priority. However this phenomenon could be logically explained as an artifact of systematic undercounts in previous estimates (Scahill & Bearss, 2009). Wing and Potter (2002) examined possible reasons for the increase in prevalence of autism amongst the UK population. They considered seven potential explanations including, different methodologies, recognition of associated behaviors and the development of specialist services. They concluded that nearly all of the observed rise in autism disorders was attributable to changes in diagnostic criteria and the growth of awareness among parents and professionals. However, the authors recognised that there may have been a genuine rise in the numbers of children with ASD, which is difficult to measure without applying current diagnostic criteria to earlier studies.

Another observable trend is that the autism epidemic appears to have clustered in certain communities. A study conducted in California, U.S, revealed that wealthier communities with a larger Caucasian population and higher average levels of educational attainment tended to have higher rates of autism (King, 2008). It is possible that these factors may have resulted in a higher rate of parent advocacy which could have been responsible for the increase in diagnosis. Results may also have been biased as families of lower socio-economic status may have had reduced access to support services. It is now recognised that autism affects families of all socio-economic levels, races and ethnicities (Yeargin-Allsopp, et al. 2003) but there remains considerable discourse relating to the underlying causes of autism which have significant implications for parents in terms of their coping strategies and acceptance of their child’s disorder.

1.2.3 Theories of Causality

Midway through the last century a popular theory developed in the United States proposed that autism was the result of cold parenting (Bettelheim, 1967; Kanner, 1943). This hypothesis led to the coining of the term ‘refrigerator mothers’, which suggested that autistic behaviors were cultivated by maternal emotional frigidity. As a result many mothers of children with autism spectrum disorder experienced feelings of blame, guilt and self-doubt about their parenting skills. Evidence to disprove this theory emerged when cases of children who had been cruelly mistreated and almost entirely neglected did not present as having autism (Clarke & Clarke, 1976) and were able to form social ties to carers (Curtiss, 1977). Subsequent medical research has largely discredited the ‘refrigerator mother’ theory and has provided greater understanding of the biological basis of autism (see Muhle et al. 2004; Steffenburg, 1991; Szatmari, 2003; Wing & Potter, 2002) however the effects of this theory can still be felt by parents who may feel responsible for their child’s condition. Although parents of disabled children inevitably experience feelings of sadness and may feel some responsibility for their child’s condition, they do not tend to be judged by society as having caused the child’s disorder, which could occur for parents of children with autism.

As early as 1944, Asperger noticed similarities between the characteristics held by parents, particularly fathers, and their children with autism. He proposed that the condition could be inherited and subsequent research supported this opinion (Bolton et al., 1994; Le Couteur et al., 1996; Piven, Palmer, Jacobi, Childress & Arndt, 1997). Twin studies also lend weight to the genetic argument with the concordance rate of autism in monozygotic twins being significantly higher than in fraternal twins (Bailey et al., 1995; Folstein & Rutter, 1977). Researchers identified other indicators which suggest that autism is a neuropsychiatric disorder, such as the manifestation of developmental delay, co-morbidity with epilepsy, other dysmorphic features, complications during pregnancy, an unequal sex ratio and extremes of head size (Chakrabarti & Fombonne, 2001; Zwaigenbaum et al., 2002). Despite the consensus amongst professionals for the genetic theory, as yet scientists have been unable to isolate a single gene, due to unrecognisable patterns of manifestation. Instead they propose that multiple gene interactions may be responsible, making the development of any medical treatments highly complex (Risch et al,. 1999). This uncertainty about the possible development of medical treatments for autism places pressure upon parents, as vagueness regarding prognosis could provide false hope or increase parental distress.

More recently there has been publicity indicating that the measles, mumps and rubella vaccine (MMR) is responsible for the dramatic increase in the numbers of children with autism, however there is no solid epidemiological evidence that the MMR vaccine is a risk factor (Taylor et al., 2002). Further studies explored a possible relation between autism and thimerosal, which is a potentially toxic preservative used in some vaccines in the U.S. during the 1990's. Two studies identified participants born during epochs of low, high and no exposure to thimerosal. Their findings showed that there was a steady rise in the prevalence of autism even after the U.S. ban on the vaccine in 2001 (Fombonne, Zakarin, Bennett, Meng, & MacLean-Heywood, 2006; Schechter & Grether, 2008). For parents, the decision to vaccinate their child is usually made early in infancy, before any visible manifestation of autism has occurred. However, as public discourse continues to question the potential causes of autism, parents are left poorly informed and could feel accountable for their child's condition. This could further exacerbate stress or feelings of guilt and result in negative outcomes for both the parent and child.

The advance in medical research has certainly removed some of the guilt felt by parents when ASDs were considered to be psychogenic in origin. However, researchers still face a considerable challenge trying to conduct rigorous studies of causation. Although the specific etiology of autism remains unknown, the predominant view is that autism has a biological origin and can be affected by environmental factors (when environmental in this context could include any event occurring after fertilisation). Whilst moving in the right direction, the causality of autism is not fully understood which makes it difficult for parents to digest. This uncertainty creates an environment where parents are left isolated and helpless as they may not know what to read and what to discount. Other childhood conditions can often provide answers about causality, treatment and prognosis, but none of these areas can be pinned down within autism spectrum disorders making it particularly difficult for parents to deal with.

1.2.4 Raising a Child with Autism

There is ample evidence that raising a child with autism is a particularly difficult challenge for parents (see Davis & Carter, 2008; Dunn, Burbine, Bowers, &

Tantleduff-Dunn, 2001; Eisenhower, Baker & Blacher, 2005; Hastings & Johnson, 2001; Meirsschaut, Roeyers & Warreyn, 2010; Olsson & Hwang, 2001; Sivberg, 2002). Children with autism typically present with impaired social and emotional competencies and often have maladaptive associated behaviours which make parenting particularly stressful (Davis & Carter, 2008; Hastings & Johnson, 2001). Existing research has shown that mothers of children with autism have higher stress levels than those of typically developing children or children with other disabilities (Eisenhower et al., 2005; Estes et al, 2009; Mugno, Ruta, D'Arrigo, & Mazzone, 2007). In addition, studies have shown that mothers of children with autism are at an increased risk of developing depression (Olsson & Hwang, 2001). There is also a small amount of research which suggests that mothers of children with autism believe themselves to be less competent and have restricted family adaptability than mothers of children with Down syndrome or those raising children without disabilities (Rodrigue, Morgan & Geffken (1990).

Comparative studies reveal that parents suffer from poorer mental and physical health, and report a lower quality of life than parents raising typically developing children (Allik, Larson & Smedge, 2006; Herring et al., 2006; Mugno et al., 2007). Furthermore, longitudinal studies suggest that emotional and behavioural traits exhibited by youngsters with autism remain stable into adulthood (Eisenhower et al., 2005; Herring et al., 2006), potentially placing a life long burden on parents.

Raising a child who may experience difficulties expressing love in a typical or overt way could be particularly distressing for parents. In addition, the social communication impairments in children with autism often present in a way that could appear to be a rejection of warmth and care or disinterest in parental affection. However it is important to note that not all parents of children with autism experience difficulties forming affectionate bonds with their child.

1.3 Diagnostic Issues

1.3.1 Disparities within Syndrome Diagnoses

Autism and Asperger syndrome lie on the same spectrum yet there are some within syndrome distinctions that affect diagnosis and subsequently parents' responses. Autism tends to be diagnosed at an earlier age due to the increased possibility of associated language disorders and obviously delayed cognition, whereas parents experience longer delays in their child's diagnosis of Asperger syndrome, where the disabilities are less pronounced (Howlin & Asgharian, 1999). In addition, children with Asperger syndrome often present with typical development and the appearance of advanced expressive language, which can contribute to the delay in diagnosis.

The time lapse between parents' initial suspicions and receiving a final diagnosis can increase dissatisfaction with the diagnostic process (Baird, McConachie & Scrutton, 2000; Nursey, Rohde & Farmer, 1991). Howlin and Asgharian's (1999) study revealed that the time lapse experienced for parents of children with autism is significantly less than those with children diagnosed with Asperger syndrome, suggesting that the latter group are more likely to be dissatisfied.

Within their study, Howlin and Asgharian surveyed parents of children with ASDs in the UK to explore their diagnostic experiences. In their comparative study they examined two populations; the first comprising of 614 parents of children who had received a diagnosis of autism and a second group of 156 parents of children diagnosed with Asperger syndrome. This balance of participants is proportionate to the general population as recent survey data reveals that the incidence of autism is five times higher than for Asperger syndrome (Fombonne, 2001). Their findings showed that the average age upon receiving a diagnosis was significantly lower for the autism group (mean 5.49 years) than in the Asperger syndrome group (mean 11.13 years). They concluded that associated with the longer delays, parents of children with Asperger syndrome experienced greater frustration in obtaining a diagnosis. The delay in diagnosis of Asperger syndrome can increase parents' anxieties as their child's behaviours are often misinterpreted as 'naughty' and judgements are inferred about the adequacy of parenting. Whilst the sample size in this study was relatively large, it is worth noting that there may have been a bias within the sampling due to the nature of recruitment being dependent upon parental pro-activity. Moreover a reliance on retrospective narrative can be open to errors.

Whilst the findings of Howlin and Asgharian's study imply that parents of children diagnosed with Asperger syndrome experience more difficulties than those of children with autism, there is evidence to demonstrate that the latter group experience similar difficulties. Studies have shown that many parents of children with autism remain dissatisfied with the diagnostic process (Howlin & Moore, 1997; Smith, Chung & Vostanis, 1994). Despite increasing evidence that autism can be accurately diagnosed in very young children (Bryson, Rogers, & Fombonne, 2003; Lord et al., 2006), a diagnosis is often delayed due to a number of factors. Inadequate screening practices (Dearlove & Kearney, 1990; Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003), slow response by paediatricians to parents' initial concerns (Glascoe, 1997; Shevell, Majnemer, Rosenbaum, & Abrahamowicz, 2001) and a lack of awareness about symptoms (Shah, 2001,) all contribute to drawing out the diagnosis period. Furthermore, due to some similarities between autism and other disorders, misdiagnosis is a risk (Noterdame, Amorosa, Mildenberger, Sitter, & Minow, 2001) as autism often presents alongside other behavioural or developmental symptoms, such as mental retardation (Bonde, 2000; Chakrabarti & Fombonne, 2001). Children with autism can also exhibit impulsivity problems (Goldstein & Shwebach, 2004) or extreme behavioural difficulties (Remington, Sloman, Konstantareas, Parker, & Gow, 2002).

Identifying that a child has autism is fraught with difficulties and the nature of autistic behaviours can be so extreme that parents are usually desperate to know what is wrong with their child. A diagnosis of autism may be more difficult for parents to accept as the behaviours associated specifically with the condition, such as bad behaviour, being socially inept or withdrawn, carry a negative image. These issues can make a diagnosis particularly difficult for parents as they have to contend with unique factors related to receiving a diagnosis of autism.

1.3.2 Factors Contributing to Parental Response

There are a number of interrelated external and internal factors that could contribute to a parent's response to their child's diagnosis of a disability. Furthermore it is clear when examining these factors that parents of children with ASD face distinct challenges which have a big impact on parents' emotional wellbeing and subsequent engagement with interventions.

The timing of a diagnosis can impact significantly on parents' emotional response. Unlike other disorders which may have physical indicators, or can be identified prenatally, autism can be more difficult to recognise. Down syndrome is typically diagnosed shortly before or after birth whereas on average autism is not diagnosed until much later and usually after a time lapse from parents' first suspicions. Many parents have reported recognising that there is 'something wrong' with their child before receiving confirmation from professionals (Sloper & Turner, 1993). A delay in diagnosis or false assurances may give parents the message that they are perceived as being unable to cope (Cunningham & Davis, 1985) or that their suspicions are not worth taking seriously. Furthermore, research has shown that a delayed diagnosis, both in terms of the child's age and delays in the diagnostic process, may affect parental adaption and their ability to cope, and is also related to dissatisfaction (Baird, et al., 2000; Howlin & Moore, 1997). This is largely attributed to the prolonged period of heightened stress associated with parenting a child with autism as there may have been many years of worry, blame and comparisons to typically developing children.

Howlin and Asgharian (1999) reported that early intervention for children with autism can help parents to develop effective behaviour management techniques in order to avoid or minimise any secondary behaviour problems (Howlin & Rutter, 1987). Thus, a delayed diagnosis, which is more likely to occur within ASDs than other childhood disorders, may not only impact on suitable provision for the child, but also on appropriate support required by parents.

Caring for a child with autism presents a significant challenge to parents (Lobato et al, 1988). Children with autism usually present with maladaptive behaviours and can have significant functional impairment resulting in increased parent stress levels (Tobing & Glenwick, 2002) which are higher than for parents of children with other disabilities (Koegel, 2000). Feinstein and Reiss (1998) identified that having children with syndromes like Fragile X, which is typically associated with elevated activity levels and autistic like behaviours, can negatively affect parental wellbeing. This is in contrast to parents of children with Down syndrome where there is a narrower spectrum of associated behaviours.

Another study shows that mothers of children with Down syndrome report more social support in comparison to maternal reports for children with autism and that the level of social support has been found to affect the emotional wellbeing of parents (Erickson & Upshur, 1989). In addition, parents of children with Down syndrome tend to be more satisfied with a childhood diagnosis than parents receiving a diagnosis of autism (Quine & Rutter, 1994). However, studies of direct comparisons have produced inconsistent results.

Another contributing factor to parental response to diagnosis is the available information that is presented. Whilst there is abundant information available for parents of children with autism, the quality can be questionable. Parents of children diagnosed with ASD are more likely to be satisfied if they rate the information they are given as high quality (Brogan & Knussen, 2003). Furthermore, whilst parents of children with ASD report a need for information at the time of the diagnosis (Whitaker, 2002), they don’t know how to evaluate the validity and relevance to their own child.

1.3.3 The Disclosure of a Diagnosis

For parents, the realisation that their child may not develop typically is a distressing time (Blacher, 1984). As well as the fears and worries experienced by all parents receiving a diagnosis for their child, parents of children with autism face additional challenges. Caring for a child with ASD is associated with high levels of parental stress and increased burden across a child’s lifespan (Siegel, 1997) but research indicates that the most difficult time for parents is when receiving a diagnosis for their child. Research has revealed that the point of initial diagnosis is associated with elevated stress levels (Howlin & Asgharian, 1999), although the effect of a diagnosis on the family is poorly understood. Whilst much research has been conducted into the disclosure of childhood disability to parents, relatively little has focused on the disclosure of a diagnosis of autism. Studies into parental satisfaction have concluded that a good disclosure depends on the manner in which the professional delivers the news and the effectiveness of any information provided (Cunningham, Morgan & McGucken,1984; Lingham & Newton, 1996).

Dissatisfaction with the disclosure of diagnosis may be inevitable for parents who have to come to terms with the fact that their child has a disability of some sort. However, measures of satisfaction do suggest that parents of children diagnosed with ASDs are unhappier about the disclosure than parents of children diagnosed with other conditions. A study by Sloper and Turner (1993) revealed that 37% of mothers with children with a severe physical disability were satisfied with the disclosure of their child's diagnosis. A more recent study by Howlin and Moore (1997) indicated that 75% of mothers of children with cerebral palsy were satisfied about the way the news was shared with them. In contrast, only 35% of parents in the UK and as little as 23% of Scottish parents of children with ASD expressed that they were satisfied with this process. This difference could be due to the higher risk of misdiagnosis amongst children with autism when compared to children with other mental and physical disabilities. Also, some manifestations of ASDs present subtly or give a false impression of advanced development, which could lead to a delay in diagnosis or a misdiagnosis altogether. This could be particularly distressing for parents, as misdiagnosis could lead to misattribution of behaviour or inappropriate treatment (Mandell et al., 2007). Lingham and Newton (1996), reported that parents should be told about their child's condition as early as possible as delays in this process could lead to dissatisfaction. But discrepancies amongst professional opinions and the complexity of the syndrome can result in a professional reluctance to diagnose until they are certain. Therefore the delays associated with the diagnosis of this condition (Smith et al., 1994) could account for higher rates of dissatisfaction amongst parents of children with autism.

A diagnosis of autism may be particularly difficult for parents to process as it still carries negative connotations associated with the condition in the past (Wakschlag & Leventhal, 1996). In recent years more knowledge has been gained about autism and related conditions and in particular the advantages of an early diagnosis in terms of positive outcomes for the child and family (Freeman, 1997). However, despite this there has been no noticeable change in the way parents retrospectively report on the information they receive from professionals disclosing the news (Marcus, Kuncel & Schopler, 1997; Quine & Rutter, 1994; Smith et al., 1994).

The possibilities for misdiagnosis are wide ranging as autism presents so differently across the population. There are many markers for autism which could be diagnosed as a variety of disorders. Unpicking the individual picture each child presents makes it difficult for parents to move forward and to accept the diagnosis.

1.3.4 Parental Attributions Following a Diagnosis

Antshel, Brewster & Waisbren (2004) identified that people make attributions when trying to understand stressful situations and the attributions made by parents in response to a diagnosis can influence their emotional and behavioural responses towards their child (see Joiner & Wagner, 1996 for a review). An earlier model proposed by Weiner (1985) identified three attribution dimensions; locus of cause, locus of stability, and controllability. Each specific dimension can influence an individual's response to stressful situations and their perceptions of the future. For example, if parents feel they have little control over a negative situation then they may experience feelings of helplessness and apathy; negative events that parents view as stable could result in low expectations about the future; and parents' attributions of causality can have a detrimental impact on their self-esteem and beliefs of self-efficacy. Whilst research is limited in the field of childhood disability, some studies have been conducted to explore parents' attributions of causality and the impact this has on their response.

Research has shown that a late diagnosis or a period of delay can have a negative effect on parents' emotional responses (Baird, et al., 2000; Howlin & Moore, 1997; Quine & Pahl, 1986, 1987) and is likely therefore to impact their subsequent attributions. This is particularly relevant for parents of children with autism who typically receive late diagnoses. Mickelson, Wroble & Helgeson (1999) conducted interviews with parents of children with Down syndrome, autism and other developmental delays, and created a ratings survey from their responses. Their findings revealed that parents of children with Down syndrome made attributions to genetic fluke, age, and fate; parents of children with autism made attributions to heredity and environment; and parents of developmentally delayed children made attributions to medical problems and stress during pregnancy. They also identified that self-blame attributions and attributions to the environment were related to poorer adjustment, which suggests that parents of children with autism find it harder to adjust than parents of children with Down syndrome or other developmental disorders. However, causation is difficult to identify as the unique features of these disabilities could be responsible for parental adjustments. Causal beliefs have also been linked to emotional wellbeing and actual parental competence (Lavelle & Keogh, 1980) and can affect parents' perceptions of their management capabilities and also indicate the likelihood of their engagement with professional health services (Morrisey-Kane &

Prinz, 1999). It is difficult for parents of children with autism to gain a clear picture regarding the cause of the child's condition, as there is still considerable professional discourse on this subject. Parents of children with autism appear to have distinctive causal beliefs about their child's condition which places some responsibility for the disorder on themselves. This creates a climate where parents shoulder the grief of having a child with autism but also make attributions that reflect their own feelings of guilt.

Currently, little is known about the contribution that attributions make to parents' emotional health and subsequent care for their child. Dale et al.(2006) attempted to rectify this gap in the research and conducted a study into mothers' attributions following their child's diagnosis of ASD. The researchers conducted a focus group consisting of nine participants and then carried out interviews and formal measures of stress, depression and expectations on a further 17 parents of children with ASD. A content analysis was used to organise the qualitative data and a non-parametric correlation was employed for statistical analysis. The results showed that there was no significant correlation between the locus of cause dimension and parents' perceived competence. This is in contrast to the hypothesis developed by the researchers based on other findings linking the allocation of self-blame attributions for disorders such as Down syndrome, to the increase in parental stress (Hall, Bobrow & Marteau, 1997). However, only a small number of participants actually allocated blame for their child's disability and most did not view it as having any importance on their situation, which could have accounted for these results. In addition, this result could be due to the prevailing ideas about causality of ASD, where parents link it to external causes such as the MMR vaccine and do not consider the possibility of a biological component, which would be widely adopted by parents of children with disorders such as Down syndrome. For many parents of disabled children, the cause of the condition can usually be explained, however the lack of consensus regarding the cause of autism impacts on the attributions that parents make and may subsequently influence the effectiveness of their parenting and their own wellbeing.

1.3.5 Resolution to the Diagnosis

Waisbren (1980) revealed that receiving a diagnosis for their child is a crisis for parents as they enter a period of mourning for the loss of the 'hoped for' child (Blacher, 1984). Accepting a diagnosis and resolving themselves to the implications and possible outcomes is a difficult process for most parents. Milshtein, Yirmiya, Oppenheim, KorenKarie and Levi (2010) identified that resolution involved parents coming to terms with and accepting their child's diagnosis. A resolved parent would have congruent internal representations of the child and themselves both before and after receiving a diagnosis (Bowlby, 1980). According to Pianta (1992a), resolved parents usually acknowledge the difficulties associated with receiving the diagnosis as well as identifying positive changes in their feelings in response to the diagnosis over time. They are also more likely to focus on the present and the future rather than dwelling on questions of causality. It is particularly important for parents of children with a disability to come to terms with their child's diagnosis in order to avoid documented parenting difficulties (Fraiberg, Adelson, & Shapiro, 1983) and to ensure the well being of both parties.

The percentage of resolved parents appears to differ depending on the childhood disability. For example, 46% of parents of children with cerebral palsy were resolved compared to 69% of mothers of children with Phenylketonuria (PKU) (Barnett et al, 2006; Lord, Ungere & Wastell, 2008; Pianta, Marvin, Britner & Borowitz, 1996). In contrast only 33% of mothers of preschool boys with ASD were resolved after receiving a diagnosis (Dolev, Oppenheim, Koren-Karie & Yirmiya, 2009; Oppenheim, Koren-Karie, Dolev & Yirmiya, 2009). However, these findings are inconclusive as other studies suggest that no such difference occurs (Pianta et al., 1996). Milshtein et al. (2010) found that 57% of parents were unresolved to a diagnosis of ASD for their child and this was associated with negative perceptions about their child and the influence the disability would have on the family functioning. Additionally an unresolved parent is more likely to develop an insecure attachment relationship with their child (Marvin & Pianta, 1996) increasing the risk for future developmental and interpersonal problems (Benoit, Zeanah, Boucher, & Minde, 1992; Greenberg, Speltz, & DeKlyen, 1993). Parents of children with autism appear to find it more difficult to come to terms with their child's diagnosis than parents of children with other disabilities possibly due to the distinctive features associated with the diagnostic process for autism and the ongoing nature of autism.. This could lead to insecure attachment which is detrimental to both parent and child.

1.4 Parenting a Child with Autism

1.4.1 Stress and the Family Unit

Deater-Deckard (2006) states that parenting stress can be defined as the aversive psychological reaction to the demands of being a parent and is a complex process linking the task demands of parenting, the parent's psychological well-being and behaviour, the qualities of the parent-child relationship, and the child's psychosocial adjustment. He concludes that parenting stress is experienced as negative feelings toward the self and the child, which are directly attributable to the demands of parenthood.

All parents experience stress at some point as raising a child can be fraught with worries and challenges and a child's additional needs may exacerbate this. However, some evidence suggests that parents interpret having a child with a disability as a positive experience and report personal growth, improved relationships with others, more patience and a better level of empathy (Hastings & Taunt, 2002; Pakenham, Sofronoff, & Samios, 2005). But there is significantly more research suggesting that parents of children with disabilities suffer a higher level of stress than parents of typically developing children, and that parents of children with autism experience higher stress still (Bouma & Schweitzer, 1990; McKinney & Peterson, 1987*).*

As well as the impact on parent health, high levels of stress can exacerbate the child's behaviours (Osbourne, 2008), further contributing to the particular complexities of raising a child with ASD, as the behaviour associated with autism can be exceptionally challenging and difficult to manage. In addition to higher stress levels, parents of children with autism are at a greater risk of depression and other mental health issues than parents of children with other disabilities (Abbeduto et al., 2004; Dumas, Wolf, Fisman & Culligan, 1991; Montes & Halterman, 2007) making them less likely to interpret the experience of parenting a child with autism in a positive way.

The barriers to positive adaptation also impact upon siblings. Research has shown that they are indeed more likely to develop emotional and behavioural problems (Fisman, Wolf, Ellison & Freeman, 2000; Howlin, 1988). These problems could be the result of the sibling being overlooked, as parents may initiate more play with the child who has autism (El-Ghoroury & Romancyzk, 1999). Studies have revealed that family members may experience different responses to having a child with autism in the family, for example, many studies have demonstrated that mothers endure more stress than fathers (Konstantareas, Homatidis & Plowright, 1992; Moes, Koegel, Schriebman, & Loos, 1992). A lack of cohesiveness within the family unit may place pressures on family members and marital relationships may be made more difficult if one parent is experiencing higher levels of distress.

A study by Hastings et al. (2005) explored the existing belief that parent well-being was exclusively dependent on the severity and behaviour of the child with autism with other familial factors and relationships not being considered. They considered the impact of spousal mental health on parental well-being and found that maternal stress, measured using a brief situational format of the COPE inventory (Carver, Scheier & Weintraub, 1989), was related to both the child's behaviour and their partner's level of depression; contrastingly paternal stress is only related to their partner's depression and not the child's autistic behaviours. It is not clear yet if these results would be true for parents of children with other developmental disabilities or if this is unique to parents of children with autism. However, the authors conclude that these findings may be the result of the different coping strategies employed by mothers and fathers of children with autism. This places extreme pressures on couples raising a child with autism as they are likely to choose differential and potentially conflicting coping strategies.

Research has revealed that relatives of individuals with autism have high rates of major depression and social phobia that cannot be explained by the increased stress associated with raising a child with autism (Piven & Palmer, 1999). This suggests that there could be a genetic link or predisposition to these conditions amongst families who have children with autism. Whilst all parents experience stress and parents of children with disabilities may endure higher levels, parents of children with autism are more likely to have additional emotional health problems. This may make parenting more of a challenge as parents may be dealing with their own emotional and psychological issues which could be negatively affected by having a child diagnosed with ASD and through the daily management of a child with autism.

1.4.2 Coping Strategies Employed by Parents of Children with Autism

Previous research has indicated that coping is context dependent (Carver et al., 1989, cited in Hastings et al., 2005) which would suggest that the nature of the stress and the unique relation between the initial stressor and the environment is likely to affect the degree of coping.

Hastings et al. (2005) examined the structure of coping strategies employed by parents of children with autism. They recruited 135 parents of children with autism in the UK and used the Brief COPE measure of parental stress (Carver, 1997). They found that parents used one of four coping strategies to varying success. Those adopting active-avoidance as a coping mechanism were at risk of mental health problems and higher stress levels in both parents, possibly due to a lack of resolution and subsequent adaptation to the diagnosis. Problem-focused coping was not found to be related to any negative mental health effects. The third coping dimension included religious strategies that helped parents adapt to having a child with autism. Despite other research that indicates the positive affect of religion in reducing stress and depression in parents raising a child with autism (Tarakeshwar & Pargament, 2001), the findings from the Hastings et al. study were inconclusive.

Finally, having positive beliefs about their child may help parents of children with autism adapt better, cope with higher stress levels and were also linked with lower levels of depression. Evidence suggests that when faced with extremely difficult events where it is almost impossible to be proactive in reducing the initial stressor, such as individuals caring for patients with HIV or AIDS or those recovering from serious heart surgery, positive reframing may be one of the only effective strategies to employ in order to cope (Affleck & Tennen, 1996; Folkman and Moskowitz, 2000). Hastings and Taunt (2002) conclude that their findings “suggest areas where coping may be different than in families of other children with other disabilities or without disabilities” (p. 387), however they acknowledge that more evidence is needed before drawing any firm conclusions. This finding may be particularly relevant for parents raising a child with autism as the negative environment associated with extreme and severe behaviours may make it harder to be positive.

There is still a debate about the nature of the relation between maternal wellbeing and raising a child with autism. Whilst some research has shown that the mothers’ psychological wellbeing is driven by a child’s general maladaptive behaviours regardless of their disability (Hastings et al., 2005), other studies suggest that it is in fact the core symptoms of autism that cause maternal distress (Eisenhower et al., 2005). This was further explored by Benson (2010) who examined the coping mechanisms of 113 mothers of children with autism using the Brief COPE measure (Carver, 1997). Benson identified four reliable coping dimensions; engagement coping, distraction coping, disengagement coping, and cognitive reframing coping. Using multiple regression the author observed the relation between these coping strategies to maternal depression, anger and well-being. Benson found that mothers' using the avoidant coping strategies of distraction and disengagement reported increased levels of depression and anger, whilst those using cognitive reframing had higher levels of wellbeing.

1.4.3 The Influence of Parenting Style

The construct of parenting style is used to capture normal variations in parents' attempts to control and socialise their children (Baumrind, 1991). This construct does not encompass deviant parenting (neglectful or abusive behaviours) and assumes that normal parenting revolves around issues of control. Baumrind asserts that although parents differ in how they try to exert control or socialise their children and the extent to which they do so, it is assumed that the primary role of all parents is to influence, teach and control their children.

McAdoo and DeMeyer (1977) observed that the high levels of stress associated with parenting a child with autism may actually affect parental personalities and subsequently parenting styles and behaviours. Research has also shown that a change in parenting style can impact negatively on the coherence of the family unit (Holroyd & McArthur, 1976). This is particularly relevant for parents of children with autism as they generally endure higher stress levels in comparison to parents of children with other disabilities, making them more likely to change their parenting behaviour and are subsequently susceptible to relational family difficulties.

Powers (2000) suggests that parents of children with autism face three common barriers to successful parenting that are not experienced by parents of children with other disabilities. They are at risk of being over protective and restrictive, they face increased risk of rejecting the child and finally they are at risk of becoming over involved or over compensating their child with autism at the risk of neglecting other children in the family.

1.4.4 Resilient Disruption

For families living with a child with autism the process of adaptation to the disability is often complex, changeable and life-long (Hauser-Cram, Warfield, Shonkoff & Krauss, 2001) and emerging research has recognised the importance of family adaptability (Ferguson, 2002). Hastings and Taunt (2002) recognised that both negative and positive response to diagnosis can occur simultaneously, termed ‘resilient disruption’ by Costigan, Floyd, Harter and McClintock (1997). They acknowledged that whilst having a child with disability can cause significant disruption to a family, many will nonetheless develop resilience to this change in their family life. That is, these families adapt better to having a child with a disability.

Families raising a child with a disability face challenges that put pressure on their resources and affect their functioning as a family unit (Patterson & Garwick, 1994). These challenges are often heightened for parents of children with autism as the maladaptive behaviours associated with autism can often place considerable restrictions upon a family. This can interfere with normal routines, such as shopping or holidays; thus requiring higher levels of resilience from parents.

Parental resilience is associated with healthy adaptation (Chehrazi, 2002), where parents are more likely to manage the stressors associated with raising a child. Where this differs for parents raising children with autism, is in the degree of the stressors associated with autism, thus making adaptation and resilience harder to achieve.

A study conducted by Schertz and Odom (2007) identified potential barriers to resilience for parents of children with autism. These included difficulties associated with diagnosis, problems coming to terms with the child’s diagnosis, limited child response to traditional services, co-occurrence of familial disabilities, broader family stressors, and lower expectations of the child’s potential and of their own competence and self-efficacy. These factors combine to create a distinctive climate for parents of children with autism and could impact upon effective adaption.

1.5 Issues of Support

1.5.1 The Importance of Social Support and Autism-Related Support Services

After receiving a diagnosis of a childhood disability parents enter a process of adaption where they learn to adjust to the difficulties of raising a child with a life long impairment. It is crucial that parents adapt in order to meet the child's needs, nurture their own well-being and maintain the coherence of the family unit. Research indicates that parents of children with autism can adapt more successfully if they receive adequate levels of social support and appropriate levels of involvement in the child's life (Henderson & Vandenberg, 1992; Sanders & Morgan, 1997, Siklos & Kerns, 2006; Waltz, 1999). However, the uncertainties and common misunderstandings associated with autism can impact on the nature of social support that families receive.

Social support encompasses any information which makes individuals feel that they are cared for and esteemed and manifests through a network of mutual obligation and communication (Cobb, 1976). Social support could include spousal support, extended family and friends, free time to engage in leisure activities, professional help, involvement in community programs and the availability of services specifically for families with a disabled child (Siklos & Kerns, 2006). Of particular importance is the quality of the support received by parents and not just the amount. In a study by Konstantareas and Homatidis (1989), parents of children with ASD reported more dissatisfaction with the social support offered to them than parents of typically developing children who were accessing the same amount. In a follow up study Konstantareas (1991) identified that parents of children with ASD also experienced more aggravation related to the support they received than parents of children with mental retardation. In comparison to parents of children with other disabilities, receiving good social support appears to be a particular challenge for parents of children with ASD for a number of reasons. Embarrassment about the severity of their child's behavioural problems could prevent parents from approaching support services or seeking informal support from family members (Gray, 1993). Also, parents of children with autism emphasise the lack of practical and financial social support (Boyd, 2002) which influences their ability to facilitate their child's progress. Siklos and Kerns (2006) report that 93% of parents of children with autism said that they were receiving inadequate financial support for their child's needs in comparison to only 63% of parents raising children with Down syndrome, indicating a lack of appropriate funding reaching families of children with autism. Furthermore, parents have reported experiencing rejection and a lack of interest or understanding from social support (Farrell & Barnes, 1993), possibly due to the complexity of autism disorders. Finally, Gray (1993), identified that a large proportion of parents do not reveal their child's condition to work colleagues as they are afraid of stigmatisation or reduced promotion opportunities. The stigmatisation could stem from the early theories relating the disorder to poor parenting. All of these factors may make parents of children with autism more vulnerable and isolated from social support.

The influence of social support on parents' stress has also been documented. A study by Fisman and Wolf (1991) reveals that even the belief that they are receiving adequate social support is enough to reduce stress and the possibility of depression amongst parents of children with autism. Parents with these perceptions are more likely to cope successfully with raising their children (Donovan, 1988). These findings have considerable implications for professional support services that need to evaluate parents' beliefs about the support they are receiving and ensure these match up with the provision offered.

Siklos and Kerns (2006) modified the Family Needs Questionnaire (FNQ; Waaland, Burns & Cockrell, 1993) in an attempt to establish which needs parents believe to be the most important and whether these needs are being met by existing agencies and professional services. They employed a between subjects comparison design across 2 groups of participants; parents of children with ASD and parents of children with Down syndrome. The findings showed that parents of children with ASD rated needs relating to professionals working with their child and the family as most important, in contrast to the Down syndrome group who believed social opportunities for the child to be one of their most important needs. Siklos and Kerns (2006) report that parents of children with ASD have a greater desire for consistent therapies, as well as engagement with professionals who are knowledgeable about autism. This may be due to parental beliefs about the possibility of curing or significantly improving the condition with intensive intervention, consistent with findings from earlier studies that showed the significant positive effect from certain interventions (see Lovaas, 1987; McEachin, Smith & Lovaas, 1993). For other disorders parents may lower their expectations about their child's potential or the impact that experts may have on changing outcomes for their child, but autism provides some hope for improvement. This creates a different climate for parents of children with autism as there may be significant discrepancies between their expectations and outcomes.

Given the complexity associated with autism and the disparities between treatment packages it is clear that parents of children with autism may not have their needs met as often as parents of children with other disabilities. In addition, it appears that parents of children with ASD are heavily reliant on the expertise and involvement of professionals in the treatment and management of their child and consequently have significantly higher expectations which are more difficult to meet through an already stretched provision.

Disorder specific support groups form part of social support and tend to be based upon evidenced psychological and sociological theories. People who attend support groups typically report high levels of satisfaction from participation (Solomon, Pistrang & Barker, 2001). Other benefits include reports that parents feel less socially isolated, feel more emotionally supported, are better able to parent their disabled child and have the opportunity to gain important information about appropriate services (Kerr & McIntosh, 2000; Law, King, Stewart & King, 2001). However, accessing appropriate support groups appears to be particularly difficult for families of children with autism. Krauss, Gulley, Sciegai & Wells (2003) found that parents of children with autism were more than twice as likely to have problems with referrals, appointments, and finding appropriate providers and coordinated care than parents of children with other special healthcare needs, (cited in Mandell & Salzer, 2007). This could be attributed to a lack of an effective and cohesive system providing accurate information for parents of children with autism (Jacobsen & Mulick, 2000) This, coupled with the maladaptive behaviours and other symptoms associated with ASD can create higher stress levels in families, social isolation, marital problems and a detrimental impact on parents' health and wellbeing (Dunn et al., 2001; Sivberg, 2002). Thus effective support services are particularly important for parents of children with ASD, as families raising a child with autism are at a greater risk of experiencing these negative outcomes than families of children with other disabilities.

Siklos and Kerns (2006) conclude that parents of children with autism do not receive the same type of reinforcement from parenting compared to parents of children with Down syndrome or a typically developing child. Many parents of children with autism face extreme behaviours, have restricted functional communication with their child, and are not able to interact socially with their child. These features make effective service delivery much more complex for parents of children with autism as much of the support focuses on diagnosing and treating the child and less on helping families to cope.

Families with more than one disabled child can experience problems with support services (Krauss et al, 2003; Thomas, Morrissey, & McLaurin, 2006). This is particularly relevant for parents of children with autism as the recurrence rate of autism in siblings is 2% to 8%, which means that parents are at risk of having more than one child with ASD (Muhle et al., 2004) thus making them more likely to have difficulties accessing support services. Research findings indicate a need to develop autism-related services to meet the needs of all families of children with ASD and to break down some of the barriers that may prevent access to support services.

1.5.2 Parents’ Perspectives on Searching for Information and Dealing with Professionals

For any parent raising a disabled child, receiving effective and relevant information is crucial to effective parenting. Information about ASD is particularly prolific given its heightened profile in recent years. There is a wealth of information available to parents of children with ASD, especially for those with access to the internet. However, despite the significant amount of useful information available, a considerable quantity lacks the experimental rigour associated with evidence based research. An interesting paradox is the reported need parents have for more information at the point of diagnosis (Whitaker, 2002) but the acknowledgement that the amount of information available is overwhelming (Mandell & Salzer, 2007). In 2003 the National Autism Plan for Children (NIASA) was developed in an attempt to add coherence to the information and support provided by services to families of children with ASD but further research is needed to establish fully what this package should look like. Research has revealed that useful information based on evidenced research can be a protective factor in helping parents to understand their child and adopt positive coping strategies (Randall & Parker, 1999), making this an important issue for autism-related services.

Parents of children with autism are likely to encounter a wide range of professionals during the assessment and diagnostic period. Any subsequent support or care with autism-related services will introduce even more professional involvement. Riddick, (2008) observed that this could raise issues of responsibility, with many professionals assuming that someone else should be or is passing on particular information. Another particular problem faced by parents of children with ASD is that the complexity of the disorder may require referrals to other professionals for advice or support with specific issues such as toileting or diet. Children with autism may need support from a wide range of services as their condition can impact on many areas of their life, such as speech and language, play, interaction, communication, behaviour, self-help, independence and learning. The immense range of potential problems faced by children with autism creates a challenging environment for their parents who have to negotiate with many individual professionals and don’t tend to have one point of contact.

1.6 Parents' Engagement with Interventions

1.6.1 Evidence-Based Behavioural Interventions for Individuals with ASDs

A review of literature (Rogers, 1998) revealed that there does appear to be some plasticity of autism in the early developmental years but any question of a full recovery needs further research (Rogers & Vismara, 2008). This adds to the uncertainty experienced by parents and professionals alike as to how much change can be brought about through effective treatment. In the current climate there is increasing pressure on service providers to offer information and services to parents which are based on scientifically proven practices (Yell, Drasgow & Lowrey, 2005). In addition, there needs to be substantial evidence for the efficacy of treatments which is often demonstrated through the use of rigorous research methods (Odom et al., 2003; Reichow, Volkmar & Cicchetti, 2008). A lack of cohesiveness in this provision adds to the challenges faced by parents of children with autism seeking to obtain or provide effective care for their child. The wide array of non-evidence based treatments for autism that are easily accessible to parents, via the internet for example, place a duty of care upon service providers to actively inform parents of rigorously researched interventions. Theories of possible cures still abound and are often accepted without recourse to evidence resulting in a plethora of supposedly effective treatments. This would not be the case for parents of children with Down syndrome as the epidemiology is widely researched and documented.

There is an increasing body of research which has shown that home-based early intensive behavioural intervention (EIBI) founded on the principles of applied behaviour analysis (ABA) can produce dramatic improvements for young children with autism. Research has shown that EIBI can enable children with autism to develop an effective skills repertoire, reduce their challenging behaviour, achieve successful integration into mainstream schools and some studies have even shown 'normal' levels of functioning are possible (e.g., Lovaas, 1987; McEachin et al., 1993; & Remington et al., 2007). The challenge facing service professionals is how to direct parents of children with autism to this type of intervention in order to prevent them from engaging with treatments that have little or dubious evidence, such as dolphin therapy.

Lovaas's pioneering (1987) study showed that a group of children receiving 40 hours weekly of home-based Early Intensive Behavioural Intervention

(EIBI) achieved significant gains in assessed IQ and social functioning in comparison with control groups receiving either a less intensive intervention or a standard treatment offered by educational services. Subsequent studies have also shown gains in language, self-care, social and academic development (Anderson, Avery, DiPietro, Edwards & Christian, 1987), higher scores of cognitive, linguistic and adaptive functioning (Howard, Sparkman, Cohen, Green & Stanislaw, 2005), and gains in expressive language, verbal comprehension, motor skills and increased response to joint attention (Remington et al., 2007). In fact, the remarkable claims made by Lovaas and his colleagues gave parents hope that their child with autism could make a full recovery. However, Lovaas' findings need to be treated with considerable caution due to concerns around internal and external validity. Also, Lovaas' sample consisted of high functioning individuals who might have made the same progress with a different type of intervention. A follow-up found that lower functioning children did not have the same IQ gains after intervention (Smith, Eikeseth, Klevstrand & Lovaas, 1997). Furthermore, Salt et al., (2002) failed to replicate Lovaas' results, although their intervention was much less intensive, which could have accounted for the observed outcome.

For parents of children with autism, findings like these provide hope that their child could make remarkable improvements. Many other childhood disorders do not appear to have such possibilities for improvements in the child's condition so parents of children with autism face many uncertainties. However, the disparities between research findings and uncertainties surrounding the effectiveness of such treatments mean that parents' hopes are often unfulfilled.

Widespread awareness of autism as a childhood condition is relatively recent, and attempts to understand and treat it are still in their infancy. This makes it difficult to provide parents with accurate answers. In 2008, Rogers and Vismara conducted a comprehensive review of the empirical studies of treatments for children with ASD published in the last 10 years. They used empirically researched criteria to determine if studies were well established (see Chambless, et al., 1996 and Chambless et al., 1998 for specific criteria) and assessed methodological rigour based on Nathan and Gorman's (2002) criteria. Amongst their conclusions was the recognition that there were very few truly randomised clinical trials, so whilst many studies indicate that young children with autism can make developmental gains, a large proportion of the research had significant methodological flaws. Of the 22 treatment interventions they evaluated, only four met the most stringent criteria for methodological soundness (see Aldred, Green & Adams, 2004; Jocelyn, Casiro, Beattie, Bow & Kneisz, 1998; Sallows & Graupner, 2005; Smith, Groen & Wynn, 2000). However, it is worth noting that many of the studies deemed to be less rigorous did not have critical design flaws and still provided useful information which on the whole suggests that intensive treatment programs can have a positive impact on young children with autism.

Researching treatments for children with autism is considerably more difficult than research into treatment effectiveness for other areas of childhood psychology or for disorders with a less complex manifestation. Rogers and Vismara (2008) conclude that while other research "focuses on specific symptoms such as non-compliance, or disorders with a more limited set of symptoms than autism…autism treatment needs to address every developmental area, all areas of adaptive behaviour, and then a whole set of aberrant behavioural responses, involving both positive and negative symptoms" (p.32). Whilst many studies reveal the positive impact of some interventions for children with autism, there is a considerable journey ahead for researchers in this field in order to overcome some of the obstacles created by the complexity of the disorder. The confusion amongst researchers fuels the uncertainties faced by parents in choosing the right treatment. Many parents rely on professional guidance to aid their decisions about how best to treat their child, however researchers are still attempting to understand the complexity of the disorder themselves.

Dale et al. (2006) found that parents that hold the belief that their child's condition can be partly or completely overcome may be more likely to engage in interventions. However, the possibilities that remain about the potential for positive outcomes amongst children with ASD and the uncertainties that surround the likelihood of this make parenting children with autism particularly difficult. For other disorders with recognised chromosomal or brain abnormalities for example, the child's condition is usually accepted as being irreversible. However, behavioural treatments for ASD suggest that there is the possibility of some reversal or reduction of negative symptoms. This creates a distinctive situation for parents of children with autism who face many uncertainties about their child's future and their role in possible treatments.

1.6.2 Parent Involvement in Interventions

Early interventions between the ages of two and four years can produce significant learning and developmental gains for children with disabilities (Green, 1996; Rogers, 1996). In addition, it has been widely documented that early intervention with intensive behavioural programs produces the most significant gains for children with autism (see Green, 1996; Lovaas, 1987). Logistically, early intervention places increased pressure on parents and extended families as this significant period of time falls before full time schooling years and thus is dependent on a high level of parental involvement.

Lovaas became an advocate for home-based interventions after identifying that children with autism were losing the benefits of ABA interventions when they returned to clinic based settings and that gains were more likely to be maintained when they remained in the home environment. Green (1996) reported that effective EIBI may depend critically on parents' involvement and commitment to a programme after receiving their child's diagnosis. Since this time, parental involvement in their child's early intervention programme has been considered an important component (Harris, 1994). A study conducted by Levy, Kim and Olive (2006) examined intervention studies and found that those that included parental involvement yielded the most positive outcomes for children. In their recent study, Reed, Osbourne and Corness (2007) replicated Lovaas' original 1987 study and found that parent delivered intervention was successful in bringing about developmental change for children with more severe autism in a home-based setting. Furthermore, research has shown that parent training can positively influence the effectiveness of behavioural treatments (Schreibman, 2000; Schriebman & Anderson, 2001) and can also have a significant impact on the child's communication skills (Moes & Frea, 2002).

Further complicating the situation faced by parents of children with autism is the sheer amount of contradictory evidence. Whilst some studies have demonstrated that home-based programs performed well in comparison to control groups (Sheinkopf & Siegel, 1998), others found that there were no gains at all in a parent led approach (Salt et al., 2002). Smith et al. (2000) found that home-based gains were only reported when the intervention was being carried out near to the supporting clinic. McConachie and Diggle (2007) question whether there is substantial evidence to suggest that parent implemented interventions are beneficial for children with ASD. They state that much of the research in this area lacks a systematic approach which reduces the validity. Other studies have also relied on single case studies reducing their generalisability. The authors go on to say that these methodological weaknesses may confound the conclusions of research in this area and so any findings should be treated with caution.

Despite the criticisms much of the current research appears to indicate the efficacy of treatments and interventions which employ parents as teachers. However, parental involvement in treatments for children with autism requires careful consideration as these parents are already at increased risk of negative outcomes such as stress (Hastings et al., 2005) and depression (Singer, 2006). Other problems include the administrative duties expected of parents, lack of support for siblings and feelings of intrusion, by therapists, into the family home (Grindle, Kovshoff, Hastings & Remington, 2009).

These findings imply that children with autism may have better outcomes if their parents become highly involved in the treatment programmes. This places a heavy burden upon parents of children with autism who may feel that they have to take on considerable responsibility for their child’s treatment. This may have financial implications for a family as a parent may have to give up work to care for their child and undertake any training that is necessary. Also, parents may feel the added pressure of being responsible for the treatment outcomes, which could impact negatively on their emotional wellbeing if progress is not as expected. Implementing their own child’s treatment could affect a parent’s social life or relationship with their partner or other children as they take on sole responsibility for their child’s care. Adopting a therapeutic role may also affect the nature of the parent-child relationship. Any parent who has a child undergoing a treatment of some sort is likely to feel worried and anxious, but most can place faith in or rely on professionals and experts. Parents of children with autism face a situation where the most successful interventions appear to be those with significant parental involvement which may result in parents making substantial changes to their lives.

1.6.3 Complementary and Alternative Medicine

Evidence has shown that families of children with autism are more dissatisfied with professional support than those families of children with other mental and physical disabilities (Liptak et al., 2006). Consequently these families may be more likely to turn to complementary and alternative medicine (CAM) to help support their child (Liptak et al., 2006). CAM encompasses “health-related products and practices which are not accepted presently as a part of conventional medicine; for example, herbal supplements, acupuncture…chiropractic manipulation” (Senel, 2010, p. 494).

A study by Senel (2010) identified that the most popular CAM treatment used by parents for their child who has autism were vitamins and minerals and an adapted diet. The findings were similar to those of other studies (Hanson et al., 2007; Wong & Smith, 2006) and indicated that these treatments were highly beneficial. Singh and Ernst (2008) suggested that the placebo effect may have an impact on parents’ efficacy ratings of CAM treatments as their personal beliefs and experiences could influence their expectations. Goin–Kochel, Mackhintosh & Myers (2009) state that it is difficult to measure the effectiveness of CAM for children with ASD because of the variability of autistic behaviours and responses. They also state that it is difficult to conduct randomised, double blind, placebo-controlled trials due to ethical considerations. Furthermore, studies have revealed that parents often use multiple CAM treatments at the same time which makes it harder to identify the efficacy of a single treatment (Green et al., 2006).

While the use of CAM is not necessarily unique to parents of children with autism, there has been a rise in the popularity of CAM use among this population. Green et al., (2006) surveyed 111 parents on the internet and found that 52% of parents reported that they were using at least one form of CAM to support their child who has autism, which Ernst (1999) believes is due to a perceived effectiveness rather than empirically based research. Parents of children with autism may be increasingly turning to alternative medicine as there is a lack of cohesiveness for evidenced based treatments. Autism experts have found it difficult to be specific about the potential improvements that a treatment package can bring about which can lead to a lack of faith in professional advice or uncertainty about how to proceed.

Clearly parents may try a range of interventions and treatments in order to help their child and claims of success can influence their decision making. Weiss, Fiske & Ferraiol (2008) observed that “this understandable desire for a ‘cure’ leaves many vulnerable and susceptible to the appeal of treatments that are based solely on hearsay, anecdotal evidence, and biased report” (p.33). As long as the prognosis for children with autism is based on contradictory evidence, parents remain vulnerable in their search for answers.

1.7 Conclusion

For parents, discovering that their child has a physical or mental disability of any kind can be extremely distressing. Parents have to enter a period of adjustment in order to adapt their lives and resolve themselves to the fact that their child is disabled. Parents may enter a period of mourning for the ‘hoped for’ child (Blacher, 1984). Furthermore, grieving or significant levels of distress can continue for the child or parent’s life span. Individuals who experience significant negative emotions and who may be in denial are never able to fully reconcile themselves to having a disabled child (Pianta et al., 1996). This has implications as those parents who lack resolution may alter their parenting behaviours with a negative impact and could experience many difficulties parenting a child with disabilities (Fraiberg et al., 1983). An adapted parenting style and approach to managing their child may result in an insecure attachment between child and parent (Marvin & Pianta, 1996). In addition, to adapting their lifestyles and adjusting expectations, parents face an uncertain future in relation to the prognosis for their child. They also have to negotiate relationships across many professional systems and sort through vast amounts of paperwork making decisions about the care and support their child needs. It is not surprising that research has shown how parents of children with a disability are more likely to endure higher levels of stress than parents of typically developing children (Shonkoff, Hauser-Cram, Kraus & Upshur, 1992) and that parents of children with autism face more stress still (Davis & Carter, 2008; Hastings & Johnson, 2001).

There has been much research examining the dyadic relationships between disabled children and their parents, but arising from this research is the recognition that pervasive developmental disorders, such as autism, are significantly different to other childhood disabilities, both in the way that they manifest and the impact that they have on parents, siblings and the family unit as a whole. Research has shown that parents of children with autism have higher levels of stress than parents of children with other disabilities (Eisenhower et al., 2005). These parents are also at more risk of developing depression and experiencing other psychologically negative effects on their wellbeing (Olsson & Hwang, 2001) in comparison to parents of children with other disabilities. Also, mothers in particular have been found to have poorer mental and physical health and report a reduced quality of life (Allik et al., 2006).

Evidence has been gathered to attempt to explain this phenomenon and largely points to the interaction of a variety of factors which are absent from other disorders. Compared to disabilities such as Down syndrome which are often diagnosed prenatally or shortly after birth (Batshaw, 1997), ASDs are typically diagnosed later in a child's life. This delay can increase uncertainty amongst parents about their own parenting skills (Bailey, Skinner, Hatton & Roberts, 2000). Poehlmann, Clements, Abbeduto and Farsad (2005) explored the difference between the degree of uncertainty between parents of children with Down syndrome and fragile X syndrome; they suggest that "perhaps concerns related to uncertainty fade over time for the Down syndrome group as families begin participating in intervention and networking with parents and professionals, whereas uncertainties in the fragile X syndrome group intensify over time as the child's developmental difficulties and problematic behaviours begin to unfold and increase (Abbeduto at al. 2004 cited in Poehlmann et al., 2005)" (p. 265). This is applicable to parents of children with autism as fragile X syndrome is also diagnosed later on in the child's development and manifests in a similar way to ASDs.

Raising a child with autism can have significant negative outcomes on marital relationships and the well-being of siblings, putting these families at the increased risk of family breakdown (Fisman et al., 2000). These difficulties may be a result of the high degree of maladaptive behaviours and significant functional impairment usually associated with autism, which results in increased parent stress levels (Tobing & Glenwick, 2002).

Many studies have highlighted the difficulties faced by parents of children with ASD compared to parents of children with other disabilities, when accessing support services and appropriate information (Krauss et al., 2003). Research suggests that parents of children with autism are more than twice as likely to face difficulties relating to referrals, appointments, finding service providers and accessing cohesive care and support than parents of children with other medical needs (Krauss et al., 2003). Dunn et al., (2001) reiterate that families with a child who has autism face greater problems in these areas than other families of children with disabilities.

Finally, the huge rise in interest in autism in recent years has resulted in a wealth of information about possible cures and effective interventions that are available to parents of children with autism. The sheer amount of information accessible to parents of children with ASD (Kendall & Hammen, 1998) presents an enormous challenge to identify how best to support the child and to meet the needs of the family as a whole.

It is clear that parenting a child with autism presents parents with a particularly difficult challenge for a myriad of reasons. Whilst research is increasingly providing answers to the unique interactions between children and parents who are learning to live with ASDs, more longitudinal research needs to be conducted to evaluate the effectiveness of interventions and the impact that raising a child with autism has on the family unit as a whole. Listening to individual accounts and exploring parents' beliefs about their perceptions of the future could provide useful insights into the specific impact a diagnosis has for a family coming to terms with raising a child who has autism, and could highlight the particular challenges they face.

Section 2: Empirical Paper

Parents’ Responses to their Child’s Diagnosis of Autism Spectrum Disorder (ASD)

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ABSTRACT
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PARENTS’ RESPONSES TO THEIR CHILD’S DIAGNOSIS OF AUTISM SPECTRUM DISORDER (ASD)

By Amber Jennifer Evans

2.1 Abstract

Although a significant amount of research has reported the level of parental satisfaction with the disclosure of a diagnosis, little has documented their emotional responses after the diagnosis, their perceptions of the future, and the potential impact this has on the uptake of evidence based early interventions.

The aim of this study was therefore to explore parents’ responses to their child’s diagnosis of Autism Spectrum Disorder (ASD) in order to contribute to a greater understanding of parental experiences, to inform future practice and to help shape effective support services and intervention packages.

Using a semi-structured format, 15 parents were interviewed about receiving a diagnosis of ASD for their child in order to obtain detailed first person accounts of their experiences. The data were analysed using a thematic analysis.

Five main themes were identified. These were; (1) Positive response to a diagnosis; (2) Negative response to a diagnosis; (3) Perceptions of the future; (4) Factors possibly facilitating engagement with professional services; and (5) Factors possibly preventing engagement with professional services.

The implications of these findings for professionals involved in the diagnostic process and support services are discussed. Suggestions for future research based on the findings and limitations of this study are also identified.

2.2 Introduction

2.2.1 Definitions and Prevalence of Autism Spectrum Disorders (ASDs)

Autism is a pervasive developmental disorder characterised by impaired social interaction and communication and by restricted and repetitive behaviour (American Psychiatric Association, 2000). Autism spectrum disorders (ASDs) encompass Asperger syndrome, which lacks the delays in language and cognition associated with autism; and PDD-NOS (Pervasive Development Disorder- Not Otherwise Specified) which is diagnosed when the full criteria for autism and Asperger syndrome are not met (Johnson & Myers, 2007).

ASDs are of particular concern to parents and professionals alike owing to the astonishing increase in prevalence in recent years. Recent figures suggest that approximately one in 160 children are diagnosed with ASD (Fombonne, 2005), higher in frequency than childhood diagnoses of spina bifida, cancer or Down syndrome (Muhle, Trentacoste & Rapin, 2004). The significant increase in numbers may be largely attributable to changes in diagnostic criteria and the growth of awareness among parents and professionals (Wing & Potter, 2002). However, this does not mean that it can be ignored as professionals working within the spheres of education and health are dealing with increasing numbers of children with autism.

2.2.2 The Diagnosis of ASD

Alongside the rise in prevalence it has been recognised that a diagnosis of ASD presents a complex challenge to parents. Prior research has shown that parents receiving a diagnosis of autism for their child endure higher stress levels (Eisenhower, Baker & Blacher, 2005) and are at a greater risk of depression (Singer, 2006) than parents of children with other disabilities. Children with ASD are usually diagnosed at a later age than children with other disabilities, which contributes to increased stress levels (Howlin & Moore, 1997; Howlin & Asgharian, 1999). The recent development of an integrated early detection programme (Oosterling et al., 2010) may help to reduce this delay and improve diagnostic services for parents of children with autism, but at present parents' experience a time lapse of approximately two to four years between the arousal of their first suspicions of a problem and the final diagnosis (Howlin & Moore, 1997; Smith, Chung & Vostanis, 1994).

ASDs are complex and difficult to diagnose as children may present with a heterogeneous set of skills and deficits (Thomas, Ellis, McLaurin, Daniels & Morrissey, 2007) that can make the diagnostic process uncertain for parents and professionals alike. In addition, autism is usually associated with a degree of functional impairment and the presence of maladaptive behaviours that can further exacerbate parental stress (Tobing & Glenwick, 2002). High levels of parental stress after their child's diagnosis of ASD are associated with factors relating to the child (e.g. concerns around their education, health and future well-being), but also to a lack of help or support for the family (Kasari & Sigman, 1997). Parental stress has been found to be alleviated if training gives parents coping strategies together with social support (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001) and if training reduces management problems, bringing about change in the child's behaviour (Koegel et al., 1992).

The higher stress levels associated with parents of children with autism has led researchers to begin to explore parents' responses to receiving a diagnosis of ASD for their child.

2.2.3 Parents' Responses to a Diagnosis of ASD for their Child and its Implications

Much research has been conducted into parents' responses to receiving a diagnosis of disability for their child (see Barnett et al. 2006; Poehlmann, Clements, Abbeduto & Farsad, 2005; Sheeran, Marvin & Pianta, 1997). Early studies reveal that when parents first learn about their child's diagnosis, they react with feelings of loss and mourning for the "hoped-for child", similar to bereavement associated with the death of a family member or friend (Blacher, 1984). Other literature reveals that receiving a diagnosis of childhood disability is a crisis point for parents (Waisbren, 1980). Understanding parental responses to their child's diagnosis is crucial as research has shown that significant levels of chronic parental stress or denial of the child's disorder can result in a lack of resolution to the child's disability (Pianta, Marvin, Britner & Borowitz, 1996). Without achieving resolution to a diagnosis, parents can experience difficulties raising their child (Fraiberg, Adelson & Shapiro, 1983) and this is associated with insecure attachment between child and parent (Marvin & Pianta, 1996). Despite the overwhelming risk of negative outcomes for both parents and child, there is scant empirical research specifically focusing on the emotional responses of parents of children with autism.

Little was understood about the diagnostic process for parents of children with ASD until two studies conducted by Howlin and Moore (1997) and Howlin and Asgharian (1999). They surveyed over a thousand parent members of autism societies about their views of the diagnostic process and concluded that parents were often dissatisfied with the disclosure of a diagnosis and that it was also a considerable source of stress to them.

Much of the subsequent research has continued to focus on the disclosure of a diagnosis of autism in terms of parental satisfaction. Satisfied parents rated the manner of the professional and the quality of the information they were given more highly (Brogan & Knussen, 2003). Whereas dissatisfied parents included those who felt there had been a delay in the diagnosis (Baird, McConachie & Scrutton, 2000; Howlin & Moore, 1997), a common occurrence for parents of children with autism. Focusing on the response to the diagnosis in terms of satisfaction does not reveal how parents feel about their child’s diagnosis or how they have interpreted these feelings. It merely reveals a snapshot of the diagnostic process and fails to encompass the wider picture of parenting a child with autism, which continues long after the initial diagnosis is made (Cottrell & Summers, 1990). A considerable body of evidence suggests that parents’ find the diagnostic process emotionally stressful, and research suggests there is widespread dissatisfaction (Graungaard & Skov, 2007), however, very little is known about the impact of a diagnosis of childhood autism beyond parents’ initial reactions to the disclosure.

A study conducted by Sicile-Kira (2003) exclusively recruited parents of children with autism and reported that these parents describe the process of coming to terms with a diagnosis as a painful experience, encompassing feelings such as shame, guilt and self-pity. Another study by Whitaker (2002) collected data through a semi-structured interview and revealed that some parents reported strong emotional responses to their child’s diagnosis, such as fear, shock, uncertainty and a sense of isolation. These two studies highlighted the significant emotional impact that receiving a diagnosis of autism for their child has on parents, but these were not explored in any great detail as the emotional responses of parents were not the primary focus of the research. Specifically exploring parental experiences after receiving a diagnosis of autism for their child is essential in order to identify potential risk and resilience factors, to develop reliable and valid procedures for early identification of families at risk and to aid the development of effective intervention procedures (Marvin & Pianta, 1996).

Much of the previous research into parents' responses to diagnosis has employed quantitative methodologies. For example, Howlin and Asgharian (1999) conducted surveys; formal measures, such as the Parenting Stress Index (Abdin, 1995) and the Beck Depression Inventory (Beck, Steer & Brown, 1996) were used by Dale, Jahoda and Knott (2006); and rating scales were employed by Brogan & Knussen, (2003). Whilst providing useful categorical information about the type and incidence of parents' feelings, they were unable to depict accurately the emotional climate created after a diagnosis is received.

Attempts have been made to gather parents' accounts of their experiences of having a child diagnosed with ASD using qualitative analytic approaches. The bulk of this research has focussed on parents' resolution to a diagnosis (Pianta et al., 1996) and the attributions they make about causality (Dale et al., 2006). As well as the formal measures, Dale et al., (2006) conducted interviews in order to examine the nature and impact of parents' beliefs about their child's ASD. They analysed their results using a content analysis which provide a model for systematic qualitative analysis, but results generated from a content analysis can be regarded as trite (Silverman, 1993) when they rely exclusively on frequency outcomes.

A number of factors have been found to moderate parents' responses to their child's diagnosis of autism. For example, lower functional impairment and the presence of fewer maladaptive behaviours have been linked to lower levels of stress (Tobing & Glenwick, 2002). Furthermore, Dale et al. (2006) reported that mothers of children with ASD respond to a diagnosis by making a diverse and complex range of attributions about cause and prognosis. However, despite an increased understanding of potential factors which may influence parental response to a diagnosis of ASD and some illumination of parents' attempts to search for meaning following their child's diagnosis, no research has looked specifically at how parents respond emotionally in the immediate period after the disclosure and how this response affects their perceptions of the future. It is critical to explore this as it may aid the identification of parents who are finding it difficult to come to terms with their child's diagnosis and are consequently at increased risk of negative outcomes for themselves, their families and their child who has autism.

Researchers adopting a longer term perspective have found that parental adaptation to a child’s disability is a complex, lifelong process, involving ongoing changes at multiple levels of family life (e.g. Hauser-Cram, Warfield, Shonkoff & Krauss, 2001; Seltzer & Heller, 1997). Reports of extreme concern about a child’s future, safety and protection are common (Ivey, 2004). Again, these studies are not autism specific and need to be treated with caution when applied to the unique autism population. Whilst we can assume with some certainty that the critical period of time after diagnosis undoubtedly influences parents’ perceptions of the best way to manage concerns about future expectations of their child, this needs to be explored further with the population receiving diagnoses of autism.

Pianta et al.(1996) explored parental resolutions after receiving a diagnosis of ASD for their child. They found that parents who accepted the diagnosis and reconciled themselves to it usually acknowledged difficulties and could recognise positive changes in their feelings over time. These parents also described the process of moving on in their lives by thinking about the present and the future instead of dwelling on the past, such as questions about the cause of their child’s condition. Whilst the findings from these studies tell us something about how parents’ attempt to make sense of a diagnosis in their search for meaning, they fail to indicate how parents’ emotional reactions could influence their actions in the future. This could provide valuable information for service providers to help them develop appropriate and effective support services for families’ identified as becoming disengaged with vital support services or treatment packages.

Scant research has focused on the actions taken by parents following a diagnosis of ASD for their child. Some parents reportedly changed their behavior and galvanized themselves for intensive activity and care of their child. Others described the time after their child’s diagnosis of ASD as a process of personal development, learning skills such as advocacy or learning to redefine themselves as ‘experts’ (Fleischman, 2004). Fleischmann’s findings suggest that it is possible that parents’ emotional responses to their child’s diagnosis of ASD could impact on their engagement with successful intervention programmes, but as yet this has not been explored.

In a later study, Solish and Perry (2008) explored the factors that could influence parental involvement with intensive behavioural interventions for their child. Amongst other things they identified that parents’ stress levels may influence their ability to be involved effectively with their child's intervention. As parent stress levels are reportedly higher after receiving a diagnosis of ASD for their child (Howlin & Asgharian, 1999) this is a potential barrier to the engagement with interventions. In addition, high levels of parental stress can have a negative impact on the success of interventions (Robbins, Dunlap, & Plienis, 1991). Conversely, parents who feel less stressed may be better equipped to support their children emotionally, cognitively and physically (Solish & Perry, 2008). Solish and Perry's study examined a variety of variables to see if they were related to, or could predict parental involvement with interventions. Although they determined the effects of parental stress on involvement, they did not explore if other negative parental responses, such as significant sadness, feelings of isolation or shock, could have a similar impact on engagement with interventions. There is currently a paucity of research about why parents may or may not choose to engage in these interventions but it is crucial to identify how parents' respond to their child's diagnosis, and how this may impact upon their perceptions of the future, in order to identify the impact this has on engagement with interventions.

Overall, despite some awareness of the impact of the disclosure of a diagnosis and some understanding of how parents attribute meaning to it, parental reactions to a diagnosis of autism for their child has not been explored in a way that provides real insight into parents' emotions and wellbeing, or their perceptions about their child, family and future. Exploring these areas further may highlight potential barriers to engagement with beneficial intervention programmes or conversely could identify ways to facilitate this involvement.

2.2.4 Methodological Issues

Many previous studies employed quantitative approaches to understand parental reactions to a diagnosis, which are useful but have some associated weaknesses such as, confirmation bias, narrowness and artificiality. However these weaknesses can be overcome by adopting qualitative data collection which allows participants to express themselves in ways that are not constrained and dictated by the researcher (Wilkinson, Joffe & Yardley, 2004). Furthermore qualitative approaches are diverse, complex and subtle (Holloway & Todres, 2003). To date, there is scant research exploring parents' experiences of having a child diagnosed with ASD using qualitative approaches.

Within qualitative methodology some approaches are tied fairly rigidly to a particular epistemological position, such as grounded theory (Glaser, 1992), or narrative analysis (Murray, 2003). The disadvantage of this is that the method is fairly limited within the theoretical framework. In contrast, some methods are independent of theory and can be applied across a range of epistemological approaches. Thematic analysis is one such method which has the flexibility to provide a rich, detailed and complex account of the data. Despite not being wedded to a specific theoretical framework, thematic analysis provides an opportunity to view the data from a realist or constructivist perspective. This provides researchers with the opportunity to both reflect the reality of the participants and to unpick a 'surface' reality which examines the ways in which perceptions and experiences are the effects of a range of societal discourses (Braun & Clarke, 2006). Not only does thematic analysis provide a method for identifying, analysing and reporting themes within the data, but it also interprets various aspects of the research topic (Boyatzis, 1998).

The reason for adopting a thematic analysis in this study is that it will allow the richness of parents' words and feelings about a highly emotive and complex emotional subject to remain visible. The aspiration of thematic analysis is to remain true to the raw data (Joffe & Yardley, 2004) and to provide first hand accounts of parents' experiences and perceptions rather than anecdotal evidence or data collected through systematic surveying. Furthermore, Joffe & Yardley (2004) recommend the use of thematic analysis with a small sample size as it avoids the potential pitfalls of having to report the frequency of occurrence which could be misleading if the sample is not large enough to provide reliable statistical generalisation to the population. Thematic analysis was deemed appropriate for use in this study as there has previously been no research into parents' responses to their child's diagnosis of autism using this type of methodology. Previous studies have employed qualitative methods but have failed to make empirically rigorous interpretations in order to reflect the richness of parent's views (e.g.Whitaker, 2002).

It is important to recognise any limitations of the research design. Thematic analysis can result in abstracting issues away from how they appear in real life (Boyatzis, 1998), however, in order to avoid this pitfall the aim will be to describe how thematic contents are elaborated by participants and to identify meanings that are valid. In contrast to previous studies (Howlin & Moore, 1997; Howlin & Asgharian, 1999) and in an effort to minimise the limitations that come with a retrospective design, parents whose children have received a diagnosis in the last two years will form the sample population.

2.2.5 Rationale and Aims of the Research

The current study was designed to employ a qualitative methodology to examine parents' responses to their child's diagnosis of ASD and their beliefs about future expectations for their child, with the additional aim of identifying factors which may influence their decisions and actions about the uptake of early intervention programmes. This study will explore the following dimensions; (1) emotional reactions to a diagnosis of ASD for their child; (2) beliefs about future expectations after receiving a diagnosis of ASD for their child and; (3) how (1) and (2) could influence the uptake of early interventions.

2.3 Method

2.3.1 Participants

Participants were recruited in several ways. First an advertisement was placed in the Surrey and Berkshire Autism Newsletters. Second, Educational Psychologists based in Hampshire identified participants who they believed met the inclusion criterion. The inclusion criterion for the research was that parents had a child who had been diagnosed with Autism Spectrum Disorder (ASD) within the past two years. There was no exclusion criterion. A total of seven participants contacted the researcher after reading the advert in the Surrey Newsletter and one participant read an advert from the Berkshire Autistic Society and contacted the researcher. A further seven participants were telephoned by the researcher after Educational Psychologists from Hampshire identified that they met the criteria for the study, of these, two declined to participate in the research. An individual parent was the main point of contact in all the families who agreed to participate.

In total 15 parents (12 mothers and three fathers) of children with ASD were interviewed. Thirteen interviews were conducted in total which comprised of 11 single parent interviews and two interviews with both parents present. The families were not offered monetary payment for participation. Demographic information was collected from all participants (Appendix D). All participants were aged between 31 and 50 with the majority (69%) aged between 31 and 40. All participants were of white ethnicity and spoke English as a first language. Out of the 13 families, one had only one child; the remaining 12 families had between two and four children. Of the 13 families, three had more than one child diagnosed with ASD. There were no other reported disabilities amongst the children in the 13 families. All but three of the participants were married to the biological parent of their children. Those that were not married were single, divorced or living with a partner and two out of the 13 families were single parent households. All 13 families had an adult in paid employment and 76% of families had an average income of over £26K.

The interviews provided information on the family life of 13 children with ASD (11 male, two female), aged between 39 and 116 months (mean = 82.9 months, SD = 24.5). These children were diagnosed with ASD between the ages of 30 to 105 months (mean = 70.6 months, SD = 24.4). All lived in the family home in the UK. None of the children had additional health problems other than difficulties often arising alongside ASD, such as speech and language impairment, sensory modulation or learning difficulties. Of the 13 children, one had been diagnosed with severe autism spectrum disorder, three with high functioning autism and nine with Asperger syndrome.

2.3.2 The Interview Structure

A semi-structured interview format was used to ensure that participants could talk freely. The content of the interview schedule (Appendix A) was prepared in advance and consisted of open-ended questions designed to gain information of a variety of topic headings and with alternative subsequent questions dependent on the answers given. The key questions asked were:

1. Tell me about your child's diagnosis of ASD?
2. What do you imagine the future will be like for your child and your family now that you have received a diagnosis?
3. Tell me about the support you have experienced since your child's diagnosis and your expectations about future support?
4. Is there anything else you could tell me about your experiences since your child's diagnosis of ASD?

Probes were used to encourage participants to expand on what they had said and prompts were used to provide a guideline for responses (see Appendix A for details of probes and prompts). The interview schedule was designed to be delivered in sequence but this was flexible depending on the responses given during the interview.

After obtaining background and demographic information (e.g., age of the child, marital status etc.) the interviews sought parents' accounts of their experiences of receiving a diagnosis of ASD for their child using the semi-structured interview. After the interview, parents were given an open-ended opportunity to comment. Interviews ranged from about 30 minutes to over an hour.

2.3.3 Procedure

Ethics.

Ethical approval was obtained from the University of Southampton School of Psychology ethics committee before the parents were interviewed (Appendix B). Prior to the interview, parents were sent an information pack consisting of detailed information about the study and a consent form indicating that confidentiality and anonymity would be maintained (Appendix C). When consent had been obtained, the researcher arranged a convenient time and place for the interview to take place.

Pilot interview.

A pilot interview was conducted to rehearse the interview schedule and to evaluate the effectiveness of the questions. The pilot study followed the procedure outlined below. The interviewee in the pilot study was also asked to comment on the performance of the researcher and the interview schedule (Appendix E). No changes to the interview schedule were deemed necessary after the pilot interview.

Interviews.

All bar one of the interviews took place in the participants' homes. The exception took place in the work place of the participant at their request. All interviews were conducted by the researcher and were audio taped. At the outset of each interview the researcher provided information about her professional role as a trainee Educational Psychologist and reiterated the purpose of the study. Confidentiality and anonymity were assured both before and after the interview. Participants were also verbally debriefed and offered a written summary of findings at the end of the study. All interviews were then transcribed verbatim.

2.3.4 Data Reduction and Coding

Following interview transcription, a thematic analysis procedure based on the fundamental stages recommended by Braun and Clarke (2006) was used to identify key themes. The process began with immersion in the transcripts which enabled thorough familiarisation with the data. An initial list of ideas was created which broadly identified what was in the data and what was interesting about them. After this, initial codes were systematically generated identifying features of the data that appeared interesting and relevant to the research questions. These codes referred to the most basic meaning of each text segment which could be a word, sentence, phrase or paragraph. Only three transcripts were coded in this way for two reasons;

(a) because time did not permit for the coding of every piece of data, and (b) because Boyatzis (1998) suggested developing codes on a subsample of data before applying them to other subsamples of data. The remaining 10 transcripts were then coded using the themes identified, but any new themes that arose were acknowledged. All the codes were then collated into potential themes and all the relevant coded data extracts within the identified themes were grouped. The resulting categorical system, including the descriptions of each category, formed the interview coding manual (Appendix F). These candidate themes were then reviewed and refined to ensure that the themes represented the data in a meaningful way with clear and identifiable distinctions between themes. This involved two levels of analysis; first, checking if the themes worked in relation to the coded extracts; and second, checking the themes against the entire data set. A thematic map of the analysis was generated (Appendix G) as a visual representation to aid the development of themes. Finally, further refinement of the specifics of each theme was carried out by generating clear definitions and names for each theme (Figure 1.), also presented visually for clarity. All coding was carried out by the researcher in the first instance.

2.3.5 Reliability

To establish inter-rater reliability, another researcher coded three (23%) randomly selected interview transcripts using the coding manual. The second researcher did not have access to the coding completed by the first researcher and was presented with un-coded transcripts. The extent of agreement between the two coders was calculated using the list of codes for each interview and a percentage agreement index formula (agreements divided by agreements plus disagreements multiplied by 100). An agreement was defined as when both raters coded a parent interview as containing a statement corresponding to a category, or when they both coded an interview as containing no statements corresponding to a particular category. Disagreements were recorded when the second coder identified a code that was not in the coding manual. Overall inter-rater agreement across all categories was 76% (range, 70-89% for individual categories).

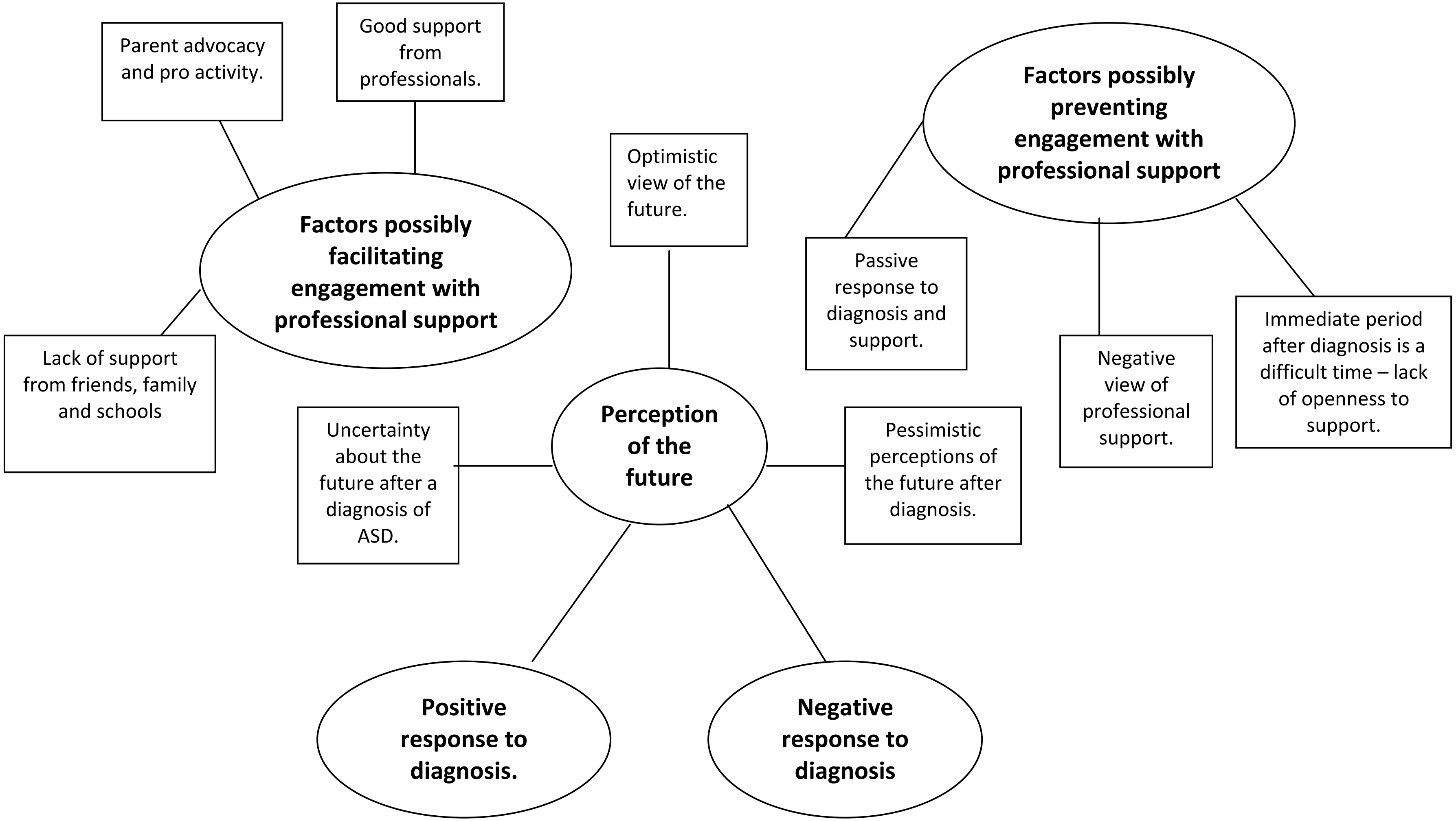


Figure 1. Developed thematic map showing five main themes.

2.4 Results

Transcripts of parents' interviews were analysed as described in the method section of this report. Parents' accounts of receiving a diagnosis of ASD for their child varied in terms of individual responses; however five main themes were identified which relate to the research questions. These were; (1) Positive response to a diagnosis; (2) Negative response to a diagnosis; (3) Perceptions of the future; (4) Factors possibly facilitating engagement with professional services; and (5) Factors possibly preventing engagement with professional services. These main themes and sub themes will be discussed in detail here and will be explicated in detail through the use of parental quotes to illustrate and support the themes.

2.4.1 Negative Response to a Diagnosis

Some parents described their experiences of the assessment period and the disclosure of the diagnosis using negative terminology. The disclosure in particular had the potential to increase parents' sadness and bewilderment at the point of diagnosis due to a number of factors ranging from the clinician's tone of voice, through to their apparent lack of empathy with the parents. Parents with negative emotional responses at the point of disclosure often described the unexpectedness of the diagnosis:

> But she suddenly said to us kind of mid flow, she sort of, I don't think she said it [the disclosure of the diagnosis] very well…She didn't even give us some time to stop and think. (P1)

It appears that participants who had not resolved themselves to a diagnosis of ASD for their child before the disclosure were more likely to experience negative emotions such as sadness, despair and grief:

> It was overwhelming, the whole thing, it [receiving a diagnosis of autism] is like being hit with a sledgehammer, and it probably took 2 years to stand up let alone walk. That is probably how I can describe it, and I'm, we're now walking and beginning to run a bit, and as time goes by more it [parenting a child with autism] will settle down but it is like being knocked over. (P1)

> I met the school nurse. I found out and they were saying look there's something wrong. I was just breaking down. (I2)

> It [receiving a diagnosis of autism] was like this despondency, like, 'oh my god my poor child, how's his life's going to be?' and it was that realisation later that it – I, I, you know, I, I had a couple of days I was like (slight pause) in tears, because it was like the actual realisation…and then it's sledge hammer, wham, oh my god he's going to have this for the rest of his life, it is not going to be an easy solution and it's going to be harder before it gets better. (I3)

Parents talked both in terms of physical and emotional responses to their child's diagnosis. Emotional responses, as evidenced in the quotes above, demonstrate the feelings of sorrow and bewilderment experienced by parents. In addition parents reported negative physical responses relating to the perceived strength needed to cope with raising a child with ASD, particularly in terms of associated behaviours such as aggression:

> There's no doubt emotionally and physically this [parenting a child with autism] has taken its toll on us, we're having to look at our own health issues because of what's happened, it's been exhausting. (P1)

> My husband has to carry him [son] down the stairs every morning, and I can't help him. I physically can't do that. (I2)

> I was so physically exhausted. Plus every single day is so physically demanding. (I12)

The timing of the diagnosis was referred to by some participants. In particular, parents reported that the diagnosis of their child at a very young age produced stronger negative emotional responses and was more difficult to cope with:

> I think especially again going back to the one's with younger children as well, trying to cope with babies and younger children, it's hard. (P1)

However, as some parents who were interviewed only had one child diagnosed with ASD they were not able to compare their emotional responses with children diagnosed at different ages.

A sub-theme arising from negative emotional responses to the diagnosis was that of relational issues within the family unit and the stresses placed on spousal relationships:

> Relationships, with your husband, your partner, whatever. I mean even now, there are days we really do struggle. There are days it is very hard. (I3)

> I think it's [the period after receiving a diagnosis of autism for their child] something we survived. I wouldn't say we survived it as a couple. We are a couple now, but we were individuals that were miserable then. (I12)

Gender differences between parents' responses to the diagnosis were identified both by the researcher and the participants themselves. Fathers appeared to find it more difficult to reconcile themselves to having a child with autism, leading to reports of relationship conflicts.

> It [receiving a diagnosis] didn't make my husband feel any better at all, he didn't want to accept it, he'd rather have a naughty child, but I'm told that's a typical male response. (I1)

> I think men and women obviously just have a different viewpoint of things, we have a different attitude, and I think just by our pure nature we react to things. Men are very much 'right, we'll take it apart and we'll reconstruct it and we'll fix it', whereas women are much more, you know, we tend to just by nature be more maternal obviously and much more, 'OK how can we make this all work?' (I3)

> He was in denial [after receiving a diagnosis of autism for his child] because he said ‘No father wants his son to have any sort of disability, let alone it be his first born’. (I5)

> You know my husband and I have discussed it a lot and I obviously went to most of the appointments because it was practical when I am part-time and he is full-time, as it generally is unfortunately. (I3)

The fathers in this sample did identify that they had responded differently to their spouses. This was attributed to mothers’ being more likely to have primary contact with the professionals involved with their child. Fathers’ also spoke about being in denial overtly, or of wanting to find a reason for the autism:

> I was in denial I just was convinced that…because he wasn’t doing anything other than not speaking, which was the only, main like, ‘oh that’s a bit odd’. (I7)

> The only thing about the diagnosis is that to begin with, whilst you accept it, you want a reason for it. (I7)

> My ex wife was a bit more sort of proactive about it [receiving a diagnosis of autism for their child] and she was so concerned that she sort of actively sort some sort of answer to the problem. (I9)

The effect of the diagnosis on siblings was also a concern to parents and often provoked feelings of guilt associated with spending less time with their other children. There was also a recognition that the family unit tended to revolve around the needs of the child with ASD, such as organising holidays, day trips out or the general morning routine:

> My heart goes out to her [sister] actually sometimes because I think it has been very difficult for her, for [son], he is a control freak, everything has got to be within his control and so she is sort of left in a, in a wake quite often and because of the very nature of his diagnosis and his issues he

> sometimes quite often is in the forefront of everything so everywhere we go or everywhere we think, we have to think of [son] first because he finds it the most difficult. (I3)

> It’s still quite hard for her [sister] really and also going places, I mean going shopping is awful, going out for the day, I mean we avoid going places, doing things I think as a family, because it’s difficult. (I2)

2.4.2 Positive Response to a Diagnosis

For some parents, the disclosure of a diagnosis of ASD for their child was not unexpected and therefore confirmed existing suspicions. These participants talked about their responses to the diagnosis in positive terms, as it provided affirmation of their concerns and consequently offered them some relief:

> It [receiving a diagnosis of autism for their child] made me feel better because it was a relief to know I wasn’t imagining things. (I1)

> Actually it’s great because I now have a name and it was almost a relief for me to be able to say to friends ‘I’ve had a diagnosis for [Daughter] for ASD, so all those little worries that I sometimes talk about it’s not me just being an idiot or an over anxious parent’. (I10)

For some participants the diagnosis led to feelings of reassurance that their parenting had not been inadequate and provides an explanation for their child’s behaviour. Parents indicated that the diagnosis also provided tangible evidence for other people who may previously have attributed the child’s unwanted or strange behaviours to poor parenting:

> When we got the diagnosis I finally felt, at last, you know, this is recognised, he has got this problem and we can move on…I felt really quite euphoric for a couple of days that, you know, I am not this awful parent, or we’re not these awful parents, we’re not, you know, we’re not treating our son and it causing him to behave this badly, he actually has a medical condition. (I3)

> I suppose getting a diagnosis meant that someone actually sort of said ‘This isn’t him being naughty, this is (pause) just something that he can’t cope with’. (I9)

Some participants talked about the positive aspects of having a label:

> In reality without that hook to hang it on it’s just a disparate collection of difficulties which are all quite nebulous and whereas if you can give a name to it, it made it easier for getting a statement which is ridiculous because his problems were the same whether he had a label or not but it meant for us that we could say yes he has autism. (I4)

Other positive emotions in response to the diagnosis were attributed to the actual disclosure by a professional, in all cases a paediatrician. Parents who were satisfied with the disclosure spoke positively of the clinician’s explanation of the diagnosis, both to themselves and their child. Some parents appreciated the privacy accorded to them during the disclosure of a diagnosis. Others referred to the clinician’s manner during disclosure and also the time they were given to process the information:

> We went to the meeting with the consultant paediatrician, she was lovely. (P1)

> The first thing she [the paediatrician] did was listen, because obviously by the time I saw her there was a lot of pent up frustration and I was upset and frustrated and I didn’t know what’s happened to my poor guy, you know he’s having a hell of a time. And so she just sat and listened for a long time and then she asked me right what I thought, why did I think it was Asperger’s. (I3)

> Actual receiving the diagnosis itself was very good. (I8)

The recognition by parents that schools and other professional services may take more notice of their child’s needs after the diagnosis was also discussed. A common belief was that members of school staff who had previously been reluctant to recognise the child’s needs or had interpreted the child’s behaviour in a negative way would respond to a diagnosis of ASD and would subsequently have a more positive perception of the child:

> It was a huge relief to have confirmed what I felt I knew already. I felt vindicated in the noises I’d been making at school, and I also thought ‘well they have got to do something now to help him, we will get some help that we need’. (I5)

> It [the label] gave the school something to focus on all of a sudden because they could, ‘cos it was there, you know, official, I saw a massive difference in the attitude from the school. (I11)

> So as soon as I mentioned the word ‘Asperger’s then the school stood back and thought ‘hang on a moment, let’s look he might have Asperger’s. So they changed their tack. (I3)

During the interviews some parents identified positive coping strategies they employed to manage the stress of raising a child with autism. Positive reframing was apparent in some parents’ descriptions of their response to the diagnosis. Other strategies involved prior planning:

> We don’t tend to do anything that’s spur of the moment because it is generally not a good thing to do. Um, if we are going anywhere we plan for. (I12)

> We have different cutlery nowadays and every so often he will sit down, he’s obviously feeling slightly (pause) uncomfortable and he’ll sit down at the table and he’ll go ‘That’s the wrong cutlery’. I don’t have a fight with him, just change the cutlery. (I9)

2.4.3 Relationship between Parents’ Emotional Responses to a Diagnosis and their Perceptions of the Future

It was noticed that some parents’ responses to their child’s diagnosis was linked to their perceptions of the future. When asked about their response to the diagnosis, several parents spoke spontaneously about the future as justification for their emotional reaction. Parents related their negative emotions to the recognition that their child may not have a normal future and the realisation that life will be harder to cope with:

> Everything just worried me from the minute that he got diagnosed I was just ‘oh my god what am I going to do? Do I pull him out; do I put him into an autistic school?’ (I6)

> It is stressful because you don’t understand why your child’s not doing things at the same rate as other children and you know I was a first time parent and had you know NCT group and had a group from my doctor’s surgery of parents and you see these other children doing things and you’re thinking why isn’t he doing that? (I4)

Conversely, some parents with an optimistic view of the future described their responses to the diagnosis in a positive light due to the recognition that the child will receive better support in school. One parent commented on the financial benefits associated with the diagnosis and subsequently spoke optimistically about the future:

> Getting the diagnosis was the, I suppose, a good thing because now all the teachers that he goes to, they explain that this is important to him and if you want to educate him you’ve first got to deal with this part of his behaviour. (I9)

> It’s [the diagnosis] made a difference because I have made it make a difference, I have waved it in front of enough people to say, to say ‘Look you have to deal with this, he is diagnosed, she [paediatrician] is very high up in her field, you have to start’ but if I’d have just stepped back and let

> the school do their own thing nothing would have changed, even with the diagnosis. (I1)

> Because you've officially got this label, although it doesn't change – you can be like 'OK, well I'll start to research it a bit more now I know what it is'. It [Disability living Allowance] makes a trip to Marwell Zoo a bit cheaper! It was only £20 yesterday, that was a result. (I7)

The next theme focuses on participants specific responses to questions about their views of the future.

2.4.4 Perceptions of the Future

Parents' responses largely fell into three main categories; optimism, pessimism and uncertainty. An important factor in identifying parents' stance on their views about the future was the severity of their child's autism. Participants involved in the study discussed children who fell across the range of the autism spectrum, ranging from non-verbal autism, to high functioning mild Asperger syndrome. The nature of their child's autism clearly influenced parent's perceptions of the future.

2.4.5 Optimistic View of the Future

When asked about their views of the future after receiving a diagnosis of ASD for their child, some parents expressed hopeful beliefs about the development of support services for children and families living with ASD. These participants talked about their expectations of an increase in funding to help support families raising children with autism. They also spoke in terms of problematic issues with current support services being resolved in the future, such as the development of a more cohesive support package, recognising the need to match support services with the severity of the child's needs and offering a better level of adult provision:

> I mean, more knowledge has got to be useful, you know, the more you know about it [autism] and the more, the more he knows about it, it's got to be easy-easier for him to be able to understand it and make strategies to sort of combat his problems. (I11)

> I'm hopeful that adult provision will continue to grow…I think that's very important that they do try and match up the disabilities because it [parenting course] practically felt a waste of time, but then we went on the Earlybird course and for that, for us, there was a perfect match of families. (P1)

Hopeful aspirations about the future were also expressed in terms of what parents expected their child to achieve in adulthood. Most were optimistic that their child would achieve happiness and be able to live an independent life without needing long term support. It is worth noting that many parents who were confident that their child would lead an independent adult life were referring to a child diagnosed with Asperger syndrome, at the higher functioning end of the spectrum and often associated with greater cognitive abilities. Moreover, these parents identified academic achievement as being a major contributor to future optimism:

> On a good day I think well he'll probably just carry on and absorb all the information he needs. I mean he already keeps saying 'I'm going to University and be an engineer'. So I keep thinking well he could probably just struggle through and probably just get through on maths and whatever science and end up somewhere on his own merit of being a very bright child. (I2)

> He's quite a bright little boy, um and so what we hope is he will find a niche that fits him and I mean my husband was a scientist so I mean he's now in computers which of course is perfect kind of career for someone with autism. (I4)

It is worth noting that a parent of a child with severe autism spectrum disorder did report being hopeful about the improvement of provision in the future, but they were also dubious about whether this support would materialise:

> I know that there's lots of bills trying to go through parliament, and, as these children their education system is improving, hopefully the adult provisions will improve. (P1)

2.4.6 Pessimistic Perceptions of the Future after Diagnosis

Some parents described a negative view of the future after receiving a diagnosis of ASD for their child. Parents made comparisons to the perceived future of their child and that of a typically developing child. The discrepancies they identified appeared to be at the root of their pessimism:

> Thing that’s hard is knowing that your child is always going to have to work so much harder just to fit in and, and cope with things. (I12)
>
> But the reality of that is that it’s going to be harder for her [child] to be happy in the adult world. (I10)
>
> I think the sadness I feel about [child] not being the child we hoped he would be, we feel nothing but sadness about that…As time goes by you learn how to live with that and I’ve always called it like a mini grief because the person hasn’t died but there is a grieving process for that person that you thought you had and the aspirations you had for that person have to completely change and it’s really, really hard. (P1)

It was recognised by some parents that their child may require long term care and that this could fall on the parents or siblings. Parents who recognised this as a possibility appeared to have resigned themselves to this, but were unhappy about it:

> The doom and gloom one [view of the future] is that they will be with us forever, they won’t ever be independent, but that’s not what we want for them. (I1)
>
> It is not a happy time and taking on board that it’s [parenting a child with autism] for life, and as long as I’m alive and as long as [child’s] brother is alive we’ve all got to look out for [child] and it will never go away and he’s very vulnerable and will probably need care all of his life it’s, it’s a very big impact. (P1)

Additionally, the potential for a loss of independence in adult hood was discussed by parents as a main concern for the future. Parents were worried about their child's vulnerability and the possibility that they may be taken advantage of in the future, particularly financially:

> Part of the grief is what the hell happens to this child, he's completely vulnerable to all sorts of abuse, financial, verbal y'know, I don't need to see it, but he's incredibly vulnerable. (P1)

> I do worry about his future because of all the little – you know, the children aren't that nasty at the moment, but, [this might change] I don't know. (I11)

Parents who held negative views about the future also expressed concern about their child's emotional wellbeing as they grew up. One parent was very concerned for her child's mental health and was worried about the possibility of him committing suicide due to not fitting in or being able to cope with his ASD:

> Already I kind of think he could kill himself one day because the difficulties are too great for him. (I5)

An interesting phenomenon that arose from the parental interviews was the perceptions parents' held of ASD. Some participants made repeated comparisons to typical child development, in terms of their understanding of ASD, their response to diagnosis and their views of the future. Using typical development as a benchmark proved to be distressing for some parents who became aware of their child's deficiencies and the reduced potential for future development. Accordingly their visions of the future shifted after diagnosis from that of a typically developing child to one with a disability, often associated with negative connotations:

> You know he can't ride a bike, all these things that other seven year olds eight year olds can do. (I2)

> No-one said to us it's not normal for a child to try to climb out of a moving car with, you know out of a car seat and try and open the door. I mean, we didn't have car locks on the car at that time. (I2)

Clearly parents' perceptions of ASD and their level of understanding play a significant role in their response to diagnosis and subsequent actions or lack thereof.

2.4.7 Uncertainty about the Future after a Diagnosis of ASD

Some parents talked about the future in uncertain terms. They spoke about a need to remain open minded and recognised that they could not make accurate predictions about their child's future life. In their descriptions of the future, parents who were uncertain often talked using negative terminology implying that their doubts about the future were linked to fears and worries:

> We have absolutely no idea how it's [the future] going to happen, we have to stay completely open minded, if [he] was a normal child we would have hoped for y'know the normal schooling, normal adolescence, girlfriends, learning to drive, whatever, school, further educational choices he took, and launching him into his own world but we know that's highly unlikely and he will probably need to be in care for the whole of his life. (P1)

> She plays on her own, the children are next to her, rather than interacting, but, um, but we'll see as [she get's older],then again she is still very young. (I8)

> I like to think he is going to be an independent adult. But you can't ever tell can you? (I11)

2.4.8 Factors Possibly Facilitating Engagement with Professional Support

Whilst talking to parents about their emotional responses to a diagnosis for their child, and their views of the future, many parents talked about support services and their engagement with professionals. It was clear from talking to some participants that they were more emotionally ready to engage with support services and some were actively seeking support and information.

Pro-activity and parent advocacy.

Parents spoke clearly about their role in the diagnostic process and subsequent information gathering. Parents talked about researching autism on the internet and in books and talking to friends who had children with ASD. These parents were proactive in their approach to seeking professional advice and support and implied that they were the force driving any progress with professionals and schools and were responsible for disseminating information among their friends and family:

> I think you [husband] were looking it [autism] up on the internet and I [wife] was ordering books from the library and, anything and everything we could. (I8)

> It would be nice if once you fell into the category you automatically, everything got fed through to the relevant parties, so maybe they would come to your door and say "Look, we are here to help you, instead of you having to find out which doors you might get some help from and then go banging on them, you know, begging almost. (I5)

One could assume that parents who adopt a pro-active advocacy role are seeking information and support and may therefore be more receptive to engagement with interventions and professional support.

Support from friends, family and schools.

When discussing the level of support they were receiving, parents held varied views. However, it was evident that some felt unsupported by extended family members or friendship networks. Parents often talked about this lack of support as a direct result of friends or family not accepting the diagnosis of ASD possibly due to a lack of understanding about the disorder:

> My mum staunchly refuses to believe it and, just she totally ignores [daughter's] special needs school and she just seems to be adamant that she's not autistic and that's that. (I8)

> Even friends who knew really well they're 'Oh she's fine, she's not, you know and dah dah dah' and I was just - when you look at their children and how simply the day could unfold they just had no idea. (I10)

Some parents spoke warmly of the support they have received from their extended family, friends and colleagues:

> I had the family saying 'Oh no there's nothing wrong' and my dad actually being there [at the diagnosis] actually was better because he realised actually to 'Stop saying this, you know, there is, not something wrong, but now it's official'. (I7)

> My dad comes round every day still, um, now even though (son) technically doesn't need help with speech or, he still does it now, because (son) does enjoy like doing puzzles and he does enjoy the 1:1 (I7)

Good support from professionals.

The view that professionals had useful information to distribute to parents was conveyed during the interviews by some participants:

> I mean they were brilliant, they gave us a massive folder, um, with lots of information. (I10)

> The child psychologist gave us, you know, she was very good, she gave us, a massive great book actually on, you know, various exercises that might help developmental wise, (I7)

It is possible that parents who regard professional information in a positive way will be more inclined to engage further with interventions and support services. Some parents were very positive about the support they had received from professional services:

> They referred us to the Early Bird Course which is phenomenal and fantastic and for me really, really helped. (I4)

> The speech and language [therapist] really gave me some ammunition; it was something that I felt I could talk about. (I10)

2.4.9 Factors Possibly Preventing Engagement with Professional Support

During discussions with parents it was noted that some factors may present barriers to engagement with professional support services. Most noticeable were those parents who had a negative experience of liaising with health or education professionals during the diagnosis or assessment period.

Negative view of professional support.

Some parents reported that the information they received from professionals wasn't cohesive, used unfamiliar language and was hard to sort through. One parent felt that identifying the right piece of information was down to luck. In addition, parents commented that some literature was depressing and painted a very bleak picture of raising a child with ASD:

> I don't know whether I just read up the wrong things, I always get the worse scenarios and then I get really upset and then I just stop reading. (I6)

> You don't get any visits from anybody, there is no health visitors come round, you know, because I know there are special needs health visitors. Nobody comes to help you. (I12)

Passive response to diagnosis and support.

In contrast to those parents who adopted a proactive role after receiving a diagnosis, there were some parents who reacted passively. This manifested itself in a lack of action or a reluctance to engage with support services. Participants referred to a passive coping style which included ignoring information:

> So there will be problems in the future and I – there are times when I would rather just bury my head in the sand and not think about it. (I1)

> I think that's [ignoring paperwork] a bit of ostrich head in the sand thing. (I12)

One parent felt that they had to cope in private:

> I’ve probably for a year and half been coping behind closed doors. (P1)

It is a possibility that passive coping strategies and a reluctance to acknowledge the need for help may be a barrier to engagement in support services or seeking help from professionals.

Immediate period after diagnosis is a difficult time to engage in support.

It was clear that some parents felt that they needed time after the diagnosis to process the information they had been told. Parents talked about the inability to listen to professionals delivering information immediately after the disclosure of the diagnosis. Others spoke of the shock at receiving a diagnosis and the need for time in order to digest the information. One family clearly stated that they were not ready to engage with professional support offered in the home during the period after diagnosis as it felt too intrusive. Additionally, one parent identified that a period of 6 months was needed to let the diagnosis sink in before they felt ready to move on and consider their options.

> Then the Earlybird course was perhaps 8 months after [the diagnosis] which was ok, um that gave us time to take stock I think about 6 months to give you a chance to settle down a little bit. (P1)

> Well we’d really love to do that course but – because it was so new we wanted to do it without the filming and they said ‘Yes that’s fine, no problem’ and then a week before it was about to start they phoned us up and said ‘No you can’t do it’. So we were gutted about that. Because you know, we, we said to them ‘We don’t mind you filming any other location’, but it just felt too intrusive at the time [to film at home]. (I8)

2.5 Discussion

2.5.1 Summary of Findings

This study revealed that parents' experience a range of responses to their child's diagnosis of ASD which can be broadly categorised as positive and negative. A contributing factor to parents' responses is their prior expectations about their child's difficulties, with many parents suspecting that their child had autism due to their own research or discussion with friends who had a child with autism. Other parents had suspicions but were waiting for a diagnosis from a professional to remove uncertainties. Few parents were surprised at the point of diagnosis. These findings support Howlin and Asgharian's (1999) research which identified that parents often wait longer for their child to be diagnosed with ASD and therefore often have early suspicions about the nature of their child's disorder. However, in nearly all of the cases in this study parents described their initial feelings as largely negative, using words like 'shock', 'sadness' and 'overwhelming'. This is similar to previous findings (Blacher, 1984; Whitaker, 2002).

Parents who spoke about their child's diagnosis in positive terms revealed their relief at having their suspicions confirmed. Children with ASD tend to be diagnosed at a later age than children with other disabilities (Howlin & Moore, 1997) which means parents have a longer time lapse between first noticing something is wrong and receiving an official diagnosis. The parents who had been expecting the diagnosis talked about the positive aspects of having a 'label' as it motivated them and others to action in order to better support their child. The relief felt by parents may reflect their belief that the label of autism helps to shift some responsibility for the care of their child onto educators and health professionals. This has implications, particularly for teachers, who may benefit from specific training in order to effectively manage and engage the individual needs of the child and avoid potential discrepancies between parents' expectations and the actual support they can offer.

While the findings indicate that not all parents respond negatively to their child's diagnosis it does highlight the need to avoid professional complacency and to provide parents with emotional support after a diagnosis is revealed. This study identified that some parents were not able to access some forms of social support, such as assistance and understanding from their extended family. Research indicates that parents of children with autism can adapt more successfully if they receive adequate levels of social support and appropriate levels of involvement in the child's life (Waltz, 1999). Therefore it is crucial to ensure that support services are accessible to all parents during and after the diagnostic process as parental resilience is associated with healthy adaptation (Chehrazi, 2002), where parents are more likely to manage the stressors associated with raising a child with autism.

The diagnosis also offered parents the reassurance that their child's behaviours and difficulties were not the result of inadequate parenting. This is supported by studies of causality which have mainly concluded that autism is a developmental disability and neuropsychiatric disorder (Szatmari, 2003) and not the result of 'cold mothers' or poor parenting as previously believed (Kanner, 1943). This finding is important not just for the parents themselves but also for the extended social group, as family and friends may offer a better level of support if they understand the epidemiology of ASD preventing them from making judgements based on misguided understanding.

Some parents' responded passively to the diagnosis; showing reluctance to engage in any positive action and ignoring information as it was perceived as a source of stress. A passive response to a diagnosis is equivalent to the active-avoidance coping style described by Hastings et al., (2005), which increases the risk of mental health problems and increases stress levels. Parents adopting a passive coping style are therefore more likely to be at risk of negative outcomes. An evaluation conducted shortly after diagnosis may highlight the parents who are at risk of coping in this way. Subsequently, targeted support could facilitate parents' engagement with support groups and social networks in order to promote emotional wellbeing.

Despite only a small number of fathers taking part in this research, there appeared to be clear differences in the way that fathers and mothers responded to the diagnosis. This was revealed not only from the fathers involved but also the mothers interviewed individually, who spoke of the differences in responses between themselves and their partners. In general, fathers had more difficulties with the resolution of a diagnosis than mothers. This could be because fathers have less contact than their wives with the professionals working with their child and subsequently have fewer opportunities to develop productive relationships (Philip & Duckworth, 1982). They also tend to receive second hand information from their wives which is open to misunderstanding (Hornby, 1992). Steps should be taken to ensure that fathers are equally engaged during and after the diagnostic process to increase the chances of healthy adaptation.

A consequence of gender differences appeared to be increased pressures on spousal relationships, as parents not only respond differently to diagnosis but also employ different coping strategies (Hastings et al., 2005). It is not entirely clear if they blamed the diagnosis of their child for these problems or whether this is a phenomenon encountered in all parents of children with a disability and not just those with autism, however, parents of children with autism are dealing with considerable stresses and strains above and beyond that of other couples (Hastings, 2008). Offering advice and support to parents of children with ASD to specifically target their own wellbeing and internalisations may aid resolution and reduce the possibility of negative marital outcomes. In some circumstances, focussed psychological treatment may be beneficial when potentially serious problems have emerged. There are also implications for gender specific support, perhaps in the form of fathers' groups.

A key finding from this research is that some parents felt that they needed time to come to terms with the diagnosis before engaging in any specific support or intervention. Solish and Perry (2008) identified that stress may be a barrier to engagement with professional services and the present study identifies additional factors. After receiving a diagnosis parents may feel particularly vulnerable and be reluctant to open themselves up to support services or professional involvement, particularly if this is home based involvement. It is possible that parents felt that they needed time after the diagnosis to reconcile themselves, but may be unaware of the importance of intervening as early as possible in order to achieve the best outcomes for their child. Additionally a negative view of professionals could impact upon any future engagement.

The benefits of engaging in interventions or other types of support may be hindered by a number of factors associated with the parent-professional relationship. There exists a wide array of literature that suggests such relationships are problematic due to inconsistencies during contact (McLachlan, Dennis, Lang, Charnock & Osman, 1987), unevenness of power (Knox, Parmenter, Atkinson & Yazbeck, 2000,) or conflict (Williams & Robinson, 2001). Parents experiencing these feelings may be less receptive to any professional involvement, regardless of the impact this may have on their child.

Previous research has also shown that most families raising a child with ASD have a support network made up of friends, extended families and work colleagues and that this network offers both functional and emotional support (Hastings, 1997; Huws, Jones & Ingledew, 2001). It is possible that these families are less likely to access support from professional services or engage with interventions as their needs are being met elsewhere. This is supported by Guruge and Humphreys (2009) who identified that in the absence of informal sources of support, such as friends and family, women tend to access professional support services. Over time, formal support services may be relied upon and can take the place of support previously performed by informal support networks (Grant, 1993; Todd & Shearn, 1996b).

It is also possible that parents may be more likely to engage in professional support when their understanding of ASD is more comprehensive and the value of the diagnosis is appreciated. Cho and Gannotti (2005) concluded that service providers who are aiming to engage parents need to offer support, sensitivity and respect for parents' emotions and requests. Another factor that may facilitate engagement in interventions is positive approaches to coping. There is gathering evidence that parents who employ positive reframing as a coping strategy, when they have children with disabilities such as autism, are less likely to suffer with depression (Hastings & Taunt, 2002). Subsequently, one could infer that parents with a healthier mental attitude will be more effective at caring for their child who has autism and may be more likely to undertake interventions and engage positively with professional support services.

Despite a developing literature base on some aspects of parenting a child with ASD, no published studies to date have examined parent’s perceptions of the future after receiving a diagnosis of ASD for their child. The data presented here provides an insight into parental views of the future which could have important implications for service providers and support agencies. Understanding how a parent perceives the future after receiving a diagnosis of ASD for their child could inform service providers about how best to improve their provision both in terms of capacity building and in terms of effective emotional and practical support.

Parents’ responses to their child’s diagnosis of ASD appeared to be closely linked to their perceptions of the future, in terms of expectations for their child, themselves and their family as a whole. It is possible that parental expectations may be unrealistic and service providers could ascertain if parents have a relatively accurate and realistic view of how a diagnosis of ASD may change their lives in order to create effective provision. In addition, at the point of disclosure, it may be appropriate for professionals to discuss future implications with parents to ensure that initial perceptions are not potentially damaging to parent wellbeing.

Parents' views about the future varied considerably, including optimistic, pessimistic and uncertain perceptions. Those parents who described the future optimistically often verbalised that nothing had really changed as a result of the diagnosis. They also referred to the expectation of an increase in knowledge about autism and the development of better services and more effective interventions in the future. It is not entirely clear how parents reached these conclusions but it is possible that the rise in prevalence of autism amongst children and the raised profile in the public eye may have reassured parents that it is a problem that cannot be ignored.

It is apparent that parents with a pessimistic view of the future often compared the future of their child with ASD to that of typically developing children. The discrepancy between what they perceived their child was capable of achieving and that of the average population was a source of great worry. It is not clear what the impact of typically developing siblings in the home may have played in the development of this concept. Parents who expressed uncertainty about their child's future perhaps reflects the controversies and uncertainties surrounding ASD in terms of possible treatments and 'cures' (Dale et al. 2006).

A key factor in parents' perceptions of the future was the severity of the child's ASD. Parents of children with considerable maladaptive behaviour, speech impairment or severe learning difficulties usually had a bleaker view of the future in terms of what their child may be able to achieve. Their fears were largely associated with the perceived levels of independence their child may achieve and subsequently the level of care they may have to provide in the long term. This could be a result of the increased stress experienced by parents of children with extreme maladaptive behaviour (Tobing & Glenwick, 2002). Perhaps the most significant implication of this research is to match support to each family's individual needs, which may be dictated to a large extent by the severity of the child's autism. This also has implications for the delivery of care to adults with ASD and the provision of respite to families caring for an adult who has autism, in the long term.

2.5.2 Limitations

A number of study limitations should be considered. This study was carried out with a small sample of parents of children with ASD. Therefore it is not possible to tell how typical their experiences are in comparison to the wider population. However, the nature of the experiences described by parents in this study does bear resemblance to those described by other researchers (e.g. Blacher, 1984; Sicile-Kira, 2003). A related limitation is that the majority of respondents in this research were mothers; therefore these findings may not be generalisable to fathers.

Some of the parents in this study volunteered to participate which may have created some bias, however, others were recruited through other means which may counteract the effects of bias. Another shortcoming of this study is that some variability within the sample may have confounded the results by contributing to parents' responses to a diagnosis and their subsequent perceptions about the future independently of the actual diagnosis of ASD. For example, the severity of the child's ASD may play a significant role in parents' responses which was not accounted for in this study.

Lincoln and Guba (1985) identified researcher bias as a threat to the validity of qualitative research. It is possible that the assumptions and preconceptions held by the researcher may in some way affect their behaviour in the research setting. These biases and viewpoints may impact upon the design of the interview, the selection of data for reporting or analytic interpretation. Whilst attempts were made by the researcher to reduce this threat, through debriefing and supervisory support, it is possible that the researcher may have introduced bias.

Finally, the retrospective design may have affected the reliability of parents' recall, particularly of their emotional responses to diagnosis. This may have been avoided to some extent as parents were only recruited if their child had been diagnosed within the last two years. However, the qualitative methodology employed in this research focussed on parents' interpretations of their experiences which must be considered to be valid, regardless of possible errors in recollection.

2.5.3 Future Directions

Despite these limitations there are important implications related to these findings. Adopting a qualitative methodology reveals individuals' views, experiences and perceptions but it cannot determine the prevalence of these views and their relative influence on behaviour. Future research should incorporate quantitative methods to explore the key themes identified here in more detail. It would be useful to determine the prevalence of particular emotional responses and views about the future that have been expressed by the participants in the study and to test directly how they are related to the uptake of interventions. Now that parents' responses have been described in some detail, future researchers could develop a survey instrument to enable the systematic collection of parents' response to diagnosis and their perceptions of the future along with various demographic, child, parent and other family related variables. In particular a survey could explore differences in views held by fathers and mothers; specific factors affecting positive and negative responses to a diagnosis, such as time lapse or severity of the child's needs; and the relation between positive and negative views of the future and the uptake of interventions. This may be of significant practical value in helping service providers to develop appropriate packages of support.

Whilst the focus to date has been on addressing the needs of parents at the point of diagnosis perhaps more needs to done in the immediate period after diagnosis to help parents come to terms with their child's ASD. This is particularly important considering the negative impact that unsuccessful resolution can have on parents' wellbeing and subsequent management of their child (Benoit, Zeanah, Boucher, & Minde, 1992; Greenberg, Speltz, & DeKlyen, 1993; Marvin & Pianta, 1996). During the immediate period after diagnosis parents may benefit from psycho-social interventions which have been found to be useful for parents of children with autism (Bitsika & Sharpley, 2000). One such therapy is Acceptance Commitment Therapy (ACT; Hayes, Stroshal & Wilson, 1999) which is an approach that was developed to treat the significant and long lasting levels of distress that may have debilitating effects on functioning in multiple life domains (cited in Grindle, Kovshoff, Hastings & Remington, 2008). Research has shown that ACT can be a successful intervention for parents of children with autism as it reduces parental depression and distress and helps parents to adjust more successfully to raising their child (Blackledge & Hayes, 2006). Future research could explore whether an ACT-based intervention for parents may help produce a 'readiness' to engage with interventions for their child.

Earlier diagnosis would reduce the amount of time parents are worrying needlessly about their own parenting skills and instead could offer useful behaviour management strategies to empower them. The recent development of an integrated early detection programme (Oosterling et al., 2010) may help to reduce this delay and improve diagnostic services for parents of children with autism and needs to be researched further. In addition, information about the causes of autism needs to be more widely distributed so that parents don’t blame themselves for a disorder that is not the result of poor parenting.

The findings from this study reveal a difference between mothers and fathers in terms of their response to diagnosis. Future research may seek to explore this further in order to develop appropriate support packages for both parents which may need to be distinctive in order to be effective. Much of the research to date has focussed on mothers in terms of their responses to disclosure, coping strategies and attributions. Even those studies designed to include both sexes have reported that the majority of respondents were mothers. Consequently, little is know about fathers’ perspectives and experiences of having a child diagnosed with ASD. Furthermore, the high levels of pressure placed particularly upon parents of autism can impact on relationships between couples. Research could look further at this to identify any mediating factors which may influence the successful adaptation of a couple raising a child with ASD, rather than the focus being on individual parents.

2.5.4 Conclusion

The diversity of views expressed by parents reflects the complex emotional process they undergo after receiving a diagnosis of autism for their child. Listening to parents’ accounts and acknowledging their responses to diagnosis may better enable professionals to support parents during this difficult time. It may also help to facilitate complementary relationships between parents and professionals which may increase the chance of positive outcomes for children with autism and their families.

Appendix A: Interview Schedule

Semi-structured interview schedule

Introduction

Hello, my name is Amber Evans and I am a Trainee Educational Psychologist studying at Southampton University. Thank you very much for agreeing to be interviewed today. You were contacted for this study because you have a child who has been diagnosed with Autism Spectrum Disorder (ASD) in the last 2 years. The purpose of this interview is to find out about your personal experiences and responses to your child's diagnosis of ASD. Your comments will remain anonymous in any written report and any personal information will remain confidential. There are no right or wrong answers so please do not worry but try your best to answer the questions. I am only interested in your opinions and personal experiences. Please feel free to clarify any of the questions you are asked. With your permission I would like to tape record this interview in order to carefully transcribe it later on. Tape recordings will be destroyed after the information has been transcribed and all data will be held in accordance with the Data Protection Act.

Probes will be used to get interviewees to expand on a response. These are not standardized as they will be used to pursue what the respondent says.

1. Tell me about your child's diagnosis of ASD? [Related to research question 1.]

Probes

Can you describe your initial reactions to the diagnosis?
What effect has time had on your feelings about the diagnosis?
Can you describe how others told you about your child's diagnosis?
Have there been any practical issues to deal with?
What do you think the diagnosis means?
Do you have any reasons about why your child has ASD?
What understanding do you have about ASD?
Have there been any differences in your daily routine since the diagnosis?
Tell me about the relationships between your child and other family members since the diagnosis?
What have your experiences of adjustment to the diagnosis been?
Can you describe if you think the diagnosis has changed your views on what's important for you and your family?
Can you explain if there have been any financial implications after the diagnosis?

Have your experiences of looking after your child changed since their diagnosis?
Tell me about the impact this has had on you and your life?
What strategies do you use to manage your life since your child's diagnosis?

2. What do you imagine the future will be like for your child and your family now that you have received a diagnosis? [Related to research question 2.]

What do you think life will be like in the future for your child?
What you think your child's education will be like?
Tell me about the expectations you have of your child?
What do you think your child will achieve in the future?
Tell me how you think your child might achieve this?
What do you think life will be like in the future for your family?
What do you think life will be like in the future for you?
How do you think your child's ASD may impact them as they grow older?
How do you view your role in helping your child in the future?
What do you think will happen in the immediate future for your child and your family? In 5 years? 10 years?
What do you think will change for your child as they grow into adulthood?
What do you think will change for you and the rest of your family as your child grow into adulthood?
Imagine your child in 5 years. What do you hope they will be like?
Do you think this is achievable? If so, how?
What is the most that you hope for, for your child?

3. Tell me about the support you have experienced since your child's diagnosis and your expectations about future support? [Related to research questions 2 and 3.]

Probes
What experiences have you had of professional support?
What experiences have you had of receiving support from friends and family?
Tell me about any advice you have been given?
What are your views on any advice you have been given?
What do you think may help you to get the right support?
What do you think may stop you from getting the right support?

Do you think anything is going to be able to help you and your child?
Do you have any thoughts about how you can support your child?
Tell me about the level of commitment you think may be needed to support your child?
Are you aware of any strategies/interventions/support that may benefit you and your child? If so what and how did you hear of them?
Describe the type of support package you would like to receive?
Do you think there might be difficulties getting support for your child?
What could cause these difficulties?

4. Is there anything else you could tell me about your experiences since your child's diagnosis of ASD?

Thank you very much for giving up your time today.

More general probes

- *Can you tell me more about that?*
- *What was the experience like for you?*
- *Anything more?*
- *What is your own personal view on this?*

Or

- *A period of silence*
- *An enquiring/encouraging glance*
- *'mmhmm…'*
- *Repeating back all or part of what has just been said*

Appendix B: Ethical Approval

Your Ethics Form approval

Psychology.Ethics.Forms@ps2.psy.soton.ac.uk

[Psycholgy.Ethics.Forms@ps2.psy.soton.ac.uk]

Sent: 26 May 2009 09:53

To: Evans A.J.

This email is to confirm that your ethics form submission for “Parents’ responses to their child’s diagnosis of Autism Spectrum Disorder (ASD).” has been approved by the ethics committee.

Project Title: Parents’ responses to their child’s diagnosis of Autism Spectrum Disorder (ASD)
Study ID: 876
Approved Date : 2009-05-26 09: 53: 50

Appendix C: Consent Form, Information Sheet and Debriefing Form

CONSENT FORM (Version 2/ 15.5.09)

Study title: Parents' responses to their child's diagnosis of Autism Spectrum Disorder (ASD).
Researcher name: Amber Evans
Study reference: 876

Parent's responses to their child's diagnosis of Autism Spectrum Disorder (ASD).

My name is Amber Evans, and I am a Trainee Educational Psychologist studying at the University of Southampton. I am requesting your participation in a study regarding parent's responses to their child's diagnosis of Autism Spectrum Disorder (ASD). This will involve an interview conducted by myself at your home. Interviews will last for approximately 1 hour and will be tape recorded. You will be asked to complete a demographic survey about the details, of your age, gender and ethnicity etc., and will then be asked a series of questions about your experiences of having a child diagnosed with ASD. Personal information will not be released to or viewed by anyone other than researchers involved in this project. Results of this study will not include your name or any other identifying characteristics. Your continued participation in this research will be taken as evidence of your giving informed consent to participate in this study and for your data to be used for the purposes of research, and that you understand that published results of this research project will maintain your confidentially. Your participation is voluntary and you may withdraw your participation or the data you provide at any time.

Completion and return of this consent form will be taken as evidence of you giving informed consent to be included as a participant in this study, for your data to be used for the purposes of research, and that you understand that published results of this research project will maintain your confidentially. **If you agree to take part in this research please return the consent form in the freepost envelope provided**.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ.
Phone: (023) 8059 5578.

To request a project summary or if you have any further questions, please contact me, Amber Evans at aje2v07@soton.ac.uk.

UNIVERSITY OF Southampton

Consent form

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information outlined on the Participant Information sheet and have had the opportunity to ask questions about the study.	☐
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	☐
I agree to my interview being tape recorded.	☐
I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected.	☐

Name of participant (print name)………………………………………………….

Signature of participant……………………………………………………………..

Date………………………………………………………………………………….

Please return this consent form in the freepost envelope provided.

Researcher's name and contact details:
Amber Evans
School of Psychology
Educational Psychology
34 Bassett Crescent East
Southampton
SO16 7PB
E-mail: aje2v07@soton.ac.uk
Telephone: 02380 59 5320/2609

Participant Information Sheet

Study Title: Parents' responses to their child's diagnosis of Autism Spectrum Disorder (ASD).
Researcher: Amber Evans
Supervisor: Prof. Bob Remington,
E-mail: R.E.Remington@soton.ac.uk,
Telephone 02380 592626
Ethics number: 876

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

My name is Amber Evans and I am a Trainee Educational Psychologist studying at the University of Southampton. In order to gain my Doctorate in Educational Psychology I am required to undertake a piece of research in my final year of study. I am conducting some research into the area of parent's responses to their child's diagnosis of Autism Spectrum Disorder (ASD) as this is an area of personal interest and will be useful in my future profession when working with families who are coping with ASD. My research questions are about parents' emotional responses to their child's diagnosis of ASD, parents' beliefs about the future expectations for their child and their views on support programmes for families of children with ASD.

Why have I been chosen?

Participants have been identified for this study through Autism societies in the south of England. The criterion for participation was that parents had a child who had been diagnosed with ASD within the last 2 years.

What will happen to me if I take part?

If you agree to take part in this research, the researcher will contact you via telephone or e-mail to arrange a suitable time and date to conduct an interview. The researcher will travel to your house to conduct the interview. You will be asked to complete a demographic survey which provides information about your age, gender, ethnicity etc, and then you will be interviewed by the researcher for approximately 1 hour. The interview will be tape recorded.

Are there any benefits in my taking part?
The information gathered through this research is hoped to be useful in gaining a better understanding of parents' responses to their child's diagnosis of ASD. It is hoped that this may inform the delivery of effective support packages for parents and children living with ASD.

Are there any risks involved?
There is deemed to be no risk to participants. However, as questions are about personal experiences participants may experience a negative emotional response to some questions.

Will my participation be confidential?
All data will be dealt with in accordance with the Data Protection Act and the University of Southampton policy. Information will remain anonymous and will only be used for the purpose of this research project. Once data has been transcribed from the tape recorder, the tapes will be erased. The data from the transcripts of interviews will be data coded and stored on password protected computers. Participants can withdraw their data from the study at any time.

What happens if I change my mind?
Your participation is voluntary and you may withdraw consent at any time without having to provide a reason.

What happens if something goes wrong?
If you have any questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Telephone: (023) 8059 5578.

Where can I get more information?
The research supervisor, Bob Remington, who can be contacted at R.E.Remington@soton.ac.uk or telephone: (023) 80592626

Parents' responses to their child's diagnosis of Autism Spectrum Disorder (ASD).

Debrief

The aim of this research was to find out about parents' responses to their child's diagnosis of ASD. It is hoped that the information gathered from this research will help to inform how to effectively support both parents and their children after a diagnosis of ASD. Your participation will hopefully help to develop a better understanding of how parents' feel after their child has been diagnosed with ASD. The information you have provided will also show parent's beliefs about the future for their child and their views about current support programmes. This information is a vital component in developing effective support for families and children living with ASD. The results of this study will not include your name or any other identifying characteristics. The research did not use deception at any time. If you would like a summary of the research findings once the project is completed then please contact me using the details below.

If you have any further questions please contact me, Amber Evans at aje2v07@soton.ac.uk

Thank you for your participation in this research.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ.
Phone: (023) 8059 5578.

Appendix D: Demographic Information Form

UNIVERSITY OF Southampton

Researcher's name and contact details:
Amber Evans
School of Psychology
Educational Psychology
34 Bassett Crescent East
Southampton
SO16 7PB
E-mail: aje2v07@soton.ac.uk
Telephone: 02380 59 5320/2609

Demographic Information Survey

Please complete the form below by circling the correct response or writing additional information. Once completed, all data will be coded to ensure your anonymity.

1.	**Gender.**				
Male			Female		
2.	**Age.**				
18-30	31-40	41-50	51-60	60+	
3.	**Ethnicity.**				
White	British	Irish	Other white background		
Mixed	White/Black Caribbean	White/Black African	White and Asian	Other mixed background	
Asian/Asian British	Indian	Pakistani	Other Asian background		
Black/Black British	Caribbean	African	Other Black background		
Chinese					
Other					
4.	**Number of children.**				
1	2	3	4	5	5+
Please specify their ages:					

5.	**Number of children with disabilities or additional needs.**				
1	2	3	4	5	5+
Please specify their disability or additional need:					
6.	**Number of adults (over 18yrs) in household with a disability or additional need.**				
1	2	3	4	5	5+
Please specify their disability or additional need:					
7.	**Marital status.**				
Single	Divorced	Widowed	Separated		
8.	**Are you a lone parent household?**				
Yes	No				
9.	**Is there currently a member of your household in paid employment?**				
Yes	No				
10.	**Please state the highest level of education you have completed.**				
Please state here:					
11.	**Approximate total household income per annum.**				
Lower than 15K	16-25K	26-35K	36-45K	45K+	
12.	**What is your postcode?**				
Please write your postcode here:					

Thank you for completing this survey.

Appendix E: Interview Technique Evaluation

Interview technique evaluation:P1

Q Do you think that the questions were appropriate, do you think that they got useful information?

A I thought the questions were very good they seemed to sort of cover everything, um Yeah I did, yeah,

Q We had one issue about rephrasing which I'll take on board,

A Yeah, I got a bit confused by that question, um, I almost want to say I don't know if I was a little bit hurt by it but that's perhaps because I'm because it's a sad, y'know I see it as quite a sad time,

Q I felt after asking it that it was insensitive, I felt that it hadn't been phrased correctly, which is why I apologised…I'm sorry if I upset you and I will now take that on board and be able to change things before interviewing somebody else. But it was very useful to hear that it was phrased incorrectly and wasn't appropriate really. Were the questions too general or too specific?

A No I like the way you sort of asked it and then helped a little bit by perhaps guiding a little bit in the right way you weren't guiding it in the wrong way, I thought that was right, cos I think sometimes when you're in a one to one and you hear the question, you need time to process it anyway and you need time to work out, yeah and I did find it helpful you followed you quite nicely I thought.

Q Did you feel there are any questions I should have asked that I didn't?

A Yeah, nothing has jumped out at me, and I suppose I didn't really pre think it I've just done this, as I say if I do think of anything I will, I'll let you know.

Q Do you think there were too many questions or too few?

A No, I'm kinda thinking Oh gosh did we touch on this or did we touch on that but I'm a bit too full to kinda think exactly what I'm thinking, um, cos I suppose getting the understanding of where you're taking this anyway as university research your trying to help families after the diagnosis to get them on the right track so I think I did come up with some our own personal experiences that were quite valid to that.

Q Did you feel that I responded to your answers sensitively?

A yes, I thought you were brilliant, absolutely , absolutely no problems at all,

Q: Super, could I have prompted you differently, made things a bit more articulate,

A No, I think you could see probably where I was struggling or perhaps needed more time, and I think you were, you were fine, and when I got upset you were very sweet about that because it's inevitable, um no I think you were absolutely perfect.

Q Good!. And did you feel that I was listening and was interested in what you had to say.

A Yes.

Q And I made appropriate eye contact and body language?

A Yes, much better than I did (laughs)

Q Was the purpose of the interview explained to you did you feel like you knew what we were going to talk about or did anything come as a surprise?

A Yes , I think I wonder if I might like to have known, because you aid at the beginning that you said you were training to be an Educational Psychologist and I would have perhaps liked to know a bit more about, are you going to be in all sorts of disabilities so it's not just specialising in autism, um so this interview has been about autism so are you perhaps talking to other parents with different disabilities as well or are you focussing, no you said you were focusing

Q So you would have liked a bit more clarification around my intentions,

A That little bit was brilliant but t was perhaps quite quick, but you said it so you weren't wrong, you did say it, what am I thinking (pause), no I've got that wrong you did say ASD. Maybe a little but more chat about that about maybe has your child seen an educational psychologist, that's what I'm training for, so maybe a bit of interaction on that level maybe to understand you a little bit more.

Q (explains EP role).

A Whether just a little bit more (about your EP work and teaching and experiences with ASD children) at the beginning or discreetly offering the chance to chat a little bit about it first. I do remember at the beginning when I was starting to talk about T using PECS and I was thinking Gosh do you even, cos a lot of people haven't even heard of PECS. I do remember you did send paperwork through and there was a little bit of chat there, that was good, anything else that expands on you and your purpose.

Q Ok, so perhaps starting the interview by just giving the opportunity to ask a little bit about why I'm here and why I'm doing this.

A yeah, before launching into the questions.

Q Yes that can certainly be incorporated and I think that will be quite useful as well Do you think the interview was well organised.

A Yes,

Q you wouldn't have rather had it somewhere else, you felt happy having it in your living room.

A Yes,

Q And was the length ok?

A Yeah, It's funny 'cos I could talk about the autism and the effects for along time there's a lot of issues, um, y'know so I didn't feel it was short but I certainly feel gosh I bet there's so much we haven't even touched on.

Q We've scratched the surface.

Appendix F: Coding Manual

	CODE NAME	DESCRIPTION	EXAMPLES FROM TEXT	THEME
P1:A35	Diagnosis in a clinical setting	Dissatisfaction with disclosure of diagnosis by professional.	"but she suddenly said to us kind of mid flow, she sort of, I don't think she said it very well," "she didn't even give us some time to stop and think" "I think especially again going back to the ones with younger children as well, trying to cope with babies and younger children, it's hard, " "I cried every day, every day maybe 3 times a day as it hit me and as I say that's the grief part and I sobbed every day, I sobbed every day for a year" "in the beginning that word raw is such a good word"	Negative experience associated with disclosure of diagnosis.
P1:A37	Diagnosis delivered by a stranger			
P1:A44	Abrupt diagnosis by professional			
P1:A45	Dissatisfied with disclosure of diagnosis			
P1:A48	Dissatisfaction with disclosure -Lack of eye contact			
P1:A50	Dissatisfaction with diagnosis – no time to stop and think			
P1:A75	Aspergers children have a later diagnosis – easier to take in	Timing of the diagnosis has an impact on how parents cope. Earlier diagnosis is more difficult to cope with.		
I11:A21	Lucky to get a diagnosis before senior school			
I8:A31	Diagnosed too young to be clear about level of severity			
P1:A210	Harder to cope when child is diagnosed at a younger age			
P1:A36	Misguided expectations during diagnosis	Unprepared for disclosure of diagnosis relating to lack of knowledge and understanding about what the diagnosis may mean and when it will be delivered during the assessment process.		
P1:A39	Unprepared for diagnosis			
I2:A10	Parents had no idea that child may have ASD			
I8:A9	Autism was masked by the hearing problem			
P1:A54	Lack of knowledge about the diagnosis.			
P1:A102	Grief reaction to diagnosis – over a period of time.	Negative emotions in response to the diagnosis.		
P1: A28	Negative emotions grow after diagnosis			
P1:A240	Feeling raw after the diagnosis			
I9:A27	Worries that a label is an excuse for the way the child is.			
I9:A29	Contradictory – label shouldn't make any difference but it may help him.			
I8:A3	Diagnosis was a shock			
I10:A23	The diagnosis could determine how you live your life.			
I10:A17	Feelings of disloyalty and upset after relief			
I10:A20	Feelings of disloyalty towards child explaining how they have problems			
I10:A21	Feelings of disloyalty during the diagnosis – noticing all the child's negative traits.			
I9:A30	Worries that the child will use the label to excuse his behaviour			
I10:A2	Don't want to categorise children or compare against benchmarks			
I1:A1	No one takes a blind bit of notice of a borderline diagnosis			
I8:A15	Feelings of sadness			
I1:A27	Guilt about how parent dealt with child before the diagnosis			

I1:A6	Typical male response to diagnosis – would rather have naughty child than autistic child			
I11:A15	Danger with diagnosis but unsure what they may be			
I9:A31	Child identifying with the label – may change how he sees himself.			
I11:A14	Child got more emotional about the diagnosis than parent expected.			
I2:A25	Diagnosis made no difference at school			
P1:A56	Floored by diagnosis			
I6:A3	Label is horrible			
I6:A5	Discharged from other services after ASD diagnosis			
I6:A6	Gutted about diagnosis – even though child hasn't changed			
I6:A30	Got drunk after diagnosis			
I6:A34	Negative response to diagnosis because child is not normal and may not have a normal future			
I6:A18	Gutted about having to share diagnosis with child			
I7:A13	Started to notice autistic traits after the label had been given			
I7:A10	Confused thoughts about what the diagnosis might mean			
I7:A18	Grandfather devastated – wanted to do all he could			
I12:A14	Diagnosis was a total shock			
I12:A16	Expected to identify support strategies not a diagnosis			
I12:A18	Realisation that this is a forever thing			
I12:A17	Professional explained that it wasn't poor parenting			
I12:A19	Feeling numb			
I12:A22	Then shock for a really long time and profound sadness			
I12:A24	Husband really angry – why was his son different to everyone else			
I12:A27	A lot of husbands don't accept the diagnosis			
I3:A5	Child had a sad reaction to the diagnosis			
I3:A12	Like a sledgehammer – have it for the rest of his life			
I5:A6	After diagnosis you have a fight ahead of you			
I3:A4	Once diagnosed there's no going back			
I3:A35	Husband absent from diagnosis – hard because they are not involved			
I1:A2	Disclosure of diagnosis from professional to the child	Satisfaction with the disclosure of diagnosis.	"we went to the to the meeting with the consultant paediatrician, she was lovely" "you just cant do enough and the love that we feel for him is just absolutely	Positive experience associated with disclosure of diagnosis
I1:A4	Professional offers explanation to child – brain wired differently			
I11:A7	Professional had a fantastic way of describing ASD to			

	child		incredible and that got stronger and stronger" "I've heard other people describe it as a signpost, and it points you in the right direction, this is what it is, this is the route we have to pursue and look into"	
I8:A7	Professional didn't say much during disclosure of diagnosis – let it sink in – positive thing			
P1:A43	Positive attributions to the professional delivering diagnosis			
I7:A9	Diagnosis given in a private way			
I7:A20	Professional was very positive during the diagnosis			
I9:A17	Disclosure of diagnosis was very informal – not a surprise.	Parents expect the diagnosis prior to the disclosure.		
I11:A1	Prior reading – not surprised at diagnosis			
I8:A1	Professional suggests a 'possibility of autism prior to the diagnosis			
I6:A26	Treat him as autistic before the diagnosis.			
I6:A33	Not a surprise but like being hit with a baseball bat			
I9:A20	Label did not come as a surprise.			
I7:A1	Father suspected autism because of prior experience			
I3:A7	Prepared for diagnosis but hoping it wasn't ASD			
I5:A2	From the first meeting – parent knew they were headed toward a diagnosis of ASD			
I4:A16	Parents diagnosed before professionals – felt held up by the assessment process			
P1:A116	Diagnosis led to a label – nice to have a label – confirmation of suspicions	Positive emotions and outcomes related to the diagnosis.		
P1: A26	Positive emotion towards child			
P1: A27	Positive emotion towards child increases after diagnosis			
I9:A7	Positive impact of diagnosis – changes perception of child.			
I11:A19	Diagnosis led to people being less critical of parenting			
I10:A16	Relieved that there was name for it			
I8:A16	Feelings of sadness changed suddenly into wanting to be proactive			
I8:A2	Relief when they knew what they were dealing with			
I8:A4	Diagnosis helps explain behaviour			
I10:A22	Change of opinion about how useful it is to have a label			
I10:A18	No different to before the diagnosis but relived to have a name			
I9:A8	Positive impact of diagnosis – changes perception of the child and adults make allowances.			
I9:A28	Label may give him understanding from school			
I10:A34	Diagnostic process has helped parents to sing from the same hymn sheet			

I11:A10	Diagnosis was a massive positive – gave the school something to focus on – explanation for behaviour			
I11:A11	Prior to diagnosis – child’s behaviour put down to naughtiness and bad parenting			
I1:A3	Show people the diagnosis to prove parent isn’t mad.			
I1:A20	Hopeful expectations form diagnosis			
I1:A34	There are positives to aspergers			
I9:A26	Positive outcome of diagnosis – teachers know there’s a reason for behaviour and can accommodate it.			
I1:A5	Diagnosis proved parent wasn’t imagining things			
I2:A23	Diagnosis was a relief – reason for behaviour			
I2:A24	Diagnosis removed guilt from parent			
I9:A38	Biggest difference to child’s education is teacher’s understanding his problem and getting the balance right			
I9:A47	Diagnosis gave parent a label to give to the education authority			
I9:A36	School took the child’s problem on board an helped.			
I9:A4	Recognition that older child may have had the same issues but was not diagnosed and suffered educationally.			
P1:A117	Diagnosis leads to a label – helps point in the right direction			
I6:A4	Label gets you the help you need in school			
I6:A16	Diagnosis – on his paperwork – helps people to make allowances for him			
I6:A35	Diagnosis made it official – your son is not perfect			
I7:A15	Grandfather present at diagnosis – recognised that there was an official explanation			
I7:A25	Diagnosis helped parent to accept it			
I7:A26	Financial benefits from diagnosis			
I12:A1	Great conversations – one of the plus sides of ASD			
I12:A2	Positive attribute – so focussed and interested in things			
I12:A8	Wouldn’t take ASD away form him because it make him who he is.			
I12:A20	Have an image of what an autistic child is like			
I12:A21	The relief was about 2 minutes			
I3:A11	Realisation that everyone’s going to help my son			
I3:A30	Diagnosis – raised parents expectations			
I5:A4	Parent felt vindicated after receiving diagnosis			
I5:A24	Child felt happier after diagnosis had been explained			

	– like a weight had been lifted off him			
I4:A14	Doubt parenting skills prior to diagnosis			
I4:A17	Diagnosis – pulled together all difficulties in to a cohesive understanding of needs			
I3:A8	Euphoric – its not our fault as parents but due to his medical condition			
I4:A30	Floundering if left undiagnosed			
P1 : A2	Suspicions emerging – delay in language	Delay in language or change in child's emotional temperament first raise suspicion that something is not right but parents wait for professional confirmation.	"We had been told his hearing was fine so that was a good indicator that autism was a big, big possibility, we kind of knew but no-one had told us" he started crying a lot which we put down to teething	Perceptions of ASD – comparison to normal development
P1: A3	Prior to diagnosis -Emotion – child happy			
P1: A4	Suspicions arise – Emotional change – crying			
P1: A15	Delay in language indicated problem			
P1:A41	Realisation that Autism diagnosis was likely			
P1: A19	Recognition of the possibility of Autism			
I2:A17	Child spent a lot of time playing alone – obvious when you look back			
I2:A21	Main difficulty with socialising			
I9:A1	Poor academic performance and behaviour issues indicated something was wrong			
P1:A42	Suspicions but waiting for professional diagnosis			
P1: A5, A7	Parent's normalise behaviour	Explain child's behaviour in terms of normal development.		
P1: A13	Coping – normalising behaviour			
I2:A1	Initially behaviour was interpreted as misbehaving			
I2:A22	Child behaviours attributed to not being able to cope			
I2:A33	Teacher misunderstanding child's needs			
I2:A49	Not badly behaved but autistic			
I2:A50	Teacher describes behaviour as naughty			
I10:A1	Delays in development put down to personal traits			
I8:A28	Parents don't want to believe it's autism			
I8:A29	Interpret behaviour as a normal little girl			
I10:A3	Compare ASD child's development with second child			
I11:A4	Never met anyone like your son – parents fearful and researched ASD themselves.			
I10:A4	Others put behaviours down to being a slow achiever			
I8:A27	Grandmother refuses to believe it autism – don't understand			
I1:A19	Might scream if child I compared to normal development – people say behaviour is not due to autism			
I9:A2	Accepts differences as normal child behaviour not due to ASD			
I2:A12	Recognition that something's wrong – self diagnose oppositional behaviour			
I2:A6	Could tell that something wasn't right.			

P1:A62	Child looks normal			
P1: A16	Beliefs about origins of Autism			
P1: A20	Medical problem can be solved – implied that Autism cannot be fixed.			
P1: A24	Coping – facing up to the autism. Beliefs about the onset of Autism after birth			
P1:A66	Implied cause of autism from friends – negative judgements about parenting			
P1:A67	Judgment on parenting skills – cause of autism			
P1:A136	Implied autism onset at time of diagnosis			
I9:A12	Origin – biological trait			
P1:A180	Cause of Autism – brain disability			
I2:A16	Mother thinks child's behaviour is due to not being firm			
I2:A18	Attribution of child playing alone to parental illness			
I2:A13	Cause of autism believed to be because mother couldn't run after him.			
I6:A37	Beliefs about origins of autism – lack of oxygen			
I6:A38	Beliefs about origins of autism – damage during pregnancy			
I6:A39	Don't care how he got it – just deal with it.			
I6:A40	Parents blame themselves for child's disability			
P1: A25	Recognition of Autism as a disability.			
I7:A38	Parents guilt and anger about origin of ASD			
I5:A8	Genetic link to autism			
I4:A10	Some info suggested you could cure autism – angry response - throw something at the screen			
I4:A11	Some people read info to try and cure autism			
I4:A32	People equate disability with being stupid			
I5:A22	Adult brother undiagnosed – wouldn't make a difference to his life if he was diagnosed			
I5:A23	Pattern within wider family			
P1:A59	Lack of knowledge after diagnosis	Parent's cognitions about understanding autism.		
P1:A60	Shocked at lack of understanding of Autism			
P1:A192	Language implies severity of autism			
I10:A9	Easier to misdiagnose if child is female.			
I9:A6	Became a problem only when it began to affect the child's life.			
I2:A20	Doesn't fit stereotypical description			
I10:A13	Autism is rain man			
I10:A14	Understanding of autism			
I8:A30	Generation thing – now ASD is more understood whereas in the pats it was hushed up and kept behind			

	closed doors			
I9:A25	Fathers perceptions about normality good to be quirky and a little weird.			
P1: A6, A9	Parent's understanding of Autism			
I6:A36	Cognitions about autism- dyslexia and autism are the same gene			
I7:A2	Difference between parents in terms of understanding child's difficulties			
I7:A37	Need to let go of trying to understand why the ASD happened to their child			
I7:A32	Parents are still trying to understand so how can the child understand			
I7:A16	Grandfather treated it like something that they could beat			
I7:A21	Feel like a fraud as child is so easy to manage			
I12:A10	Never occurred that parent would have a special needs child			
I12:A29	Difficulty distinguishing autistic behaviour from normal behaviour			
I5:A21	Diagnosis of ASD – recent phenomenon – other causes would have been looked for in the past			
I5:A11	No father wants a disabled child – especially first born			
I5:A1	School attributed behaviour difficulties to mother having a fourth child			
I5:A7	Sometimes bright people are socially inept			
I4:A13	Start to believe that child's issues are due to neuroses of parent			
I4;A12	Not looking for a cure, just strategies			
P1: A8, A198	Comparison to normal development	Normal development used as a benchmark for ASD child's development.		
P1: A10, A193	Comparison to normal behaviour			
P1: A14	Expectations that child may catch up with peers			
I9:A5	Comparison to normal development – child is different			
I2:A39	Associated problems – comparison to normal development			
P1: A11	Comparison to normal behaviour – Long time for differences to emerge			
I2:A14	First son therefore cannot compare to normal development			
I2:A15	No experience of what a normal boy would be doing.			
I9:A18	Comparison to friend's child who has autistic traits – helped to identify what was wrong with him.			

P1: A17	Professional confirmation that development is abnormal			
I7:A4	With your first child – don't want to appear over the top			
I12:A5	Thought I was a useless parent compared to other people			
I12:A7	Shocked and miserable at recognising difference in child			
P1:A58	Parents tell others about the diagnosis	Sharing information about autism with friends who don't understand. Parent's explain to others and use comparisons to normal parenting as evidence for their claim.		
P1:A61	Friends bombarded parents with questions about Autism			
P1:A63	Friends try to normalise behaviour			
P1:A64	Parent advocate for child – explain autism to others			
P1:A68	Comparison to normal parenting			
P1: A69	Continue to explain to people			
I11:A6	Difficult for others to understand because traits are so diverse			
I8:A38	Worried that other parents will make judgements about being a bad parent			
PI:A70	Support of friends			
I8:A26	The more people know the better			
I2:A48	Parenting an Autistic child is not understood by other people			
P1:A71	Regulating information given to others			
I1:A35	Wish there was more understanding			
I10:A19	Relief to explain daughters behaviour to friends in terms of ASD not bad parenting			
I2:A57	Family members say parents are being too protective			
I11:A9	Frustrated at other peoples perception of child			
I2:A56	Lack of family support from wider family			
I2:A58	Prepare in advance to avoid situations			
I2:A59	Issues with family – lack of understanding about Autism.			
P1:A72	Surprise at shocking thing's friends say through lack of understanding			
I7:A28	Want people to be aware of it but not make it a big issue			
I3:A16	Don't tell anyone unless you have to – people change when they know			
I3:A17	Not ashamed, but don't want people to be prejudiced			
P1:A40	Multi professional involvement	Wide variety of professional services with the provision to support families. Belief that professionals will give the right support.	we had to completely change everything	Receptive to engage in support
P1:A89	Professional support from educational system			
P1:A182	Support from social services			

P1:A212	Varity of professional services to provide help.			
P1:A213	Health visitors offer support initially bit then back off			
P1:A215	Support for a child with disability from the Citizens advice bureau.			
I2:A37	Information given form the hospital			
I2:A38	Evening workshop signposted by medical professionals			
P1:A227	Professionals have more experience and can identify effective support			
P1:A81	Engage in support – quite quick after diagnosis- 5 months, about right.	Open to engage with support services.		
P1:A202, A203	Openness to support			
P1:A137	Desperate for help.			
P1:A225	Support needs to be delivered slowly			
I10:A33	Openness to someone coming to the home or school and teaching strategies			
P1:A197	Want to support to help child at home			
I6:A31	Openness to support but wouldn’t ask for it unless it was offered			
I6:A32	Portage support at home was great			
P1:A219	Need to beg and hope to get support	Need more proactive help from professionals to offer the right type of support.		
I1:A25	Would like more social support for son.			
I2:A11	Involved with coffee morning down to chance			
P1:A222	Prefer somebody else to initiate the support			
I1:A30	Only find out about support from word of mouth			
I2:A66	Getting a statement of SEN in the future is going to be a really huge task.			
P1:A130	Parents learn PECS – takes a long time to teach it right	Some successful strategies employed at home by parents		
P1:A131	Using PECS at home			
P1:A132	PEC proved effective			
P1:A140	Recognition of progress with PECS			
I1:A11	Family have adapted a lot			
P1:A141	Use of schedule board at home			
I8:A39	Coping- ignore everyone else and focus on the child			
P1:A144	Use of rewards at home – behavioural training			
I2:A27	Parents take photos to support child in school			
I2:A52	Parents tried strategies at home			
I2:A53	Varying success with strategies used at home – depends on child’s mood.			
I11:A13	Explaining aspergers to child – book as a resource			
I9:A9	Strategy for managing behaviour – be clever with it,			

	don’t go for straightforward confrontation			
P1:A142	Use of visual timetable at home			
I7:A12	Take one step at a time to cope			
I7:A23	Use humour as a coping strategy			
I12:A4	Patience as a management strategy			
I12:A6	Took child to outdoor places where he could run about			
I12:A15	Have little routines already that you’re not aware of			
I12:A33	Don’t do anything spur of the moment			
I12:A34	Use photos and emails to prepare son for change			
I3:A14	Need to adapt for the child			
I5:A25	Strategies have a limited life span.			
I5:A26	Showing picture cards to reduce language			
I4:A29	Steer obsessions in to socially acceptable obsessions			
I3:A23	Changes to how parents spoke to child			
I3:A24	Use of timers			
I3:A25	Introduce games with his sibling where there is no competition			
I3:A31	Thinking positively projects onto child			
P1:A125	Diagnosis – had to change everything as a result.	Belief that life will have to be different after the diagnosis		
I7:A33	Thoughts about the future changed as a response to diagnosis			
I4:A4	Better to have home visits	Positive attitude towards receiving support in the home.		
I4:A7	Nice to have support in your own home			
I5:A27	Would welcome support at home – want it generated by professionals – not parent who has to go begging			
P1:A73	NHS parenting course was good	Positive views and experiences of professional support offered.		
P1:A80	Effective support – match between child’s needs and input and similar families.			
P1:A82	Inappropriate support- can still learn from it – no regrets			
P1:A84	Earlybird course is fantastic			
I2:A29	Earlybird course was fantastic			
P1:A93	Support for child – positive view on educational setting			
I8:A12	Already receiving appropriate support for hearing problem which was applicable to ASD			
I2:A63	Care and support phone up to offer help occasionally			
I1:A14	Pleased to have a professional point of contact			
I10:A25	Feel that support is out there			
I10:A6	Relieved that nursery wanted to help			
I9:A40, A41	Intention to join a support group			
I2:A36	Fantastic support from the NAS			

P1:A214	NAS provides information on available support			
I7:A6	Knowing things were going to happen was a comfort			
I7:A8	Break for parent knowing someone else was having the child for 2 hours			
I7:A19	Psychologist provided book on developmental exercises			
I7:A24	Lots of intervention helped			
I12:A32	Early bird has been life changing for us – literally fantastic			
I3:A6	School doctor was fantastic – never felt rushed			
I5:A9	Information pack given by professionals – useful contact numbers			
I5:A18	Talks are amazing			
I5:A19	Support group has become social group			
I4:A6	Support group – a place to stop pretending that everything's fine			
I5:A10	Hear other parents talk – finally accept own child's diagnosis			
P1:A124	Accessing support – child care issues - responsibility to share info with partner	Wider family factors affect logical aspects of accessing support		Other factors affecting openness to engage in support.
P1:A134	Wider context affects support			
I9:A42	Caring for 3 children as a single parent means that going to support groups is not high on the priority list.			
P1:A77	Availability of support- Child care needed to access support			
I3:A15	Parents work commitments interfere with support groups			
I5:A17	Don't have a lot of free time due to other children			
I4:A25	Parent reconsiders going back to work because of care needed for ASD child			
P1:A207	Some parents still aren't accessing the right support	Support services are not cohesive and don't offer a joined up package to support families of children with ASD		
P1:A208	Support services aren't joined up			
I9:A33	Discord between professional opinions.			
I9:A35	Pressure to act between professionals – different levels of understanding.			
I1:A15	Parent often fobbed off by the system			
I2:A26	Recognition that child needs more support – lengthy process involving other professionals			
P1:A211	No pulling together of services			
I5:A29	Element of suspicion about professionals			
I5:A30	Finding the right professional is a minefield			
I4:A3	Loss of support due to cost cutting			
P1:A100	Reliance on friends for child care.	Other factors affecting coping aside from the		

P1:A143, A147	Associated behaviours could make things more difficult	diagnosis itself.		
P1:A103, A104, A106	Wider factors affect coping			
I2:A61	Parent having to support their parent's as well as child			
I2:A62	Health problems mean it isn't good at the moment.			
P1:A239	Coping strategies depend on the individual			
P1:A234	Culture, lifestyle and personality affect coping strategy			
P1:A241	Coping – you learn to live with grief as time goes by	Passive attitude to coping. Doesn't require any pro activity.		Passive response to diagnosis and support.
P1:A237	Cope because you have to – parental role			
P1: A31	Resolution over time – live with it			
I12:A31	Head in the sand – don't read depressing books any more			
P1:A196, A201	Coping inevitable – linked to parental role			
I8:A36	Filming parents at home felt too intrusive at the time.	Reluctance to undertake interventions at home		
P1:A133	Difficulties with using interventions at home – takes two people			
P1:A195	Employ Strategies to cope behind closed doors	Coping in private to avoid judgement of others.		
I2:A73	Parent couldn't leave the house – just hell			
P1:A200	Coping behind closed doors - private			
P1:A94	Proactive information seeking	Proactive information seeking from a variety of sources and organisation of information.		Parent advocacy and pro activity.
P1:A99, A95	Pressure placed on self – taking on responsibility			
P1:A111	Being proactive and organised			
P1:A118	Parent proactvity			
P1:A121	Information seeking – books/internet			
I9:A15	Proactively sought professional advice			
I8:A10	Parents reading anything and everything they could to find out information			
I8:A20	Reading about ASD was helpful – provided reasons for behaviour			
I2:A7	Parents proactively seek diagnosis			
I9:A21	Proactive information seeking on the internet			
P1:A204	Proactive information seeking before engaging in intervention			
I1:A16	No-one else to fight the child's corner	Parents have to be advocates for their child.		
I1:A18	If I hadn't pushed for it he would still be undiagnosed			
I1:A21	Parent has to be an advocate for child even after diagnosis			
I6:A1	Pushed for a re diagnosis after initial diagnosis showed Speech delay			

I6:A2	Pushed for diagnosis			
I6:A19	Parent has to phone continuously to get professional support			
I3:A13	Support - Women initiate it all			
I4:A18	Parent needs to make a network of connections			
I4:A19	Parent in the middle of the web with no lead professional			
I4:A20	Some parents need an advocate			
I4:A21	Some parents are scared of talking to the doctors			
I10:A27	More realistic about the future since the diagnosis	Image of the future is created in comparison to parent's perceptions of a normal child's future. Recognition that future for an ASD child will be different from normal.		Pessimistic perceptions of the future after diagnosis.
P1:A152	Existing expectations for a normal child			
P1:A163	Grief response related to change in future expectations			
P1:A174	Academic achievement is not a reality in the future			
P1:A166	Parents hopes unable to be fulfilled.			
I9:A45	Child will develop late because of it (ASD)			
I10:A8	Comparison to other children developing normally			
I11:A22	Parent trying to programme child into having a normal future			
P1:A153	Highly unlikely that future will be normal			
I7:A35	Feel very protective over child			
P1:A120	Coping affected by parents experiences of child rearing –related to normal development	Parents make comparisons to peers normal development which makes it harder to cope.		
P1:A127	Comparison to normal development			
P1:A128	Learn coping mechanisms for comparison to normal development			
P1:A145	Comparison to peers			
P1:A146	Recognition that child is different to peers			
P1:A154	Resolved to life long future care – not sue what it will look like	Resolved to future life long care for child but do not want this burden placed on sibling or parents.		
P1:A155	Hopeful for life long care in independent housing			
P1:A156	Hopeful that the future will not involve a burden on sibling			
P1:A157	Belief that sibling shouldn't be responsible for care – differs from professional opinion			
P1:A171	Family decisions made based on future expectations for child.			
I10:A30	Would rather child live at home than had a difficult adult life			
P1:A165	Conflict between parents choices of care in the future			
P1:A158	Care of sibling will hinder leading a normal life.			
P1:A164	Fearful of the future due to child's vulnerability	Negative views of the future after receiving a diagnosis of ASD for their child.		
P1:A167	Parents unable to influence future for child.			

P1:A168	Negative emotions about future			
P1:A169	Sadness about child’s inability to be independent			
I1:A17	It’s going to get worse into adulthood			
P1:A184	Scared if son cannot fly the nest			
I1:A42	Worried that autism is a priority for the government at the moment – this will change			
I1:A32	Find a job that will work with the aspergers – do you disclose to future employers- increase chance of discrimination?			
I2:A83	Worried he could go down the wrong path and end up in prison			
P1:A181	Future – need for more support			
I2:A82	Don’t want him to be hurt or bullied			
I1:A29	Expectations might be too high			
I2:A85	Uncertainty about child being independent – lack of self help skills			
P1:A34	Hard to cope with change in future expectations for child			
I2:A67	What’s going to happen at secondary school if his refusal to work carries on.			
P1:A113	Negative change to future expectations			
I10:A28	It will be harder for child to be happy in an adult world			
I10:A31	Worry that it’s going to get worse			
I10:A29	Worry more about the future			
I1:A31	Worried about relationships in the future – sexual side of things			
P1:A115	Fearful of the future – recognition of care – reference to parents and siblings role in supporting child with Autism			
P1:A33	Change in expectations for child’s future			
I2:A19	Harder to deal with ASD issues as child gets older			
P1:A185	Worries about coping if child cannot live independently			
I6:A7	Worry on the whole about the future			
I6:A8	Everything worried me form the minute he was diagnosed			
I6:A9	Should child be put in an autistic school			
I6:A14	Worry about people taking advantage of him in the future			
I6:A15	Build an annex to let son live there to protect him			
I7:A11	Parents are natural worriers about the future			
I12:A9	Will be harder for child to fit in and cope			
I4:A15	Worried that label may become negative as he gets			

	older			
I12:A30	Nobody has an open mind about the future – based on own childhood experiences – diagnosis meant rug was pulled from under feet about future expectations			
I12:A37	More anxious because there is a known element to the future now.			
I12:A36	Things other children take for granted we have to teach to our son			
I3:A9	Childs life is going to be hell sometimes			
I3:A10	Despondency thinking about child's future life			
I3:A28	Worried about secondary school			
I3:A29	Don't want to envisage a negative future			
I3:A32	Terrified that he may be bullied by people not understanding him			
I5:A13	Painfully aware that there will be difficult periods in the future			
I5:A14	Worried he may kill himself in the future			
I4:A23	Stressful and worried about the future – how will child cope as an adult			
I4:A27	Moving house to make journey to school less stressful			
I4:A28	Possibility of moving house is horrendous for child with autism so parents feel stuck.			
P1 : A1	Diagnosis –Long process	The assessment process is lengthy and weighty in terms of importance with lots of professionals involved.	"we then entered a, the big journey of all the assessments" "there was a lot of assessments" "when anybody gets a diagnosis of anything y'know it's a very important moment" "It's a lot for one little family to cope with, they're big issues,"	Negative views of the assessment period.
P1: A18	Assessment process is big			
P1:A38	Lots of assessments during diagnosis process			
P1:A46	Importance of diagnosis			
I9:A16	Lengthy assessment process indicated autism was likely			
I2:A4	Waiting a year for professional involvement			
P1:A249	Big issues for a little family			
I2:A8	Multi professionals involved in the diagnosis			
P1: A21	Long assessment process.			
I5:A3	Parent informed during the assessment process			
I8:A5	Assessment period was a bit like limbo – an odd time	Negative experiences of assessment period		
I8:A6	Assessment period was stressful – not knowing			
I4:A22	Pre-diagnosis - Lurched from one thing to another – lots of issues			
P1:A243	Look after own emotional well being	The negative impact on parent's physical and emotional well being not taken into account or supported.		Negative impact on parents' physical and emotional wellbeing.
P1:A244	Emotional support offered by the carer's association			
P1:A245	Not prepared for impact on health			
P1:A246	Affect on parents physical health -stress			
P1:A247	In trouble if parent's health fails.			

P1:A242	Lack of emotional support for parents			
I2:A86	Really hard time – each day is another battle			
I1:A39	God take me away from this - Respite would be fantastic- for child and parent			
I1:A40	Don’t want to deal with it any more			
P1:A248	Support should offer info on possible health implications			
P1: A30	Hard to cope with sadness	Parents have found it difficult to cope with raising their child with ASD.		
P1:A138	Parent advocate – feelings of inadequacy			
I2:A74	Night time routine is an emotional drain			
I2:A44	The hardest part has been getting the child out of the house to school.			
I2:A47	It’s a battle over every single thing			
I1:A9	Feel like bad parents because we challenge the autistic traits in child			
I2:A51	Things at home are hard			
P1:A109	Coping – keeping your head above the water just about.			
I12:A11	Every day was stressful			
I12:A23	Physically exhausted			
I12:A25	Realised how difficult it was making life			
I3:A3	Pent up frustration – having a hell of a time			
I5:A28	Get worn out – ignore other children			
P1:A159	Physically taken a toll on parents	Parents need to be physically strong in order to provide effective care in the future.		
I2;A71	Avoid going out as a family because parent cannot physically cope			
I2:A45	Parent unable to physically help child – which support agencies can help with this?			
P1:A160	Physical strength needed for life long care is unsustainable by parents			
P1:A223	Support needed to prevent the family breaking	Poor support can ultimately influence the security of the family unit and may lead to the break up of the family.		Negative relational issues arising from diagnosis.
P1:A224	Without the right support family can reach breaking point			
I12:A26	Survived it as individuals – now becoming a couple again			
I3:A34	Diagnosis has affected the relationship with partner – real struggle			
I3:A37	Considering breaking up as a family			
I3:A38	Everyone deals with diagnosis differently – can cause family friction			
I2:A69	Sibling has had to learn to deal with ASD brother	ASD diagnosis has an impact on siblings.		
I1:A41	Trying to find support for siblings			
I6:A13	Hopeful that sibling will have a supportive relationship			

	with ASD child in the future			
I2:A70	Sibling attends young carers group			
I4:A24	Sibling offers a lot of support and care			
I10:A24	Wider family live a long way away	Negative views of support offered from friends and family		Lack of support from friends, family and schools.
I8:A25	Support from family and friends – that's where it goes downhill			
I6:A27	Husband finds it hard – he's an army man			
I6:A28	Stepmother is rubbish at looking after son.			
I3:A21	Grandmother wouldn't recognise autism -generation gap			
I2:A2	School didn't act on concerns for a long time.	Not supported by school in terms of the diagnosis and support strategies		
I2:A3	Suggestions not acted on by the school			
I2:A34	Strategies suggested by professional not implemented by school			
I2:A55	Conflict between parent/school and child's expectations			
I2:A43	School not accepted the diagnosis			
I2:A35	Parents advocate for support on school			
I10:A7	Nursery didn't help in the right way through lack of understanding			
I2:A46	Moved schools to get more support from school			
I1:A7	School shocked at diagnosis			
I1:A8	Teacher doesn't believe there is such a thing as aspergers			
I1:A12	Parent had to nag the school to get support			
I1:A22	Conflict between school and parents			
I1:A23	Schools are major bugbear			
I1:A24	Would like school to take on advocacy role			
I2:A28	School reassuring parent they know strategies to support ASD – parent concerned about hr individual child's needs			
I2:A31	Conflict between parent and school in terms of support needed for the child			
I2:A42	Let down by school.			
I2:A5	Not told anything by school			
I4:A33	Battle to get teachers and assistants in school the training to understand autism			
P1:A231	Government funding to help autistic families	Hopeful beliefs about the future of support for families of children with ASD.		Optimistic view of the future
P1:A232	Belief that issues of support can be resolved			
P1:A161	Coping gets easier over time	Parents are hopeful that life will be easier to manage in the future. Hopeful emotions about future provision for and a better understanding of autism.		
P1:A172	Future – would like child to achieve happiness			
P1:A173	Future – would like child to reach their potential			
I2:A79	Hopeful he could have an adult relationship			

I2:A80	Child might just be able to manage in the future			
P1:A175	Independent life skills for the future			
I11:A20	More knowledge about ASD will make future easier			
I10:A32	Optimistic that there's more support			
I2:A81	Would like to be a guiding sprit to independent child in the future			
I8:A32	Happy with a special needs school in the future			
I8:A33	Open minded about the future			
I8:A34	Hope that child can be happy in the future			
I8:A35	Main hope is for independence			
I2:A68	Statement of SEN would give one to one support			
I11:A17	Good to see adults with Aspergers doing well			
P1:A176	Relief that autism is understood – effective provision			
P1:A148	Good sibling relationship – more than parent's hoped for			
P1:A179	Hopeful about the future			
I9:A49	No doubt that child will learn social skills in time			
I9:A44	No limitations for child			
I2:A84	Future could be positive as he's quite clever			
I9:A46	He can do whatever he wants in the future.			
I9:A50	Comparison to normal children who get the hang of it – expectation that son will get the hang of it in time			
I2:A75	Hopeful that the child will struggle through on his on merit – child has high expectations for himself			
I2:A76	He is bright so future could be hopeful but h needs to be motivated in his educations and that is missing			
I9:A24	Not worried about the diagnosis			
P1:A186	Hopeful for the growth of adult provision			
I6:A11	Parent teaching child life skills to encourage independent living			
I6:A12	Need to break the apron strings to help child live a more independent life in future			
I12:A35	Hopeful that son will catch up academically and experience success			
I3:A26	Would like to child to find a little niche			
I5:A16	Want him to live a normal life within the parameters of his disability			
I5:A15	If he gets support he will be ok.			
P1:A51	Immediate inability to listen after the diagnosis	The immediate period after the diagnosis is a difficult time for parents and not the optimum time to provide information.	"we heard the words 'he's on the autistic spectrum , we both heard no more as she prattled on we were taking stock of what she said"	Immediate period after diagnosis is a difficult time – lack of openness to support.
P1:A52	Professional not recognising parent needs to digest info. after diagnosis			
P1:A53	Need time after diagnosis to take stock			
P1:A55	Unable to process and retain info after diagnosis			

I8:A17	You need a bit of breathing space		“we were completely floored,” “then the Earlybird course was perhaps 8 months after which was ok, um that gave us time to take stock I think about 6 months to give you a chance to settle down a little bit” “I think the first 6 months to first 2 years (sighs) Trying to sort of look back at it, (p) again it was all a little bit bewildering”	
I8:A18	Don’t remember reading info straight after the diagnosis			
I8:A19	Too much to take in after diagnosis so you miss information			
P1:A83	Need time to take stock and settle after the diagnosis			
P1:A49	Lots of paperwork			
I8:A13	Paediatrician gave parents space to digest the diagnosis			
I8:A14	Parents needed time to think about it			
I8:A24	Quite intense after diagnosis – so many forms to fill out.			
P1:A205	Initial period after the diagnosis was bewildering			
I4:A2	In limbo after diagnosis – cant treat it with medication			
I4:A5	Couldn’t do Earlybird course because it was too soon after the diagnosis – too much to take in.			
I4:A8	Period after diagnosis was too busy – too much going on to focus on finding support			
I9:A37	Diagnosis did not necessarily change the level of support offered in school.	Parents have neutral response to the diagnosis and identify that the diagnosis won’t change anything.		Recognition that diagnosis does not change parent’s perceptions or actions.
I2:A41	Getting a diagnosis was ok.			
I1:A28	Child hasn’t changed since the diagnosis – they are who they are.			
I11:A8	Doesn’t matter to parent if child is diagnosed as ASD or not			
I11:A2	Diagnosis of child – recognise autistic traits in other family members			
I11:A5	Diagnosis didn’t rate that high in the scheme of things – doesn’t change anything			
I9:A39	Diagnosis didn’t affect the way father managed child.			
I7:A3	Not in denial but not expecting it either			
I7:A34	Diagnosis doesn’t change anything – expectations based on child s abilities			
P1:A78	Inappropriate support – Mismatch between support and the child’s needs	Effective support needs to be matched to the severity of the child’s needs.		Effective support should be matched to child’s needs.
P1:A74	Aspergers and autism are poles apart – support to parents should be different			
P1:A79, A86	Pointless support – mismatch between support and child’s needs			
I1:A38	Support dependent on severity of autism			
I2:A64	Coffee morning does not deal with individual differences between each child – still feel like you’re on your own.			

P1:A221	Link between degree of autism and type of support needed			
I7:A7	More helpful to be around parents with similar issues even if severity levels were different			
I7:A22	Training – what am I doing here – everyone else is worse off than us.			
I12:A3	Parent considers herself lucky as sons ASD is not as bad as others			
P1:A110	Support from family – already experienced with autism	Positive views on support offered from friends and family.		Supportive network of family and friends.
P1:A250	Most support from other mum's with similar children			
P1:A206	Support from family with experience of autism			
I2:A65	People who've been through it can give help and advice			
I11:A18	Reassuring to meet with mums with aspergers children – not unique			
P1:A209	Using other parents to signpost available support			
I7:A17	Grandfather has helped tremendously			
P1:A149	Future expectations – cannot predict and no guarantees	Uncertainty about the future after their child's diagnosis of ASD.		Uncertainty about the future after a diagnosis of ASD.
P1:A150	Future expectations alter with glimpses of possibilities			
P1:A151	Need to stay open minded about the future			
P1:A162	Uncertainty about the future – completely open			
P1:A177	Uncertainty about adult provision			
P1:A178	Uncertainty about adult provision – government changes			
P1:A170	Coping – try to relax about the future as it's not here yet.			
I1:A26	Doom and gloom versus optimistic view of the future			
I1:A33	Would like to bury head in the sand about the future but need to address it as it occurs			
P1:A183	Uncertainty about funding for adults with autism			
I6:A10	Child uses parent as a security blanket, child is letting go but parent cant			
I7:A29	Would parent let child down if they didn't share the diagnosis with them			
I7:A30	Haven't thought about how to tell child			
I7:A31	Worried about the outcome of revealing diagnosis to child			
I7:A36	Diagnosis shouldn't lead to child being smothered or over protected			
I12:A38	Don't think about the future because you can't			

	influence it.			
I3:A27	Future depends on how he gets on at secondary			
I3:A33	Have to see what the future holds			
I8:A11	Information sent by professional	Good information sent by professionals		Good information from professionals.
I8:A22	NAS sent magazines and other info.			
I10:A15	Given lots of information			
I8:A21	Lots of info but most reliable was from NAS			
P1:A88	Information seeking/receiving – negative view – variety of sources	Negative view to sorting through information to find what's useful. Too much information, hard to organise, not cohesive and the use of unfamiliar language made it challenging.		Negative view of professional support.
P1:A90	Receiving/sorting information – negative view –long period of time.			
P1:A91	Receiving/sorting information – negative view – positive expression about the future			
P1:A92	Accessing information – down to luck.			
P1:A96	Sorting information – difficulties identifying what's useful			
P1:A97	Hard to sort through information			
I2:A30	Support – signposted through word of mouth			
P1:A98	Sorting through all the forms was too much to bear			
I11:A3	Reading about autism scared the life out of me			
P1:A101	Sorting information – heavy workload – like a part time job'			
P1:A107	Difficulty with information sorting – organisation			
P1:A108	Sorting information is less important after the right educational provision is found			
P1:A122	A lot of information to take in			
P1:A216	Absence of a cohesive information pack			
I9:A34	Written communication can get lost in translation.			
P1:A233	New language to deal with			
I12:A28	Books really depressed them			
I4:A9	Steer clear of American websites – scaremongering			
P1:A76	Inappropriate support - Negative feelings of distress and irritation	Negative feelings towards professional support offered.		
P1:A87	Inappropriate support leads to frustration			
P1:A135	Lack of support – feel there should have been more			
P1:A220	Inappropriate treatment from professionals in support services			
P1:A230	Support offered not appropriate			
P1:A188	Funding influences availability of support			
I1:A13	Got lucky in terms of support			
P1:A218	Now a family with complex needs – takes bravery to ask for support from social services			
P1:A226	Vagueness of support on offer			

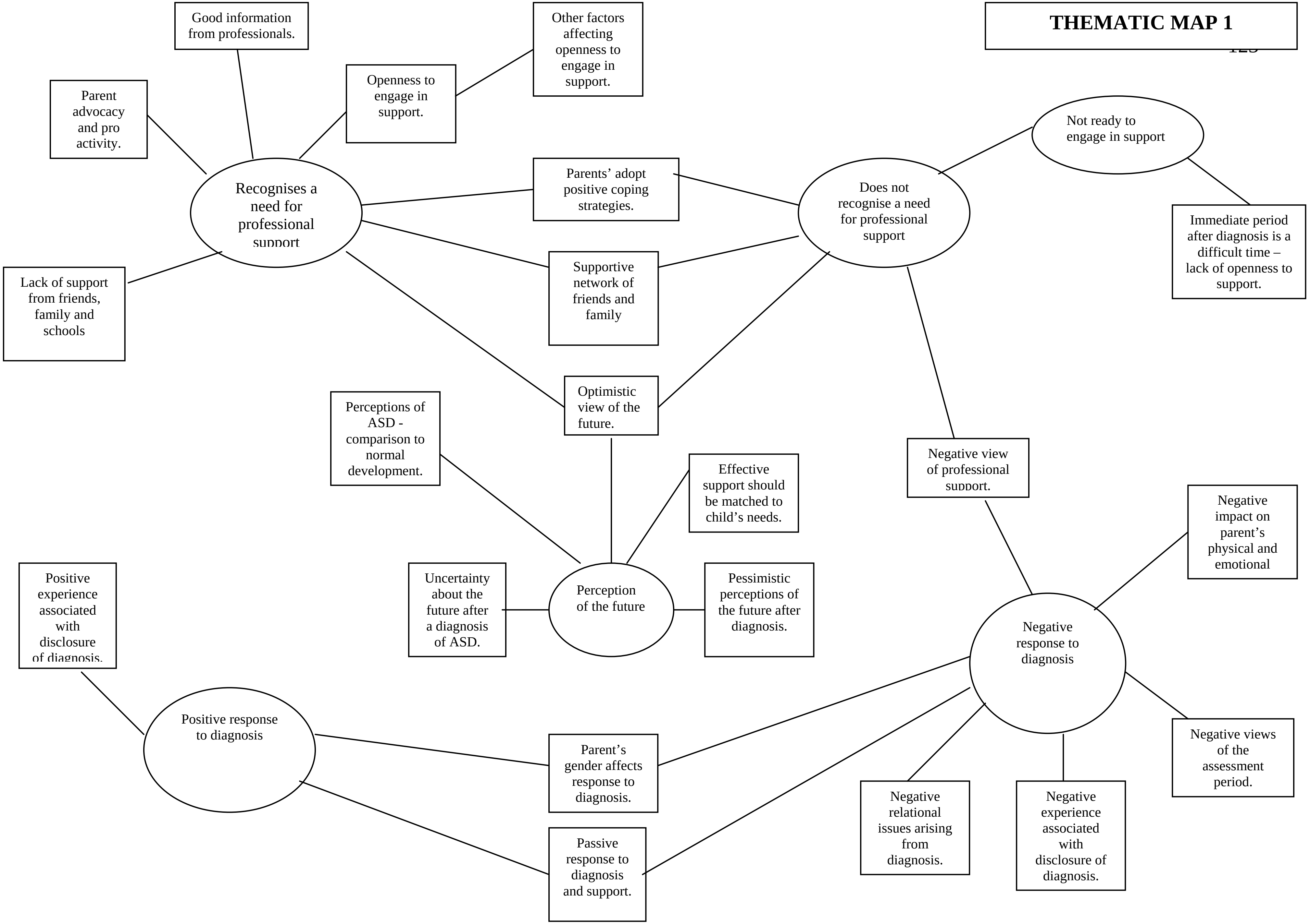
P1:A228	Uncertainties about type of support needed			
I11:A16	Disappointed at offer of medical support via prescriptions			
P1:A229	Support offered clutching at straws			
I10:A11	Paid for private speech and language support			
I10:A26	Don’t want to be part of the ASD community – focussing on the bad thing they have in common.			
I2:A9	Other factors affecting professional involvement.			
P1:A189	Support less available for invisible disability			
P1:A194	Respect disability – deserve support			
I8:A23	Filling out disability forms were a nightmare			
P1:A129	Takes a long time to get into the right educational setting			
P1:A236	Families and children need more effective support			
I6:A20	Professional documentation was full of mistakes			
I6:A24	Reading makes parent more worried			
I6:A25	Panicky about the future after reading information			
I6:A21	Not been invited to useful support groups			
I6:A22	Parent felt abandoned by professionals after diagnosis			
I12:A13	Delay due to professional illness and understaffing			
P1: A23	Coping – facing up to the autism.	Parents adopt positive strategies to cope with the diagnosis		Parents adopt positive coping strategies.
P1:A57	Coping - Hugging after diagnosis			
P1:A114	Negative emotions as a result of diagnosis – using love as a Coping strategy			
P1:A187	Breathing technique as a coping strategy			
I1:A10	More difficult being autistic as an only child – large family/more siblings helps			
P1:A251	Best tonic is meeting other families with similar children			
I8:A37	Meet parents with similar children – feel more comfortable – don’t have to explain behaviour			
I9:A43	Keeping calm is important			
P1:A238	Coping strategy – shy away from the emotions			
I7:A14	Parent looking for positives in child – focus on those aspects of ASD			
I3:A18	Different responses from men and women – harder for men who want to fix it.	Different responses from men and women who have different cognitions and employ different coping strategies.		Parent’s gender affects response to diagnosis.
I3:A19	Mother deals with ASD child better – undermining husband’s authority – causing a rift.			
I3:A36	Father has a lower patience threshold and finds it harder to cope			

Description of grouped codes	Theme
Dissatisfaction with disclosure of diagnosis by professional	Negative experience associated with disclosure of diagnosis.
Timing of the diagnosis has an impact on how parents cope. Earlier diagnosis is more difficult to cope with.	
Unprepared for disclosure of diagnosis relating to lack of knowledge and understanding about what the diagnosis may mean and when it will be delivered during the assessment process.	
Negative emotions in response to the diagnosis.	
Satisfaction with the disclosure of diagnosis.	Positive experience associated with disclosure of diagnosis.
Parents expect the diagnosis prior to the disclosure.	
Positive emotions and outcomes related to the diagnosis	
Delay in language or change in child's emotional temperament first raise suspicion that something is not right but parents wait for professional confirmation.	Perceptions of ASD - comparison to normal development.
Explain child's behaviour in terms of normal development.	
Parent's cognitions about understanding autism.	
Normal development used as a benchmark for ASD child's development.	
Sharing information about autism with friends who don't understand. Parent's explain to others and use comparisons to normal parenting as evidence for their claim.	
Wide variety of professional services with the provision to support families. Belief that professionals will give the right support.	Receptive to engage in support.
Open to engage with support services.	
Need more proactive help from professionals to offer the right type of support.	
Some successful strategies employed at home by parents	
Belief that life will have to be different after the diagnosis	
Positive attitude towards receiving support in the home.	
Positive views and experiences of professional support offered.	
Wider family factors affect logical aspects of accessing support	Other factors affecting openness to engage in support.
Support services are not cohesive and don't offer a joined up package to support families of children with ASD	
Other factors affecting coping aside from the diagnosis itself.	
Passive attitude to coping. Doesn't require any proactivity.	Passive response to diagnosis and support.
Reluctance to undertake interventions at home	
Coping in private to avoid judgement of others.	
Proactive information seeking from a variety of sources and organisation of information.	Parent advocacy and pro activity.
Parents have to be advocates for their child.	

Image of the future is created in comparison to parent's perceptions of a normal child's future. Recognition that future for an ASD child will be different from normal.	Pessimistic perceptions of the future after diagnosis.
Parents make comparisons to peers normal development which makes it harder to cope.	
Resolved to future life long care for child but do not want this burden placed on sibling or parents.	
Negative views of the future after receiving a diagnosis of ASD for their child.	
The assessment process is lengthy and weighty in terms of importance with lots of professionals involved.	Negative views of the assessment period.
Negative experiences of assessment period	
The negative impact on parent's physical and emotional well being not taken into account or supported.	Negative impact on parent's physical and emotional wellbeing.
Parents have found it difficult to cope with raising their child with ASD.	
Parents need to be physically strong in order to provide effective care in the future.	
Poor support can ultimately influence the security of the family unit and may lead to the break up of the family.	Negative relational issues arising from diagnosis.
ASD diagnosis has an impact on siblings	
Negative views of support offered from friends and family	Lack of support from friends, family and schools.
Not supported by school in terms of the diagnosis and support strategies	
Hopeful beliefs about the future of support for families of children with ASD.	Optimistic view of the future.
Parents are hopeful that life will be easier to manage in the future. Hopeful emotions about future provision for and a better understanding of autism.	
The immediate period after the diagnosis is a difficult time for parents and not the optimum time to provide information.	Immediate period after diagnosis is a difficult time – lack of openness to support.
Parents have neutral response to the diagnosis and identify that the diagnosis won't change anything.	Recognition that diagnosis does not change parent's perceptions or actions.
Effective support needs to be matched to the severity of the child's needs.	Effective support should be matched to child's needs.
Positive views on support offered from friends and family.	Supportive network of friends and family.
Uncertainty about the future after their child's diagnosis of ASD.	Uncertainty about the future after a diagnosis of ASD.
Good information sent by professionals	Good information from professionals.
Negative view to sorting through information to find what's useful. Too much information, hard to organise, not cohesive and the use of unfamiliar language made it challenging.	Negative view of professional support.
Negative feeling towards professional support offered.	
Parents adopt positive strategies to cope with the diagnosis	Parents' adopt positive coping strategies.
Different responses from men and women who have different cognitions and employ different coping strategies	Parent's gender affects response to diagnosis.

Appendix G: Thematic map 1

THEMATIC MAP 1



References

Abbeduto, L., Seltzer, M.M., Shattuck, P., Krauss, M.W., Orsmond, G., & Murphy, M.M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome and fragile X syndrome. *American Journal of Mental Retardation*, *109,* 237-254.

Abdin, R.R. (1995). *Parenting Stress Index,* 3rd edn. Florida, CA: Psychological Assessment Resources.

Affleck, G., & Tennen, H. (1996). Constructing benefits from adversity: Adaptational significance and dispositional meanings. *Journal of Personality*, *64*, 899-922.

Aldred, C., Green, J., & Adams, C. (2004). A new social communication intervention for children with autism: Pilot randomized controlled treatment study suggesting effectiveness. *Journal of Child Psychology and Psychiatry*, *45,* 1420-1430.

Allik, H., Larson, J.O., & Smedge, H. (2006). Health-related quality of life in parents of school-age children with Asperger's syndrome or high-functioning autism. *Health and Quality of Life Outcomes, 4,* 1.

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th Ed. – text revision). Washington, DC: Author.

Anderson, S.R., Avery, D.L., DiPietro, E.K., Edwards, G.L., & Christian, W.P. (1987). Intensive home-based intervention with autistic children. *Education and Treatment of Children, 10,* 352-366.

Antshel, K., Brewster, S. & Waisbren, S. (2004). Child and parent attributions in chronic pediatric conditions: Phenylketonuria (PKU) as an exemplar. *Journal of Child Psychology and Psychiatry, 45*, 622-630.

Asperger, H., (1944). Autistic psychopathy in childhood. Translated and annotated by U. Frith. In U. Frith (Ed.). (1991). *Autism and Asperger Syndrome*. Cambridge: Cambridge University Press, 37-92.

Bailey, A., Le Couteur, A., Gottesman, I., Bolton, P., Simonoff, E., Yuzda, E. (1995). Autism as a strongly genetic disorder: evidence from a British twin study. *Psychological Medicine*, *25,* 63-77.

Bailey, D.B., Skinner, D., Hatton, D., & Roberts, J. (2000). Family experiences and factors associated with the diagnosis of fragile X syndrome. *Developmental and Behavioural Paediatrics*, *21*, 315-321.

Baird, G., McConachie, H., & Scrutton, D. (2000). Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood*, *83*, 475-480.

Barnett, D., Clements, M., Kaplan-Estrin, M., McCaskil, J.W., Hill Hunt, K., Butler, C.M., et al. (2006). Maternal resolution of child diagnosis: Stability and relations with child attachment across the toddler to preschooler transition. *Journal of Family Psychology*, *20*, 100-107. Doi: 10.1037/0893-3200.20.1.100.

Batshaw, M. (1997). *Children with Disabilities* (4th Ed). Baltimore Brookes.

Baumrind, D. (1991). The influence of parenting style on adolescent competence and substance use. *Journal of Early Adolescence*, *1*, 1, 56-95.

Beck, A.T., Steer, R.A., & Brown, G.K. (1996). *Manual for the Beck Depression Inventoy*, 2nd edn. San Antonio, TX: Psychological Corporation.

Benoit, D., Zeanah, C.H., Boucher, C., & Minde, K. (1992). Sleep disorders in early childhood, associations with insecure maternal attachment. *Journal of the American Academy of Child and Adolescent Psychiatry*, *31*, 86-93.

Benson, P.R. (2010). Coping, distress, and well-being in mothers of children with autism. *Research in Autism Spectrum Disorders*, *4*, 217-228. Doi:10.1016/j.rasd.2009.09.008.

Bettelheim, B. (1967). *The Empty Fortress: Infantile Autism and the Birth of the Self*, The Free Press: New York.

Bitsika, V. & Sharpley, C. (2000). Development and testing of the effects of support groups on the well-being of parents of children with autism, II: Specific stress management techniques. *Journal of Applied Health Behaviour*, *2*, 8-15.

Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? *American Journal of Mental Deficiency*, *89*, 653-656.

Blackledge, J.T., & Hayes, S.C. (2006). Using acceptance and commitment training in the support of parents of children diagnosed with autism. *Child and Family Behaviour Therapy*, *28*, 1-18.

Bolton, P., Macdonald, H., Pickles, A., Rios, P., Goode, S., Crowson, M., Bailey, A., & Rutter, M. (1994). A case-control family study of autism. *Journal of Child Psychology and Psychiatry, 35,* 877-900.

Bonde, E. (2000). Co-morbidity and subgroups in childhood autism. *European Child and Adolescent Psychiatry, 9,* 7-10.

Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46 (6),* 722-730.

Bowlby, J. (1980). *Attachment and loss: Vol. 3. Loss: Sadness and depression.* New York: Basic Books.

Boyatzis, R.E. (1998). *Transforming qualitative information*. London: Sage.

Boyd, B.A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities,* 17, 208-215,

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology, *Qualitative Research in Psychology,* 3, 77-101.

Brereton, A.V., Tonge, B.J., & Einfeld, S.L. (2006). Psychopathology in children and adolescents with autism compared to young people with intellectual disability. *Journal of Autism and Developmental Disorders, 36,* 7, 863-870.

Brogan, C., & Knussen, C. (2003). The Disclosure of a Diagnosis of an Autism Spectrum Disorder: Determinants of Satisfaction in a Sample of Scottish Parents, *Autism,* 7(1), 31-46. Doi: 10.1177/362361303007001004

Bryson, S., Rogers, S., & Fombonne, E. (2003). Autism spectrum disorders: Early detection, intervention, education, and psychopharmacological management. *Canadian Journal of Psychiatry,* 48(8), 506-516.

Carver, C.S., Scheier, M.F., & Weintraub, J.K. (1989). Assessing Coping Strategies: A Theoretically Based Approach. *Journal of Personality and Social Psychology,* 56: 267-283.

Carver, C.S. (1997). You want to measure coping but your protocol’s too long: Consider the Brief COPE. *International Journal Behavioral Medicine, 4,* 92-100.

Chakrabarti, S., & Fombonne, E. (2001). Pervasive developmental disorders in preschool children, *Journal of the American Medical Association*, 285, 3141-2.

Chambless, D.L., Sanderson, W.C., Shoham, V., Bennett Johnson, S., Pope, K.S., Crits-Christoph, P., et al. (1996). An update on empirically validated therapies. *The Clinical Psychologist*, 49, 5-18.

Chambless, D.L., Baker, M.J., Bancom, D.H., Beutler, L.E., Calhoun, K.S., Crits-Christoph, P. et al. (1998). Update on empirically validated therapies, II. *The Clinical Psychologist*, 51, 3-16.

Chehrazi, A. (2002). Healthy adaptation in parents of children with autism: Implications of personality and resilience. *Dissertation Abstracts International Section B: The Sciences and Engineering*, 63(2-B), 1017.

Cho, S., & Gannotti, M.E. (2005). Korean-American mothers' perception of professional support in early intervention and special education programs. *Journal of Policy and Practice in Intellectual Disabilities*, 2, 1, 1-9.

Clarke, A.M., & Clarke, A.D.B., (1976). Formerly isolated children. In A.M. Clarke & A.D.B. Clarke (Eds.). *Early Experience: myth and evidence*, 27-34. London: Open Books.

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, 38, 300-314.

Cook, R.E. (2006). Autism Spectrum Disorders: A Crisis of Urgent Public Concern. In, Plante, T.G. (Ed.) *Mental Disorders of the new millennium: Biology and function*, 3, 55-77. Greenwood Publishing Group.

Costigan, C.L., Floyd, F.J., Harter, K.S.M., & McKlintock, J.C. (1997). Family Process and Adaptation to Children With Mental Retardation: Disruption and Resilience in Family Problem-Solving Interactions. *Journal of Family Psychology*, 11, 4, 515-529.

Cottrell, D.J., & Summers, K. (1990). Communicating an evolutionary diagnosis of disability to parents. *Child: Care, Health and Development*, 16, 211-218.

Cunningham, C.C., Morgan, P. & McGucken, R.B. (1984). 'Down's Syndrome: Is Dissatisfaction with Disclosure Inevitable? *Developmental Medicine and Child Neurology*, 26, 33-39.

Cunningham, C.C., & Davis, H. (1985). Early parent counseling. In *Mental Handicap – A Multi-disciplinary Approach*, M.Craft., J. Bicknell, & S. Hollins (Eds.). Bailliere Tindall, London.

Curtiss, S. (1977). *Genie: a psychological study of modern-day 'wild child'*. New York: Academic Press.

Dale, E., Jahoda, A., & Knott, F. (2006). Mothers' attributions following their child's diagnosis of autism spectrum disorder. *Autism*, 10, 463-479. Doi: 10.1177/1362361306066600

Davis, N.O., & Carter, A.S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Research*, 38, 1278-1291.

Dearlove, J., & Kearney, D. (1990). How good is general practice developmental screening. *British Medical Journal*, 300, 1177-1180.

Deater-Deckard, K. (2006). Parenting stress and child adjustment: Some old hypotheses and new questions. *Clinical Psychology: Science and Practice*, *5*, 3, 314-332.

Dolev, S., Oppenheim, D., Koren-Karie, N. & Yirmiya, N. (2009). Emotional availability in mother-child interaction: The case of children with autism spectrum disorders. *Parenting: Science and Practice*, 9, 3, 183-197.

Donovan, A.M. (1988). Family stress and ways of coping with adolescents who have handicap: maternal perceptions. *American Journal on Mental retardation*, 92(6), 502-509.

Dumas, J.E., Wolf, L.C., Fisman, S.N., & Culligan, A. (1991). Parenting Stress, Child Behaviour Problems, and Dysphoria in Parents of Children with Autism, Down Syndrome, Behaviour Disorders, and Normal Development. *Exceptionality*, 2:97-110.

Dunn, M., Burbine, T., Bowers, C. & Tantleduff-Dunn, S., (2001). Moderators of Stress in Parents of Children with Autism, *Community Mental Health Journal*, 37: 39-52.

Eisenhower, A.S., Baker, B.L., & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual and Disability Research*, 49, 657-671.

Eisenmajer, R., Prior, M., Leekman, S., Wing, L., Gould, J., Welham, M., & Ong, B. (1996). Comparison of clinical symptoms in autism and Asperger's Syndrome. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35, 1523-1531.

El-Ghoroury, N.B., & Romancyzk, R.G. (1999). Play interactions of family members towards children with autism. *Journal of Autism and Developmental Disorders*, 29, 249-258.

Erickson, M. & Upshur, C.C. (1989). Caretaking burden and social support: comparison of mothers of infants with and without disabilities. *American Journal of Mental Retardation*, 94:250-258.

Ernst, E. (1999). Prevalence of complementary/alternative medicine for children: A systematic review. *European Journal of Pediatrics*, 158 (1), 7-11.

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, 13, 375-387.

Farrell, M.P., & Barnes, C.M. (1993). Family systems and social support: A test of the effects of cohesion and adaptability on the functioning of parents and adolescents. *National Council on Family Relations.*

Feinstein, C. & Reiss, A.L. (1998). Autism: the point of view from fragile X studies. *Journal of Autism and Developmental Disorders*, 28: 393–405.

Ferguson, P.M. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *Journal of Special Education*, 36, 124-130.

Fisman, S., & Wolf, L. (1991). The handicapped child: psychological effects of parental, marital, and sibling relationships. *Psychiatric Clinics of North America*, 14 (1), 199-217.

Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *Canadian Journal of Psychiatry*, 45, 369-375.

Fleischmann, A. (2004). Narratives Published on the Internet by Parents of Children with Autism: What do They Reveal and Why is it Important? *Journal of Autism and Developmental Disorders,* 19,(1) 35-43.

Folkman, S., & Moskowitz, J.T. (2000). Positive Affect and the Other Side of Coping. *American Psychologist* 55: 647-54.

Folstein, S., & Rutter, M. (1977). Infantile autism: A study of 21 twin pairs. *Journal of Child Psychology and Psychiatry*. 18:297-321.

Fombonne, E. (2001). Ask the Editor: What is the prevalence of Asperger Disorder?. *Journal of Autism and Developmental Disorders,* 31, 363-364.

Fombonne, E, (2005). Epidemiology of autistic disorder and other pervasive developmental disorders. *Journal of Clinical Psychiatry*, 6, 3-8.

Fombonne, E., Zakarin, R., Bennett, A., Meng, L., & MacLean-Heywood, D. (2006). Pervasive developmental disorders in Montreal, Quebec, Canada. Prevalence and links with immunizations. *Pediatrics*, 118, 139-150.

Fraiberg, S., Adelson, E. & Shapiro, V. (1983). Ghosts in the nursery: A psychoanalytic approach to the problems that cloud the mother-infant relationship. *Psychiatrie-de-l'Enfant*, 26, 57-98.

Freeman, B.J. (1997). Guidelines for evaluating intervention programs for children with autism. *Journal of Autism and Developmental Disorders*, 27, 6, 641-651.

Glascoe, F. (1997). Parents' concerns about children's development: Pre-screening technique or screening test? *Pediatrics*, 99 (4), 522-528.

Glaser, B. (1992). *Basics of grounded theory analysis*. Sociology Press.

Goin-Kochel, R.P, Mackhintosh, V.H., & Myers, B.J., (2009). Parental reports on the efficacy of treatments and therapies for the children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 3, 2, 528-537. Doi: 10.1016/j.rasd.2008.11.001.

Goldstein, S., & Schwebach, A. (2004). The Co morbidity of pervasive developmental disorder: Results of a retrospective chart review. *Journal of Autism and Developmental Disorders,* 34(3), 329-339.

Grant, G. (1993). Support networks and transitions over two years among adults with a mental handicap. *Mental Handicap Research*, 6, 36-55.

Graungaard, A.H., & Skov, L. (2007). Why do we need a *diagnosis*? A qualitative study of parents' experiences, coping and needs, when the newborn *child* is severely disabled. *Child: Care, Health and Development*, 33 (3), 296-307. doi:10.111/j.1365-2214.2006.00666.x

Gray, D. (1993). *Perceptions of stigma: The parents of autistic children.* Sociology of Health and Illness, 15, 102-120.

Green, G. (1996) Early behavioural intervention for autism what does research tell us? In. Maurice C., Green G., and Luce S. (Eds) *Behavioural Intervention for Young Children with Autism*. Austin, Texas : Pro-Ed

Green, V., Pituch, K., Itchon, J., Choi, A., O'Reilly, M. & Sigafoos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, 27, 70-84.

Greenberg, M.T., Speltz, M.L., & DeKlyen, M. (1993). The role of attachment in the early development of disruptive behaviour problems. *Development and Psychopathology*, 5, 191-213.

Grindle, C.F., Kovshoff, H., Hastings, R.P., & Remington, B. (2009). Parents' Experiences of Home-Based Applied Behaviour Analysis Programs for Young Children with Autism, *Journal of Autism and Developmental Disorder*, 39 (1), 42-56. Doi: 10.1007/210803-008-0597-2.

Guruge, S., & Humphreys, J., (2009). Barriers affecting access to and use of formal social supports among abused immigrant women. *Canadian Journal of Nursing Research*, 41 (3), 64-84.

Hall, S., Bobrow, M., & Marteau, T. (1997). Parents' Attributions of Blame for the Birth of a Child with Down syndrome: A Pilot Study, *Psychology and Health*, 12, 579-587.

Hanson, E., Kalish, L.A., Bunce, E., Curtis, C., McDaniel, S., Ware J. et al. (2007). Use of complementary and alternative medicine among children diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 37, 628-636.

Happé, F. (1994). *Autism: an introduction to psychological theory*. Psychology Press Ltd, UK.

Harris, S. (1994). Treatment of family problems. In: *Behavioural Issues in Autism,* Schopler, E., Mesibov, G, Eds. New York Plenum Press, 161-175.

Hastings, R.P. (1997). Grandparents of children with disabilities: A review. International Journal of Disability. *Development and Education*, 44, 329-340.

Hastings, R.P. (2008). Stress in parents of children with autism. In E. McGregor, M. Nunez, K. Williams, & J. Gomez (Eds.), Autism: An integrated view, Oxford: Blackwell, 303-324.

Hastings, R.P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioural intervention for their young child with autism. *Journal of Autism and Developmental Disorders,* 31, 327-336.

Hastings, R.P., & Taunt, H.M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal of Mental Retardation,* 107, 116-127.

Hastings, R.P., Kovshoff, H, Brown, T., Ward, N.J., degli Espinosa, F., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism, *Autism,* 9, 377-391. Doi:10.1177/1362361305056078.

Hastings, R.P., Kovshoff, H., Ward, N.J., degli Espinosa, F., Brown, T., & Remington, B. (2005). System Analysis of Stress and Positive Perceptions in Mothers and Fathers of Pre-School Children with Autism, *Journal of Autism and Developmental Disorders*, 35, 5, 635-644. Doi: 10.1007/s10803-005-0007-8.

Hauser-Cram, P., Warfield, M.E., Shonkoff, J.P., & Kraus, M.W. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development*, 66, 3, Serial No. 266.

Hayes, S.C., Stroshal, K., & Wilson, K.G. (1999). *Acceptance and commitment therapy: An experiential approach to behaviour change.* New York: Guildford Press.

Henderson, D., & Vandenberg, B. (1992). Factors influencing adjustment in the families of autistic children. *Psychological Reports*, 71, 167-171.

Herring, S., Gray., K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, 50, 874-882.

Holloway, I. & Todres, L. (2003). The status of method: flexibility, consistency and coherence. *Qualitative research,* 3, 345-57.

Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal of Mental Deficiency*, 80, 431-436.

Hornby, G. (1992). A review of fathers' accounts of their experiences of parenting children with disabilities, *Disability and Society*, 7, 4, 363-374.

Howard, J.S., Sparkman, C.R., Cohen, H.G., Green, G., & Stanislaw, H. (2005). A comparison of intensive behaviour analytic an eclectic treatments for young children with autism. *Research in Developmental Disabilities*, 26, 359-383.

Howlin, P. (1988). Living with impairment: The effects on children of having an autistic sibling. *Child: care health and development*, 14, 395-408.

Howlin, P., & Rutter, M. (1987). *Treatment of Autistic Children.* Chichester, UK: Wiley.

Howlin, P., & Moore, A. (1997). Diagnosis in autism: a survey of over 1200 parents in the UK. *Autism: International Journal of Research and Practice*, 1, 135-62.

Howlin, P., & Asgharian, A. (1999). The diagnosis of autism and Asperger syndrome: findings from a survey of 770 families, *Developmental Medicine and Child Neurology*, 41: 834-839.

Huws, J., Jones, R.S., & Ingledew, D.K. (2001). Parents of children with autism using an e-mail group: A grounded theory study. *Journal of Health Psychology*, 6, 569-584.

Ivey, J. (2004). Do Parents Expect? A study of Likelihood and Importance Issues for Children with Autism Spectrum Disorders. *Focus on Autism and other developmental Studies*, 19, 27-33.

Jacobsen, J., & Mulick, J. (2000). System and Cost Research Issues in Treatments for people with Autistic Disorders, *Journal of Autism and Developmental Disorders*, 30: 585-93.

Joceyln, L.J., Casiro, O.G., Beattie, D., Bow, J. & Kneisz, J. 91998). Treatment of children with autism: A randomized controlled trial to evaluate a caregiver-based intervention program in community day-care centers. *Developmental and Behavioural Pediatrics*, 19, 326-334.

Joffe, H., & Yardley, L. (2004). Content and thematic analysis. In D.F.Marks, & L. Yardley, (Eds.). *Research Methods for Clinical and Health Psychology,(*2004), SAGE Publications, London, 56-68.

Johnson, C. P., & Myers, S. M. (2007). Council on Children with Disabilities. Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120(5):1183–215.

Joiner, T., & Wagner, K. (1996). Parental, Child-Centered Attributions and Outcome: A Meta-Analytic Review with Conceptual and Methodological Implications. *Journal of Abnormal Child Psychology*, 24: 37-52.

Kanner L. (1943). Autistic Disturbances of Affective Contact, *Nervous Child 2* : 217-250.

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders*, 27, 39-57.

Kendall, P.C., & Hammen, C. (1998). *Abnormal psychology* (2nd edn.), Boston: Houghton Mifflin Company.

Kerr, S. & McIntosh, J. (2000). Coping When a Child Has a Disability: Exploring the Impact of Parent-to Parent Support. *Child: Care, Health, and Development*, 26, 309-321.

King, M. (2008). Diagnosis, diffusion and substitution in the autism epidemic. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 69 (6-A), 2466.

Koegel, L.K. (2000). Interventions to facilitate Communication in Autism, *Journal of Autism and Developmental Disorders*, 30, 383-391.

Koegel, R.L., Schriebman, L., Loos, L.M., Dirlich-Wilhelm, H., Dunlap, G., Robbins, F.R., et al. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders*, 22, 205-216.

Konstantareas, M.K. (1991). Autistic, learning disabled and delayed children’s impact on their parents. *Canadian Journal of behavioral Science*, 23 (3), 358-375.

Konstantareas, M.M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry*, 30(3), 459-470.

Konstantareas, M.M., Homatidis, S., Plowright, C.M.S. (1992). Assessing resources and stress in parents of severely dysfunctional children through the Clarke modification of Holroyd's Questionnaire on resources and Stress. *Journal of Autism and Developmental Disorders*, 22, 217-234.

Knox, M., Parmenter, T., Atkinson, N. & Yazbeck., M. (2000). Family control: the views of families who have a child with intellectual disability. *Journal of Applied Research in intellectual Disabilities*, 13, 17-28.

Krauss, M., Gulley, S., Sciegaj, M. & Wells, N. (2003). Access to Specialty Medical Care for Children with Mental retardation, Autism and Other Special Health Care Needs, *Mental Retardation*, 41: 329-39.

Lavelle, N. and Keogh, B.K. (1980). Expectations and Attributions of Handicapped Children. In, J.J. Gallagher (ed.). *New Directions for Exceptional Children: Parents and Families of Handicapped Children*, -57, San Francisco, CA: Jossey-Bass.

Law, M., King, S., Stewart, D., & King, G. (2001). The Perceived Effects of Parent-Led Support Groups, *Physical and Occupational Therapy in Pediatrics*, 21, 29-49.

Le Couteur, A., Bailey, A., Goode, S., Pickles, A., Robertson, S., Gottesman, I. & Rutter, M. (1996). A broader phenotype of autism – The clinical spectrum in twins. *Journal of Child Psychology and Psychiatry*, 37, 785-801.

Levy, S., Kim, A., & Olive, M. (2006). Interventions for young children with autism: A Synthesis of the literature. *Focus on Autism and Other Developmental Disabilities*, 21 (1), 55-62.

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry.* Newbury Park, California: Sage.

Lingham, S., & Newton, R. (1996). *Right from the Start: The Way Parents Are Told That Their Child Has a Disability*. Pediatric Practice Guidelines, London: British Pediatric Association.

Liptak, G.S., Orlamdo, M., Yingling, J.T., Theurer-Kaufman, K.L., Malay, D.P., Tompkins, L.A., et al. (2006). Satisfaction with primary heath care received by families of children with developmental disabilities. *Journal of Pediatric Health Care*, 20 (4), 245-252.

Lobato, D., Faust, D., & Spirito, A. (1988). ‘Examining the Effects of Chronic Disease and Disability on Children’s Sibling Relationships’, *Journal of Pediatric Psychology*, 13, 389-407.

Lockyer, L., & Rutter, M. (1970). A five to fifteen year follow-up study of infantile psychosis: IV. Patterns of cognitive ability. *British Journal of Social and Clinical Psychology*, 9, 152-63.

Lord, C., Risi, S., DiLavore, P., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of General Psychiatry*, 63(6), 649-701.

Lord, B., Ungere, J., & Wastell, C. (2008). Implications of resolving the diagnosis of PKU for parents and children. *Journal of Pediatric Psychology,* 33, 855-866.

Lovaas, O.I (1987). Behavioural treatment and normal education and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55(1), 3-9.

Mandell, D.S. & Salzer, M.S. (2007). Who joins support groups among parents of children with autism. *Autism*, 11, 111-122. Doi: 10.1177/1362361307077506.

Mandell, D.S., Ittenbach, R.F., Levy, S.E., & Pinto-Martin, J.A. (2007). Disparities in Diagnoses Received Prior to a diagnosis of Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 37, 1795-1802. Doi: 10.1007/s10803-006-0314-8.

Marcus, L., Kuncel, L.J. & Schopler, E. (1997). Working with families. In *Handbook of Autism and Pervasive Developmental Disorders*, (2nd edn), 631-649, Wiley, New York.

Marvin, R.S., & Pianta, R.C. (1996). Mothers’ Reactions to Their Child’s Diagnosis: Relations With Security of Attachment. *Journal of Clinical Child Psychology*, 25, 4, 436-445.

McAdoo, W.G., & DeMeyer, M.K (1977). Research related to family factors in autism. *Journal of Pediatric Psychology,* 2, 162-166.

McConachie, H. & Diggle T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *Journal of Evaluation in Clinical Practice,* 13, 120-129.

McEachin, J.J., Smith, T., & Lovaas, O.I. (1993). Long-term outcome for children with autism who received early intensive behavioural treatment. *American Journal of Mental Retardation*, 97(4), 359-372.

McKinney, B., & Peterson, R.A. (1987). Predictors of stress in parents of developmentally disabled children. *Journal of Pediatric Medicine*, 12, 1, 133-150.

McLachlan, M., Dennis, P., Lang, H., Charnock, S. & Osman, J. (1987). Do the professionals understand? *Mental Handicap*, 15, 5-7.

Meirsschaut, M., Roeyers, H., & Warreyn, P. (2010). Parenting in families with a child with autism spectrum disorder and a typically developing child: Mothers' experiences and cognitions. *Research in Autism Spectrum Disorders*, doi:10.1016/j.rasd.2010.01.002.

Mickelson, K.D., Wroble, M., & Helgeson, V. (1999). Why My Child?: Parental Attributions for Children's Special Needs. *Journal of Applied and Social Psychology*, 29: 1263-92.

Milshtein, S., Yirmiya, N., Oppenheim, D., Koren-Karie, N. & Levi, S. (2010). Resolution of the Diagnosis Among Parents of Children with Autism Spectrum Disorder: Associations with Child and Parent Characteristics. *Journal of Autism and Developmental Disorders*, 40, 89-99. Doi: 10.1007/s10803-009-0837-x.

Moes, D., Koegel, R.L., Schreibman, L., & Loos, L.M (1992). Stress profiles for mothers and fathers of children with autism. *Psychological Reports*, 71, 1272-1274.

Moes, D. & Frea, W. (2002). Contextualised behavioural support in early intervention for children and their families. *Journal of Autism and Developmental Disorders*, 32: 519-533.

Montes, G., & Halterman, J.S. (2007). Psychological functioning and coping among children with autism: A population-based study. *Pediatrics*, 119, 1040-1046.

Morrisey-Kane, E., & Prinz, R.J. (1999). Engagement in Child and Adolescent Treatment: the Role of Parental Cognitions and Attributions. *Clinical Child and Family Psychology Review*, 2, 183-198.

Mugno, D., Ruta, L., D’Arrigo, V.G., & Mazzone, L. (2007). Impairment of quality of life in parents of children of children and adolescents with pervasive developmental disorder. *Health and Quality of Life Outcomes*, 5, 22.

Muhle, R., Trentacoste, S.V., & Rapin, I. (2004). The Genetics of Autism. *Pediatrics*, 113, 5, 471-486. Doi: 10.1542/peds.113.5.e472.

Murray, M. (2003). Narrative psychology. In J.A. Smith, (Ed.), *Qualitative psychology: a practical guide to research methods*. Sage, 111-31.

Nathan, P., & Gorman, J.M. (2002). *A guide to treatments that work*. New York: Oxford University Press.

NIASA. (2003). *National Autism Plan for Children*. London: National Autistic Society.

Noterdame, M., Amorosa, H., Mildenberger, K., Sitter, S. & Minow, F. 92001). Evaluation of attention problems in children with autism and children with a specific language disorder. *European Child & Adolescent Psychiatry*, 10(1), 58-66.

Nursey, A.D., Rohde, J.R., & Farmer, R.D.T. (1991). Ways of telling new parents about their child and his or hew mental handicap: a comparison of doctor’s and parents’ views. *Journal of Mental Deficiency Research*, 35, 48-57.

Odom, S.L., Brown, W.H., Frey, T., Karasu, N., Smith-Carter, L., & Stain, P. (2003). Evidenced-based practices for young children with autism. Evidence from single-subject research design. *Focus on Autism and Other Disabilities*, 18, 176-181. Doi: 10.1007/s10803-009-0825-1.

Olsson, M.B., & Hwang, C.P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual and Disability research*, 45, 535-543.

Oosterling, I.J., Wensing, M., Swinkels, S.H., van der Gaag, R.J., Visser, J.C., Woudenberg, T., Minderaa, R., Steenhuis, M.P., & Buitelaar, J.K. (2010). Advancing early detection of autism spectrum disorder by applying an intergrated two-stage screening approach. *Journal of Child Psychology and Psychiatry*, 51 (3), 250-258.

Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2009). Maternal insightfulness and resolution of the diagnosis are associated with secure attachment in preschoolers with autism spectrum disorders. *Child Development, 80*, 2, 519-527.

Osbourne, L.A. (2008). A dynamic transactional model of parent-child interactions. In P.Reed (Ed.) *Behavioural theories and interventions for autism*. New York: Nova Publishers.

Packenham, K.L., Sofronoff, K., & Samios, C. (2005). Adjustment in mothers of children with Asperger Syndrome. *Autism,* 9, 191-212.

Patterson, J.M, & Garwick, A.W. (1994). Levels of meaning in family stress theory. *Family Process,* 33, 1-18.

Philip, M., & Duckworth, D. (1982). *Children with disabilities and their families. A review of the research.* Windsor, NFER-Nelson.

Pianta, R.C. (1992a). *Manual for classification of the reaction to diagnosis interview.* Charlottesville: University of Virginia.

Pianta, R.C., Marvin, R.S., Britner, P.A., & Borowitz, K.C. (1996). Mother's resolution of their children's diagnosis: organized patterns of care giving representations. *Infant Mental Health Journal*, 17, 239-256.

Piven, J., Palmer, P., Jacobi, D., Childress, D. & Arndt, S. (1997). Broader autism phenotype: Evidence from a family history study of multiple incidence autism families. *American Journal of Psychiatry,* 154, 185-190.

Piven, J., & Palmer, P., (1999). Psychiatric disorder and the broad autism phenotype: Evidence from a family study of multiple-incidence autism families. *The American Journal of Psychiatry, 156,* 557-563.

Poehlmann, J., Clements, M., Abbeduto, L., & Farsad, V. (2005). Family Experiences Associated With a Child's Diagnosis of Fragile X or Down Syndrome: Evidence for Disruption and Resilience, *Mental Retardation*, 43, 4, 255-267.

Powers, M.D. (2000). Children with autism and their families. In M.D.Powers (Ed.) *Children with autism: A parents' guide* (p. 119-153). Bethesda, MD: Woodbine House.

Quine, L. & Pahl, J. (1986). First Diagnosis of Severe Mental Handicap: Characteristics of First Encounters between Doctors and Parents. *Social Science and Medicine*, 22, 53-62.

Quine, L. & Pahl, J. (1987). First Diagnosis of Sever Mental Handicap: A Study of Parental Reactions. *Developmental Medicine and Chid Neurology*, 29, 232-242.

Quine, L. & Rutter, D.R. (1994). First diagnosis of severe physical and mental disability: a study of doctor-patient communication. *Journal of Child Psychology and Psychiatry*, 35 (7), 1273-1287.

Randall, P., & Parker, J. (1999). *Supporting the families of children with autism.* Chichester: Wiley.

Reed, P., Osbourne, L.A., & Corness, M. (2007). Brief Report: Effectiveness of Different Home-based Behavioural Approaches to Early Teaching Intervention, *Journal of Autism and Developmental Disorders*, 37, 1815-1821. Doi: 10.1007/s10803-006-0306-8.

Reichow, B., Volkmar, F. & Cicchetti, D. (2008). Development of the evaluative method for evaluating and determining evidence-based practices in autism. *Journal of Autism and Developmental Disorders*, 38, 1311-1319.

Remington, G., Sloman, L., Konstanteraes, M., Parker, K., & Gow, R. (2002). Clomipramine versus haloperidol in the treatment of autistic disorder: A double-blind, placebo controlled, crossover study. *Journal of Clinical Psychopharmacology*, 21(4), 400-444.

Remington, B., Hastings, R.P., Kovshoff, H., Espinosa, d. F., Jahr, E., Brown, T. et al. (2007). Early Intensive Behavioural Intervention: Outcomes for Children With Autism and Their Parents After Two Years. *American Journal of Mental Retardation*, 112, 6, 418-438.

Richman, S. (2001). *Raising a Child with Autism*, Athenaeum Press, Gateshead, Tyne and Wear.

Riddick, B. (2008). Parents' perspectives on receiving, searching for and evaluating information relating to autism spectrum disorders: sorting the wheat from the chaff. *GAP*, 9, 1, 58-64.

Rimland, B., & Hill, A.L. (1984). Idiot savants. In J. Wortis (Ed.). *Mental retardation and developmental disabilities*, 13., 155-69. New York: Plenum Press.

Risch, N., Spiker, D., Lotspeich, L., Nouri, H., Hinds, D., Hallmayer, J. et al. (1999). A genomic screen of autism: evidence for a multi-locus aetiology. *American Journal of Human Genetics,* 65: 493-507.

Robbins, F.R., Dunlap, G., & Plienis, A.J. (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention*, 15, 173-184.

Rodrigue, J.K., Morgan, S.B., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology*, 19, 371-379.

Rogers, S.J. (1996). Brief Report: early intervention in autism. *Journal of Autism and Developmental Disorders*, 26 (2), 243-246. Doi: 10.1080/15374410701817808.

Rogers, S. J. (1998). Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child Psychology,* 27, 168-179.

Rogers, S.J., & Vismara, L.A. (2008). Evidence-Based Comprehensive Treatments for Early Autism. *Journal of Clinical Child and Adolescent Psychology,* 37 (1), 8-38.

Rutter, M., & Schopler, E. (1987). Autism and pervasive developmental disorders: conceptual and diagnostic issues. *Journal of Autism and Developmental Disorders*, 17, 159-86.

Sallows, G.O. & Graupner, T.D. (2005). Intensive behavioural treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation*, 110, 417-438.

Salt, J., Shemilt, J. Sellars, V. Boyd, S., Coulson, T., & McCool, S. (2002). The Scottish Centre for Autism preschool treatment programme II: The results of a controlled treatment outcome study. *Autism*, 6, 33-46.

Sanders, J.L., & Morgan, S.B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: implications for intervention. *Child and Family Behaviour Therapy,* 19 (4), 15-32.

Scahill, L., & Bearss, K. (2009). The rise in Autism and the Mercury Myth. *Journal of Child and Adolescent Psychiatric Nursing,* 22, 1, 51-52. Doi: 10.1111/j.1744-6171.2008.00152.x

Schecter, R., & Grether, J.K. (2008). Continuing increase in autism reported to California's developmental services system. *Archives of General Psychiatry,* 65, 19-24.

Schertz, H.H., & Odom, S.L. (2007). Promoting joint attention in toddlers with autism: A parents-mediated developmental model. *Journal of Autism and Developmental Disorders*, 37, 8, 1562-1575. DOI: 10.1007/s10803-006-0290-z.

Schreibman, L. (2000). Intensive behavioural/psychoeducational treatments for autism: research needs and future directions. *Journal for Autism and Developmental Disorders*, 30, 373-378.

Schreibman, L. & Anderson, A. (2001). Focus on integration: the future of the behavioural treatment of autism. *Behavioural Therapy,* 32: 619-632.

Seltzer, M.M., & Heller, T. (1997). Families and care giving across the life course: Research advances on the influence of context. *Family Relations*, 46, 321-323.

Senel, H.G. (2010). Parents' Views and Experiences About Complementary and Alternative Medicine Treatments for Their Children with Autism Spectrum Disorder, *Journal of Autism and Developmental Disorder*, 40, 494-503. Doi: 10.1007/s10803-009-0891-4.

Shah, K. (2001). What do medical students know about autism. *Autism*, 5(2), 127-133.

Sheeran, T., Marvin, R.S., & Pianta, R.C. (1997). Mothers' resolution of Their Child's Diagnosis and Self-Reported Measures of Parenting Stress, Marital Relations, and Social Support, *Journal of Pediatric Psychology*, 22, 2, 197-212. Retrieved from http://jpepsy.oxfordjournals.org on March 26, 2010.

Sheinkopf, S.J. & Siegel, B. (1998). Home-based behavioural treatment of young children with autism. *Journal of Autism and Developmental Disorders*, 28, 15-23.

Shevell, M., Majnemer, A., Rosenbaum, P. & Abrahamowicz, M. (2001). Profile of referrals for early childhood developmental delay to ambulatory subspecialty clinics. *Journal of Child Neurology*, 16(9), 645-650.

Shonkoff, J.P., Hauser-Cram, P., Kraus, M.W., & Upshur, C.C (1992). Development of infants with disabilities and their families. *Monographs of the Society for Research in Child Development*, 57, 1-153.

Sices, L., Feudtner, C., McLaughlin, J., Drotar, D., & Williams, M. (2003). How do primary care physicians identify young children with developmental delays? A national survey. *Journal of developmental and Behavioural Paediatrics*, 24 (6), 409-417.

Sicile-Kira, C. (2003). *Autism Spectrum Disorders: The Complete Guide*. London: Vermillion.

Siegel, B. (1997). Coping with the diagnosis of autism. In D.J. Cohen & F.R. Volkmar. (Eds.). *Handbook of autism and pervasive developmental disorders* (2nd ed., 5-38). New York: Wiley & Sons.

Siklos, S., & Kerns, K.A., (2006). Assessing Need for Social Support in Parents of Children with Autism and Down syndrome. *Journal of Autism and developmental Disorders*, 36, 921-933. Doi: 10.1007/s10803-006-0129-7.

Silverman, D. (1993). *Interpreting Qualitative Data.* London: Sage.

Singer, G.H.S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal of Mental Retardation*, 111, 155-169.

Singh, S., & Ernst, E. (2008). *Trick or treatment (alternative medicine on trial).* London: Bantam Press.

Sivberg, B. (2002). Family System and Coping Behaviours, *Autism*, 6, 397-409.

Sloper, P. & Turner, S. (1993). Determinants of Parental Satisfaction with Disclosure of Disability, *Developmental Medicine and Child Neurology*, 35, 816-825.

Smith, B., Chung, M.C., & Vostanis, P. (1994). The path to acre in autism: is it better now? *Journal of Autism and Developmental Disorders*, 24, 551-564.

Smith, T., Eikeseth, S., Klevstrand, M. & Lovaas, O.I (1997). Intensive behavioural treatment for preschoolers with severe mental retardations and pervasive developmental disorder. *American Journal on Mental Retardation*, 102, 238-249.

Smith, T., Groen, A.D., & Wynn, J.W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation*, 105, 269-285.

Solish, A., & Perry, A. (2008). Parents' involvement in their children' behavioural intervention programs: Parent and therapist perspectives. *Research in Autism Spectrum Disorders*, 2, 728-738. Doi: 10.1016/j.rasd2008.03.001.

Solomon, M., Pistrang, M., & Barker, C. (2001). The Benefits of Mutual Support Groups for Parents of Children with Disabilities, *American Journal of Community Psychiatry*, 29, 113-130.

Steffenburg, S. (1991). Neuropsychiatric assessment of children with autism: a population-based study. *Developmental Medicine and Child Neurology*, 33, 495-511.

Szatmari, P. (2003). The causes of autism spectrum disorders. *British Medical Journal,* 326, 173-174.

Tarakeshwar, N., & Pargament, K.I. (2001). Religious Coping in Families of Children with Autism. *Focus on Autism and Other Developmental Disabilities*, 16: 247-60.

Taylor, B., Miller, E., Lingam, R., Andrews, N., Simmons, A., Stowe, J. (2002). Measles, mumps and rubella vaccination and bowel problems or developmental regression in children with autism: population based study, *British Medical Journal,* 324: 393-6.

Thomas, K., Morrissey, J., & McLaurin, C. (2006). Use of autism-related services by families and children. *Journal of Autism and Developmental Disorders,* 37,5, 818-829.

Thomas, K., Ellis, A., McLaurin, C., Daniels, J. & Morrissey, J. (2007). Access to Care for Autism-Related Services. *Journal of Autism and Developmental Disorders*, 37, 1902-1912. Doi: 10.1007/s10803-006-0323-7.

Tobing, I. & Glenwick, D. (2002). 'Relation of the Childhood Autism Rating Scale-Parent Version to Diagnosis, Stress and Age', *Research in Development Disabilities*, 23, 211-23.

Todd, S. & Shearn, J. (1996b). Struggles with time: the careers of parents of adult sons and daughters with learning disabilities. *Disability and Society*, 11, 379-402.

Waaland, P.K., Burns, C., & Cockrell, J. (1993). Evaluation of needs of high and low income families following paediatric traumatic brain injury. *Brain Injury,* 7, 2, 135-146.

Waisbren, S.E. (1980). Parents' reactions after the birth of a developmentally disabled child. *American Journal of Mental Deficiency*, 84, 345-351.

Wakschlag, L.S. & Leventhal, B.L. (1996). Consultation with young autistic children and their families. *Journal of American Academic Child and Adolescent Psychiatry,* 35, 963-965.

Waltz, M. (1999). *Pervasive Developmental Disorders: Finding a diagnosis and getting help for parents and patients with PDD-NOS and Atypical PDD.* Sebastopol, CA: O'Reilly.

Weiner, B. (1985). An Attributional Theory of Achievement, Motivation and Emotion, *Psychological Review*, 92, 548-573.

Weiss, M.J., Fiske, K., & Ferraiol, S. (2008). Evidenced-based practice for autism spectrum disorders. In J.L. Matson (Ed.), *Clinical Assessment and intervention for autism spectrum disorders*. New York: Academic Press.

Whitaker, P. (2002). Supporting families of Preschool Children with Autism: What Parents Want and What Helps. *Autism,* 6, 411-426. Doi: 10.1177/1362361302006004007.

Wilkinson, S., Joffe, H., & Yardley, L. (2004). Qualitative data collection: Interviews and focus groups. In D.F.Marks, & L. Yardley, (Eds.). *Research Methods for Clinical and Health Psychology,(*2004), SAGE Publications, London, 39-55.

Williams, V., & Robinson, C. (2001). More than one wavelength: identifying, understanding and resolving conflicts of interest between people with intellectual disabilities and their families. *Journal of Applied Research in Intellectual Disabilities,* 14, 30-46.

Wing, L. (1988). The continuum of autistic characteristics. In E. Schopler, G.B., Mesibov (Eds.), *Diagnosis and assessment in autism*. New York: Plenum Press.

Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9, 11-29.

Wing, L., & Potter, D. (2002). The Epidemiology of Autism Spectrum Disorders: Is the Prevalence Rising? *Mental retardation and Developmental Disabilities Research Reviews*, 8: 151-161. Doi:10.1002/mrdd.10029.

Wong, H.H.L., & Smith, R.G. (2006). Patterns of complementary and alternative medical therapy use n children diagnosed with autism spectrum disorders. *Journal of Autism and Developmental Disorders,* 36, 901-909.

Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). Prevalence of autism in a US metropolitan area. *Journal of the American Medical Association,* 289, 49-55.

Yell, M.L., Drasgow, E., & Lowrey, A.K. (2005). No child left behind and students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities,* 20 (3), 130-139.

Zwaigenbaum, I., Szatmari, P., Bryson, S.E., MacLean, J.E., Tuff, L.P., Bartolucci, G., et al. (2002). Pregnancy and birth complications in autism and liability to the broader autism phenotype. *Journal of the American Academy of Child Adolescent Psychiatry*, 41, 572-9.