The University of Hull

The Impact of a Child's Autism on the Parenting Process

Being a thesis submitted in partial fulfilment of the requirements for the

Degree of Doctor in Clinical Psychology

In the University of Hull

By

Peter Burbidge BSc (Hons)

July 2007
Acknowledgements

I would like to thank all the parents that took part in this study and shared their experiences with me.

I would like to thank my son Joseph who was the reason that I chose a career in clinical psychology. He was the inspiration for this thesis and he was the principle obstacle to its completion.

I would like to thank my daughter Ceire who suffered in ‘silence’ as I neglected her over the last few months.

I would like to thank my wife for her ongoing support and for keeping me sane throughout this process.

Last of all I would like to thank Professor Masud Hoghughi for his unrelenting enthusiasm and perfectionism.
Abstract

This is an exploratory study investigating the impact of a child’s autism on parenting. It uses a psychological model of parenting to compare the process for a child with autism and for a child without autism. Nine parents were interviewed and the transcripts were analysed using Interpretative Phenomenological Analysis.

Three superordinate themes were identified: ‘What we do because of autism’ focuses on the parenting process and the extra demands that are placed on parents as a result of the child’s autism. ‘What autism has done to us’ describes the impact of the child’s autism on the parents and the family. It describes how the families of children with autism become isolated and socially excluded. The third superordinate theme ‘Different’ emphasises how children with autism are ‘different’, they are different from their siblings and they are different from other children.

All the themes are discussed in relation to previous research and in terms of the Hoghughi (2004) model of parenting: ‘Care’, ‘Control’, and ‘Development’. The parents’ accounts of their experience of parenting a child with autism highlighted several possible ways in which services could be improved and generated several possible areas of future research.
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CHAPTER 1: INTRODUCTION

Overview

This is an exploratory study of the impact of a child’s autism on the parenting process. This will be explored by using a model of parenting to compare the process of parenting a child with autism with that of a child without autism. This chapter describes autism and the historical background of the study of autism. It also sets out the theoretical bases on which this study was conceived.

The information in this chapter is based on a comprehensive literature review. The information was sourced from the author's own extensive collection of books and papers, use of the internet, electronic and hand searches of the Hull University library and comprehensive use of the web based academic search engines such as ‘psycinfo’ ‘webofscience’ and ‘ebscohost’.

What is Autism?

Autism is a pervasive developmental disorder, which is characterised by qualitative impairment in social interaction, communication and restrictive repetitive and stereotyped patterns of behaviour (American Psychiatric Association, 2000). It has been described as a broad spectrum of disorders (Wing and Gould, 1979) that covers a wide range of abilities and deficits. At one end of the spectrum, is the severely affected child with no language, that may spend hours on end staring along straight edges or flapping a piece of
string. At the other end is “the mad professor” who is highly skilled in his specialist subject but lacks ‘common sense’, is not able to have a meaningful conversation or make and maintain friendships.

What these extreme cases and all those that fall between them have in common is the triad of impairments described by Wing and Gould (1979) the severity and the style of the disability can vary enormously, but the three core deficits remain the same.

**Core Deficits and Features of Autism**

**Social interaction**

Deficits in social interaction are detectable from birth but are very subtle. They become much more noticeable as the child gets older and deviates from the normal developmental path.

Baron-Cohen & Bolton (1993) found that social deficits seen in babies that are later identified as on the autistic spectrum are;

- Difficulties in breast-feeding
- Not comforted when picked up
- Failure to engage in turn taking and baby talk
- Rarely give eye contact to anyone but the mother, and the eye contact has an unusual intensity
- Do not show preferences to faces over objects
- Do not orientate to social stimuli
• Prefer to be left alone to being played with
• Do not pick up emotional cues from body language

As the child gets older, the social deficits become more apparent. This includes deficits in non-verbal communication, lack of eye contact, failure to initiate interaction or maintain interaction. He may treat people as objects or as tools to get what he wants without any apparent recognition that the person exists in any other context.

**Communication**

This deficit goes beyond language. Some children with autism never develop language; others develop precocious language skills but are not able to have a meaningful conversation. Communication is limited to meeting their immediate needs. Some children without autism have language delays or do not develop language but they are still able to communicate using signs or gestures. Early signs of autism are a failure to show preference to speech like sounds over non-speech sounds and a lack of 'pro-declarative' gestures or vocalisation to direct other people's attention to something of interest (Klin, 1991). Many children with autism have no desire to communicate anything other than their basic needs.

Those children that do develop speech have deficits in understanding and expression. Common language abnormalities in autism include:-

• Echolalia, this is the repetition of a phrase or word that has been said to them, either immediately or delayed.
• Pronoun reversal: this is related to echolalia as children with autism will refer to themselves in the same way that others refer to them. They may use their own name or “you” instead of “I”.
• Poor pragmatics: this is the inability to infer meaning from a statement or to take a literal meaning from a statement.
• Inability to read nonverbal cues: a child with autism may go up to a complete stranger and say “you are fat” or tell them everything that they know about dinosaurs without any regard for the person’s reaction. They cannot detect the subtle cues that say “I want to speak now” or “I am not really interested in what you have to say”. The result of this is their speech can be a monologue about their favourite subject.

Imagination

The impairment in imagination is also described as restricted, repetitive and stereotyped patterns of behaviour or interests (APA, 2000). Children across the autistic spectrum often display narrow patterns of interest, for example a preoccupation with train timetables, Thomas the Tank Engine’ or dinosaurs. They lack imaginative or pretend play. They are unlikely to dress up as mummy or daddy or use a toy car to represent the real thing. Instead, they may become fascinated with parts of objects or arrange all their toys in neat rows. They can also use toys as part of ‘self stimulatory’ behaviour. Kanner describes two of the boys in his case studies as, “spinning every thing that could be spun and jumping up and down in ecstasy when they watched the
objects whirl about" (Kanner, 1943 p246). Other 'self stimulatory' behaviours include rocking and hand flapping. These tend to be more frequent when the child is not engaged in a meaningful activity or is distressed and have been related to deficits in their ability to initiate activities or interaction.

Incidence

It is more than 60 years since Kanner first described what is now known as classic autism (Wing & Gould, 1979) and at that time it was thought to be extremely rare. Since then the broadening of the concept of autistic disorders has resulted in a steady rise in the prevalence rates. In 1966 the prevalence using Kanner's Criteria was 4.5 per 10,000 children (Lotter, 1966). In the late seventies Wing and Gould (1979) found a prevalence rate of 15 per 10,000 based on the triad of impairments described above. In the 1990's, a total population study including all schoolchildren in the Gothenburg area of Sweden Ehlers & Gillberg (1993) found a prevalence rate of 36 per 10,000 using the Gillberg and Gillberg criteria for autism and Asperger's syndrome (Gillberg & Gillberg, 1989). This figure rose to 71 per 10,000 when they included children that met the criteria for Asperger's syndrome but had been previously undiagnosed.

In a more recent study Scott, Baron-Cohen, Bolton, & Brayne (2002) did a survey of all the schools teaching 5-11 year olds in the Cambridge area. They only included children with a definite diagnosis of autism. With a response rate of 79%, they calculated a rate of 50 in 10,000 children in the Cambridgeshire area. This was considered a conservative estimate as it did not include children with Statements of Special Educational Needs that
stated “suspected autism” and it assumed that there were no children with autism in the 21% of schools that did not respond.

Cost of Autism

In the UK there is no universal database that holds the numbers of people with autism or the cost of any treatment or benefits that they might be receiving. However, the fact that the costs to society are unknown and hidden does not make them any less significant. The true financial cost of autism is difficult to calculate as it is spread across multiple agencies including health, education, social services and the family.

Jarbrink & Knapp (2001) carried out a comprehensive study of the lifetime costs of autism. They separated them into costs to services and costs to the family.

Costs to services was based on

- Hospital services
- Other health and social services
- Living support
- Voluntary support
- Special education
- Medication
- Sheltered work
- Day care provision

The cost to the family were calculated as
- Productivity loses for people with autism
- Family members time costs
- Family expenses

They found that the average lifetime cost of a person with autism and an IQ below 70 was £2.94 million. Which, using a prevalence rate at five per 10,000 translates to an annual UK expenditure in excess of £1 billion.

The above did not include costs for adaptations to the home, or money spent on unvalidated treatments or indirect costs. These costs represent a significant financial burden to the parents. They include expenditure on:

- Damage to the house, furniture, clothes
- Transport
- Activities
- Extra education and therapy
- Court cases/ tribunals
- Extra help

Jarbrink, Fombonne, & Knapp (2003) estimated these expenses to be in the order of £65-£75 per week. This rose to approximately £300 per week when loss of income was considered. The financial considerations alone make autism an important political concern.
The Impact of a Child’s Autism

Historical Background

Some form of autism has probably always been around. Accounts of changelings and fairy children have been related to autism. In 1801 the French doctor Itard was given charge of a boy known as “The Wild Boy of Aveyron” at the time Itard thought that the child’s unusual behaviour was due to the fact that he had lived separated from humans. However, reading his reports with contemporary knowledge shows that he was almost certainly autistic (Wing, 2002). The account that he had a broad scar across his throat also hints at the fate of other autistic children in the past.

An alternative view is that autism is a relatively new disorder and its apparent growth since the 1940s is connected to the use of Thimerosal, a mercury-based preservative in vaccinations. Bernard Rimland is one of America’s leading researchers in to the causes and treatments of autism. He has charted the rise in incidence of autism from a few reported cases in the 1940s to it becoming the most common childhood disorder in the 1990s. This he speculates is directly linked to the introduction of Thimerosal in the 1930s and the increase in its use to date (Rimland, 2000).

It is more likely that there are multiple causes of autism, some ancient and some modern, and that its expression is the final common pathway of a variety of neurological and biological insults (Rutter, 1983). The different theoretical perspectives of autism and their implications to treatment will be discussed below.
Autism, in the modern sense, was first described by Leo Kanner in 1943 in a study of what he termed at the time ‘early infantile psychosis’. In a case study of 11 children, he observed that though each child was different in many ways, they had in common a number of characteristics that made up a unique syndrome. The parents of the children in his study had referred to their children as ‘in a shell’, ‘happiest’ when left alone’ and ‘acting as people weren’t there’. Kanner described them as follows.

“This is not, as in schizophrenic children or adults a departure from an initially present relationship; it is not a withdrawal from a formally existing participation. There is from the start an extreme autistic aloneness that, wherever possible, disregards, ignores, shuts out anything that comes to the child from the outside”

(Kanner, 1943 p. 242).

Kanner described six distinct traits that were common to all the children in his study.

1. Extreme autistic aloneness: This was characterised by a failure to socialise with people in a normal way.

2. Anxious obsessive desire for the preservation of sameness: children became extremely distressed at changes in routine or environment.

3. Excellent rote memory

4. Delayed echolalia: Children repeated language that they had heard but were not able to use language beyond the satisfaction of their immediate needs. Kanner also described pronoun reversal as part of this trait.
5. Hypersensitivity to stimuli: The children reacted very strongly to certain sound or textures.

6. Limitations in the variety of spontaneous activity: Kanner described this as related to the insistence of sameness. Children would spend hours playing with simple toys in a repetitive and ritualistic way.

Kanner acknowledged that this was probably not a new condition and that children like these had existed previously. In the past individual cases had been identified but they never previously been linked together to form a discrete syndrome. Following his 1943 publication, Kanner treated approximately 100 children that met his criteria and became aware of many more (Kanner, 1951). This confirmed what he had previously believed, that “early infantile autism” as he now called it was a lot more prevalent than had been initially thought.

Shortly after the publication of Autistic Disturbances of Affective Contact (Kanner, 1943), Hans Asperger published his first paper on what is now called ‘Asperger’s Syndrome’ (Asperger, 1944). This was a study of a group of children that also had a consistent pattern of behaviours. He was aware of Kanner’s work and described the children in his study as having some autistic traits but he believed that they represented a separate syndrome (Wing, 2002).

The current thinking is that Asperger’s syndrome is a variant of autism and is considered to be a sub-group of within the autistic spectrum disorders and
has its own diagnostic criteria (Attwood, 1999). The main diagnostic differences between Asperger’s syndrome and autism are:-

- Children with Asperger’s syndrome appear to develop normally until the age of three or four, whereas in autism developmental delay and deviation are apparent much earlier.

- Children with Asperger’s have precocious language abilities characterised by over pedantic speech, whereas in autism it is often the delay or absence of language that first alerts parents and professionals that something is wrong.

- Intellectual profiles of Asperger’s syndrome usually show a significant discrepancy between performance IQ and Verbal IQ with the latter being higher, whereas in autism where there is a discrepancy it tends to be in the other direction.

- Children with Asperger’s syndrome tend to be clumsy and adopt awkward postures, and lack athletic ability, whereas in autism children tend to have better gross motor skills and be more athletic.

There are also differences in social interaction, intellectual ability and the focus and intensity of interests (Volkmar & Lord, 1998).

As Kanner’s autism became more well known, many more children were identified that did not strictly meet the criteria for ‘early infantile autism’ or ‘Asperger’s syndrome’ but shared many features and benefited from similar interventions. With more children being identified the criteria for autism was broadened to what is now known as the ‘autistic spectrum’. This incorporates the whole range of autistic features with ‘Kanner’s’ or ‘classic’ autism at one
end of the spectrum and 'high functioning autism' and 'Asperger's syndrome' at the other end. The common thread that unites the spectrum is the 'The Triad of Impairments' (Wing and Gould, 1979).

**Theories of Autism**

When Kanner first described autism, he described it as an "innate inability to form the usual, biological contact with people" (Kanner, 1943 p. 205). At this early stage, Kanner recognised it as something that the child was born with. He described the parents of his case studies as "not warm-hearted mothers and fathers" they were instead highly intelligent, obsessive people who were preoccupied with their own academic achievements or careers. Kanner never actually blamed the parents but his observation that the parents were cold and intellectual was the bases for the psychogenic theory that autism was a withdrawal into the self as a consequence cold unavailable parents.

**Psychogenic Theories**

Bettelheim (1967) argued that some children had an inborn disposition to withdraw from the world and that this was then triggered by the fear they experienced from the mother. He likened the relationship between a mother and her autistic child to the relationship between a concentration camp guard and the prisoner. A relationship based on so much fear that the prisoner focused all attention on the guard and eventually became insensitive to all experience, hence the prisoner's withdrawal into his or her inner world. He
concluded that in autism, this 'withdrawal' into the inner world was caused by cold, unemotional, inadequate parenting and the stereotype behaviours and language abnormalities were the child's expression of hostility towards parents that did not fulfil his or her needs. Some of the children that he treated may well have had cold unemotional parents but careful examination of the cases presented in "The Empty Fortress" reveals that at least some of the children that the book is based on would not meet the current criteria for autism. Other psychogenic theories have been based on 'attachment theory' (Bowlby, 1969), 'object relations theory' and from studies of social deprivation in primates (Krech, Rosenzweig, & Bennet, 1966). The early psychogenic theories of autism did not stand up to rigorous empirical research and have been largely discredited (Rutter, 1971). More recently, the study of Romanian orphans has linked extreme deprivation with autism. However, the autistic features found in these children were atypical and tended to fade, as they got older. This suggests that this is not the same condition (Bailey, Philips, & Rutter, 1996).

**Cognitive Theories of Autism**

The study of the cognitive deficits in autism has two aspects, the broad and the narrow. The narrow focuses on specific deficits that effect only social-cognitive functioning, whereas the broad focuses on deficits that affect both social and non-social development (Bailey *et al.*, 1996). Historically the study of autism from a cognitive perspective has gone from broad in the 1970s to narrow in the 1980s and 90s and broadened out again to present.
The Narrower Perspective

Failure to find one broad deficit that could explain all the features of autism caused the research focus to shift to looking at the cognitive processing of specific information. Rutter (1983) looked at how children with autism process facial information, emotional expressions and the mental inner states of others. He found that children with autism tend to process the face as a set of unconnected component parts rather than as a whole. A study of how children with autism process emotional information found that rather than group faces by emotional expression they would group them based on another feature like the size of their hat (Bailey et al., 1996) this was in contrast to the controls who were inclined to group them by displayed emotion. Rutter’s study of the inner mental states of others was the first in what is now a large body of research into the ‘Theory of Mind’

The ‘Theory of Mind’ hypotheses (Baron-Cohen, Leslie, & Frith, 1985) are based on the finding that children with autism perform badly on tests of what other people might think. The most famous test is the “Sally, Anne Test” in this test, the clinician plays out a story in which there are two dolls. One doll puts an object in a basket then leaves the scene. The other doll then takes the object from the basket and places it in a box. The child is asked where each doll would look for the object. Children with autism will only choose the place where the object is. They cannot see the situation from another’s perspective. This deficit is not explained by a general impaired mental ability as children without autism with a lower mental ability can pass the test with ease.
Leading researchers in this area believe the triad of impairments found in autistic children stems from their lack of ability to read other peoples thoughts and intentions. It also accounts for the child's lack of pretend play, which, in a normally developing child "demonstrates the emergence of a startling new cognitive capacity, on which are built many of the child's most important abilities" (Happe & Frith, 1995 p. 179).

The Broader Perspective

The observation that patients with known brain lesions to the frontal lobes exhibited some behaviour that was consistent with autism has led researchers to look at the role of executive function. This is the ability to problem solve, inhibit behaviour, disengage from external context, plan and generate a sequence of willed actions and the ability to monitor one's own performance and respond to feedback (Bailey et al., 1996). Children on the autistic spectrum have deficits in all these areas (Ozonoff, 1994).

'Executive dysfunction' explains autism as difficulty in generating behaviours. Another way to look at it as a difficulty in processing information, Frith (1989) described this as a weak central coherence. In normal processing, humans view a situation as a whole. Sound, vision, touch and smell are integrated to form a complete image of the event. When the event is later recalled the individual details may be lost but the overall picture and the meaning of the event are retained. For a person with a weak central coherence the details
are not integrated so the event is processed as a series of parts. The sounds are not connected to the image or the smells. A person with autism may remember every single detail of the event without ever having integrated them into a whole, or understood the meaning.

This is consistent with the way that people with autism process faces. They see the face as an eye or a nose or as a mouth but not as a whole (Rutter, 1983). Personal accounts from people with high functioning autism describe how they may see a person as a series of parts, an eye, a nose or a hand but they do not perceive the person as a whole (Williams, 1996)

**Biogenic theories**

**Genetic transmission**

Evidence from twin and family studies show that there is a genetic link in autism, but the mode of transmission is complex. Folstein and Rutter (1977) found a 36% pair wise concordance rate in monozygotic twins and a 0% concordance rate in dizygotic twins. The rates of incidence in siblings is considerably higher than in the normal population approximately 3-7% (Bailey et al., 1996). This represents an increased probability of 50-100.

**Obstetric Factors**

Several environmental factors have been linked with autism but the evidence is inconclusive (Bailey et al., 1996). In the 1970s, autism was found to be quite common in children with congenital rubella. However, follow up studies
found that the autistic symptoms faded over time. Congenital rubella is extremely rare in today's society so it cannot be considered a significant factor in modern autism. Maternal infections during pregnancy have also been linked to autism but systematic study has found no evidence to support this (Bailey et al., 1996).

Folstein & Rutter (1977) found a link between obstetric complications and autism, mothers of twins reported more complications with the twin with autism than the one without. Though this is unlikely to be a factor as the complications were minor and the association between autism and obstetric complications and autism in singletons is very weak (Bailey et al., 1996).

As described above the increased prevalence of autism has been linked to the increased use of vaccinations containing the mercury-based preservative Thimerosal (Rimland, 2000).

**Behavioural perspective**

Ferster (1961) was the first to describe autistic children from a behavioural perspective. He suggested that contrary to the popular opinion of the time that autism was not indicative of an underlying emotional disturbance but was in fact due to a failure to learn from normal social stimuli such as praise and social reinforcement. To test this theory Ferster & DeMyer (1961) taught children with autism to pull levers by using food as a primary reinforcer. Ferster's work was important, as it was the first to show that learning theory
could be applied to children with autism and it showed that autistic behaviours were related to environmental events (Lovaas & Smith, 1989).

The previously discussed theories of the aetiology of autism each try to explain possible causes of autism. However, autism represents a heterogeneity of symptoms and behaviours. The diagnosis of autism may in reality represent a multiplicity of behavioural problems and a multiplicity of aetiologies (Rutter & Schopler, 1978). The behavioural approach is different in three major areas.

Firstly, the behavioural approach does not try to find one all-embracing cause or treatment of autism; it breaks the problem down into smaller units and looks at the causes of individual behaviours. This bottom up approach allows for analysis of behaviours, whether or not all children with autism exhibit them.

Secondly, instead of trying to establish the aetiology of problem behaviours this approach looks at what in the current environment triggers the behaviour. In this way, experimental manipulations of the current environment are used to establish effective interventions.

The third difference between the behavioural approach and the other major theories is that it is deductive rather than inductive (Lovaas & Smith, 1989). Each study in this paradigm builds on the knowledge gained from the previous studies as opposed to trying to replicate or falsify them.
The behavioural theory is the only one that offers any scientific bases for treatment. The difficulty is that the treatment places enormous demands on the family. In order for children with autism to learn and develop to a similar level as children without autism they need intensive one to one teaching for at least 40 hours per week (Lovaas & Smith, 1989).

**Prognosis**

The prognosis for a child diagnosed with autism is poor. According to the National Autistic Society (National Autistic Society, 2007), approximately 5-10% of autistic children will become independent as adults 20-30% will make good progress but will still need support and supervision, the rest will remain severely handicapped and dependent on their parents or on institutional care for life. Estimates of outcomes vary dependent on the inclusion criteria for the studies and the education offered. What does remain consistent is that the outcomes fall into three groups. These can be considered as good, moderate and poor.

Freeman (1997) describes the three groups as half of children remain in "the retarded range" and need high levels of care through out their lives. A quarter develop normal motor movement and language before the age of five and go on to be able to live in supported living. The final quarter have IQs in the normal range and go on to have jobs and some even have families.

A recent longitudinal study described the adult outcomes of 64 adults with autism (Howlin, Goode, Hutton, & Rutter, 2004). All the participants had been
assessed as children and had IQs over 50. They found that 10% were able to live independently as adults, 35% were in supported living and the rest remained highly dependent on their parents or residential care. They also found that an IQ over 50 was not a predictor of good outcome but an IQ over 70 was.

In order to appreciate the impact that autism has on the parenting process it is first necessary to examine the parenting process for non-disabled children and for children with disabilities other than autism.

**Parenting**

The Oxford English Dictionary defines parenting as *'the concern or occupation of parents'*. This highlights the breadth of the concept of parenting. It can be thought of as a catchall phrase that encompasses the array of skills and activities that are performed by adults in relation to childrearing. Most people will become parents at least once in their lives (Wollet & Nicolson, 1998). The desire to have children is not only a natural “instinct” but is also shaped by the social construction of what it means to be a complete man or woman (Arendell, 1997).

Historically, expectations of parenthood were based on tradition, practical experience and religious and cultural ideologies. In contemporary parenting, this is still true to a certain extent. However, prospective parents are exposed to ideologies and models of parenting depicted in magazines, childcare
manuals, documentaries and commercial television. The result of all this information is that people have complex expectations of what it is to be a parent in a society like contemporary Britain. Though most people would not be able to articulate what that expectation is, they would be able to tell if their own experience of parenthood deviated significantly from it.

It is not possible to describe parenting as a single activity that is situated in time a space. It is more a multitude of activities that are dependent on demography and history (Arendell, 1997). The social context of parenting is ever changing and is very different now to how it was 30 years ago. In the United Kingdom, fathers now work longer hours, there are more families where both parents work and conversely there are more families where neither parent works. These changes are set in a climate of more single mothers, an increased divorce rate and reconstituted families. Many children have more than two parent figures and live in more than one home (Utting & Pugh, 2004).

The context of parenting is ever changing and varies considerably across cultures but the process remains the same. It is a two-way interaction between the child and the parent, characteristics of the child can influence the style of parenting as parenting style can influence characteristics of the child. The child is not a passive recipient of parental input and the parent is not a ubiquitous provider. The child may at one time demand care from the parent and at another feel satiated with care and reject the parent’s advances (Hoghughi, 2004). The parenting activities change with time as a child and
the parents get older the roles change. The care giving roles are gradually equalised and then reversed with the adult child eventually caring for his elderly parents.

Quality and style of parenting varies between individuals, and there is no known formula or need for perfect parenting (Hoghughi & Speight, 1998). The concept of ‘Good enough parenting’ was first described by Winnicott (1958) and is based on the premise that the vast majority of parents provide their children with enough of the core elements of parenting to meet their needs. The difficulty lies in defining what these core elements are.

**Models of Parenting**

*Belsky and Vondra (1989)*

Belsky and Vondra (1989) reviewed previous research which identified factors contributing to optimal parenting behaviours and positive outcomes for children. The model that they developed presumes that the parenting is directly influenced by the parent’s personality, the child’s characteristics and the broader social context within which the parenting takes place. Their model is summarised below.

**Parent**

Sensitivity, including:

- Sensitivity to the child’s capabilities, developmental tasks and cues
- Capacity to empathise and nurturant orientation
- Realistic expectations and appropriate ascription of child’s intentionality
Psychological maturity, with:

- A stable sense of self, self esteem and internal locus of control
- Belief that own psychological needs are being met
- Capacity to show affection
- Ability to enable others
- Active coping styles recognition of effects of one’s own behaviour

Mental health, including:

- Warmth, parent initiated interactions and spontaneity
- Environment stability and organisation

Developmental history of:

- Affectionate parenting
- Intact family

Child

Physical, including:

- Obstetric and developmental health

Temperament, such as:

- Easy to parent
- Reinforces parent’s sense of control

Context

Support, from:

- Partner
- Social network
Another way to look at parenting is to use the “Assessment Framework for Children in Need and their families” (Department of Health, 2000). It is poignant to look at this model (Figure 1) as all the children in this present study would be classed as children in need by the Children’s Act (Department of Health, 1989). Not all disabled children classed as “Children in Need” will have been assessed under this framework, as some have enough social support through extended family and friends not to seek additional help. These children have been described as existing with in a buffered system (Belsky & Vondra, 1989). It is only when the buffers are not sufficient that the parents may seek outside help.

Figure 1. The assessment framework for children in need

The assessment framework can be viewed as three interrelated domains each of which has a number of critical dimensions.
Child’s developmental needs

Health

This includes physical and mental wellbeing, receiving appropriate health care when ill, an adequate diet, exercise, immunisations and developmental checks. It also includes dental and optical care and information on sex education and substance misuse.

Education

This is cognitive development from birth including opportunities for play and socialising with other children. An appropriate adult should be interested in the child’s activities, progress and achievements.

Emotional and Behavioural Development

This is about early attachment, the temperament of the child, its ability to adapt to change and the appropriateness of responses to the feelings of parents and others. The child needs to be able to manage stress and demonstrate self-control.

Identity

The sense of self as a separate and valued person. This includes self-esteem and a sense of belonging and acceptance by family, peer group and wider society.

Family and Social Relationships

This relates to the development of empathy, it includes the capacity to place self in someone else’s shoes; it includes stable and affectionate relationships with parents and good relationships with siblings and peers.

Social Presentation
Concerns child’s understanding of how appearance and behaviour are perceived by others.

**Self Care Skills**

Practical skills like dressing and washing, as the child gets older opportunities to undertake activities away from the family and learn independent living skills.

**Parenting capacity**

**Basic Care**

Providing for the child’s physical needs, and appropriate medical and dental care. Includes provision of food, drink, warmth, shelter, clean and appropriate clothing and adequate personal hygiene.

**Ensuring Safety**

Ensuring the child is adequately protected from danger both in the home and elsewhere. This includes contact with unsafe adults or children.

**Emotional Warmth**

Ensuring the child’s emotional needs are met and giving the child a sense of being specially valued and a positive sense of own identity. Includes ensuring the child’s requirements for secure, stable and affectionate relationships with significant adults. Appropriate physical contact, comfort and cuddling.

**Stimulation**

Promoting child’s learning and intellectual development through encouragement and cognitive stimulation and promoting social opportunities. Encouraging the child’s play, and promoting educational opportunities.

**Guidance and Boundaries**
The parent’s role is to model appropriate behaviour and control of emotions so that the child can develop an internal working model of moral values and conscience appropriate to the society in which they live.

**Stability**

Providing a sufficiently stable family environment to enable a child to develop and maintain a secure attachment to the primary caregiver(s) in order to ensure optimal development.

**Family & environmental factors**

**Family History and Functioning**

Family history includes both genetic and psycho-social factors. It is influenced by who is living in the family home and how they are related to the child this includes parents, stepparents and siblings.

**Wider Family**

Who are considered to be members of the wider family by the child and the parents? Includes related and non-related persons and absent wider family.

**Housing**

Is the accommodation suitable to the needs of the family? Basic amenities include water, heating, sanitation, cooking facilities, sleeping arrangements and cleanliness, hygiene and safety and their impact on the child’s upbringing.

**Employment**

Who is working in the household, their pattern of work and any changes? What impact does this have on the child? How is work or absence of work viewed by family members?
Income

Is the family income sufficient to meet its needs? Are there financial difficulties, which affect the child?

Family’s Social Integration

This is the family in the context of the community in which they live. Are they able to integrate into society or are they isolated. What are their social networks and peer groups.

Community Resources

This is the facilities and services in a neighbourhood that are available to the family, including primary health care, day care and schools, shops and leisure activities.

Hoghughi (2004). Care, Control and Development

The Hoghughi model was developed to help define what constituted ‘good enough’ parenting in response to well publicised incidences of child abuse, including the murder of Jamie Bulger by two ten year old boys, the apparent racist killing of Stephen Lawrence and the murder and abuse of many children by Fred and Rosemary West (Hoghughi & Speight, 1998).

Parents do many things for, and about, their children in many different social and environmental contexts. Given the vast array of activities that parents do, both positive and negative, parsimony demands finding what the core activities that are both necessary and sufficient for ‘good enough’ parenting. Hoghughi and Speight (1998) defined the core activities of ‘good enough’ parenting as:

1. Love, care and commitment
2. Control/Consistent limit setting

3. Facilitation of development

These were later refined to:

*Care, Control and Development* (Hoghughi, 2004)

**Care**

Care encompasses activities that enhance a child's chances of survival. These activities are divided into physical care, emotional care and social care.

*Physical care* consists of providing the child with what he needs to survive, food, warmth and shelter. Physical care also includes keeping the child safe from harm. Threats to the child's wellbeing include accidents in the home or garden, road traffic accidents, infections and diseases or harm from others. Activities that parents do to enhance physical care are, working to provide a suitable home for the child, providing the child with adequate healthy food, ensuring that the child gets enough sleep and minimising their exposure to dangerous environments and diseases.

*Emotional care* involves activities are aimed at keeping the child happy and secure. Adequate emotional care consists of providing a calm and stable environment where the child is the subject of unconditional love and is able to form secure attachments. It is important that the child has a secure base and is able to experience consistent positive interactions with the environment; this will enable the child to develop an optimistic orientation to new experiences (Hoghughi, 2004).
Social care encompasses activities aimed at making sure that the child is not isolated from their peers and adult role models, such as grandparents and teachers. The ability to form these relationships is an important part of the child's sense of self and their self-esteem. When a child is disabled, their opportunity to form these important relationships can be compromised, either through their inability to communicate with others, or others inability or unwillingness to communicate with them (Linnington, 2002).

Control
Control consists of setting and enforcing boundaries for the child so that he or she learns to behave in a cultural and age appropriate way. The emphasis of parental control is necessarily on behaviour as this is the outward expression of thoughts and emotions. The manner and the method of control vary greatly from family to family, and from culture to culture. The effectiveness of control is determined by many factors, including the parents' own history and early experiences of control, the resources available to the parents, and the levels of competing peer pressure experienced by the child (Hoghugh, 2004). Parental stress can lead to ineffective methods of control, which can conversely lead to higher levels of parental stress (Beresford, 1994). This is a common factor in parents caring for disabled children (Burke, 1994; Roll-Pettersson, 2001).

Development
Most parents want to see their children fulfil their maximum potential. Once a child’s care and control needs are met then the parents can encourage their child to participate in activities that are aimed at encouraging experiential growth (Hoghughi, 2004). For example by providing the child with a range of opportunities such as, sport, music and art or to travel and see a wide range of landscapes and cultures.

This is a similar concept to Maslow’s Hierarchy of Needs (Maslow, 1962) where a person’s cognitive and self-actualisation needs can only be addressed once all their lower order (physiological and security) needs have been met. This concept is described quite eloquently in a social services guide to what constitutes ‘good enough’ parenting; it states that society has an expectation that parents will

"...provide an environment in which a child can grow adequately in an atmosphere of security, affection and acceptance; be protected from danger and be nurtured and controlled adequately. The child also needs to be able to play and have sufficient freedom to explore and to learn; parents are also expected to ensure children are educated…"

(Bentovim & Bingley, 1985 p.45)

The three models of parenting described above have their individual merits and each one could have been used to study the impact of autism on the parents or the family. The Belsky and Vondra (1989) model looks at the meso-system, examining the parent’s own history of being parented, mental
health, support and relationships, the social context and the child characteristics.

This could have been a useful tool to examine how the family cope with the child’s autism and how the characteristics of the child and the personality of the parents contribute to the way that they cope.

The Department of Health (2000) model examines the macro-system including extended family, social context, employment, housing and community support. This also could have been used to look at how economic and social factors influence the parent’s ability to cope and what support they may need.

However this study aims to examine the impact of the child’s autism on the parenting process, the micro-system. The Hoghughi (2004) model will be used as it is the only one that examines the parenting process not the parent’s themselves. It is hoped that this model will enable this study to compare how each parent’s experience of parenting his or her child with autism is different from the experience of parenting his or her child without autism. The other models described were not chosen as they are more relevant to looking at differences between parents, as opposed to within parents.

Use of this model also builds on previous research that has used the care, control and development model to examine parenting amongst refugees and
asylum seekers (Koschalka, 2006) and to examine parenting children with epilepsy (Nattycoombe, 2006).

**Parenting a Child with a Disability**

Parenting a child with a disability is a qualitatively different process from that of a child without a disability though it need not necessarily be a less rewarding one (Beresford, 1994). However, the majority of the research views it negatively when compared to parenting a child without a disability. The literature reviewed below falls into two broad categories, stress and extra demands on parents caused by having a disabled child (Burke, 1994; Hassall, Rose, & McDonald, 2005; Roberts & Lawton, 2000; Roll-Pettersson, 2001) and the loss and stigma that parents feel in reaction to having a disabled child (Dale, 1996; Gray, 2002; Hannam, 1988; Roll-Pettersson, 2001)

All parents expect to care for their children; with young infants, this care is total with parents being responsible for all aspects of care. As a child gets older, they become more autonomous and the level of care that they need changes. Disabled children require the same levels of care as non-disabled children. In addition, they need the specialist care that is the consequence of their disability.

Roberts & Lawton (2000) examined the records of 40,000 disabled children whose parents had applied to the family fund for financial help. The main areas of extra care that they identified were washing, dressing, meal times,
The high level of care that is required by some disabled children can leave parents with little time and energy for control and development. This extends beyond the disabled child to his or her siblings. Burke (1994) studied the impact that this had on 20 families with particular reference to the siblings. He found that parents were often more lenient with their disabled children, allowing them leeway that was not tolerated in their non-disabled siblings. This led to additional behavioural problems in the disabled child and resentment and attention seeking behaviour in the siblings. In some cases, the siblings took on the symptoms of a disability as a maladaptive way of attaining the perceived attention and lenience showed to their brother or sister.

Dale (1996) describes parents' reactions to the diagnosis of disability in terms of grief and loss. She describes stages similar to those of grieving after the death of a child. The stages are shock, denial, sadness, adaptation and reorganisation. In this model, the parents mourn the loss of the expected child before they can accept the disabled child. This implies that parents go
through a linear process. However, parents do not always go through all the stages in a set order, sometimes they can oscillate between stages. The stage model also implies that there is a final stage of acceptance and adaptation. Russell (1983) found that some parents never fully accept the disability and he proposed that this is not necessarily a pathological way of coping, just a different way.

These findings are in line with the “Chronic Sorrow Model” (Olshansky, 1962) in which well-adjusted parents of disabled children still have feelings of sorrow for the loss of the expected child for many years. In this model, periods of acceptance are interspersed with periods of sorrow. Sorrow is often triggered by significant events such as the onset of puberty, 21st birthdays and when siblings or other people’s children are getting married and starting families. The feelings of loss felt by the parents can adversely affect the way in which they interact with the child.

Acceptance of the disability enables parents to value the child and celebrate all his achievements however small. Where parents have not fully accepted the disability they may see the child for what they are not, the future dreams and aspirations that this child will not fulfil. Once the mother receives the news that her baby has a problem she can no longer clearly imagine it as a toddler, as a child or as a parent or as some one who might take care of her when she is old. Not only has she lost her ideal baby, she has also lost the fantasy of the future for her and her family (Linington, 2002)
Roll-Pettersson (2001) interviewed 47 parents of children with mild to severe cognitive disabilities. She found some of the parents went through the stages mentioned above from initial shock through to acceptance. However, the majority of parents reported the recurrence of difficult events and long periods of stress or sadness, as the care needs of their children did not diminish over time. Another significant finding was that parents of children with severe disabilities tended to live one day at a time, as thinking about the future was too difficult or too painful. This has, in the past been seen as a maladaptive coping mechanism where as Roll-Pettersson found it to be an adaptive response to overwhelming demands.

Hannam (1988) interviewed the parents of mentally handicapped children over a period of 13 years. He found that, the way in which people had been told about their child’s diagnosis had had a deep and long lasting affect on the way in which they perceived the disability, how they interacted with professionals and services and what coping mechanisms they used. He also found that not thinking about the future, living one day at a time, was a common response in the parents of young severely disabled children. This only became a maladaptive strategy as the children got older. In his sample of 12 families, some did eventually accept the disability and make plans for the future before the children were at school leaving age. However the ones whose children had severe behavioural problems struggled on until things reached crisis point before their children were found appropriate adult placements.
Gray (2002) found that the most difficult disabilities for parents to accept were in normal looking children with behavioural problems. He found that the parents of these children reported that they were reluctant to go out as a family, they were less likely to invite people around to the house or be invited to others houses. Several of the parents reported that they felt it would be easier to cope if their child looked disabled as they do in Down's syndrome, they felt that people would then be more tolerant of their child's behaviour.
Parenting a Child with Autism

The larger part of the literature on parenting a child with autism either looks at parents experience and reactions to receiving a diagnosis of autism (Brogan & Knussen, 2003; Mansell & Morris, 2004; Midence & O'Neill, 1999) or the stress experienced by parents and their ways with coping with it (Bromley, Hare, Davidson, & Emerson, 2004; Higgins, Bailey, & Pearce, 2005; Honey, Hastings, & McConachie, 2005; Sivberg, 2002; Weiss, 2002).

Receiving the Diagnosis

For the parents of a child with autism the experience is about more than stress and coping and more than the reaction to the diagnosis (Caldwell, 2000; Maurice, 1993). The whole experience has been described as a journey that begins with the birth of the child (Andron, 2001; Kleinfield-Hayes, 1996; Maurice, 1993). There are no 'physical signs' of autism revealed in obstetric tests, no genetic tests or chromosome abnormalities to give an indication of what the future holds. The parent's are free to plan and fantasise about the future with their seemingly perfect child. This period of normality can last anything from six months to two years but the average is about 18 months (Midence & O'Neill, 1999).

Gradually parents start to notice unusual features. The child does not care whether they are in the room or not. he does not raise his arms to be picked up, he does not engage in mutual gazing or baby talk, he does not prefer to
look at his mother's face, he does not show interest in most toys he will not role over or crawl - all features found in normal children. Not because he cannot but because he has no desire, he is not interested in anything (Mansell & Morris, 2004). The feature that most commonly brings the child to the attention of professionals is language development. For some children with autism their language is delayed, for some it never develops, for others it develops in an unusual way.

The onset of autism has been described in many different ways by different parents. For some the child does not reach developmental milestones, for others the child develops normally up to 18 months and then loses skills and language that he has previously learned.

“When Brandon was 18 months old, I began to notice changes in him. For example, he was always good at completing puzzles. Now, he would just scatter the pieces. He wouldn’t wave bye-bye or respond to his name. He could no longer drink from a cup. He lost the few words that he had acquired.”

(Klienfield-Hayes, 1996 p.373)

The period of time between the parents first noticing that there is something not right with their child and them receiving a formal diagnosis has been described as the “pre-diagnosis period” (Mansell & Morris, 2004). This period can take anything from a few months to several years. During the pre-diagnosis period parents experience a mixture of confusion and self-doubt.
Parents are aware that something is wrong but do not know what it is. The not knowing can lead parents to doubt their own ability and to believe that the child's difficulties are due to something that they have done wrong (Midence & O'Neill, 1999).

During this period, parents often suspect autism but many experience long delays in getting a diagnosis. Midence & O'Neill (1999) recount a parent's experience of repeatedly taking her child to the GP and being told that nothing was wrong. Maurice (1996) describes parents having to "hound the paediatrician" and even then having their concerns denied or underplayed. Professionals give false reassurances and misleading information or "soft diagnoses" such as "developmental delay" or "language delay". These imply a temporary condition where the child will eventually "catch up" (Avidi, Griffin, & Brough, 2000). Parents are made to feel that they are making a fuss about nothing and that their child would be ok if they would just let them develop at their own rate.

Parents have different reactions to receiving the diagnosis of autism. Midence & O'Neill (1999) described as a mixture of relief and shock. The relief for parents is the feeling that somebody has finally confirmed what they had suspected and that they now have a label that will help explain the child's behaviours to themselves and others. Relief also because the diagnosis can act as a sign post to point the parents in the direction of the appropriate research and support (Jackson, 2002). Parents also feel shock and disbelief, as they start to contemplate the meaning of a life with autism.
and a duty of care that will last for the rest of their lives and beyond (Seigal, 1997).

The way that the diagnosis is given to the parents can make a significant difference to their reaction at the time and the way that they cope in the future. Mansell and Morris (2004) surveyed parents' reaction to diagnosis and how it changed over time. They found that the way in which the diagnosis was given made a difference to the way that they perceived autism and the amount of subsequent contact they had with services. The things that were perceived as helpful at the time of diagnosis were the diagnosis being made before school age, provision of information about interventions and available services, optimism about the future from the professional giving the diagnosis, follow up appointments shortly after the diagnosis and the feeling that the parent's concerns were being taken seriously.

Things that parents did not find helpful were having to wait a long time between first alerting professionals to their concerns and getting the diagnosis, being given a vague diagnosis such as developmental delay or communication difficulties, being given little or no information on the possible interventions and services, being left with a very bleak outlook to the future and having no follow up appointments once the diagnosis was made.

Similar findings were reported by Brogan & Knussen (2003) who carried out a study in Scotland on 126 parents to find out the level of satisfaction with the diagnosis and the diagnostic process. They found that those more likely to be
satisfied were the ones who were given plenty of information at the time of diagnosis, those who received the diagnosis before school age, those who received a definite diagnosis and those who received a diagnosis of Asperger's syndrome rather than autism.

This study did not look at the possible link between the severity of the autism and the overall satisfaction with the diagnosis. However, the fact that parents of children diagnosed with Asperger's syndrome, which is at the milder end of the autistic spectrum, reported that they were more satisfied with the diagnosis hints that this may have been a factor.

The period of time immediately post diagnosis can be a difficult period of searching and grieving. Adaptation to the diagnosis has been described as grieving for the "hoped for child" (Seigal, 1997). This is a unique experience to the parents; there is no funeral or ceremony to mark the occasion. To other people, nothing has changed; the child is exactly as he was the day before the diagnosis. What has changed for the parents is the future; all the hopes that they had for the child and for themselves as a family have gone. Some parents have said that it would have been better if the child had died (Schall, 2000) at least then they would be able to get over it and move on. However, they are never able to get over it as they are left with outwardly normal child and all the challenges of living with autism (Midence & O'Neill, 1999). Instead of being able to work through the normal stages of grief (Kubler-Ross, 1969), the post diagnostic period is a mixture of grief for the lost future, hope that things will get better and denial that anything is wrong.
The denial drives the parents to search for information, for treatments and for cures. During this time, they are vulnerable to the purveyors of expensive unvalidated treatments and ‘pseudo-professionals’ offering quick cures (Maurice, 1996).

The post diagnostic period can last anything from a few months to several years. During this time, parents are gradually working their way towards acceptance and adaptation. This stage seems to be very much open to interpretation, Midence and O’Neill (1999) found that parents eventually learned to accept autism as part of their child’s characteristics and successfully adapted in a way that allowed them to lead a normal life. However, acceptance and adaptation seem to be related to the severity and nature of the impairment. Roll-Pettersson (2001) found that many parents, particularly those, whose children had severe behavioural problems, did not accept and adapt. She found that parents moved into a stage of coping where they were able to get on with their lives but this was a delicate state that only existed between crises.

Acceptance is a difficult concept in autism as it is not a concrete thing like a physical disability; it is the failure to learn from a normal social environment (Ferster, 1961). Children with autism can be taught social skills and play skills and their presentation can be improved but it requires specialist teaching methods and commitment to an intense education programme (Lovaas & Smith, 1989). The prognosis for children with autism is not set, it can be improved, but the improvement can be disproportionately poor
compared with the amount of input that is required (Hastings & Johnson, 2001). The knowledge that something can be done makes it difficult for parents to reach the point of acceptance because that can also be seen as the point of giving in.

**Stress**

This is the paradox in parenting a child with autism, the more resources that parents have the more they are able to work at, or campaign for better education and better treatments for their child. The knowledge that something can be done drives parents to invest large amounts of time and money into their child's development. However, this investment does not reduce the stress that the parent's experience.

Hastings and Johnson (2001) studied the stress in UK families conducting an intensive home-based behavioural intervention programme based on applied behavioural analysis (ABA) for their autistic child. Previous research has found that ABA programmes can either reduce stress or increase stress, ironically for very similar reasons. They reduce stress as the family has a team of dedicated tutors in the home for many hours a week helping with the care and education of the child (Birnbrauer & Leach, 1993) or they can increases stress as the home is invaded for months at a time by tutors who come and go (Cattell-Gordon & Cattell-Gordon, 1998).

The Hastings and Johnson (2001) study compared the levels of stress in the primary caregivers of autistic children using an ABA programme with the
levels of stress in the primary caregivers of other autistic children and other disabled children. What they found was that the primary caregivers of the autistic children in both groups experienced significantly more stress than the primary caregivers of the other disabled children. They also found that there was no significant difference between the autistic groups.

Parents of children with autism learn to live with stress and develop different ways of coping. Dunn, Burbine, Bowers, and Tantleff-Dunn (2001) carried out a survey of 58 parents of children with autism to investigate which protective factors moderated stress. They measured social support, ways of coping, parenting stress, locus of control and life experiences. They found that social support was not related to feelings of isolation; whereas coping styles were. They also found that 'locus of control' did not moderate the relationship between stressors and negative outcomes. The strongest relationship to stress that they found was coping styles, with escape-avoidance being the least effective and distancing and positive reappraisal being the most effective. However, with no measure of the severity of the symptoms there is no way of knowing whether the different coping styles were a reaction to the symptoms. Escape avoidance may be a reaction to the increased stress not the cause of it.

Bromley et al. (2004) examined the association between psychological distress in mothers of autistic children and three different factors: child characteristics, the socio-economic situation of the mothers and the levels of formal and informal support. The study found that overall mothers of autistic
children are exposed to high levels of psychological distress. There were no associations due to developmental delay or specific autistic behaviours but there were significant associations between maternal distress and challenging behaviour and between maternal distress and low levels of family support. These findings were consistent with those found by Hassall et al. (2005).

Higgins et al. (2005) studied the perceptions and experiences of the families of children with autism and how these were related to the behavioural characteristics of the child. What they found was that the families were most concerned about aggressive behaviour and misbehaviour in public. The result of this concern was that families were less likely to go on spontaneous outings, less likely to do things as a family as a whole. In terms of family functioning Higgins et al. found low marital satisfaction, low family adaptability and low family cohesion compared to normative data and with families of children with Down’s syndrome. They also found that the coping mechanisms that the family used were not related to family adjustment. The conclusions drawn were similar to those of Bromley et al. (2004), that the behavioural characteristics, or at least the parents’ perception of the behavioural characteristics, were not mediated by coping strategies.

**Rationale**

The studies discussed above have explored how parents cope with having a child with autism through the stages of pre-diagnosis to acceptance and accommodation; they have explored how functioning style, family support
and coping styles moderate stress. All are agreed that having an autistic child puts a great deal of strain on the parents and the family.

However, none of the above studies has explored how the experience of parenting a child with autism is qualitatively different from the experience of parenting a child without autism. This study aims to use an established model of parenting (Hoghughi, 2004) to explore the process of parenting a child with autism and how it is different from the process of parenting a child without autism in terms of care, control and development.
CHAPTER TWO: METHODOLOGY

Research Aim
This study aimed to explore the impact of a child's autism on the parenting process by comparing it to the parenting process of a child without autism. This was achieved by interviewing parents that had a child with autism and a child/children without autism. It was hoped that the findings of this study would improve understanding of parent's experience and help professionals to improve the way in which they engage with parents and the services that they offer them.

Design
This study details a qualitative phenomenological analysis of issues deemed to be significant to parenting a child with autism. The information was gathered from semi-structured interviews designed to examine the three core dimensions of the parenting process.

The parents in the sample were identified by local divisions of the National Autistic society as meeting the criteria for the study and being willing to participate in this study.

The interviews were each approximately one hour long; they were recorded on a cassette tape and then subsequently transcribed. The interviews were then analysed using Interpretative Phenomenological Analysis. The analysis of the interviews was then shared with participants and they were given the
opportunity to comment on how accurately they felt that they represented their experience.

**Theoretical bases of the method**

Interpretative Phenomenological Analysis

The aim of Interpretative Phenomenological Analysis (IPA) is to explore in detail how people make sense of their personal experience of the world. In IPA studies, it is the meanings that people attach to their experiences, states or events that are of interest. The process is phenomenological in that it is a detailed examination of a person's experience of the world; the aim of an IPA study is to explore the participant's personal experience or perception of the object or event. It is not an attempt to establish the truth or the facts (Smith & Osborn, 2003).

IPA is a 'two stage' interpretation process- the participants attempt to make sense of their internal world and then the researcher tries to make sense of their making sense of their world. It is unavoidable that the researcher is an active participant in this process. The questions asked and the reflections given guide the narrative. It is the researcher's role to try to see the participants' world from the inside, to understand what it is like from their point of view. To achieve this, the researcher must be both questioning and empathic towards the participants, he must take their side but at the same time question what they are saying in their texts (Smith & Osborn, 2003). Is there more going on, is there a theme bubbling under the surface? Is the participant presenting the researcher with the face that he shows to the world, is he hiding his true feelings?
IPA relies on the connection between language, thoughts and emotions. However, it acknowledges that this is not a simple connection and participants may struggle to express what they are feeling or may not wish to express what they thinking. The researcher has to try to interpret the participants' thoughts and emotions from what they say and from what they do not say. Long pauses and humour can sometimes say more than words.

IPA is most suited to exploratory studies where the research questions are open-ended and the goal is to discover new information. It is not suited as means to test existing hypotheses. It is appropriate for studies into complex subject matter where the inner world and experience of the participant is the subject of interest. The aim of IPA is gain a detailed understanding of the particular group in the study, not to generalise the finding to larger populations. Because of the time consuming nature of transcribing and analysing interviews IPA studies tend to use small samples.

When using small samples it is important to select participants carefully so that they form a relatively homogenous group for whom the research question is relevant. How this achieved depends on the study. For example, in this study, the subject matter is rare and the inclusion criteria specific, therefore the sample was defined by the people that met the criteria and were willing to participate. For other studies, the sample may be drawn from a population matched for socioeconomic and cultural profiles (Smith & Osborn, 2003).
IPA makes use of semi-structure interviews. Semi-structured interviews are based on a schedule of predetermined, open-ended questions. These are used to guide the interview through the subject matter, without dictating every step. The questions act as routes into areas of interest, concerns or experiences without imposing limits on what is covered. This form of interview is well suited to an exploratory study as it enables the participants the freedom to bring in ideas and experiences not anticipated by the researcher whilst staying within the framework of the research question (Smith, 1995). The interviewer is also free to change the order of the questions so that they fit with the way that the participant chooses to tell his story.

Transcription

To capture all the information that is required for IPA it is necessary to record the interview and then transcribe it word for word. Writing notes during the interview would only capture the general ideas without the details and the process would interfere with narrative (Smith & Osborn, 2003). Recording also allows the researcher to note the nonverbal clues such as pauses, stutterings and laughter.

The process of transcribing the interview is the first stage of the analysis. The necessary time it takes to transcribe the interview enables the researcher to become familiar with the text and develop early ideas about meanings. Once the transcription is complete, the transcript is read through several times.
significant points are highlighted and interpretations are noted in the left hand margin. Once this first stage is completed the notes in the left-hand margin are assimilated into emergent themes, these are written in the right hand margin. The themes sum up the essence of what has been said in a concise phrase. The phrase should be in the language used by the participant.

There is no strict rule on how this done, some researchers complete the first stage on all the interviews before going on to the second stage others complete stage one and two for the first transcript and then look for recurring themes in the subsequent transcripts.

**Rationale for using qualitative research methods**

Qualitative research in psychology aims to explore, describe and interpret the experiences of participants'. These methods are appropriate either when it is an exploratory study into a new or under researched area or where numbers alone cannot adequately describe the subject (Smith, 2003).

Quantitative methods have been used to measure the stress in parents of children with autism and have concluded that they experience more stress than parents of normally developing children (Bromley et al., 2004) and that they experience more stress than parents of children with other disabilities (Hastings & Johnson, 2001). Quantitative studies have also found that children with autism require more physical care than normally developing children (Roberts & Lawton, 2000). However, these findings would come as no surprise to a parent of a child with autism. They confirm what most would
suspect but they do not capture the intensity of the experience. Quantitative research can give an accurate representation of certain aspects of autism. Whereas a qualitative study using IPA should give a very detailed picture of the experience of a few people.

This study acknowledges that parenting a child with autism is more stressful and that children with autism require more care. It aims to add depth to the existing knowledge on the subject, by describing in detail the experiences of a small group of parents and by giving them, the opportunity to express what is important to them. It tries to tell the story from the parents' point of view.

Participants
The sample of nine parents was drawn from the membership of three local divisions of the National Autistic Society based in The East Riding of Yorkshire.

Inclusion Criterion
Each participant had to be the parent of at least one child with a diagnosis of an autistic spectrum disorder and at least one child without.

Exclusion Criterion
There were no exclusion criterion for this study; all parents that volunteered and met the inclusion criterion were interviewed.

Recruitment
The participants were recruited through three local branches of the Hull and East Riding National Autistic Society. The researcher attended meetings and gave a brief presentation detailing what the research aims were and what participation would involve. He then left introductory letters and participant information sheets with the Chair of each group. The Chair then distributed them to the members of the group that she felt met the inclusion criteria.

**Sample**

All the names of the participants have been changed. The pseudonyms given to each person remain consistent throughout this study to give continuity to the quotations in chapter four. The sample consisted of nine parents, four mothers, one father and two couples, making seven interviews in total. Interview one and two are with the father and mother of the same family respectively. Interview five and seven were with the mother and father together. In both these interviews, the mother took the lead and the father supported her.
Table 1 Participant information

<table>
<thead>
<tr>
<th>Interview</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<tr>
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<td>Mother</td>
<td>Mother</td>
<td>Mother</td>
<td>Mother &amp; Father</td>
<td>Mother &amp; Father</td>
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<tr>
<td>Index Child</td>
<td>David</td>
<td>David</td>
<td>Timothy</td>
<td>James</td>
<td>Terry</td>
<td>John</td>
<td>Andy</td>
</tr>
<tr>
<td></td>
<td>5 yrs</td>
<td>5 yrs</td>
<td>7 yrs</td>
<td>11 yrs</td>
<td>16 yrs</td>
<td>9 yrs</td>
<td>5 yrs</td>
</tr>
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<td>Autism</td>
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<td>Autism</td>
<td>Autism</td>
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<td>Autism</td>
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<td>Robert 6</td>
<td>Tammy 14</td>
<td>Emily 8</td>
<td>Hazel 18</td>
<td>Sam 14</td>
<td>Simon 7</td>
</tr>
<tr>
<td></td>
<td>Lucy 14</td>
<td>Lucy 14</td>
<td>Stella 5</td>
<td></td>
<td></td>
<td>Amelia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ben 15</td>
<td>Ben 15</td>
<td></td>
<td></td>
<td></td>
<td>8 mths</td>
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<td>Married</td>
<td>Married</td>
<td>Divorced</td>
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**Ethical considerations**

**Confidentiality and anonymity**

The following measures were taken to insure confidentiality and anonymity.

1. All participants were provided with an information sheet that detailed the measures that were taken to ensure anonymity. (Appendix 1)

2. Details of the circumstances in which the interviewer would have to break confidentiality were explained at the beginning of each interview.
3. At the point of transcription, all participants, schools and places, were given pseudonyms. These pseudonyms remained constant throughout as to aid continuity for the reader.

4. Once the interviews had been transcribed, the tapes were destroyed.

5. All hard data were kept in a locked filing cabinet and electronic data were stored on a password-protected computer.

Informed consent

The following measures were taken to ensure that the participants had given their informed consent.

1. The participants were identified and contacted through three local branches of the Hull and East Riding National Autistic Society. Each possible participant was given an introductory letter and an information sheet (Appendix 1) that explained who the researcher was, what the study was about and what was expected of participants. The participant then had the option to contact the researcher to participate or to disregard the letter.

2. Each of the participants that agreed to take part re-read the information sheet and signed the consent form (Appendix 2) in front of the researcher before the start of the interview.
Semi-structured Interview

An open ended semi structured interview schedule (Appendix 4) was adapted from the “Parenting Process Questionnaire-Epilepsy” (Hoghughi & Nuttycoombe, 2006), with the aim of exploring the participants experience of parenting a child with autism. The interview schedule was designed to outline the areas of interest to be discussed in this study (Smith, 1995) without being overly restrictive. The areas explored by this study were care, control and development (Hoghughi, 2004). The schedule was used as a guide that could be adapted to suit the participant, the order of the questions were altered to follow the narrative and extra prompts or questions were added to follow up novel points introduced by the participant. The interviews were all approximately one hour long. However, the content varied from 6,600 words to nearly 12,000 words due to the speed at which the participants spoke.

Procedure

Ethical approval

As the participants in this study were identified through a private organisation and were not themselves patients, ethical approval from the full committee of the Hull and East Riding Local Research Ethics Committee was not appropriate. However, to insure that the study was conducted in an ethical and professional way a proposal of the study was submitted to the chair of the committee for ethical opinion. The opinion of the Chair was that the study was ethical and could proceed with a few minor alterations (Appendix 3) to
the 'quantitative' part of the study, but this part was subsequently dropped. Therefore the qualitative part of the study was considered to be ethical.

Participant interviews

Each participant was given the choice of being interviewed in his or her own home or in a meeting room at a mutually convenient place. All chose to be interviewed in their own homes. For interview one and two, the child with autism was in the house but was being looked after by the other parent. For all other interviews, the child with autism was not present. Five of the interviews were with one parent and two were with both parents. Where both parents were interviewed, the mother took the lead and the father supported her.

Each interview was recorded on a cassette tape and then transcribed at a later date.

Data analysis

Analysis began with transcribing the interviews this was a slow process that enabled the researcher to become familiar with the texts. Once the transcription was complete, the interviews were read through twice. Anything that the researcher saw as significant or interesting was underlined and interpretations were noted in the left hand margin. Once this initial analysis was completed, the notes from the left hand margin were assimilated into emergent themes in the right hand margin. These emergent themes were
then organised into clusters that were the beginnings of the superordinate themes. Each superordinate theme was linked back to the text to ensure that they represented the data. At this point themes that were not supported by the data were dropped.

**Group analysis of transcripts**

The above process was repeated for all seven transcripts. All the emergent themes from each transcript were then printed on separate pieces of paper. These were then organised into clusters by putting connected themes together. The strongest of these clusters became the superordinate themes the others were discarded. Some themes were chosen because of the number of references to them in the scripts, others were chosen for the richness of the text. Only themes that were consistent across the majority of transcripts were selected. There were several strong themes that only ran through one or two of the transcripts, these were discarded.

**Verification of themes**

An IPA group was set up with three other researchers currently using IPA. The group each read sections of the others transcripts and commented on the validity of the emerging themes. The themes were also reviewed by the research supervisor. The consensus was that the themes were a valid analysis of the data. There was some discussion on how the themes clustered together into the superordinate themes and these were altered accordingly.
A second verification was to send a copy of the themes and supporting quotes to the participants that had consented to further involvement with the study. They gave their opinion as to whether they felt the themes were a valid representation of their experience. The three participants that consented all felt that the themes did represent their experience.
CHAPTER 3: RESULTS

Overview of Superordinate Themes

From the Interpretative Phenomenological Analysis of the seven interviews 19 themes were generated. These were organised into three superordinate themes: “What we have to do because of autism”, “What autism has done to us” and “Different”. Within the superordinate themes, the themes naturally hung together in clusters. The superordinate themes, themes and clusters are represented in Table 2.

It is recognised that this is a comparatively large number of themes, particularly in the superordinate theme 2. However, it was felt preferable to present separate themes rather than conflate them, because it better represents the complexity and nuances of being the parent of a child with autism.

Each theme will be described and then illustrated by direct quotes from the interviews. At the beginning of each quote there is a number representing the participant and the first line of the quote. Where the quote is from an interview with both parents an F or an M will be used to represent the father or the mother respectively. For example 7F. 279 represents the father from interview 7 and the quote starts from line 279. Where the quote represents a conversation, the quotes will be labelled Mother, Father or Researcher. In the interviews all place names have been removed, all the people have
pseudonyms that remain constant throughout to help the reader follow the themes as they develop through each interview. Where a name is followed by a label in parentheses, the label refers to the child with autism. For example “I think that Simon (older brother) would like to go” Simon is the older brother of the child with autism, not the person speaking. In this study all the children with autism were male, so from this point onward the child with autism will always be referred to as he as opposed to ‘he or she’.
### Table 2: Overview of Superordinate Themes

<table>
<thead>
<tr>
<th>Superordinate Theme 1: ‘What we have to do because of autism’</th>
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<tbody>
<tr>
<td><strong>Theme 1.1</strong>: Constant supervision – ‘eyes on double’</td>
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<tr>
<td><strong>Theme 1.2</strong>: Never ending care – ‘day to day’</td>
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<tr>
<td><strong>Theme 1.3</strong>: Never ending care – ‘a life time and beyond’</td>
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<tr>
<td><strong>Theme 1.4</strong>: Intense Parenting</td>
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<tr>
<td><strong>Theme 1.5</strong>: Preparing the way – ‘like curling in front of him’</td>
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<td><strong>Theme 1.6</strong>: Adapt to autism</td>
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<table>
<thead>
<tr>
<th>Super Ordinate Theme 2: ‘What autism has done to us’.</th>
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<tbody>
<tr>
<td><strong>Theme 2.1</strong>: Judged by others – ‘keep your head down’</td>
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<tr>
<td><strong>Theme 2.2</strong>: Avoid other people – ‘empty beaches’</td>
</tr>
<tr>
<td><strong>Theme 2.3</strong>: No one else can understand</td>
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<tr>
<td><strong>Theme 2.4</strong>: Isolated – ‘never invited back’</td>
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<tr>
<td><strong>Theme 2.5</strong>: Time bomb – ‘on edge the whole time’</td>
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<tr>
<td><strong>Theme 2.6</strong>: Not able to control – ‘he just never does’</td>
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<tr>
<td><strong>Theme 2.7</strong>: Guilt – ‘neglecting siblings’</td>
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<tr>
<td>‘not doing enough’</td>
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<tr>
<td>‘doing it wrong’</td>
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<tr>
<td><strong>Theme 2.8</strong>: I am ok but…- ‘shipwrecked’</td>
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<tr>
<td><strong>Theme 2.9</strong>: Hope – ‘optimistic future’</td>
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<tr>
<td><strong>Theme 2.10</strong>: Despair</td>
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<tr>
<th>Superordinate Theme 3: ‘Different’</th>
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<tr>
<td><strong>Theme 3.1</strong>: Hidden disability – ‘outwardly normal”</td>
</tr>
<tr>
<td><strong>Theme 3.2</strong>: Comparison with siblings</td>
</tr>
<tr>
<td><strong>Theme 3.3</strong>: A longing for normality – ‘if only’</td>
</tr>
</tbody>
</table>
Superordinate Theme 1: ‘What we have to do because of autism’.

Theme 1.1: Constant supervision – ‘eyes on double’

1. 69 “You can’t just just go in somewhere and think oh well David is just going off and playing you always have your eyes on double you’ll be, he needs more care, yeah.”

This theme incorporates elements of both care and control. The care element is that parents believe that if left unsupervised their child would inevitably come to some harm. The control element is that parents have to watch the child so that they can intervene at the point when the child is about to expose himself to danger.

These parents both describe how they have to watch their child continuously even when he is playing in the garden.

2. 176 “he’s not turfed out on his own because you wouldn’t know where he was, he can’t be unsupervised, no no you can’t, no (laughs). It’s like a nightmare if he goes missing, if he has managed to get out. because you know he can get through into the field and he quite likes going and playing in the ditch with the water, you know and a couple of times he’s got through there, on his own, and it’s like a nightmare. Until you actually find him you just don’t know what he would do, so.”

4. 9 “He needs a lot more one to one. you can’t leave him unsupervised, you have got to watch him all the time, even if he is playing outside…..normally at his age, a child of 11 would be going out on his bike or something with his friends and that, but he can’t do anything independently. What ever he does I have to go with him and supervise.”

The need to watch the child constantly can put parents under a level of stress that others find difficult to comprehend.
Theme 1.2: Never-ending care – ‘day to day’

All the parents said that a child with autism needs more physical and emotional care than a child without autism. However, it was the continuous nature of the care, not the amount that the parents found most distressing. For some, it was the fact that the child was not able to settle to do one thing.

3. 337 “You see he can’t settle himself to do anything, so he never plays, he’s just on and on and on all the time (sigh) and he just won’t do anything. He won’t get in the bath and then he won’t get out, he won’t get dressed. He just, he is very difficult all of the time. Very difficult, yes.”

For others, it was that the child was so active that it was impossible to keep up with them. The only chance that parents had to tidy up, do anything for themselves or relax was after the child was a sleep.

7F. 708 “they are home at about four o’clock and in bed by eight and that four hours can sometimes, if he is in that kind of mood can sometimes feel like 14 hours. And it is only four hours that he has actually been home but you get to the point when you think “god just switch off and go to sleep” because you can’t like do any more you know”.

Theme 1.3: Never ending care – ‘a life time and beyond’

Another feature of care that parents described was that there was no perceivable end to it. They all shared the belief that, the duty of care that they
had for their child with autism would continue for the rest of their natural lives and beyond.

One parent described how she could see no alternative to her son living at home. David is only five and has just started going to school, up until that point she and her husband looked after him at home, with almost no outside support.

2. 253 "I just feel that he is always going to be with us. So all the ideas that we had about the future the sort of children going off and us having our old age together and things that's all completely different because I just think that you know. David will always be with us"

This couple's child had also only recently started school and they had been largely unsupported until then. They shared the feeling that their son would always be with them.

7M. 401 "I think that Andy will stop with us. We'll do our best won't we?
Father. "If either of us is still alive and Andy needs looking after then we will look after him."
Mother. "Yeah, we'll support him"

For the parents with the higher functioning children the nature of the care was different but the burden was the same. This mother had pieced together an effective support network around her child and believed that, with the right support he would be able to live semi-independently as an adult. Her worry was that his support network existed in a fragile state and would require constant maintenance.

6. 494 "I just feel that it is a scary future a head of him without the right support and, you know, we are not getting any younger, any of us. You do worry terribly about what is going to happen in the future. Erm I am just so grateful that we have Sam (older brother) and Amelia (baby sister), I wouldn't want him to be a burden to them in their lives but I know that they will
The Impact of a Child’s Autism

oversee things for him... I am determined to get up a big support network around him by the time that I leave this earth (laughs)."

Theme 1.4: Intense parenting

This theme is about development. Most parents want their children to reach their full potential and they are prepared to invest time effort and money to help them achieve this. Parents of children with autism want the same things for their children; the difference is that they feel they have to invest far more for smaller returns.

This father described how in his experience he had had to put in a lot more effort just to achieve the little things that people take for granted with children without autism.

1. 228 “it's a lot more intense David is the fourth and I would say that, that the sort of time and care that you lavish on David is is more than yeah than you would have done on your first one. I mean when your first child is born you do go over the top don't you you know. But, I would say that you have to do a lot more, erm lavish a lot more sort of time and care and things on David. But it is just getting him to achieve the little the little things j just a little step is wonderful, where as with the others it just naturally happens, they learn how to walk and they lie, where as with David he couldn't even chew. We had to teach him how to chew things. If you just put a piece of cheese or what ever in his mouth he'd just gag whereas well you know it seems that you have to teach him everything so yeah."

1. 360 “the only thing that I would say is different about it is that it is more intense. Some how, it’s an intense parenting thing. I like being a parent, that's what, what I like to do. Erm so it, it, it is different and you are having to look at the fine, you can't just use broad brush strokes. Like you can with the other kids you've got to use fine, fine brush. You know, you've got to be looking at the details and things like that. But it's just as rewarding I think, any achievements that David does they might only be tiny little achievements that really normally developing kids its its just you don't even notice but with David you do so it is special somehow.”
For parents of children with autism teaching normal developmental tasks can become a marathon of endurance, as the children appear to resist learning.

4. 743 “The amount of extra work I think, that they entail, I seemed to have a lot more problems with James’ toileting than I did with the other two erm it took about two years because I was determined to get him out of nappies but for two years I was just constantly cleaning it up and”

Because of this resistance to learning children with autism do not benefit from education in the same way that other children do. Parents have to become experts so that they can teach their child themselves or so that they can teach the teachers how to teach them.

1.305 “I feel that David with the way that the education erm side of things is set up erm that David will have trouble fulfilling his potential if it was just left to the state, definitely. I think that, erm there, there is a lot of other work that is being done by people out there and there is a lot of different, erm research that has been done, different interventions and stuff that can help autistic kids and developmentally delayed kids and its its I personally find that its sad that they won’t do it in the schools… having a child like David, it it makes you it it gees you up, you need to, have plenty of oomph and go looking around for stuff (laughs) and things so yes. No I don’t I don’t know, but I can’t, I can’t see without some, without us having to spend money, and hopefully and choosing the right interventions for David. If it was just left to the state I don’t think that he would reach his full potential.

This mother reflects on the struggle that she and her husband have had, to get a satisfactory education for her son.

5 M. 281 “And you sometimes wonder, like if we hadn’t done the things that we have done with him, what he would be like now, if we hadn’t used a bit of our own savvy and you know. And money, and our own money and done things with, you know what stage he would be at now.”
Theme 1.5: Preparing the way

This theme is about the things that parents do in order to make their child’s and consequently their own, life easier. It involves going a head of them and removing all obstacles and dangers. One mother described it like sweeping the ice in front of the stone in curling.

6. 505 “... it is like curling in front of him (laughs) ...., whatever environment your child is in, the people within that environment, you have got to get in there first and put them in the picture about where your child is coming from. You know, what the difficulties are and what helps him along and so on ..... But yeah it is. it is a constant process of being there first and letting people know really”.

This also links in to the theme of ‘hidden disability’, because it is often the fact that the child looks normal that necessitates the explanation of the behaviour.

6. 131 “I meant, because I wanted provision in place before he started school, because to send a child with suspected ASD into a school environment without support in place would be horrendous, because his behaviour would be so open to misinterpretation that he would just automatically be classed as a ‘bad behavioural problem’, and that is very negative and I didn’t want that because that would damage his self esteem as time went on and it would turn everyone around him against him.”

Another part of this theme was the need to warn people for their own safety.

1. 98 “I would have to warn, warn them what, that David’s autistic, that he has these peculiar behavioural traits, erm and that he, he could, he could, erm erm sort of use them, not as a punch bag but as a sort of foil to get what he wants, you see he could, he could use bad behaviour against them if he wants a biscuit or some sweets or whatever”
Theme 1.6: Adapt to autism – ‘*change to suit him*’

This theme represents the parents experience that you cannot change the child to fit ‘your world’ but you actually have to change ‘your world’ to suit him. This can be about small things, such as tolerating behaviour not acceptable in other children.

5F. 440 “It is very different, you have to live by a different set of rules. The rules have to suit the child rather than the child suiting the rules. What you could class as pre conceived rules because they won’t work, they can’t work. An autistic kid’s mind doesn’t work like a standard kid’s mind if you can use the word standard”

7M. 165 “He is totally different to a normal child, you know a child that is neuro typical is it, should I say. Erm so it is harder, well I think so cos you’ve got challenging behaviour you actually have to learn to live your life yourself around routine and setting things in the right motions and getting it prepared and pre planning all the time but it is harder”

Or it can mean revising expectations of the child’s future. This mother describes how she has had to re-evaluate her expectations so that she can see his progress as a series of successes instead of as a series of failures as he gradually deviates from the “normal” developmental pathway.

6. 797 ‘Erm well I think erm it is important not to think that once that your child has a diagnosis of autism then that is the end it maybe the end of what your original hopes and dreams were going to be but er you just have to find a new direction and realise that there are a lot of positives that come out of being autistic and er a lot of these kids have far more potential than I think you know, we are at first led to believe, and it is quite an exciting journey at times to see what actually they are capable of achieving. John surprises us all the time with the little bits and pieces that he picks up learns, and things so you know, never lose sight of the fact that its not all negative stuff you know. That is about it really (laughs)
Superordinate Theme 2: ‘What autism has done to us’.

This superordinate theme consists of themes that describe the impact of the child’s autism on the parents and the family. There were 10 separate themes and these naturally hung together in three groups, the first was about isolation and alienation, the second was about how it made the parents feel, and the third was about ways of coping or not coping.

The first cluster of themes relates to the feeling expressed by the interviewees that they were living outside formal society. The nature of their child’s disability and other people’s perceived, or actual, attitude towards it was causing them and their child to be excluded from services, places and events. Of all the clusters of themes, this one stood out as the strongest, it had by far the most references and was consistent across all participants.

Theme 2.1: Judged by others – ‘keep your head down’

All parents spoke of this theme, they described it in terms of being embarrassed and humiliated by the way that their child behaved and the way in which others reacted to that behaviour.

6. 64 “I just looked back at the, at all the parents standing at the gate and they were all shaking their heads and laughing and I just felt really humiliated”

All parents whose child misbehaves in public will have feelings of humiliation and embarrassment, unless they truly do not care how their child behaves. For parents of children with autism, this feeling is much more acute as many of them have become expert in behavioural management techniques yet they
are still not able to control their child in public. Their perceptions are that others look at the way the child is behaving and conclude that the child is naughty and that the parents are to blame. One participant described how her experience had changed, as her child got older.

3. 177 “....and he's quite a big seven and I think that people are looking more now and thinking, look at him. I mean yeah you get used to keeping your head down don't you, but I think now they are really, people are looking.”

Parents described feeling that other people were quick to judge their ability to parent, without having any understanding of what they were actually going through.

3. 433 “people put it down to poor parenting which they never specifically say, but they are always good to put their two penneth in aren't they? Yeah, 'if he was mine' (laughs).”

7M. 187 “. I mean I can go out there, going out erm, if he goes on one of his tantrums or whatever, and he's on the floor and he is screaming and you get people looking and you think, and they all look and they think 'oh god that child is like, wants to be on little angels or something like this', don't they, they do, looking and thinking 'oh god he needs to be on that programme' and they do and they are looking and I think you've just no idea you know. It is really hard in that respect because it used to get to me quite a lot actually. I have had to really learn to become hardened to this, when people do stare and look um whatever, because you can 'here we go again' and 'we've got an audience looking', but they've no idea, they just think that he is a really horrible child which they do, a really naughty child”

The alternative to 'keeping your head down' to avoid other people's disapproval is to try to explain to people about autism and the effect it has on a child's behaviour.

4. 246 “you try to explain to people and it is just a waste of time with some people because they won't even listen. They think that you are just making it up as an excuse. I have even had people say, you know he needs a real good telling off or whatever, you know. They think that I have got an unruly child that I can't control.”
Other times, parents feel that they just need to get away, back to the protection of isolation from others.

7F. 289. "we are going back to say that the child looks normal and people don’t understand that they are autistic and when it comes to that situation and you are stood there and you’ve got people looking at you it gets embarrassing and you have got to do something on the spur of the moment to take peoples faces away from you"

Theme 2.2: Avoid other people – ‘empty beaches’

Parents find interactions with other children and other parents so difficult and potentially traumatic that they seek isolation in order not to upset or to be upset by others. Holidays can be a particularly difficult time as parents are away from their support networks and often in close proximity to other people. One family resolved this problem by holidaying in isolated villas.

1. 435 "..if we go away we tend to go to places that there aren’t, that aren’t overly populated, do you know what I mean, so we can get away. So we tend to have a holiday every year we mainly go to places like (name of place), hire a car you can get out of the resorts, there’s loads of empty beaches and all that sort of stuff. And we can just be a family together, David is no problem to us and he’s no problem to anybody else."

For this parent, a holiday was an ordeal, something that had to be endured for the sake of the other children.

6. 318 "we have only had three. (Laughs) In the whole time that we have had him, we had one holiday down between (name of town) and (name of town), and we stayed in one of those luxury caravans and just sort went off and had day trips out to dinosaur parks and things and erm yeah, it was an ordeal (Laughs). Again, park situations, the activities that we tended to do as a family where we could contain him were a lot easier, like going on the boating lake or going to see the dinosaur park, or watching the falcons. But anything that involved socialising or going out in the evening". 
All the other interviewees owned caravans, often precisely in order to avoid others. They described taking the caravan on holiday as about taking a part of their home with them. This way, at least, part of the holiday was always the same. The child got used to sleeping in the caravan. Caravans were also used as a way to contain the child and the autism.

7M. 670 “it is a shame really because I think that Simon (older brother) would like to go abroad but again, may be we will do it when he is a little bit older. I'll may be try and attempt to get him on the aircraft and whatever, you know but at the moment, we are like, you know, he likes his caravan and its, we go every year and he knows and he is smashing in it”.

This theme is not just about holidays but also about keeping away from other people in order to avoid conflict and humiliation. However, it is not always possible to stay in isolation.

4. 92 “He can’t cope with crowds, if there are a lot of people about erm, like we went to Asda at the weekend on the way to my mum and dads and that was a complete nightmare.....There was this big glass container on the counter and before I realised what was happening he swiped that and broke the top off it, because he couldn’t cope if there’s a lot of people he is better in quiet places I find, and open spaces.”

Many of the places that parents want to take their child with autism are popular with other children and parents and can cause conflicts.

6. 47 “I used to dread going to parks because if another child went on to an item that he actually wanted to go, the big slide or roundabout and they got there first woe. woe betide them. he would just hoick them off and erm, you know enjoy himself and of course that would cause parents to come running. and I seemed to be constantly having confrontations with. with. with other parents in parks and play groups”
Theme 2.3: No one else can understand

Each parent described his or her own experience of raising a child as a unique experience that no one else could understand. Even a person who has had close personal or professional contact with children with autism could not understand her unique experiences.

This parent described meeting another mother of a child with autism:

2.348 “one of the other girls from the group (NAS Parent Group) came and her little boy is autistic but he was totally different to David, you know I mean totally different so there, there was no comparison. David was doing strange things and screaming and carrying on and her little boy was doing something else. So you couldn’t even sit and sort of say, “yeah they’re alike” and yeah you know there was no sort of erm, I didn’t feel comfortable with them because they weren’t alike at all. They both had their separate problems, and that didn’t even bring us together. I have never met anyone else with a child like David”

Even close family members that looked after the child on a regular basis could not understand the unique experience of being a parent. Managing difficult behaviours per se was not the real problem; it was the continuous nature of the behaviour that caused the distress.

7F: 316 “I think that the other family members don’t, when we actually said what he has done or what he has been like on a specific night they don’t seem to, sometimes believe us because he acts totally different when he is in their houses and that’s what, what gets frustrating for us because we think to ourselves ‘why’ why is he like that there and he is completely different when he is at home. Is it because when he goes there he is actually the centre of attention all the time, obviously when you are running a household with two kids. But usually when he goes and sleeps out he is the only child in the house”

Many of the things that children with autism do are simply extreme versions of normal behaviour. For example, many children like to watch the same video repeatedly, but a child with autism can take it to another level by
watching a brief passage of a video repeatedly for hours on end. Parents found that others could not comprehend the intensity of the autistic behaviours and tried to normalise them by comparing them to their own child.

7M. 169 "...and then you get people who say, well my son does that he takes his clothes off and you get people saying this and you think, they have just no idea, and they do 'oh yeah my son he does that and he likes Thomas the Tank and yeah he does these things' and you think oh no they just, and you know it's just, and again it is just down to the understanding of it and you think, no they are talking about something completely different here."

Sometimes, people do try to understand. Other times it is as if they do not want to understand. Trying to think about the reasons why people do things can interfere with their simple views of the world.

4. 522 "some people can be quite understanding, some people you explain and they are quite sympathetic. Erm but others can be very rude and ignorant because they don't really understand, they don't even understand what autism is let alone anything else you know they're, and some people live in such a perfect world everything has just got to be so and so. And if anybody just, you know interrupts that"

Theme 2.4: Isolation – ‘never invited back’

This theme is about the isolation that parents feel due to being excluded, either actually or perceptually, from places and events that they would like to go to or be part of. This is different to the isolation described by the theme “empty beaches”. “Empty beaches” is where parents seek isolation in order to avoid conflict, confrontation and humiliation.

4. 82 "James and I have become quite isolated really because, even when he was little I couldn't go to a lot of people's houses with him and we did go to one persons house once and she had these big pot tigers on the floor and of course he broke one he knocked the head off it and she never asked us round after that so (laughs).....I do have a few friends
and family that we go and see but its people that’s used to him. People that’s not used to him
don’t invite you round much, so....”

This parent felt very isolated and sought solace in a group of other parents of
children with special needs, but even there she had no sense of belonging.

2. 506 “and I just used to sit and chatter because that’s all I wanted to do I just wanted
somebody else to talk to about it and, erm we started going to the portage group and that
was, I felt really isolated there because the other children seemed to be normal with a
speech, you know, slow to talk but they could do things. And I used to think what the heck; I
would be delighted if David was like this.”

This feeling of isolation is not limited to the parents. The child can become
isolated. This parent describes the experience of her son who is at the high-
functioning end of the autistic spectrum, and is socially aware enough to seek
friendship but is not skilled enough to maintain it.

3. 123 “he really wants people to be friends with him but he doesn’t seem to be able to
keep them. He never gets invited back, which is sad, to people’s houses,...... he’ll
sometimes have friends here but he’ll often just leave them, if anybody comes here he’ll just
go upstairs. “Oh they’ll wait for me,” he says, but he doesn’t realise that they won’t”

The child’s condition can also affect the siblings. This mother describes the
effect it has had on her two daughters. Her son with autism stays at school
for three nights a week and she feels that other parents only let their children
come to play if they know that he is not at home.

4. 344 “I think that they (two younger sisters) would go round to their friends more and their
friends would come round here if it wasn’t for James but even like, friends parents will sort of
ask “oh is James at home tonight?” and you sometimes feel that they steer clear a bit if they
know that he is about. Because we did have Emily’s friend around the other day, she came
for most of the day but they say “is James at home today?”
Such isolation is even a problem for high-functioning children with good social skills and appropriate levels of support. What some people would consider to be trivial can cause such distress as to isolate the child and the family from things that others would take for granted.

6. 331 We can't go to the family pub in town because they have got a big monkey there, a man dressed up monkey and that just does his head in (Laughs) so we just have to leave which is really inconvenient at times you know. And it is a shame because it has stopped him from attending a lot of parties that he has been invited to when he has been younger because all the kids like to go to the family pub and he won't go you see so I think that they sort of take offence about the fact that he won't go and then they don't bother inviting him again (Laughs). Which is a nuisance.

**Theme 2.5: Time bomb – ‘on edge the whole time’**

This is about the unpredictability of a child with autism. It has some similarities with theme 1.1 ‘Constant supervision-eyes on double’ but it is more about the fact that parents feel that they can never relax. Even if things are going well and their child is on his best behaviour the parents are always on edge because of what might happen.

This theme has two components. The first is what might happen in the immediate.

5M. 213 “because there was no reasoning with him, because I didn’t know him. Like with Hazel (older sister) I knew her and I knew what she was going to do next I didn’t with Terry because you never knew what he was going to do next. He was like a little time bomb sometimes”
1. 65 "I would say that he does need, I don't know if he needs more care or if you're more on edge because you are just waiting for something to happen. It might happen and it might not, do you know what I mean?"

4. 451 "his behaviour is very unpredictable; you never know what he is going to do from one minute to the next. He can be perfectly calm and you think that he is going to be alright, then all of a sudden he could just throw something up at the lights or something or he might just swipe something."

7M. 537 "you never know what is going to happen next I always say that, that's what makes it hard, you never know wherever you go now, you just can't predict what is going to happen. That's right isn't it you are on edge the whole time."

The second component is more long-term in that when a family embarks on an outing or journey they have no idea how long it will last or how it will end. The feeling described below is that things could wrong at any time. No amount of planning can cover every eventuality. It may only take a chance encounter with an ice-cream van and the whole day is ruined.

5M. 121 "I remember that we went to the seaside the four of us and Terry wanted something, we couldn't explain to him that he couldn't have, that it was too much money, and he didn't understand that. He wanted it, he was focussed on it there was no getting round it we had to come home. We hadn't been there half an hour and we had, you know that was our day out ruined and this is how it was and in the end we didn't take him anywhere he wasn't going to cope with or it was going to make it difficult".

It is difficult to combine the wants of the child with autism and the wants of the rest of the family.

6. 263 "it was just so stressful and then you know, we would try and leave the park and he'd refuse to leave the park and he would be screaming and you would have to drag him away and there was no, you couldn't go anywhere else you know we had all gone out for the day
to go and look round a medieval hall and all I remember is having this confrontation in the park and we couldn’t go anywhere else after that. We couldn’t even go to the café for a drink (Laughs) it was horrendous and you just come away and think “awe no, we have got no life” (Laughs)."

6. 325 “we tried one evening to go and join one of the family fun sessions in the big entertainment bar, and we were doing quite well, we had got sat down we bought drinks and then this blooming great big (Laughs) this chap dressed up as a huge bear walked through and it just completely freaked him out. Anything that is dressed up that looks strange, and that was it we had to go (Laughs) we had to leave our drinks and “eewooahhrr” that was it he just could not cope with it.”

Even trips that are organised specifically for the enjoyment of the child with autism have the potential to end in disaster.

7M. 224 “we was away on holiday and we went to, we took him on the (name of railway) steam train. We thought that he’d love it being into trains and he did. He was ok going over but of course when you get off on the platform they have a little shop and they have all Thomas the Tank things in and I did take him in and he was ok he liked looking at the things and I even bought him a little Thomas the Tank hat erm course we went out for a walk around (name of town) was it? We brought him back and of course he wanted to go back in the shop again and I did it one more time but then, when we got out he wanted to keep going back in again and of course it was, we got to go now, we’ve got to get on this train and of course he did an almighty, it was really bad didn’t he all over the platform and of course there was about sixty people….. we have got to get on this train and that’s it. But then it made it worse coming back on the train because he was screaming in the carriages and everybody was looking at us again and this is what it is like, it so hard int it. it is you know “

Theme 2.6: Not able to control – ‘he just never does’

This relates the feeling that all the parents had that they were not able to control their child with autism. For the fathers of smaller children there was the option of just picking them up and removing them from the situation.
3. 180 "and there were a couple of difficult incidents where he wouldn't get off the playground and also when we are getting him out of the swimming pool and Ben (father) has to physically lift him because he, he just never does. He doesn't do anything for a reward or a punishment at all. He has to do it because he wants"

7F. 293 "It has happened to me maybe one or two times when I have been out with Andy and he has done the same thing and I have just literally just picked him up from where he is and walked out of the shop"

However, for the mothers and for the larger children this was not an option so they are left with the choice of taking a chance and living with the consequences,

6. 57 "I felt absolutely demoralised I am school; teacher and I have worked with children for many years and I thought, "why can't I control my own child" it used to make me look ridiculous."

4 252 "Erm it is especially if I have got all three of them on my own because if James starts playing up that's it really we have got more or less go home. Erm now that he is getting older it is getting more difficult to restrain him. When he was younger, I could restrain him a bit, but like he is nearly as big as me now."

or to avoid the situation altogether by not taking the child out into the community.

2. 88 "The situation that I avoid because I completely avoid taking him into town. If I had to take David into town and wasn't in his buggy and I was having to walk I just wouldn't do it. I so wouldn't. If I go into town and I have David he's in his buggy,

2. 101 "if David plonked himself down in the middle of the floor in the middle of town and started having a screaming fit or, I just wouldn't be able to cope. I couldn't physically pick him up because he's too big. I would avoid it because that would just be extra stress and my stress level is pretty high (laughs) I am pretty stressed out most of the time"."
Theme 2.7: Guilt

Parents described three different feelings of chronic guilt that can not be resolved because to reduce one would inevitably increase another.

2. 290 "it makes me feel guilty because I feel that we should be doing for 24 hours a day and we can’t because of the amount of time we have to spend with David and then you feel guilty because of the other children.

The first was the feeling that they were not doing enough. In all the interviews bar one, there was a feeling of urgency, things needed to be done as soon as possible to maximise the child’s potential. This was particularly strong with the youngest child.

1. 386 “I still feel David, that its, in there, speech is there, its coming out. But that gets you down some times because time is slipping away and I assume that there must come a point in, in, in a developing child that things get set, and then that’s it”

Along with the urgency was the feeling that it was the parent’s responsibility for then child to achieve as much as possible and that if he did not reach certain goals then they had failed.

2. 260 “we’ve seen the input that there’s got to be put into David and I, I don’t know that we would manage to do it. I don’t. I don’t feel that David will reach his full potential, with just us with just our input, and I don’t know. I don’t know I mean now we are thinking of you know shall we get a tutor shall we get some body to come into the house. I just don’t know. I think it could, not destroy you but it must, it’d depress you. really depress you to really, to know that, yeah there is something that could be done but it is going to take massive amounts of input and and and work to achieve it and we just can’t do it.”

The second feeling that parents described was the guilt at neglecting the other children. All the families in this study had a least one other child.
had three. The birth order and the ages and numbers of children varied. 
Where the siblings were older, the parents described them as independent and undemanding but recognised that they were missing out in some ways.

6. 635 “Where as Sam (older brother) bless him I hardly give him another thought because I know that he is ok, he is quite capable and he is living his life and he is out there every night with his basket ball and doing his stuff. You know sometimes that I feel that I neglect him to a degree, you know because erm er I am so focussed on John’s progress all the time. I hope that it does not affect Amelia (baby sister) either because it is all consuming is autism as you know. Erm er it’s taking a step back some times and learning to address the fact that you have obligations to all of them”

Where the siblings were younger or close in age the feelings of guilt appeared much stronger and were accompanied by concern as to the possible effects of the neglect.

4. 259 “all the attention is on James and I can’t really give them (two younger sisters) the attention that they need, even with the school work erm helping them with their reading or their spellings or whatever and if James is about he will interrupt deliberately and erm yeah its difficult. Because even as babies they never really got the individual attention that James got.”

2. 371 “The amount of effort that goes into David to get a little tiny bit of something back is huge compared to Robert or Ben or Lucy (older siblings). The time spent with him trying to get him to do one sign is hours and hours and hours erm where as the others, you know, you sort of sit for ten minutes with Rob reading his book and its “good you have done your reading” and that’s great. you sign his card in his reading bag. Ben and Lucy, sometimes I feel that I hardly ever see them anymore, because all I seem to do is David.”

The third feeling that parents described was the feeling that they were ‘doing it wrong’.
3. 187 "Well its just sad isn't it and also it makes you feel a bit of a failure of what have you done wrong."

Children with autism follow the normal rules of Learning Theory (Ferster, 1961) and can be taught to do things for reward. Most of the parents in this study have become experts in behavioural management, either through trial and error or through extensive research. However, they found it difficult to maintain the consistency for this technique to be effective in the long-term and would occasionally give in for short-term gains.

2. 213 "you think well he doesn’t really understand. But really I think that he does understand and he shouldn’t (laughs) we should be intervening. So he gets away with a lot more things like that”.

2. 235 “and I would just give him anything he wants, just to keep him quiet. Erm so I wasn’t being strict I wasn’t saying no you’re not having it because I knew that he would just kick off or cry all the time so all I wanted was for him to be happy, quiet and calm and you know. Have what you want basically, so giving in.”

Techniques learned in one environment did not translate to other environments. The consequence of this was that they would often use strategies that they knew were ineffective in the long term as quick fix to get them out of a difficult or embarrassing situation.

7F. 245 “I think that sometimes you don’t always do the right thing as well, you have to do something on the spur of the moment and I think, if you look back at the end of the day and think to myself well may be I should have done something different, maybe I should have done it this way and so I mean, were not always, right in what we do”

Parents expressed a feeling that they felt responsible for the management of their child and their behaviour. When things went wrong they would attribute it to their own poor management.
6. 758 “you want to be everything to your child and you want to be able to be successful in
terms of parenting and erm you are not always successful, you get it wrong many times, and
when you get it wrong and it all goes hay wire then you reel with guilt and you reel with guilt
because you feel that you are letting the other one down you know it is a catch 22 at times.”

Theme 2.8: I am ok but – ‘shipwrecked’

This theme emerged as parents expressions of wellbeing varied throughout
the interview.

All of the parents interviewed expressed feelings that they were better now
than they had been in the past. They also expressed feelings that things
would get worse in the future. It was as if they were in a temporary sanctuary,
like shipwrecked sailors that had made it to a desert island. They were better
off than when they were in the water, but they still had an uncertain future.

Parents were much better describing distress in a way that detached it from
their current situation. It was ok to talk about how bad things were in the past
as long as it was qualified with something positive about the present.

2. 327 "when he was diagnosed when he was 11 months onwards. It was like, I never
knew what the future held; I couldn’t imagine what things were going to be like so it was like
getting through each day. It was just let me get through this day and then let me you know
and and let me get through the next day. And it it it was like that. There didn’t really seem to
be a light at the end of the tunnel, but now with David he can feed himself and he can drink
and he is starting to do a little bit of communicating.”

The first few years while the parent (usually the mother) is at home all day
with the child are very difficult. The parents whose children had started
school described this as a turning point. They were then able to share some of the responsibility of looking after the child. The child being out of their care for a few hours each day gave them time to reflect on their journey so far.

7M. 715 "when Andy was two and three before he started school I mean I have had some bad days with Andy and I've just, when you (child's father) have got in I have thought 'right' and I have just gone to see mum and dad I have just dropped down in tears because it can get to you can't it? And I think god I just can't exist like this. Then it got to taking Simon (older brother) to school first and I had to take Andy with me and his behaviour was just and I, I just thought I can't, I mean it used to get me down didn't it? And I just used to think 'oh god' you know, so I think, you know, if you're actually, you know at home all day with that child. Like I say, he is at school most of the day now since September. So I do get a little bit of respite now a bit of normality to myself."

For this mother the memories of how it had been were so traumatic that she struggled to recall them.

5M. 210 "you push it to the back because it was so bad at the time. Now that he is a lot lot better its hard to recall it again. But, he was very hard work he was, he was an awful child to bring up. The first six years of his life where the worst six years of mine"

Another aspect of this theme is 'We are ok but it could be really difficult for other people.' Using the shipwreck analogy the parents feelings are 'it is ok for us because we like living on an island'.

1. 454 "I think a lot of people would see it as a negative as as being, feeling cut off from, er well we've got, we have have, well they still are friends but they don't understand what it is like having an autistic kid, and they don't, they don't, we don't see much of them because they are busy going about their own lives erm and I mean we only sort of know each other sort of socially really. Ahm and you get stuff like that and if I were, we were very social and liked going out and socialising and all that sort of stuff I could see it being, of that being a big negative but we are not, we are quite happy being just family orientated. I some times think
of us as being like a little CIA clan, we’re just happy as a family unit you know. So I don’t. I don’t see, see that as being a negative with us but I can see it being a negative with other people, if they like that sort of social life sort of thing.”

For this mother, she is ok because she is a good swimmer. It would be much worse for people who cannot swim.

6. 558 “I am very lucky because I can see things from a variety of different perspectives because of the teaching background erm having the first child being neurotypical and erm er having John with his autism so I’ve kind of got a finger in all pies. But I think that you, that is just the type of person that I am you know I can see things from different perspectives and erm, but I can imagine that if Sam had been the autistic one and he had been my first child then the impact of that could have been much more devastating erm because you know, you could have taken it as something that you had done wrong. I kind of, I am reassured that Sam has turned out absolutely fine (laughs) erm er so the techniques that I used there must have been working ok and the fact that they didn’t work the second time with John as well erm you know, obviously its, it makes it apparent that there was a reason for that. So again I am luckier than a lot of people that perhaps have an autistic child first.”

This father describes how things are fortunate for them because their journey appears to be coming to a satisfactory conclusion. They have been in the water, they have been on the island and now they have ‘just arrived at Dover’. They still have a difficult journey ahead of them but they are over the worst. Their son has just started an adult residential college and things are going well.

5F. 751 “I think that we are fortunate in as far as we can see an end result as that we can class as satisfactory. I think a lot of people don’t have that possibility. and I think that a lot. It would be very hard without that. I don’t know if he will get there but the fact that he could get there is massive to us.”
Theme 2.9: Hope – ‘optimism about the future’

The parents in this study all described the difficulties and struggles that they had had, and were still having. However, they all remained hopeful about the future. Optimism about the future helped them to cope with the present.

3. 299 “we hope he will be happy and will have a friend and hopefully he’ll meet somebody that can help him to have a normal life and a family like anybody else and that he can have a job that he really likes.”

The Parents hope that as their child develops they will gradually learn new skills that make him more independent. Independence was the goal that all the parents strived for.

6. 462 “He wants to be an artist you know. He wants to drive a train (laughs) erm and he has some literacy and numeracy skills erm and I think that given the right support he could live quite an independent life …….. I even feel sometimes that he would be capable of a relationship with the right sort of person, you know because he has managed to sustain a couple of friendships….. If he was ever to find a lady friend that was quite happy to go along with his ideas and is charmed by him and loves him for who he is and accepts, then there is no saying that he might not get married erm erm because he could and that would be lovely.”

1. 257 “when David was first erm looked at by by the doctor and we got the the the sort of. When he was basically he was one and he was doing nothing, he was just, he like a three month old baby erm and we didn’t think he would ever walk we didn’t think and and all these little things he’s doing but what the future could be, I mean the ideal. I know that you can’t get rid of autism but the ideal would be that he’d be able to be independent and function in society. That would be my ideal.

5F. 370 “I would expect, if Terry carries on as he is doing that he will live a semi independent life.
Mother. That’s what we both hope

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Father. He, and this is what this college course is all about he is in that house now. house sharing but they do have house parents in there

Mother. House parents.

Father. And in the next year or possibly two years he will move into a 90% independent flat with three other kids and they will have to get on and do everything for themselves with just some one to pop in every now and then to make sure what they are doing.

For some, small improvements enabled them to keep a positive outlook. As this parent says, the alternatives to a positive outlook are not helpful.

7M. 414 “I do have a lot of hopes for Andy I do I think that he will improve. Now we have picked it up so early and now that he can communicate and he is actually learning and he can say letters and things and he’s got, I mean the other day he got an achievement award so I do think now, I am trying to train myself to have a positive outlook. And if I am negative he is not going to get anywhere and now that, I have been feeling a bit positive now that, he has been doing quite well at school so I do think yeah, I do think now I have got hopes for Andy, I do. you never know.”

Theme 2.10: Despair

This is the opposite of hope, parents for the most part managed to maintain a positive outlook. This theme was rarely mentioned but it was there, just below the surface of the conversation. On the occasions when it was about to surface parents would make a joke of it.

6. 779 “I try to get them to try to look beyond the autism at John and his interests and things and he has some lovely little ways and he you know, he means well there is no malice in him at all it is pure autism (laughs) when he is being horrible (laughs). If he did not have the autism he would be quite a lovely natured child you know”

However, it was such a strong theme that it did break the surface on several occasions. For some it was the effect that it had on their lives that got them down.
4. 288 “I have suffered a lot of depression through it because, it has got me so down that I haven’t been able to get out and do things that I would normally do, because it has just not been worth it going out you know, when I have got all three of them. Erm, so I have sort have been like a prisoner in my own home a bit.”

For others it was the uncertainty of the future.

2. 381 “it has effected the way that I feel emotionally dreadfully, I mean I I went, when he was first diagnosed I was on antidepressants for, erm, not that long really about six months. I was really, really depressed and I still have some really black moments, not for a while, maybe not even this year, you know. But yeah, sometimes I just feel like crying, because you don’t know what is going to happen or what the future, or you feel exasperated because, erm, things don’t seem to be coming together. So yeah it is, it is emotionally difficult, with him, mmmm. And trying to cope with every thing else, the business, everything that we have going on in the home.”

This parent talked about despair in terms of losing the will to try anything. She had learned through experience that most things she tried to do ended in failure.

3. 518. “I think sometimes one just despairs really. You sometimes think of what you want to do and you think well it’s just not worth it. But then we have got him and we have got the positive bits to him as well and Tammy (older sister) will say “he always spoils everything” which he does really he always spoils things.”

This parent kept up a positive front throughout the interview but occasionally she would give a hint of her true feelings.

6. 646 “you just sometimes you just look around you and it is a constant reminder that he is never going to manage that and he won’t drive and you know. It is the hopes and dreams that you had for him and at each stage you sort of think well umm that’s not going to happen and that’s not going to happen.”
Superordinate Theme 3: ‘Different’

In this theme parents emphasised the fact their child with autism was ‘different’, ‘not normal’ this was a very strong theme that ran across all the interviews.

Theme 3.1: Hidden disability – ‘outwardly normal’

Parents described the need to emphasise the difference between a child with autism and a child without because of the fact that they look ‘normal’. Parents said that it would be easier for them if there were obvious physical symptoms. Outside of the recorded interview one parent said she had t-shirts with ‘I’m not naughty I’m autistic’ printed on them. Another mother had cards with a synopsis of autism on them (Appendix 5) that she gave to people when she felt that they were judging her.

7M. 202 “I think that now, if someone were really, really looking and chittering and talking I would maybe go up and give them one of my autism cards I think. I just ‘here you are would like to read this’ yeah I would I’d say right and then think right you know”.

Several of the parents made the comparison to disabilities with obvious physical features. They felt that other people would be more tolerant of children with autism if they looked different.

7F. 176. “Cos he looks normal. people think that he is”

Mother. “Exactly”

Father. “He doesn’t have autism”

Mother. “That’s what I have found is worse as well. when you see a child with Down’s syndrome or cerebral palsy. you glance. you look. you know there is a problem but like you
say with the autistic child or the adult they will just look, of course they are normal, they look fine and that’s what makes it harder. I think that is what is the most hardest thing. definitely.”

Parents talked about how they felt that people did not believe them.

3. 192 “he’s such a bonnie lad and it’s such a hidden disability. I think that nobody could really understand. I think that, and you couldn’t ever know what he is like at home and how bad things could get. You could never know because he can be so good. I think that it is very hidden and when they look fine, and it’s not as if you have got a child with a physical disability where they look different. People have the sympathy vote whereas if they look fine they’ll think that he is just naughty, its just the parents, who can’t handle him.”

Theme 3.2: Comparison with Siblings

The parents in this study felt that their child or children without autism were very different to their child with autism. This was highlighted the different expectations that they had for the siblings. Some of the parents referred to their other children as being able “to fly”. This seemed to reflect the parents own feelings being trapped by their child’s autism.

1. 270 “the other kids we would love to all go of to university, we would like them all to go and travel the world, see everywhere and and just spread their wings and fly basically. But I can’t see that with David.

5M. 401 “Hazel (older sister) could fly, couldn’t she, she has got the world at her feet really.”
Father. “I mean one child is going to be fully independent have relationships and everything else. These are the two big issues really”
Mother. “Yeah, relationships”
Father. “Relationships and the independence side, they are totally different aims……Terry will do low level work, repetitive work, he’ll get paid for it and hopefully he will enjoy his time doing it. you know… Whereas Hazel, she could do more or less anything at the moment couldn’t she?”
2. 251 “my other children I hope that they are going to have fantastic jobs, fantastic lives, go off and see the world, get married and have children and for David I just feel that he is always going to be with us.”

The high expectations that parents had for their other children was in stark contrast to their honest view of what the future held for their child with autism.

6. 479 “Sam (older brother) is university material I mean he has always been top of the class for things and he is very bright in maths and science and very eloquent and real good all rounder really. He is just one of the lucky ones I suppose and I see him going on to have a good career I think that Amelia (baby sister) will, she is pretty bright and with John I would like to think that there is some kind of further education that we can gear him into but, obviously, I don’t think that university is going to be an option, realistically (laughs).”

The way parents described the things that the other children would do seemed like it was their true thoughts of the child with autism would not do.

4. 368 “I think that they (younger sisters) will be a lot more independent hopefully. I think that they’ll be able to go to college and whatever and get descent jobs I feel sure that they will be able to look after themselves and live independently”.

7M. 403 “Simon (older brother) will just go like any other normal child he’ll grow up leave school and whatever and get a job, he’ll go out with his friends he can socialise better and everything and he has got a future of maybe getting married and having children of his own”

Theme 3.3: A longing for normality – ‘if only’

Parents of children with autism are faced with a conflict. They need to accept the child for who he is, autism and all. However, unlike other disabilities, all the treatments for autism are about changing the way that the child behaves and teaching him to be ‘less autistic’. The paradox is that to improve the
outlook of the child, the parents must not accept him as he is; to do that is to accept defeat.

1. 378  "I wouldn't have David any different than the way he is cos he wouldn't be David then. But, arm, I would, I would, I will do what ever is necessary to get the best outcome for our David but, but emotionally you get down times, you get down times with him when you just think, god I wish he could talk to you or, or you, you could. That's the main thing that's our next the next main thing for David is that I would just love him to be able to talk."

All the parents interviewed had a desire to change the way their child was, but some were not able to express this freely as it implied that they did not value the child for who they were.

6. 626. "Well I don't think that you ever stop grieving really about what could have been you know. I mean I, I, I very, I love John to bits and I wouldn't change him for the world because John is John autism and all you know. But I often stop and think if only, oh if only he could have been like Sam and we wouldn't have all this worry, every day, every day affects, because you know, and I go to pick him up from school and all that and I am thinking, I wonder what sort of day he has had today, I hope that everything has gone ok, and you know. Will I still be worrying like this? Where as Sam, bless him I hardly give him another thought because I know that he is ok"

Parents work hard to ensure that their child has the best possible outcome, but if the child were 'normal, they would not have to do so much to achieve a much better outcome. The longing for normality is not just for the child, it also for the family to have a normal life.

2. 317  "and it just takes so much bloomin effort all the time, from, from me and from John (father) and er you just, I just and sometimes you just want him to be normal, because you don't want to have to put all this effort into it all the time and, but there's nobody else to do it, you know."
This mother was able to describe the desire for normality by attributing the thought to the boy's father.

4. 281 “I think that had a lot to do with my marriage break down because me ex couldn't cope with it. He just wanted a little boy, normal boy that could play football and whatever.”

These are the themes that came from the text, they represent parents experience of what they want to say. These do not take into account nonverbal communications, suppressed emotions and clinical judgements. These will be discussed in the next chapter.
CHAPTER FOUR: DISCUSSION

Sample Characteristics

With small sample qualitative research, it is not possible to generalise the results to the population. The themes generated in this study were based on the unique experiences of nine parents from six families in the East Riding of Yorkshire. Autism is a wide spectrum of disorders with different aetiologies, outcomes and behavioural expressions and consequently, a different impact on the parenting process. As the themes show, the families in this study had many experiences in common; they also had many different experiences and different ways and levels of coping. The nature of Interpretative Phenomenological Analysis (IPA) is that it looks for the commonality rather than the difference. No measures of severity of autistic features and level of cognitive functioning were used in this study and there was no vetting of the participants. A combination of the rarity of the condition and the low response rate meant that all the parents that volunteered to take part in this research were included.

With a non-random selection process, it is possible that the sample is not representative of the population. The children in the sample were relatively ‘high functioning’. According to parental reports, five of the children had both expressive and receptive language; the sixth had good receptive language and had used a few words in the past. Three of the children were in mainstream primary schools with support, two were in special schools and one was in a specialist learning disability adult placement but had previously managed to hold down an unsupported summer job.
Autism is not affected by socio-economic status; therefore, the sample should represent the social stratification of the area. The East Riding of Yorkshire is a relatively poor area of the country. All the participants in this study lived in comfortable homes and appeared to have a reasonable household income. All the parents interviewed appeared to be well-adjusted, resourceful individuals who were distressed by, but coping with, their child's autism. It is speculated that less able parents or parents that were in a current crisis would not volunteer for such a study.

It is possible that the sample is representative of the larger population but it is more likely that it underestimates the impact of a child's autism on the parents and the parenting process.

Clinical Observations

It is not the researcher's position to speculate about the participants' mental health, but an important part of the study would have been missed if the participants' emotional states were not commented on. None of the participants was previously known to the researcher, so at the point of interview they were effectively speaking to a stranger. Unlike therapy, there was little time to build up a good therapeutic alliance before discussing some very personal and distressing material.

The consequence of this was that at the beginning of each interview the participants were guarded, they presented the face that they present to the world, their defended self. To start with, the interviews were very 'matter of
fact’. The parents described what appeared to be very distressing material in an emotionally detached manner often laughing as they described it. As the interviews went on and the participants became more at ease some of the real emotion started to seep through into what they were saying. This can be seen in the transcripts as parents started talking about something and then trailed off as if the truth of what they were saying was so painful that it could not be said.

1.235 “whereas with David he couldn’t even chew. We had to teach him how to chew things. If you just put a piece of cheese or whatever in his mouth he’d just gag whereas well you know it seems that you have to teach him everything so yeah (long pause). What was the question again sorry” (laughs)

This conflict between putting on a brave face and letting the emotion seep through can be seen in the themes 2.8 ‘I am ok but…- shipwrecked’, theme 2.9 ‘Optimistic future’ and theme 2.10 ‘Despair’

**Terminology**

Good clinical practice dictates that the classification of mental disorders is exactly that, not the classification of people with mental disorders. Therefore, it is considered good practice to refer to people as ‘people with a mental disorder’ rather than referring to them as the disorder. For example, ‘a person with epilepsy’ is preferable to an ‘epileptic person’. The former implies that he is a person separate from his epilepsy and if his epilepsy were cured, he would still be that person. Whereas the latter implies that, the epilepsy is an
integral part of who he is. This also applies to ‘people experiencing psychosis’, ‘people with depression’ and so on.

Throughout this study, the child has always been referred to as ‘a child with autism’ and the other children as ‘children without autism’. However, throughout the interviews it became clear that the parents did not share this reasoning. They consistently referred to the index child as ‘autistic’ and the other children as ‘normal’ or ‘standard’. The parents were aware of the politically correct language, but chose not to use it. In the case of autism, the parents felt that autism was an integral part of the child; if he were not autistic, he would be somebody else.

1.378 “I wouldn’t have David any different than the way he is cos he wouldn’t be David then”.
7M. 165 “He is totally different to a normal child, you know a child that is neuro typical is it?”
5F. 444 “An autistic kid’s mind doesn’t work like a standard kid’s mind if you can use the word standard”

This reflects the parents’ view that autism is different from other disabilities and autistic children are ‘different’ from ‘normal children’. This can be seen in the superordinate theme ‘Different’

The Impact of a Child’s Autism on the Parenting Process

The aim of this study was to use an established model of parenting (Hoghugh, 2004) to explore the process of parenting a child with autism and how it differed from the process of parenting a child without autism in terms of the three core dimensions of ‘good enough’ parenting: care, control and
development. The themes generated by the analysis of the interviews appear to show that parenting a child with autism is a very different experience to that of parenting a child without autism.

There were 19 themes and these naturally clumped together into three superordinate themes. The superordinate themes were, 'What we have to do because of autism', 'What autism has done to us' and 'Different'.

The first of these themes 'what we have to do because of autism' fits neatly into the care control and development model and superficially appears to be similar to what parents do for non-autistic children. Extensively it is, but more so. The three dimensions of 'good enough parenting' remain the same for all children, what differs is the methods and the amount of effort that parent's have to use to achieve them.

The second theme 'what autism has done to us' was less expected as the themes were not the result of specific questions. These themes came out of the narrative between questions. Again, the themes in this superordinate theme could be thought of as things that any parent may experience at some time or another, particularly, when dealing with 'difficult toddlers' or 'stroppy teenagers'. The difference for the parents in this study was the intensity and longevity of the experience.
The third superordinate theme “Different” shows the conviction of the parents that, not only is the process of parenting a child with autism different from parenting a non-autistic child. The child himself is different.

Superordinate themes ‘What autism has done to us’ and ‘What we have to do because of autism’ and ‘Different’ will be discussed in relation to parenting, care, control and development.

**Parenting**

Prospective parents have an expectation of what it is to be a parent. This historically, would have been based on their own experience of being parented, tradition, practical experience and religious and cultural ideologies. In contemporary parenting, this is still true to a certain extent. However, prospective parents are exposed to ideologies and models of parenting depicted in magazines, childcare manuals, documentaries and commercial television (Utting & Pugh, 2004). The result of all this information is that people, have well informed expectations of what it is to be a parent in a society like contemporary Britain.

**Social Validation**

Parenting is a socially validated experience; there are published norms with which parents can rate their child’s progress. Developmental milestone are well documented and well known by other parents, grandparents, health visitors and medical professionals. There is social validation within the school system. Children get progress reports from teachers; parents can measure their child’s ability against other children. They can share experiences and
difficulties with other parents. If a parent is experiencing problems there is a wealth of knowledge and problem solving skills at his or her fingertips from family members, teachers and professionals. The bookshops are full of books on how to parent 'normal' children.

This is in contrast to the experience of parents raising an autistic child. For each of the parents in this study it was a unique experience that they felt no one else could understand, not even parents of other autistic children. There was no collective knowledge or understanding to guide them. For these parents it was an experience of trial and error, a journey into the unknown with no map to guide them. Each parent had become an 'expert' in parenting their autistic child as well their other child(ren). This was a difficult experience because there was no validation of what they were doing. Parents described spending hours or even days teaching their child to do one simple thing that other children would pick up without a thought. Yet the achievement went unrecognised by society, as it was something that everyone else could do anyway.

The theme 2.3 'no one else can understand' describes the frustration parents felt at not having their efforts acknowledged. Parents of autistic children have to invest time, effort and money in their child's education just to get them to achieve the simplest things. Yet they still experience negative evaluations from other parents and professionals and continually have their parenting practices questioned.
Parenting, a two way Process

Arendell (1997) described parenting as a process in which children and parents are active respondents in a ‘transaction’, parents have responsibilities to their children and they have expectations of rewarding feedback and emotional intimacy from the child. When a mother gazes into her baby’s eyes, the baby is comforted and may gaze back and smile. When a parent returns from work, the child expresses excitement and pleasure at his return. When the parent reaches down to pick her baby the baby lifts its arms in response. These small interactions are what shape the relationship between a parent and child. This is very different from the experience of the parents in this study.

The earliest accounts of autism (Kanner, 1943) recognised the child’s passivity in the child-parent relationship. Autistic children do not give parents the rewarding feedback that other children give. They are not comforted by their mother’s gaze and do not lift their arms to be picked up.

When asked, the parents said that their relationship with their autistic child was the same as with their other child(ren). However, in telling their story they described how the autistic child placed many more demands on them, took up much more of their time and resources and gave them very little in return. One mother felt that her autistic child would not even notice if she was not there.
2. 360. "Yeah, yeah it is because David gets all of our time and our support and emotions and we don't really get much back from David .... I don't know whether he would notice if we weren't around, if I wasn't, if I suddenly disappeared. I don't think. I think that David would just get on with it. You know, the others would all, the others would all be obviously upset. but I think that David would just get on with things".

Hoghughi (2004) described parenting as a dynamic process where the care giving roles change as the child develops. When the child is very young, the care given by the parents is total, but as the child gets older, the care-giving roles are gradually equalised and then reversed with the adult child eventually caring for his elderly parents. This is not the case with autism theme 1.3 'Never-ending care- a lifetime and beyond' illustrates the parents' feeling that they would always be caring for their autistic child, for them the roles would never equalise or reverse. As the child gets older, his developmental path deviates further from the norm, he becomes more disabled, and the parents are faced with more and more challenges.

**Parenting in a Social Context**

The parents of an autistic child are not isolated entities and the activity of parenting occurs within a social context (Bronfenbrenner, 1979). The child's autism has an impact on every part of that social context from the proximal to the distal. As in a nuclear explosion, the shock waves move out from the epicentre in ever-increasing circles. The parents are at 'ground zero', slightly out from that are their relationships with each other and the other children, then friends and extended family, school and services, the community and
society as a whole. It affects their home, their careers, social life, mental health and plans for the future.

Previous studies have found that having an autistic child reduces marital satisfaction and family cohesiveness, and that families were less likely to do things as a family and less likely to go on spontaneous outings (Higgins et al., 2005). This study found that the autism brought some of the families closer together. However, for others it pulled them apart. Of the families that participated, only in one, were the parents separated. However, this may be an effect of the sampling. It would be more difficult for a single parent to attend National Autistic Society Meetings and to find time to participate in such a study.

The families that were drawn closer together described ‘doing things as a family’, being ‘family orientated’ and being socially ‘self-sufficient’. This can be seen in theme 2.2 ‘Avoid other people-empty beaches’ where the families seek isolation and prefer their own company. One parent described how the family did not need to socialise, as they were quite happy being family orientated “like a little clan”. He described this as a positive but it felt more, as if it was a reaction to being socially excluded not a lifestyle choice.

The other parents that were still together said that having an autistic child had put a strain on their relationships and it had damaged their relationships with the other child(ren). One way that they coped with the demands of everyday life and the demands of the autistic child was to ‘split’ the family.
One parent cared for the autistic child while the other, did things with the other child(ren).

5M. 117. "I would say it was horrendous, we just didn't go to the shops with Terry it was, one would stay in with Terry or go out with Hazel or erm, it was one in one out really".
Father. "We had to split up into two pairs"

The impact of the child's autism on the family is that it can bring them closer together, but this is because their opportunities to socialise with peers and participate in community activities are compromised by the autistic child's unpredictable and challenging behaviour. This apparent family cohesiveness is in reaction to social exclusion and isolation.

Beyond the immediate family, the impact of autism on friends and the extended family was mixed. For some of the parents they had support from grandparents but, in the main, they had little contact with extended family and friends. The parents in this study described themselves as existing outside society; the two themes 2.2: 'Avoid other people – empty beaches' and 2.4: 'Isolated – never invited back' describe the impairment to social interaction. In 'Avoid other people- empty beaches' parents and families sought isolation to avoid confrontation, stigmatisation and embarrassment. They described seeking out isolated places, empty beaches where they could exist as a family unit safe from others disapproval and having to explain behaviours to strangers. When they were in crowded places, the parents were constantly on edge in case the child did something to draw
attention to them or something that they would have to explain or apologise for.

'Isolated - 'never invited back' describes the enforced isolation that parents and families experience. This is unlike 'empty beaches' in that parents are not trying to avoid others they are attempting to join in and have a social life but they are shut out or excluded because of their child's behaviour and other people's apparent ignorance and intolerance. As a family, they feel excluded from normal society as they are not able to eat out, they cannot go to the cinema, and they cannot go to other people's houses, barbeques, weddings, funerals, school plays. They are effectively excluded from all the events to which parents would normally take their children and they have limited access to adult events due to difficulties in childcare arrangements.

All the children in this study were of school age and were engaged with various services. What the services were and what was available was not the focus of this study but parents' experience of services was. Not all parents of disabled children engage with services or request additional help with the care of their child. Belsky and Vondra (1989) describe a 'buffered system' where parents have enough social support through extended family and friends not to seek additional help. For the parents of an autistic child the options for non-professional help are limited.

The combination of normal looking children with challenging behaviour means that others are less sympathetic and consequently less likely to offer
support (Gray, 2002). This study found that the autistic child’s challenging behaviour, particularly property damage, limited the possibilities of friends or family caring for the child overnight. All the parents in this study had some support from extended family but it was not enough to ‘buffer’ the system. They all sought extra help from services but were disappointed with what was available.

A strong theme running through all the interviews that did not make the final selection was ‘fight for everything’. Parents described the struggle that they had just to be heard. Due to the nature of autism, the early signs are difficult to detect. Autistic babies are almost indistinguishable from normal babies; the differences only appear as the autistic child gradually deviates from the normal developmental path. The slow realisation that something is wrong with their child is distressing for parents (Seigal, 1997). This is exacerbated when their concerns are dismissed by others. Consistent with Midence & O’Neill (1999) and Maurice (1996), the parents in this study had to demand assessments for their children. This quote is representative of all the parents’ experience.

7.15 “I thought then that he could have been autistic, erm I also have a health visitor come to my home who sat down in my front room and when he was he lining up trains and things and I said, ‘do you think, you know, about his behaviour and things’ and she said ‘oh no he just likes all the attention’.
Erm. I took it further. I took him to my GP and said to my GP ‘do you think that he could be autistic’ and she said, ‘Certainly not, if he was he would be sat staring into space’.
So I came home and I was very despondent so, I said to my husband that we would go back again, and we went back again and we demanded, we went back to the GP and we demanded that we have him assessed”.

The Impact of a Child’s Autism
Mansell and Morris (2004) and Brogan and Knussen (2003) found that the way in which the diagnosis is given to the parents of an autistic child has a long lasting effect on the way the parents react to the diagnosis, the way they perceive autism and the subsequent contact that they have with services. In this study, it was what happened after the diagnosis that was significant. For one parent the diagnosis led to service provision, for the others it led to discharge.

Parents described receiving the diagnosis as a mixture of relief and disappointment. The diagnosis did not come as a shock, as it does for parents of children with physical disabilities or genetic syndromes (Russell, 1983; Dale, 1996), because most of the parents already suspected autism long before they received the diagnosis. The relief was at finally being heard, and having an explanation for the child’s behaviour. At this point the parents felt supported, their concerns were being validated, they had been right to be concerned. The disappointment was because the diagnosis did not lead on to a ‘next stage’ of service provision and intervention. Parents were then left alone to contemplate the meaning of the diagnosis and to search for treatments.

When a child has a physical illness, diagnosis leads to treatment. His treatment becomes the responsibility of the medical profession. With autism, the treatment and care remain the responsibility of the parents. The parents have to research the most appropriate treatments for their child and then they have to campaign to get it. Provision for autistic children was described as
haphazard and difficult to access. Parents were not aware of what they were entitled to or what was available. They felt that there was no one to guide them or point them in the right direction.

5F.229 “If you are not aware that there is any support there you don’t know that there is anything that you can tap into……. this area hides it or just doesn’t give it. I have tried twice to get into social services and been knocked back both times they just say that they haven’t got anybody who does that role, who can help and that”

7M.110 “As far as I was concerned, I found that very poor actually, I must admit, erm er. well oh. I found out lots of things me self I really have….and there are certain things like, erm direct payments, and I didn’t even know anything about that and now, after all this time, but you know, you can get certain help which we didn’t even know. So, I found the system, you know, in that way is a big break down for people with autistic children. You know, because a lot of people don’t know about it. I am even on the carers advisory committee me self for meetings and I challenged one of the, er, top people there who deals with disability children, and I said “well surely you should have something in place, some people so that when a child has a diagnosis, to go down and say, well you can get this you can have portage or you can have whatever or whatever and you get that help that way”. But, you just don’t know. I have had to really find a lot of things out myself and struggle through it myself, but I have got there in the end.”

The apparent lack of information and difficulty accessing services for their children adds to parents’ feelings of isolation and exclusion. There is no specific autism service in the area of this study and parents experience is that none of the other services is prepared to take responsibility. Autism falls between Learning Disability Services and Child and Adolescent Mental health Services, it also fall between health and education (Loynes, 2001).
Adaptation to the Diagnosis

Seigal (1997) described adaptation to a diagnosis of autism, as grieving for the ‘hoped for child’ and to some extent is, but it is also more than that. Parents grieve for the ‘hoped for child’ but they also grieve for themselves and for the impact that the ‘actual’ child will have on them and their lives. They grieve for their lost future, their lost social life, and their lost relationships with their other children. These feelings of loss were expressed throughout all the superordinate themes.

In superordinate theme 1, the theme 1.3 ‘Never-ending care- a lifetime and beyond’ illustrates some of the loss and anguish that the parents’ feel and their commitment to caring for their autistic child for as long as they are able. In superordinate theme 2, the parents lost social life, and isolation are described by themes ‘isolation-never invited back’ and ‘avoid other people- empty beaches’. The theme 2.7 ‘guilty’ describes the guilt that the parents feel that they have to neglect their non-autistic children to care for their autistic child.

In superordinate theme 3, two of the themes reflect the impact that the child’s autism has had on the parents. Theme 3.3: A longing for normality – ‘if only’ contains the unguarded comments that parents made towards the end of the interviews when their true feelings and emotions began to seep through the dialogue. The sense of this theme is that if the child were ‘normal’ then the parents would not have all the extra work, stress and worry that is caused by the autism.
In theme 3.2: ‘Comparison with siblings’ parents describe how the expectations that they have for the future of their ‘normal’ children are very different from the ones that they have for their autistic child. When the parents describe the expectations that they have for the siblings they make multiple references to ‘freedom’, ‘being able to fly’, ‘spread their wings’, ‘travel the world’, ‘do whatever they want’. It is as if the parents are really expressing their own frustration at being tethered by their duty to the autistic child.

**Care, Control and Development**

**Care**

Care encompasses activities that enhance a child’s chances of survival. These activities are divided into physical care, emotional care and social care.

**Physical care** consists of providing the child with what he needs to survive, food, warmth and shelter and the satisfactory elimination of bodily waste. It also includes keeping the child safe from harm. Autistic children need more care than normal children; this was the unanimous opinion of the participants. The most common response to this question was a guffaw or incredulous laugh. The feeling was that the child with autism needed so much extra care that it was hard to articulate all that had to be done. One parent said “everything, everything”. She likened it to looking after a baby, he was still in nappies, he needed help to feed himself, dress himself, and wash himself, like she said “everything”.
When a child is an infant the parents expect to care for every aspect of the child's life, but as the child gets older the care required changes and diminishes (Roberts & Lawton, 2000). With autism the care does not diminish over time, as the child grows the discrepancy between the care needed for the autistic child and the care needed for the other child(ren) increases. When the mother described looking after her child as like looking after a baby, she was understating the problems. In reality, it was like looking after a baby, a toddler and a five-year-old all rolled into one.

The theme 'Never-ending care-day to day' encapsulates relentless demands that are placed on parents caring for their autistic child. One parent described how her son had been in nappies until he was five and it had then taken her a further two years to teach him to use a toilet properly. He was still having 'accidents' at the age of 11. Another parent described how her five year old was still in nappies and would take his nappy off and "poo on the floor". These, as isolated incidents would be difficult to deal with, but these represent just one aspect of what is a pervasive disorder.

As well as all the extra care demands described by Roberts and Lawton (2000) the parents described having to be permanently on guard, to prevent the child from placing himself in danger. The theme 'Constant supervision-eyes on double' represents the parents' need to watch their autistic child at all times so that they are ready to 'leap into action' to prevent him from running into the road, climbing out of the window, running away, eating
inappropriate things, going off with strangers and many more. The other side of this theme is being ready to stop the child damaging property, flooding the bathroom, taking food from the cupboards or upsetting other children.

**Emotional care** was difficult concept for parents to describe, and most were not able to say what extra emotional care their autistic child needed. One parent summed it up well, she said that her son lived in a “constant limbic state”, he reacted to everything in an “emotional way”. Her understanding of emotional care was that it was all the things that she did to keep him happy, to protect him from being upset by others and help maintain his self-esteem. The themes 1.5 ‘Preparing the way-like curling in front of him’ and 1.6 ‘Adapt to autism’ represent the activities that parents do to keep their autistic children happy.

Emotional care includes making the child feel valued and the subject of unconditional love. Unconditional love in a normal parent-child relationship is a difficult concept, as children are active respondents in their own care (Arendell, 1997) and although parents may offer unconditional love, they can expect to get something in return therefore the love is conditional. Complete unconditional love may be difficult to achieve, but parenting an autistic child comes close. Parents described themselves as loving their autistic child and described their relationship as the same as with their other child(ren). However, they consistently dedicated more time, effort and resources to the autistic child and expected very little in return, they tolerated behaviour and demands that they would not tolerate from their other child(ren). In fact when
parents talked about all the things that they had to do because of their child's autism and all the things that his autism had done to them it was hard to imagine what 'conditional' love would have been like.

Another aspect of emotional care is the opportunity for managed risk taking and exercising choice (Hoghugh, 2004). Because of the need for 'never-ending care' and 'constant supervision', the opportunity for managed risk taking was limited. Parents were not able to trust the child to do the right thing. All the parents described their child as having no 'sense of danger', no 'road sense' or 'stranger danger'. One parent did describe the lengths that her and her extended family had gone to, to enable her son to go to the shop 'unsupervised'. It involved a complex, covert surveillance operation with people strategically placed to intervene at the first sign of danger. However, he was very 'high functioning' and this was somewhat exceptional.

The need for never-ending care and constant supervision prevents autistic children from engaging in managed risk taking and experimenting with the environment. The permanent presence of a parent or 'caring' adult limits the opportunity for him to experience positive interactions with peers. The consequence of this is that the child does not develop an optimistic orientation towards new experiences. This may contribute to the high incidence of anxiety and phobic disorders in autistic adolescents (Gillott, Furniss, & Walters, 2001).
Social care. Autistic children by definition are impaired in social interaction. Therefore, it would be expected that they would need more care in social situations. This was the case, the parents all said that their autistic child did need more care in social situation than their other child(ren) and the care that they needed was different. Social care for the non-autistic children was about giving them the freedom to form appropriate peer relations, allowing them to experience different adult role models by joining clubs and participating in after school activities. These correspond to the social care activities described by Hoghughi (2004).

Social care for the autistic children was very different. Parents could not give them that freedom. The need for ‘constant supervision’ meant that they were never far from an adult. The focus of social care was to encourage the child to behave in a socially appropriate way and to keep the child safe.

Most autistic children do not seek peer relations they prefer to be on their own and relate to adults when they need something. They prefer adults to children as adults are more predictable and more likely to meet their needs (Wing & Gould 1979). Some ‘higher functioning’ autistic children do seek friendships but lack the social skills needed to maintain them (Jackson, 2002). Part of theme 1.5 ‘Preparing the way’ describes what the parents did to help their child in social situations. They would go ahead of the child and remove obstacles. In one case, this was removing the balloons from a party so that the child could attend. In another case, it was explaining the child behaviour and difficulties to people so that they would not form negative
opinions of him and treat him as if he was naughty. This extends to other children. One mother described how she had invited children round to the house and tried to persuade them to be friends with her son. This had limited success and none of the autistic children in this study had a friend.

*Control*

Control consists of setting and enforcing boundaries for the child so that he learns to behave in a cultural and age appropriate way. The emphasis of parental control is necessarily on behaviour as this is the outward expression of thoughts and emotions. Control was a very strong theme in this study. A substantial proportion of the parent's interactions with the autistic child were related to control. Parents described themselves as 'strict' through a necessity for firm boundaries, structured activities and routines. They also described themselves as having to be 'easy going' to cope with their autistic child's difficult behaviour.

Parents of autistic children tolerate behaviours in their autistic child that they do not tolerate in their other child(ren). This is consistent with parenting children with other disabilities where parents are more lenient with their disabled child (Burke, 1994) though the reasoning behind it is different. Parents of children with epilepsy are more lenient because they feel that they need to compensate for the child's disability (Nuttycoombe, 2006) whereas parents of autistic children are more tolerant because they are not physically or mentally able to control every aspect of the child's behaviour. They have to make choices over which behaviours to control and which to tolerate.
The lenience shown to the disabled child can lead to resentment and attention seeking behaviours in the siblings (Burke, 1994). This was not the case in this study, parents reported that the siblings had adapted to the autism by becoming more grown up, responsible and independent. The parents considered the other child(ren) to be a good source of support in the care and control of their autistic brother.

The theme 2.6: ‘Not able to control – he just never does’ describes the feelings experienced by parents when their child did something that they were not able to stop or he would not do what they wanted him to. This theme had two components to it; one described the helplessness that parents felt in the home. At times they gave up trying to control the child and left him to do his mischief and dealt with the consequences later. The other component was the fear of going into public places; knowing that if the child started to behave in an unacceptable, way they would not be able to stop him.

The impact on the parents and family of not being able to control their autistic child was the driving force behind many of the themes in Superordinate theme 2 ‘What autism has done to us’. It affected every aspect of their social lives and the way that they function as a family.

Theme 2.1: ‘Judged by others – keep your head down’ describes how not being able to control the child’s behaviour while out in the community caused
other people to stare unsympathetically and to make the judgemental comments that the parents found so humiliating.

Theme 2.2: ‘Avoid other people – empty beaches’ describes the parents’ reaction to not being able to control the child. They seek out the ‘quieter places’ where they can avoid confrontations and being judged and humiliated by others.

Theme 2.4: ‘Isolated – never invited back’ describes the consequences for the family of the child behaving in an inappropriate manner during social events and family occasions.

Theme 2.5: ‘Time bomb – on edge the whole time’ describes the anxiety that the parents feel when they do try to go out as a family because, they know that if their autistic child misbehaves or has a tantrum then there is very little that they can do about it except give up and go home.

Hoghughi (2004) describes how the effectiveness of control is determined by many factors including the parents’ own history and early experiences of control, the resources available to the parents and the levels of competing peer pressure experienced by the child. The parents of an autistic child cannot draw on their own experience: normal child rearing methods do not work on autistic children (Ferster, 1961). The parents had to learn a completely new set of skills.
The theme 'Not able to control' only represents part of the parents' experience. For the most part they were far from 'helpless'. They had embraced the challenge of caring for their autistic child and had become experts in behaviour modification, either through research or by trial and error. The normal methods of child rearing that had worked well on their other children were not appropriate for their child with autism. Therefore, the parents had to develop their own strategies to control the child. Some of these strategies were very effective in the long-term; some were effective in the short term but not in the long term and some were not effective at all. Parents were aware of which strategies would be best; but were not always able to implement them.

The most effective method to control the behaviour of an autistic child is to break behaviours down into stimulus-response units and then use a primary reinforcer to reward the desired behaviour and give a flat 'no' to an undesired behaviour (Lovaas & Smith, 1989). All the parents were aware of this technique and aspired to use it in a slightly watered down form. The difficulty with this type of behaviour modification is it only works in a strictly controlled environment such as a schoolroom or a therapeutic setting (Schopler, Short, & Mesibov, 1989). It has been used it good effect on 19 autistic children (Lovaas, 1987). However, Lovaas (1987) had the support of a dedicated team of tutors who worked one to one with the children for 40 hours per week. This intensity of treatment is hard to achieve and is beyond the resources of most parents (Hastings & Johnson, 2001).
Another method described by the parents was containment. This consisted of keeping the child in a place where they are not able to harm themselves or others and where there were limited opportunities for property damage. Examples of containment included, having a high fence all round the garden, locking off parts of the house, using a caravan for holidays and keeping the child strapped into a pushchair whilst shopping. The other part of containment is adapting the environment to suit the child. Parents described locking cupboards and removing ‘breakables’ from the house.

Containment is an extension of normal parenting behaviour. It is usual to put a small child in a playpen or to strap them into a pushchair in order to prevent them from harming themselves. It only becomes unusual as the child gets older. The difficulty with this method of control is that it is limited to the home, school and other specialised environments. It does not help parents to access the wider community and join in with social functions.

Another technique was ‘bribery’ this consisted of persuading the child to do as the rest of the family wanted by promising a treat. This is superficially the same as reward for good behaviour, except that the balance of power was shifted from the parent to the child. This technique is only affective in the short term as it encourages the child behave in a bad way so that he gets a reward for stopping. The parents that used this technique were aware that it was damaging in the long term but felt that sometimes there was no alternative.
As described above, reward for appropriate behaviour works well in a controlled environment. The times when the parents used less appropriate techniques were whilst out in the community. Here, the parents had to use whatever they could, at the time, to avert disaster or to get them out of an embarrassing situation. The consequence of this was that it reinforced the public view that the child’s behaviour was the result of ‘poor parenting’.

Some of the parents described ‘giving in’ as a way of controlling the child. They felt that as long as they controlled the things that were important then they could let less important things go. This way they would avoid confrontation and continued negative interaction. The sorts of things that parents were prepared to give in on were mealtimes, types of food and television programmes, and engaging in repetitive behaviours. For example, the parents would allow the autistic child to eat between meals, eat different food to the rest of the family, and eat in front of the television or play in the mud, whilst insisting that the other children eat what they are given and sit at the table and behave in an appropriate way.

The final strategy that parents used to control the child was restraint; this was an integral part of the ‘constant supervision’. Parents would have to be ready to physically prevent the child from doing things that may place them in danger, cause distress to others or embarrass the parents. Levels of restraint varied from having to hold the child’s hand at all times whilst out, to physically picking the child up and removing them from the situation.
These were very different from the methods that they used to control their other children. In fact, the parents did not talk about their other children's behaviour in terms of control. The references to the other children's behaviour were in the context of things that they tolerated from their autistic child that they would not tolerate from their other children. The parents would not tolerate inappropriate behaviour from the non-autistic children because the parents believed that they knew what was 'right and wrong' therefore, bad behaviour was a deliberate act.

In the case of the autistic child, parents took a much more 'Skinnerian' approach. They believed that the child was a product of his reinforcement history and that the behaviour was a consequence of the combination of his past experience and triggers in the environment (Skinner, 1974). The result of this was that the autistic child was very rarely punished. When the child behaved inappropriately the parents attributed the behaviour to external factors or the autism.

6.779 *he has some lovely little ways and he you know, he means well there is no malice in him at all it is pure autism (laughs) when he is being horrible (laughs). If he did not have the autism he would be quite a lovely natured child you know*.

**Development**

Hoghugh (2004) describes development as activities that parents do to encourage and enhance experiential growth. These activities include sport, music and art, or to travel and see a wide range of landscapes and cultures. The aim is to develop their children's inculcation of values such as tolerance.
wisdom, fairness and respect for the equal worth of others. These activities are not an essential for survival. They can be compared to the higher order tasks in Maslow's hierarchy of needs (Maslow, 1962). The higher order tasks can only be achieved once the lower order tasks are complete.

In the case of autistic children, parents have to achieve satisfactory care and control before they can engage in the activities described above. This does not mean that parents do not put energy into their child’s development; it means that the goals of development are different. Hoghugi (2004) also described development as activities aimed at helping the child to reach his full potential.

An important part of adaptation to the diagnosis for parents is the reassessment of their expectations for the future of their autistic child. The parents in this study had all had several years to adapt to the diagnosis and they seem to have made a realistic reassessment of their expectations. The universal goal was for the child to be independent as an adult. The level of independence varied with the severity of the autism. Parents were highly motivated to help their child to reach his maximum potential as the more independent that he became the less dependent he would be on them.

If development can be defined as what parents do to help their child reach his full potential then parents of autistic children put more effort into the development of their autistic child that their other child(ren).
One parent described how he had invested a substantial amount of money in his other children's education in order to 'stretch them' and to give 'a bit of an edge' so that they would have the best possible chance in life. For his autistic son the investment was much more but the goal was much less the aim was for him to achieve some independence as an adult and be able to function in society.

The difficulty for parents of autistic children is that autism is not a set entity; Intensive 'one to one' education in a specialised environment has been shown to make a very significant difference to the level of functioning of about 50% of autistic children and a moderate difference to the rest (Lovaas, 1987). With this knowledge and the lack of appropriate state education parents feel that they are responsible for their child's outcome. One parent described, that knowing that there was something that could be done but not being able to do it was worse than thinking that there was nothing that could be done.

The parents in this study all invested time and effort into the development of their autistic child but the activities that they did were completely different from the ones that they did with their other child(ren) and the ones described by Hoghughi (2004). The activities were, the basic skills of life, teaching the child to use the toilet, to dress himself, to behave in a socially appropriate manner, to communicate and in one case to chew food. These activities were appropriate to the goal of independent living.
The Family Becomes ‘Autistic’

The impact of autism is as pervasive as the disorder. It affects the parenting process, the parents, the siblings and the way that they interact as a family and as part of the community. When the parents described the child’s autism and the effect that it had had on them and their family it was as if the family had become autistic.

Living outside of society cut off from friends and extended family, being different, having difficulties in socialising with other families and seeking isolation represents the family’s ‘impaired social interaction’. The difficulties in being heard and the frustration felt when no one else could understand what it was like to live their lives represents the family’s impaired communication. Autism itself had become the family’s narrow focussed interest. They read about it, talked about it, went to conferences about it, joined groups because of it and they planned their lives around it. It really had affected every part of their lives.

Positives

Throughout this study, autism and its impact on the parents, the parenting process and the siblings has been described in a predominantly negative way. This reflects the data and the experiences described by the parents. However, there were a few positives. Some of the parents described the positive impact of autism. These comments were sparse and not enough to constitute a theme but it would be wrong to ignore them.
The researcher always tried to end each interview on a positive note to avoid leaving the participants to dwell on negative thoughts. For the same reason some of the positive comments are listed below.

1.443 “I would say positive things its its just the whole the whole family are just aware. all the other kids, everybody’s just aware of these disabilities that people have and problems that people have and they have to try and over come and it just makes them more tolerant and it makes them better better people somehow”

2.415. “Well I don’t know, it’s funny and in some ways people say that things always happen for a reason and I know that our eldest son Benjamin definitely, he wanted to go into teaching and now he’s definitely definitely thinking of going into special needs teaching if not psychology so that’s sort of, he’s found his career. Our daughter Lucy is also thinking of along those lines......If we hadn’t if we hadn’t have had somebody with autism I don’t think anybody would have thought about special needs teaching or training or you know anything like that. An I mean it even affected us so much as we have the holiday cottages and we’ve got all these great big sheds and barns and whatever and now we are seriously considering doing a conversion for disabled we’ll get them into, like you know disabled society to see what sort of things they need and that would give me fulfilment. Yeah.”

5M.742...“it has given me a lot more patience it has yeah. and I do see things. I am not as quick to judge others, I see a much broader aspect of things when you see people having problems with their kiddies when they are out and I just have sympathy really. I don’t judge anybody about anything. I may have done before.”

6.797. “Erm well I think erm it is important not to think that once that your child has a diagnosis of autism then that is the end it maybe the end of what your original hope and dreams were going to be but er you just have to find a new direction and realise that there are a lot of positive that come out of being autistic and er a lot of these kids have far more potential than I think you know we are at first led to believe and it is quite an exciting journey at times to see what actually they are capable of achieving. John surprises us all the time with the little bits and pieces that he picks up, learns and things so you know never loose sight of the fact that its not all negative stuff you know. That is about it”
Critique

The Model

The Hoghughi (2004) model of parenting has proved to be a useful model in this study. It was used to guide the development of the semi structured interview (appendix 4). The questions were arranged into sections relating to care, control and development. This enabled the researcher to focus the interviews on the impact of the child’s autism on the parenting process, whilst allowing the parents to discuss other things that were poignant to them. Separating the questions into the three domains allowed the researcher to make direct comparisons of the experience of parenting the autistic child with that of parenting his sibling(s).

One area of difficulty with the model was that the Hoghughi (2004) definition of development was somewhat irrelevant to the autistic child. However, it did highlight the different activities that parents did with their different children. This problem was overcome by adapting the definition slightly so that activities that parents did to move their child closer to independence and subsequently reduce the need for care and control were considered to be development activities.

Overall the use of the model has added to the richness of this study and facilitated the comparison of parenting an autistic child with a normal child and with previous research on parenting a child with epilepsy (Nuttycoombe, 2006).
This was an exploratory study that utilised the parents as the ‘experts’ in their own experience and allowed them the space to tell their story the way they wanted it told. The semi-structured interview gave them the freedom to say what was important to them whilst remaining within the framework of an established theoretical model.

It has used a qualitative approach to gain a deeper understanding of the experience of parenting an autistic child and how that differs from parenting a ‘normal’ child. Selecting parents that also had at least one ‘normal’ child ensured that the comparison to parenting a ‘normal’ child was a genuine one and not a comparison to parenting an ‘idealised’ or ‘imagined child’.

The researchers own personal experience and inside knowledge of the subject matter has helped to guide the interviews and make the parents feel at ease and understood. In IPA studies it is the researcher’s role to try to see the participant’s ‘world’ from the inside and to understand what it is like from their point of view (Smith & Osborn, 2003). The researcher knows this subject from the inside and was able to be genuinely empathic to the participants whilst remaining objective and questioning. The inside knowledge has also aided the interpretation of very emotive and complex data.

This study has remained true to its purpose and focussed on the experiences of the parents and the parenting process. Consequently, the findings have
clinical utility. It will help the reader to understand the real meaning of a diagnosis of autism and the impact that this will have on the parents, both in the immediate and in the long-term.

**Limitations of the study**

**The Sample**

This was an exploratory study that aimed to gain a greater understanding of parenting an autistic child. With such a small sample it was never expected to be able to generalise the results to the population. However, it was hoped that the sample would be more representative than it was. Due to the difficulties in the selection process all the participants were white British, property owning professional people. The parents in this study had many similar experiences and the themes that did emerge represented them all. However, the experiences of parents at the extremities of the socio-economic range may have been very different.

Another feature of the sampling was that it relied on volunteers; this may have biased the sample in favour of people who were coping well and felt able to volunteer. Therefore, the findings of this study probably underestimate the impact of autism on the parenting process.

Practical implications of interviewing participants in their own homes limited the area that could be covered by the study. The consequence was that all the participants came from the same area. Therefore, the themes that related
to service provision and dissatisfaction with the diagnostic process may be unique to this area.

**Measures**

There were no measures used in this study as it was about parents experience not about definite facts. However, measures of mental health may have added to the interpretation of the data.

Likewise, there was no measure of the severity of the autism or associated learning disability. The observation that the sample was relatively high functioning was based on their educational provision and parents descriptions of their abilities and behaviour.

**The Researcher**

The researcher is the parent of an autistic child and has a strong personal involvement with the subject matter. While great lengths were taken to remain objective throughout the research process, it is possible that the researchers own experience may have influenced the content of the interviews, the interpretation of the data and the selection of themes.

**Further Research**

The process of this research has highlighted several areas of potential future research that would add to the current knowledge of the impact of autism.

- Parents in this study fluctuated between being optimistic about the future to dreading the future. It would be useful to use a longitudinal
study to investigate how parents' hopes and expectations for their autistic child changed over time and to investigate whether a more realistic view of the future is related to acceptance of the disability.

- Not being able to control the child was the foundation for many of themes that related to the impact of the child's autism on the parents. A useful study would be to examine different techniques for controlling the behaviour of the child and the contribution that they make to reduce the impact on parents.

- The parents in this study felt that they had been excluded from services that others were entitled to and that information about what was available had been denied. It would be useful to compare the services available to parents of autistic children with those available to parents of children with chronic illness and children with other disabilities.

- The ages of the children in this study ranged from 5 years to 16 years. The parents were in different life stages and in different stages of adaptation to autism. It would be interesting to do a cross sectional study to look at how the impact of a child's changed with time from the point of diagnosis.

- The majority of the participants were disappointed by their experience of the diagnostic procedure and their subsequent engagement with services. It would be useful to explore parents' thoughts on how the procedure could be improved and what a specialist autism service would look like.
Clinical implications

This study has shown that a child's autism has a serious impact on both the parenting process and on the parents. The daily demands of the care, control and development stretch parents to their limits. The time and effort that they put into their autistic child is substantially more than is required for their other children yet there is no recognition of the extra work that they do. In the absence of social validation, parents need someone to acknowledge what they do.

The lack of a specific autism service in this area means that there is no continuity of care. The parents' experience is that they fall between services and are therefore excluded from services that are available to others. For other disabilities and illnesses the point of diagnosis marks the beginning of a process or the entry into a service. The experience of parents of autistic children is that input stops at the point of diagnosis. Parents are abandoned at the point when they are most distressed and vulnerable.

In the absence of a specific autism service, another service needs to take responsibility for autistic children, to ensure that there is a clear care pathway and that parents are aware of it. The diagnosis would then open the door to service provision instead of closing it.

Parents of autistic children experience difficulties and delays in gaining a diagnosis. Many professionals are reluctant to diagnose children, as they
believe that the label is stigmatising and that it pathologises the child. This may be the case with some disorders, but in the case of autism parents welcomed the label as it confirmed what they suspected, it helped to explain the behaviour of the child and it acted as a signpost to direct them to sources of help and support.

This study has shown that not being able to control the autistic child and the fear of the consequences of not being able to control the child make a significant contribution to the parents feeling of isolation and social exclusion. Therefore, developing simple to use, generalisable techniques to control the autistic child should be priority in any intervention.

Theoretical implications

The results of this study offer a greater understanding of parents’ experience of raising an autistic child. It has given an insiders perspective on the issues that are relevant for parents and it has shown that the impact of autism goes beyond the parenting process and adversely affects the parents and the family.

It has shown that parenting an autistic child is very different from parenting a ‘normal’ child. The parents have to learn new skills to control the child and develop new ways of teaching. The use of an established model of parenting has proved a useful in the development of the study and as a tool for comparing the parenting process for different children. This study has shown
that the core dimensions of ‘good enough’ parenting care control and development (Hoghughi, 2004) remain the same for autistic children, even though the activities that parents do to achieve them are very different.

**Summary**

This study set out to explore how a child’s autism impacts on the parenting process by comparing parenting an autistic child with parenting a ‘normal’ child. It has shown that autism has a significant impact on the parenting process, the parents and the family. Parenting an autistic child is a very different experience from normal parenting. Parents have had to learn new skills and techniques to deal with the unique challenges raised by the child’s autism.

Using the Hoghughi (2004) model of parenting has shown that three core dimensions of ‘good enough’ parenting care control and development apply to parenting a child with autism but that the activities that parents do to achieve them are very different. Autistic children need so much more care and control that parents have little time for development, as it is understood in the Hoghughi model. However, if development is defined as the activities that parents do to move the child closer to independence and to reduce the need for care and control, then parents invest far more time money and effort in their autistic child than they do in their other child(ren).

One of the most significant findings of this study is the impact that autism has on the parents and the rest of the family and how they fit into the social
context. The families feel that they live outside of normal society; they feel socially isolated and excluded from places, events and services that are available to others.

The overall experience of parenting a child was described in negative terms. However, the parents’ resilience showed in their humour and their ability to find some positives.
IPA is a ‘two stage’ interpretation process- the participants attempt to make sense of their internal world and then the researcher tries to make sense of their making sense of their world. It is therefore, unavoidable that the researcher is an active participant in this process. The questions asked and the reflections given guide the narrative. It is the researcher’s role to try to see the participants’ world from the inside, to understand what it is like from their point of view. To achieve this, the researcher must be both questioning and empathic towards the participants, he must take their side but at the same time question what they are saying in their texts (Smith & Osborn, 2003).

With the researcher, taking such an active role in the interpretation it is important to consider the researchers own thoughts and experiences of the subject matter and the research process. For this purpose, I have kept a reflective diary throughout the research process and I have used it to record my thoughts, activities and discussions with my supervisor.

Completing this thesis marks the end of the latest chapter in my own adaptation to autism. It has been a long and difficult journey that started eight years ago when my two-year-old son was diagnosed autistic.

At the time he was diagnosed I was an independent retailer working in West London. Autism did not fit well with my working hours and gradually my life.
as it was, became unmanageable. I went to great lengths and invested a substantial amount of money to try to change my son so that he could fit my world. Eventually, I realised that I would have to change my world suit him.

Originally, out the frustration at the lack of service provision for autistic children and their families and more recently for my own fulfilment I embarked on my own journey of adaptation. I sold my home and business in London and moved with my family to Hull where I embarked on my training in clinical psychology. In the eight years since my son's diagnosis, I have fought and won two Special Educational Needs Tribunals. I have implemented an Applied Behavioural Analysis Programme; I have employed over 20 different tutors. I have divorced and remarried, I have obtained a first degree in psychology, and I have nearly completed a doctorate. My life has changed beyond recognition because of autism, and I have my son to thank for that.

Carrying out this research has been a difficult process; I have at times enjoyed it and at others loathed it. I have had to remain objective whilst studying things that have seriously affected my own life, my career and my ability to complete this thesis. I have worked long into the night writing about how parents cope with the demands of raising an autistic child whilst struggling to cope with the demands of raising an autistic child.

My own experience of autism means that I know this subject from the inside, I am able to understand what was like from the participants' point of view.
was able to be genuinely empathic whilst questioning what they were saying in the texts. These are the ideal qualities for IPA (Smith & Osborn, 2003).

Inside knowledge can act as a double-edged sword. My personal experience of the subject that has given me such a good understanding has also made it harder to take a neutral stance and be objective.

From the outset, I have been aware that my own personal experience may affect the interpretation of the participants’ experiences. However, I have been able to use my six years of training in psychological principles and research methods to step out of my parental persona and take an objective, clinical view of the subject matter.
References


The Impact of a Child’s Autism


Appendix 1: Participant Information Sheet

The Impact of a Child’s Autism on the Parenting Process

Participant Information Sheet

Part 1

You are being invited to take part in a research study. Before you decide it is important for you to understand, why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

I am a trainee clinical psychologist and this study is being done as part of my doctoral thesis. As well as being a trainee clinical psychologist I am also the parent of a severely autistic child, this has given me a unique understanding of the subject and the ability to empathise with all the participants. The aim of this study is to illicit the views and experiences of a wide range of different parents on how a child’s autism impacts on the parenting process.

You have been identified to me by the Hull and East Riding branch of the National Autistic Society as someone who meets the inclusion criteria of my study and has expressed an interest in participating. Approximately eight parents will be interviewed.

I hope that the information gathered in the interviews will generate a colourful picture of how the experience of parenting a child with autism is qualitatively different from that of parenting a child without autism. This information will then be used to raise awareness of the needs and experiences of parents of children with autism and to help guide the services that are offered in the future.

You are under no obligation to participate and if you choose to do so you will be free to withdraw at any time.

If you do choose to take part you will be interviewed for approximately 1hr either in your own home or if you prefer in a meeting room in a mutually convenient place.

All interviews will be audio taped. The interview will then be transcribed at this point the transcript will be anonymised and the tape destroyed. This study will be completed in July 2007. If you would like to receive a summary of the findings, details of any publications or any other information related to this study you can email me at p.burbidge@2004.hull.ac.uk or write to me at the above address.
The Impact of a Child’s Autism on the Parenting Process

Participant Information Sheet
Part 2

Right to withdraw
You have the right to withdraw from this study at any point. If you choose to withdraw after the interview then all data collected from you will be destroyed and will not make up part of the study.

Confidentiality
All information will be kept confidential. Each interview will be recorded on audio tape. The content of the interview will then be transcribed from the tape by the researcher and the tape destroyed. At this point all identifiable information will be anonymised, for example “David attends the Marlborough School in Doncaster” Would be changed to “D attends an autism specific school in South Yorkshire”.

In the final write up quotes from interviews may be used to enrich the experience of the reader but care will be taken so that participants will not be recognisable from their quotes.

The Results
The results of this study will be written up in my doctoral thesis as part of my doctorate in clinical psychology. Also as a result of this study a research paper will be submitted for publication.

Sponsor
This research is being sponsored the University of Hull and Humber Mental Health Teaching Trust.

Ethical consideration
This study has been given a favourable ethical opinion for conduct in the private sector by the Hull and East Riding local Research and Ethics Committee.

Thank you for taking the time read this information sheet. If you still wish to take part in this study please read and sign both copies of the consent form provided, please return the first copy to the above address and keep the second copy for your records.
Appendix 2: Consent Form

Participant Identification number: 003

Consent Form

Title of project: The Impact of a Child’s Autism on the Parenting Process

Researcher: Peter Burbidge

Please initia

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my rights being affected.

3. I agree to take part in the above study

-Name of participant Date Signature

-Researcher Date Signature

When completed, 1 copy for participant; 1 copy for researcher
Appendix 3: Ethical Approval

Hull and East Riding Local Research Ethics Committee

Room SC39 Second Floor
Coniston House
Humber Mental Health Teaching NHS Trust HQ
Willerby Hill Business Park
Willerby
HU10 6ED

Tel: 01482 389246
Fax: 01482 303908
Email: louise.hunni@humber.nhs.uk

22 May 2006

Mr P Burbridge
Trainee Clinical Psychologist
Dept of Clinical Psychology
The Henford Building
University of Hull
Cottingham Road
Hull
HU6 7RX

Dear Mr Burbridge,

Study title: The Impact of a child's autism on the parenting process

The Chair and Vice Chair of the Hull and East Riding Local Research Ethics Committee reviewed the above application at the meeting held on 19th May 2006.

It was noted that as this research will not be taking place within the NHS, and is not a clinical trial of a medicinal product for human use, it falls outside the remit of Research Ethics Committees as set out in the Governance Arrangements for NHS Research Ethics Committees (GAREC).

However, the Chair and Vice Chair were happy to review the ethics of the research on a voluntary basis and to offer the following opinion.

Ethical opinion

- Regarding the use of the internet for access to the questionnaire, it was agreed that you should ensure that any personal information given by the participant will be to a secure site only to maintain confidentiality
- Regarding the interview in the participants own home, it is vital that security measures are put in place to ensure your safety
- Participants must be made aware in the information leaflet that the interview will be audio-taped and transcribed. It is also good practice to inform the participant that the tapes will be destroyed after transcription

The Chair and Vice Chair raised no other ethical concerns relating to this study and although they passed a favorable ethical opinion they wish to point out that this does not constitute an approval and that approval should be sought from the relevant authority before commencing
the study. It would also be appropriate to inform your employing NHS Trust of your intentions to carry out the study.

Documents reviewed

The documents reviewed at the meeting were:

- Covering letter dated 4th May 2006
- CV (Peter Burbridge) dated 4th May 2006
- Research Proposal (undated)

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Yours sincerely

Mr G S Duthie
Chairman

E-mail: louise.hunn@humber.nhs.uk
Appendix 4: Interview Schedule

Parenting Process – Autism

Care
1. Do you feel that your child with autism needs more physical care than children without autism?
   If yes, what additional physical care do they need?
2. Do you feel that your child with autism needs more emotional support than children without autism?
   If yes, what extra emotional support do they need?
3. Do you feel that your child with autism needs more care in social situations (such as out in the community, or in company) than children without autism?
   If yes, what additional care do they need?

Control
4. Is there anything that you stop your child from doing because of their autism?
5. Is there anything that you allow your child with autism to do that you would not allow a child without autism to do?
6. Does having a child with autism make you a strict or easy going parent?
   Why do you think this is?

Development
7. What hopes do you have for the future of your child with autism?
   Are these hopes different from those you would have for a child without autism?
   If yes, in what way are they different?
8. Do you think your child with autism will have difficulty in fulfilling his or her potential?
   If yes, what do you think these difficulties will be?
9. Do you feel that you have to do anything to help fulfil your child with autism’s potential that you would not have to do for a child without autism?

If yes, what do you feel that you have to do?

Parenting

10. Do you think that parenting your child with autism is different from your previous expectations of parenting?

If yes, in what way is it different from your expectations?

11. Is your relationship with your child with autism different from your relationship(s) with your child/children without autism?

12. Does having a child with autism affect your physical health, and how you feel emotionally?

13. What impact does child with autism have on the rest of the family (positive and negative)
Appendix 5: Autism Card

More Than Just A
Child With Autism
Look Beyond
The Label !!

www.Buttonsandmore.com
Is Dedicated to Raising Autism Awareness.

Public Autism Awareness
My child has Autism
He/she is not being naughty and we are not being bad parents for not reprimanding them. Children with autism can often behave in an unpredictable manner, because they find it hard to cope with many everyday situations. They are quite simply doing their best. Please be patient.

For information about autism please visit
www.autism-society.org