Parenting a child with autism: mothers' and fathers' experiences, with regard to stress, perception of child attachment and coping style

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by

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Abstract

Experiences of mothers and fathers with regard to stress, perception of child attachment and parental coping style were investigated in a study comparing 44 parents of children with autism with 32 parents of children with other learning disabilities. Both mothers and fathers of children with autism reported significantly more parenting stress and significantly lower perceived attachment from their child, than parents of children with other learning disabilities. These results highlight the autistic child’s lack of emotional reciprocity as a source of potential parental stress for both mothers and fathers.

Parents of children with autism were also found to perceive parenting as more difficult than parents of children with learning disabilities, with mothers carrying significantly more parenting burden. Mothers were found to make greater use than fathers of social support as a coping strategy; it is suggested that this difference may explain the absence of a gender effect for psychological outcome despite the greater burden carried by mothers.

Areas of future research are identified. Among these, it is recommended that larger scale research be employed to investigate possible factors associated with both positive and negative outcomes of parenting an autistic child.

Limitations of the study are also addressed, including associated problems with sample size. Clinical implications of the results, in reference to the literature, are discussed including the recognition of perception of lack of child attachment as a parental stressor. Clinical services are encouraged to consider the needs of both parents, and to recognise the important, though understated, role of fathers.
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INTRODUCTION
1.1 Autism

1.1.1 Overview

The present study investigates differences in the experience of mothers and fathers with autistic children, with regard to stress, perception of child attachment and coping style. One specific focus of the study was to provide new information concerning fathers’ perceptions of their child’s attachment to them, and how this might relate to stress and coping in fathers, in order to compliment the focus of much existing literature on mothers’ experiences.

This introductory chapter reviews literature research concerning parents’ experiences of stress in relation to parenting an autistic child. Attachment difficulties in autistic children will be discussed as one specific stressor facing parents. The review will then consider the experience of fathers of autistic children. Finally, the chapter will present information concerning stress and coping styles in relevant populations and consider possible associations between gender and preferred coping style.

This review will primarily consider research on parents of children with autism, but will additionally draw on studies involving parents of children with other learning disabilities. The chapter will end by presenting research questions generated from the preceding literature review. The first section will briefly address the issue of definition of autism, with particular reference to social impairments.
1.1.2 The Nature of the Disorder

"Typical autism is just one sub-group in a continuum of disorders involving social and communication impairments that are life long in their effects, although they vary in their severity from profound to minimal and subtle but still detectable"

(Wing, 1996, p. ix)

The first systematic description of autism was provided by Leo Kanner in 1943 in America (Rutter, 1979; Howlin, 1998). During the same period Hans Asperger was describing a similar group of children in Europe (Happe, 1994; Howlin, 1998). By the end of the 1970s, criteria for a diagnosis of autism were included in both the Diagnostic and Statistical Manual (DSM) and International Classification of Diseases (ICD) systems1. These criteria were based on Kanner’s original description and related to children who presented with abnormal social development, abnormal communication, ritualistic/stereotyped behaviour and resistance to change (Howlin, 1998). Kanner’s name for the condition, ‘autism’, is derived from the Greek word ‘autos’ or ‘self’, in reference to the individual’s lack of interest in others. Impairment in social interaction remains a central feature for DSM-IV and ICD-10 criteria (Volkmar, Carter, Grossman and Klin, 1997).

In the 1990s, classification for the diagnosis of Asperger syndrome was added to the DSM and ICD systems (Howlin, 1998). Confusion, however, continues to exist with regard to the differences and similarities between autism and Asperger syndrome. In general it is accepted that children diagnosed with Asperger syndrome tend to have average or above average IQ scores than those with autism (Howlin, 1998). Individuals with Asperger syndrome are also thought to experience difficulties in the same areas of functioning as those who have autism, but with these difficulties presenting in a milder form. They may have broad vocabularies, but are likely to experience problems in understanding abstract language and concepts. They are

1 DSM-IV is the latest edition of the classification system used in USA, produced by the American Psychiatric Association. ICD-10 is the latest edition of the classification system used in Europe, produced by the World Health Organisation.
also likely to demonstrate an interest in engaging with other people, but their endeavours to interact with others may often seem inappropriate or disinhibited (Randall and Parker, 1999).

Clinicians currently conceptualise autism and Asperger syndrome as being on the same continuum, and hence refer to ‘autistic spectrum disorders’. There is no given age of onset for either autism or Asperger syndrome. It has, however, been suggested that an autistic child’s difficulties may be noticeable at an earlier age than those of a child with Asperger syndrome (American Psychiatric Association, 1994). Howlin and Moore (1997) found that parents of children with Asperger syndrome were aware of their child’s difficulties when the child was aged 2.5 years, whilst parents of children with autism noticed problems when their child was 18 months old. Both conditions persist throughout adulthood, though it is thought that individuals with Asperger syndrome have a better later life outcome, as they are more able to learn how to cope appropriately with situations (Howlin, 1998). Although it is acknowledged that the distinction between autism and Asperger syndrome remains somewhat subjective, the following literature review will refer to those children diagnosed with autism, rather than Asperger syndrome.

The central criteria for the diagnosis of autism is best described by Wing’s ‘Triad of Impairments’ (Wing and Gould, 1979):

i). Impairments in social relationships.
This includes difficulties in social interaction with others and in understanding social codes.

ii). Impairments in social communication
This can present as a lack of interest in communicating with others, or a lack awareness of social expectations of reciprocal conversation.

iii). Lack of social imagination
Children are generally noted for unusual play behaviour, either due to a lack of play, or of absence of imaginative play.

Children with autistic spectrum disorders share this triad of impairments, however, severity of features varies from individual to individual (Wing, 1998). Whilst it is acknowledged that all three impairments impact on each other, this study is primarily concerned with the impairments in the child’s social relationships.
1.1.3 Social Impairments in Autism

Wing and Gould (1979) recognised that social impairment varies greatly from one autistic child to another. The typical view of the isolated autistic child is by no means the norm, although these authors do recognise that the pattern may be relevant to very young autistic children or to those who are severely cognitively impaired. An awareness of the diversity of social impairment in autism is particularly important to understanding possible attachment difficulties in these children.

Initially, the three groups proposed by Wing and Gould in 1979 were as follows:

i). The Aloof Group

This category refers to the more stereotypical view of the autistic child. Children within this group may avoid physical contact and eye contact with others. They remain isolated and are unlikely to access other people for reassurance if they are distressed or in pain. They may view and treat other people as tools or objects and use them for practical tasks e.g. to pour the child a drink. They demonstrate no interest in or communication of emotion. Wing and Gould (1979) suggest that children in this group may form an attachment to a familiar adult, but this is unlikely to follow the pattern of attachment formed by children of normal development. They also suggest that children within this group are more likely to also be moderately or severely cognitively disabled.

ii). The Passive Group

Although children falling within this category do not avoid contact with others as do those in the first group, they do not initiate contact themselves, but rather appear to be the passive recipients of it. Even though the child may not reject social contact, they are unlikely to be observed to find it pleasurable. Wing and Gould (1979) suggest that this is the least common pattern of social impairment presented by autistic children. This group includes children with varying levels of cognitive disability.
iii). **The Active but Odd Group**

This group includes those children who actively seek out and initiate contact with others, but in an inappropriate way. They demonstrate a lack of understanding of social rules and have less interest in the other person’s contribution to the interaction e.g. they are likely to approach people they do not know, or talk endlessly about their own chosen subject without responding to cues from the other person. This group tends to include those children with higher IQ, and perhaps is more likely to include those children with a diagnosis of Asperger syndrome or high-functioning autism.²

In 1996, Wing suggested that it may be necessary to consider a fourth group:

iv). **The Over-Formal, or Stilted Group**

As with the third group, this category tends to include those children with higher cognitive ability. Wing (1996) suggests that characteristics of the fourth group are more obvious later in adolescence and include a preoccupation with keeping to rules, and a presentation of being ‘excessively polite and formal’, even with family members.

It is acknowledged that children with autism present in a variety of ways, according to their cognitive ability and their age. However, it is important to note, that social impairment relating to problems with emotional reciprocity, empathy and interaction involving joint attention, presents as a core feature for all autistic children (Howlin, 1998). Social impairment remains the most highly emphasised aspect of diagnostic criteria (Wing, 1998). A number of alternative theories have been proposed to explain this core feature of autism. Three of the most influential of these will now be briefly reviewed.

² Wing (1998) has emphasised that Asperger syndrome and high-functioning autism, should not be regarded as separate conditions.
1.1.4 Theories of Emotional/Social Impairments in Autism

i) Emotional Imbalance Theory

Tinbergen and Tinbergen (1983) have acknowledged that genetic influences cause some children to be more vulnerable to autism than others. However, they also suggest that there are strong indications that traumatic events experienced by a very young child may be of greater importance (e.g. traumatic birth). The autistic child’s lack of emotional reciprocity derives from a resulting ‘emotional or motivational imbalance’, driven by extreme anxiety. The child’s withdrawal is subsequently also maintained by their inability to develop skills through social interaction with other individuals, including their parents. It is stressed that parents are generally not responsible for the child’s autistic presentation.

It has, however, been suggested that since autism is more likely to present in males than females, at a ratio of about 3:1; and that about 70% of children with autism also present with a level of learning disability, the cause of the disorder is more likely to be organic (Aarons and Gittens, 1999). Over the last decade, the majority of researchers have come to agree that the autistic child’s difficulties in social interaction are caused by some form of biological disorder, rather than primarily psychological factors (Harris, Gill and Alessandri, 1991; Marcus, Kunce and Schopler, 1997).

ii) ‘Theory of Mind’ Hypothesis

Baron-Cohen (1985) is the main proponent of the Theory of Mind Hypothesis. This theory suggests that the main deficit in autism is the individual’s lack of theory of mind. This refers to an inability to have an appreciation of his/her own mental states, or to understand the connection between mental states and behaviour in others (Baron-Cohen and Sweltenham, 1997). In basic terms the consequences of this deficit includes problems in reading emotions, perceptions or intentions in others and, therefore, in predicting other peoples’ behaviour (Baron-Cohen, Leslie and Frith, 1985). Proponents of the theory suggest that since children with learning disabilities are able to engage in social interaction, and autistic children with
normal levels of cognitive ability continue to experience problems in social interaction, this
deficiency is specific to autism. Studies have found that autistic children experience
significantly more difficulties in predicting both first order beliefs (attributing a belief to
someone else) and second order beliefs (attributing to one person a belief they hold about
another person’s beliefs), than a comparison group of severely learning disabled children with
Down’s syndrome (Baron-Cohen, Leslie and Frith, 1985; Baron-Cohen, 1989a).

Lack of theory of mind has been used to explain the autistic child’s apparent indifference to
others, and their qualitatively different style of interaction, which appears to lack the presence
of joint attention skills. Whilst the child is able to demonstrate the use of ‘protoimperatives’, or
interactions involving gaze and gesture intended to use others to fulfil a physical need (e.g. to
fetch a biscuit), they do not demonstrate the use of ‘protodeclaratives’, which involve the use
of gaze and gesture in order to attract an other person’s attention for no particular useful
activity (i.e. to show them a toy) (Baron-Cohen, 1989b). It would seem that the child derives
little pleasure from the interaction itself, or from relationship with the other.

iii). **Primary Impairment in Emotional Recognition**

Some theorists do not accept ‘Theory of Mind’ as the primary psychological impairment in
autism, as a percentage of autistic children are able to demonstrate the presence of a theory of
mind (Happe, 1994). Researchers such as Hobson (1989), suggest that the specific deficit
observed in autism is a basic impairment in the individual’s ability to recognise and
appropriately respond to affective expressions in other people. As a result, the autistic child
fails to evolve a cognitive understanding of social behaviour. Therefore, the presence of autism
is understood to *result* in a lack of development of theory of mind, due to a more basic deficit
in the individual’s ability to socially interact.
As Volkmar et al (1997) have phrased it:

‘Proponents of the Theory of Mind hypothesis interpret deficits in joint attention skills as evidence of an inability to read other minds; those who posit a primary social affective problem, would see a motivation deficit in the failure of a child with autism to share their experiences with their caregiver’


Discussion about the causes of autism continues. However, whatever the causes of the autistic child’s social difficulties, their severity and early onset would be expected to disrupt normal parent-child interaction and attachment processes. The nature of this disruption and its possible effect on parents are considered further in sections 1.3.2 and 1.3.3.
1.2 Parents' Experiences of Stress in Parenting a Child with Autism

1.2.1 Introduction

Families who have a child with a disability face numerous stressors additional to those experienced by other parents, including greater financial concerns, increased demands of care giving and regular disruption to plans and activities (Rodrique, Morgan and Geffken, 1990). Parents of autistic children, however, also face additional specific stressors as a result of their child’s disorder. Research, has found that families with a child with autism experience higher levels of stress than parents of children with other disabilities (Bouma and Schweitzer, 1990; Dumas, Wolf, Fisman and Culligan, 1991). The next section will briefly consider some of these causes of stress, before focusing on disturbance in parent-child affective relations and attachment as a particular stressor for parents of autistic children.

1.2.2 Additional Stressors for Parents of Children with Autism

1.2.2.1 Uncertainty of Cause

When the first cases of childhood autism were initially documented, the parents, and especially the mothers, were blamed (Bettelheim, 1967). Early hypotheses interpreted the child’s disorder as the consequence of a mother who had not provided sufficient warmth and affection to their child, and hence reference was made to the ‘refrigerator mother’. However, this theory has been refuted by studies which have reported that children with normal development, who have been severely neglected by caregivers, recover the ability to form social relationships (Rutter, 1983). Parents were also described as ‘cold intellectuals’, as initially, autism appeared to be confined to children of well-educated, upper-middle class families. More recent studies have established that this initial assumption reflected referral bias (Aaron and Gittens, 1994).

However, research suggests that in some cases, parents report having received similar hypotheses from clinicians, relating to parent-child relationships (Fong et al, 1993; Happe, 1994). This sense of blame encourages parents to feel that they are responsible for their child’s
behaviour and characteristics, and so to doubt their competence as parents. As a result, energy and effort is drawn away from a position of actually accepting a child’s condition and learning to create the best possible environment for family life. Mothers of children with autism or communication disorders, who feel less self-blame have been rated to have better family adaptation response to their child (Bristol, 1987).

1.2.2.2 Problems of Diagnosis

By comparison to other childhood disabilities/disorders, autism is poorly understood and often mis-conceptualised by health professionals (Aarons and Gittens, 1999). Clinicians’ lack of experience of the condition and resulting lack of confidence in their ability to recognise the disorder contribute to present problems in diagnosis (Gray and Holden, 1992; Fong et al, 1993; Randall and Parker, 1999).

Evidence suggests that autistic children are now being diagnosed at an earlier age than in previous years, although, the average age at diagnosis is still as high as 6 years old (Howlin and Moore, 1997). Due to the nature of presentation and diversity of autistic disorders, parents of children with autism often endure long periods of worry and uncertainty regarding their child’s behaviour before a diagnosis is made. Gray and Holden (1992) discovered that parents of autistic children reported that they had recognised that their child had problems before age two but had not received an official diagnosis until age four. This uncertainty has been cited as a major cause of physical and psychological tension for parents. Abidin (1995), has suggested that stress in the parenting role in the child’s first 3 years of life was especially critical in relation to parent-child relationships. Bristol (1987) and Dyson (1996) have identified that prompter diagnosis of children with disabilities is needed in order to reduce parent stress.

1.2.2.3 Behavioural Problems

Autistic children often display stereotypical behaviour, unusual obsessions, communication disorders and behavioural problems such as aggressiveness, impulsivity and tantrums in response to change in routine (Gray and Holden, 1992; Fong et al, 1993). In a study of learning disabled children, high levels of stress for parents were associated with the child’s behavioural
problems (Quine and Pahl, 1985), and other studies have suggested that the most common source of stress for parents of autistic children was their child’s difficult behaviour (Dumas, et al 1991; Sharpley, Bitsika and Efremidis, 1997).

In addition, autistic children rarely look physically unusual, and indeed they are often very attractive (Marcus, et al 1997). There is, therefore, no physical evidence of the disorder (Gray and Holden, 1992). As a result, other members of the public tend to react negatively towards both children and their parents. Bouma and Schweitzer (1990), found that mothering a child with a psychological disorder (autism) was more stressful than mothering a child with physical problems. This could be the result of the associated social stigma of a psychological disorder, coupled with the lack of ‘physical’ evidence of a problem.

DeMyer (1979) also comments on the added stress caused by people (friends and family) who offer support to parents of autistic children, failing to understand that the child has a disability. Due to the fact that the child does not look unusual, people cannot accept that their behaviour will not improve. Added to this is the fact that in a minority of cases, children with autism sometimes regress. It is recognised that some autistic children lose skills such as speech that they apparently had once acquired (American Psychiatric Association, 1994). This may result in the child’s relatives experiencing even greater difficulty in accepting that their child will not recover their former skills.

1.2.2.4 Lack of Reciprocal Attachment

An additional source of stress for parents, specifically associated with autistic children is their lack of responsiveness to others. Lack of eye contact, indifference to affection and lack of emotional reciprocity are noted as diagnostic features of autism (American Psychiatric Association, 1994). Siegal (1997) suggests that higher levels of stress in parents of children with autism are mainly due to lack of reciprocal attachment from their child:

"These differences stem largely from the fact that autism is a disorder of social relatedness, and parent-child communication and attachment are
disequilibrated more than in other mental retardation or learning disability syndromes"

(Siegel, 1997, p. 747).

Before exploring the literature with regard to attachment in autistic children, the following section will briefly describe attachment theory, but with particular reference to the experience of the parent.
1.3 Attachment Difficulties in Autistic Children

1.3.1 Attachment and Parent-Child Relationships

Previous research involving children without developmental delay has acknowledged the importance of reciprocal attachment in child-parent relationships (Ainsworth, Blehar, Waters and Wall, 1978; Hoppes and Harris, 1990).

Attachment theory was developed by Bowlby (1969) to explain how and why a child develops ‘internal working models’ through their attachment to their main caregiver (in general considered to be the mother). These internal working models allow the child to make interpretations regarding their own self-worth, their expectations of other people, and provide a template for future relationships (Skolnick, 1986; Bowlby, 1988).

A child’s attachment behaviour is generally considered to be indicative of whether they experience their relationship with their caregiver as secure or insecure, which in turn is generally thought to result from the parent’s ability to provide adequate care. Secure attachment is deemed to result from a close, positive and predictable relationship between mother and child. Insecure attachment is the result of a negative, neglectful or unpredictable relationship with their main caregiver (Bowlby, 1988). Therefore, a child’s quality of attachment is thought to be the result of parental behaviour. Bowlby (1988) stresses the importance of children receiving time and attention from their parents. Interaction between parent and child builds up a close relationship, providing gratification for both parent and child. Child attachment behaviour in children with normal development is activated by need e.g. pain, fear, hunger or the unavailability of caregiver. In children with normal development, when their relationship with their attachment figure seems threatened or when a child feels vulnerable, a strong reaction is triggered in the child involving clinging behaviour, crying and anger (Bowlby, 1977; Bowlby, 1988; Worden, 1983). This attracts the parent’s reaction and they respond in such a way as to rectify the situation. As a result, the parent feels important and special to the child and the relationship between the two is strengthened. Bowlby (1988) suggests that mothers (main caregivers), are pre-adapted for ‘intensive interaction’ with their baby. Mothers
take physical cues from their child, and adapt their own behaviour to compliment the child’s reaction. Bowlby (1988) states that parental responsiveness to the child is partly an innate, biological response, and partly a behaviour which is learnt through the process of being a parent. Although it is recognised that attachment theory primarily pertains to very young children, many theorists have developed the model to refer to relationships continuing throughout life. It is also likely that attachment relationships between parents and children with special needs, are necessarily prolonged, owing to the child’s reduced level of independence and developmental age.

The parent-child relationship is, however, increasingly seen as bi-directional rather than unidirectional i.e. with the child also influencing the parent (Lamb and Meyer, 1991; Nydegger and Mitteness, 1996). Certainly, the case for autistic children would seem somewhat different, since even if the parent is skilled and responsive to the child, the child may not appear to want or respond to attentive interaction in a positive way. Various studies have focused on evaluating attachment behaviours demonstrated by autistic children to their caregivers. The next section will discuss some of these before considering the impact of these behaviours on the parent.

1.3.2 Attachment Behaviour in Autistic Children

Some studies have found that autistic children do demonstrate attachment behaviour, but are also significantly different in the type of social interaction they display (e.g. Dissanayake and Crossley, 1996). Sigman, Mundy, Sherman and Ungerer (1986) discovered that whilst autistic children did demonstrate some appropriate social interaction with caregivers, their behaviour was characterised by a lack of shared attention with them. Similarly, Snow, Hertzig and Shapiro (1987), found that although autistic children did show some positive affect in their interaction with others, this was at a far lower rate than was observed in children with comparable levels of developmental delay. The study reported that the autistic children presented with difficulties in the area of affective expression. The autistic child’s positive responses were seen to be more likely to relate to self-absorbed activities than to interaction with another person.
Autistic children interact with others less than non-autistic children, and their social interaction with caregivers is often due to the efforts of the caregiver to structure the situation so as to occasion the interaction. Kasari, Sigman, Mundy and Yirmiya (1988) reported that although levels of interaction between caregivers and autistic children were similar to those between caregivers and non-autistic children, more controlling strategies were used by caregivers of autistic children to maintain the child’s attention (e.g. holding the child on their lap). Similarly, Sigman et al (1986) reported that the level of involvement between an autistic child and their parents was, to some degree, due to increased efforts on the part of the parent. The study also reported that autistic children attempted to gain assistance from their parent to a lesser extent than children with normal development or children with learning disabilities. The autistic children were also more likely to engage in behaviour demonstrating avoidance or to distance themselves from their parent.

It seems, therefore, that although actual levels of interaction between parents and autistic children may be similar to those between parents and non-autistic children, the quality of that interaction is characteristically different (Kasari and Sigman, 1997), requiring higher levels of effortful direction on the part of the carer than is the case for normally developing children. Rogers, Ozonoff and Maslin-Cole (1991) have suggested that the formation of attachment relationships with a parent may involve a different process for autistic children, compared to non-autistic children. Their study used Ainsworth’s Strange Situation3 (see Ainsworth 1978) to observe attachment behaviour in both autistic and non-autistic children. Interactions were only observed between children and their mothers as no fathers were involved in the study. The results reported no difference in security ratings between the two groups. However, in the autism group, attachment security was related to the child’s developmental level. This was not found in the learning disability group. The authors concluded that the specific deficits in understanding emotions experienced by autistic children resulted in difficulties in their ability to construct an ‘internal secure working model’ of their mother, and that this process was mediated by cognitive ability.

In marked contrast to children with normal development, very young children with autism have been found to demonstrate less interest in the human face (Osterling and Dawson, 1994), in

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3 Assessment procedure developed by Ainsworth in order to categorise quality of attachment in children
addition to an obvious lack of eye contact with others (Volkmar, Cohen and Paul, 1986). It has been suggested that some of the more subtle and complex aspects of social interaction, such as emotional expression and verbal communication, are too overwhelming for autistic children to follow, and so the child withdraws (Dawson and Lewy, 1989, cited in Dawson, Spencer, Galpert and Watson, 1990). As a result, the child does not reciprocate emotional contact with their parent and the process of building a relationship of reciprocal attachment between parent and child is hampered. Dawson et al (1990), found that autistic children rarely smiled and looked at their mother simultaneously. As a result, the mothers smiled less in response to their child’s smile than parents of children with normal development. These findings support Tinbergen and Tinbergen’s (1983) predictions of an autistic child’s behaviour.

It would appear that research studies have identified the presence of many attachment behaviours in children with autism which are similar to those observed in normally developing children of the same age. However, these behaviours also appear to be qualitatively different to those of normally developing children and to require more encouragement on the part of the parent to prompt and sustain them. Volkmar et al (1986) suggests that research should additionally be interested in parental perception of their autistic child’s attachment behaviour. Studies which have considered parental perception, have primarily focused on the position of mothers. Thus far, little attention has been directed towards paternal perception of child attachment with regard to autistic children. The following section will discuss studies which have investigated the experience of parents of autistic children, with regard to attachment relationships with their child.

1.3.3 Impact of Attachment Difficulties on the Experience of Parents of Autistic Children

Howlin (1998) suggests that the autistic child’s ‘remoteness’ is often the first characteristic that the parents become aware of, and which subsequently causes them to become anxious about their child’s development. The autistic child does not respond to their mother in the way that they had anticipated and hoped for from their child (Bristol, 1984). In a study conducted by Hoppes and Harris (1990), maternal perception of child attachment and maternal gratification
was significantly lower in mothers of autistic children than in mothers of children with Down’s syndrome. Hoppes and Harris (1990) concluded that for the mother, the autistic child’s lack of responsiveness is the most disturbing feature of the disorder. Similarly, Rodrigue (1990), found that mothers of autistic children reported parenting as less rewarding than mothers of children with other learning disabilities. Parents of children with autism have linked the concept of ‘emotional quality interactions among family members’, as one indicator of ‘normal’ family life (Gray, 1997). Others have also suggested that raising a child who does not interact socially and resists contact with others can lead to feelings of anger, rejection and self-blame in the mother (Demyer, 1979; Liwang, 1989).

There is additional evidence to suggest that problems in the parent-child emotional relationship act as a specific stressor for the parent. In a study of parents of autistic children (Kasari and Sigman, 1997), parents of autistic children who were less responsive in their interactions with others, reported higher levels of stress. Unfortunately only a small minority of fathers (6%) were involved in this study, so no comparisons between maternal and paternal perceptions were made.

This section has briefly reviewed evidence that lack of specific reciprocal attachment behaviours in autistic children has been found to have a significant impact on mothers. There is, however, a lack of information regarding the parallel impact on fathers. The aim of the current study was to generate more information concerning the experience of fathers of autistic children, relevant stressors, coping mechanisms and outcome, and how these may differ from those reported for mothers. The following section is devoted to a review of some of the relevant literature regarding this group of parents.
1.4 Fathers’ Experiences of Stress in Parenting Children with Autism

1.4.1 Fathers in Families

Fathers are marginalised by literature, media and society, in relation to matters of child care. During the 1950s and early 1960s, 50% of children were raised in two parent families, where the father was employed outside of the home and the mother was a ‘homemaker’. Since this time the figure has dropped steeply, with the majority of children being brought up in single parent or dual earning two parent families (Cherlin, 1998). Cherlin (1998) suggests that family life is continually influenced by economic, political and cultural change. Consequently, research into the experiences of families should be continually revised, and caution should be exercised in relating findings from significantly earlier studies to the current position of families.

The majority of fathers continue to spend much of their time in employment outside of the home. This provides the opportunity of encouraging self-esteem through work, and also results in them simply spending less time than their partners with their child (Demyer, 1979). As a result, it has been suggested that fathers are more able to ‘emotionally divorce’ themselves from the stressful situation at home (Holroyd, 1974). This pattern has been thought to reflect the ‘discretionary’ feature of paternal involvement, whilst mothers are traditionally expected to provide consistent levels of involvement (Lamb and Meyer, 1991). In addition to this, society has traditionally encouraged mothers to identify with the role of caregiver, and fathers with that of provider (Pederson, 1980).

It is possible that mothers and fathers may differ in their response to having a child with a disability, and that this difference reflects the ‘traditional’ roles of parents in our society (Pederson, 1980). If so, it would be expected that fathers would experience more concern over their ability to provide for the child’s additional needs, whilst mothers are more likely to experience distress over the emotional strain of providing care. However, others studies have suggested that traditional patterns of parental care are altered in families with severely learning disabled children. It is thought that the extra needs of the child result in both parents having to be involved in provision of care (Rousey, Best and Blancher, 1992).
The role of fathers in modern families is changing. Increasing numbers of fathers are now involved in child care due to societal changes (Starrels, 1994). More women work and therefore child care tends to be more equally shared between partners (Rodrigue, et al., 1992). It has been reported that fathers whose wives work, spend more time with their children (Barnett and Baruch, 1987), in comparison to fathers whose wives are not engaged in employment outside of the home. In addition, fathers are now encouraged to be more actively involved in preparation for childbirth (e.g. attendance in pre-birth classes) and in general issues of child care. It is also increasingly recognised that fathers have the right to take paternity leave. As a result, it is likely that fathers increasingly have more expectations of parenthood, and of their relationship with their child.

Some writers have emphasised the positive role fathers play within their families. Lamb (1998) discusses the multiple and diverse roles that fathers fulfil in contemporary American families. Main components of these roles are financial support and material provision, emotional support of their partner, child-related housework, and direct interaction with the child. Lamb (1998) stresses that the importance of the different aspects of these roles vary from family to family. In a review of eight auto-biographies written by fathers of children with special needs, Hornby (1992) highlights the intensity of both negative and positive feelings described by the fathers in relation to their child. Whilst Hornby (1992) acknowledges that this sample of fathers is unlikely to adequately represent the wider population in many ways, he suggests that their responses must lead to a questioning of assumptions that the father’s role is purely instrumental rather than expressive. Research which has solely looked at mothers can also provide insight into family dynamics. Indirectly, fathers are considered to affect their child’s development through their relationship with their wife (Lamb and Meyer, 1991).

1.4.2 Lack of Research involving Fathers

Historically, investigators have primarily focused on the experience of mothers, and fathers have remained relatively under researched (Hornby, 1992). Bristol and Gallagher (1984) have suggested various reasons for the poor representation of fathers in research. Firstly, they state that researchers experience great difficulty in gaining access to fathers. Secondly, they suggest that a theoretical bias stresses the unique importance of maternal influences on child
development, to the detriment of fathers. Thirdly, they suggest that research paradigms are generally suited to dyadic rather than triadic interactions.

Few studies have considered the impact on the father of having a disabled child (Lamb and Meyer, 1991; Rodrigue et al, 1992). Even fewer studies have considered fathers of autistic children. Much of the existing research concerning parental experience has obscured the separate roles of mothers and fathers (McConachie, 1986). With regard to this, it has been suggested that in order to understand fathers we should study them directly and not project results from mothers onto them (Sloper, Knussen, Turner and Cunningham, 1991; Hornby, 1995b).

The research on parenting children with learning disabilities and autism has mainly focused on mothers. Those studies which consider both parents separately suggests that mothers and fathers are indeed affected differently (Sloper et al, 1991; Sloper and Turner, 1993). The need for further research into the impact of a child with disabilities on both mothers and fathers has been highlighted (Beckman, 1991; Sloper et al, 1991). Many of the studies that do exist are now fairly dated, and perhaps do not reflect the changes in the roles of men and women in society over recent decades.

1.4.3 Clinical Service Relevance of Understanding Father's Experiences

New techniques regarding involvement of parents in the management of autistic children require high levels of parenting time. If such intervention plans are to be implemented successfully, professionals are likely to require more information about the areas of parenting which fathers find particularly difficult and the way in which they most effectively cope with parenting stress. Existing research already suggests that it is not appropriate to simply assume that existing knowledge concerning mothers adequately informs the clinician about fathers.

Historically, professional attitudes towards parents may actually have encouraged fathers to feel less involved in their child's care. Herbert and Carpenter (1994) cite specific examples of this including examples of professionals offering appointments during the day, and letters obtaining clinical information about the child being addressed to only the mother. Some authors
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have discussed the negative feelings experienced by fathers towards professionals. Hornby (1992) suggests that fathers have less opportunity to meet and build relationships with the professionals involved in their child’s care. As fathers are often unable to attend regular meetings with professionals, they rely on information via their partner. Hornby (1992) suggests that this can lead to misunderstandings and a sense of exclusion. It is, however, important for professional services to recognise the important role of fathers within families, and to make every effort to engage them.

The literature suggests that, unsurprisingly, child development is positively influenced by paternal involvement. Lamb (1981) for example, has concluded that participation in fathering is likely to lead to better personal and social development in children. It is recognised that not all children are equally affected by fathering, or indeed parenting (Belsky, 1998). Therefore, it is acknowledged that child characteristics (other than gender), influence and moderate fathering (Belsky, 1998). Belsky (1998) also emphasises the importance of considering the effects of the child on the father, rather than solely thinking about the father’s effect on the child. Fuller research into the stress faced by fathers of children with disabilities is therefore relevant to improving outcomes for their children.

The impact of paternal involvement may effect the child directly, or indirectly. A supportive contribution from fathers is recognised as being important for healthy family functioning (Pedersen, 1980). Mothers of autistic children who felt supported by their spouse were rated as having better family adaptation (Bristol, 1987). Degree of marital satisfaction appears to be a strong indicator of a mother’s ability to cope with her child’s disability. Frey, Fewell and Vadasy (1989), found that mothers whose partner was more positive about their child was likely to be more positive themselves. They suggest that mothers are encouraged by their partner’s view.

Research findings clearly indicate that fathers can contribute to family functioning in a positive manner, and therefore, it would seem important for services to recognise fathers as distinct individuals, and to offer them as much encouragement and support as they would to mothers.
1.4.4 Fathers' Experiences of Parenting Children with Disabilities

Relatively few studies have considered the experience of fathers, in parenting children with autism or with other disabilities. Interestingly, studies which have included fathers of children with learning disabilities, have found them to report problems in relationships with their child. Krauss (1993) reported that in a study of parents of children with learning disabilities, mothers and fathers reported comparable levels of stress. Whilst mothers’ stress related to personal consequences of parenting, fathers reported more stress relating to their relationship with their child. Beckman’s (1991), study of parents of children with and without learning disabilities found that, mothers experienced higher levels of stress than fathers, whilst fathers reported more stress in relation to their own feelings of attachment to their child than did mothers. Finally, Cummings (1976), reported that fathers of ‘handicapped’ children experienced higher levels of stress than mothers, and had fewer outlets for coping. In addition, the study reported that the fathers of mentally ill children suffered more symptoms (depression and lower self-esteem) as a result of the lack of relationship gratification, than fathers with children with chronic illness or normal development. The similarity of problems identified in both father and child, may reflect the influence of shared genes.

Even fewer studies have specifically considered the position of fathers of autistic children. Demyer (1979) reported that fathers of autistic children felt ‘hurt’ over the lack of response from their child. Another study focusing on fathers (Rodrique et al, 1992), did not report fathers of autistic children to experience any more problems regarding relationship with their child, compared to fathers of children with Down’s Syndrome or normal development. However, the sample size used in this study was comparatively small, and no specific measure of fathers’ perception of child attachment was used.

Existing research has suggested that parenting a child with autism has been shown to be more stressful than having a child with other learning disabilities. One of the main reasons for this would seem to be the lack of reciprocal relationship with the child. Thus far, research has focused primarily on maternal perception and has been relatively unconcerned with how a
father might be affected by parenting a child who does not reciprocate emotion as he might have expected.

The following section will draw out relevant comparisons in the experiences of mothers and fathers who parent a child with special needs.

1.4.5 Comparison of Mothers' and Fathers' Experiences of Parenting Children with Disabilities

In a study involving parents of children with severe learning disabilities, Sloper and Turner (1993) reported that although high levels of psychological stress were identified in mothers, there was also evidence of psychological distress for a large number of fathers. Studies that have concentrated solely on parents of autistic children have found differences in the overall level of stress mothers and fathers experience. In the main, fathers are reported as experiencing lower levels of anxiety, depression and dysphoria than mothers (Demyer, 1979; Dumas et al, 1991; Gray and Holden, 1992). Moes, Koegel, Schreibman and Loos (1992) found mothers of autistic children to experience higher levels of stress than fathers. Mothers in this study also presented with depression scores which were twice as high as fathers, although their scores still remained below the clinical range. Interestingly, Sharpley et al (1997) reported that although mothers stated greater confidence than fathers in their ability to cope with their children’s disorder, they continued to report higher levels of anxiety and depression. It would seem that this finding directly relates to the amount of time each parent spent in child-care activities, and research into mothers and fathers of children with other learning disabilities tends to replicate this pattern (Beckman, 1991). In a study of parents of children with developmental delay, Trute (1995) suggested that elevated depression in mothers seemed to be the result of both a greater burden of child care responsibilities and lack of self-esteem derived from a position of employment outside of the home. Mothers of high functioning autistic children have been found to be more likely to perceive their family as ‘abnormal’ than the fathers (Gray, 1997). The author suggests that this finding could reflect the fact that mothers tend to be more involved in child care and were, therefore, more likely to take responsibility for any problems presented by their child’s behaviour. It is also likely that these findings reflect the fact that whilst fathers may
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take a more optimistic, goal-orientated view, mothers are in a position to be more realistic about their child’s actual presentation.

Only one study was found to have considered the experience of fathers of autistic children alone. Rodrigue, Morgan and Geffken (1992) reported that fathers of autistic children and fathers of children with Down’s syndrome reported few differences in their experiences, although both groups demonstrated differences from fathers of children with normal development. The differences that were reported included more financial worries and a greater awareness of disruption to family activities. Similarly, in a qualitative study conducted by Hornby (1995a), which reviewed fathers’ feelings about having a child with Down’s Syndrome, the fathers’ greatest concern reflected worry over long-term provision for their child. Results from these studies would seem to suggest that the primary concerns of fathers of children with special needs are those regarding practical provision for the child.

It would seem that the literature is currently limited in the information it offers regarding fathers’ responses to having an autistic child. Whilst overall, fathers of autistic or learning disabled children seem less affected than mothers, current literature suggests that mothers and fathers may experience stress with regard to different areas of parenting (Sloper et al. 1991; Sloper and Turner, 1993).

The following section will discuss the autistic child’s attachment difficulties as a possible source of additional stress for fathers.

1.4.6 Attachment Difficulties as a Possible Stressor for Fathers of Children with Autism

Studies of children with normal development have demonstrated that infants form attachments to both parents, and show distress at separation from either their mother or father (Lamb 1980; Main and Weston, 1981). After 12 months of age, children recognise people other than their mothers as important, and so their primary attachment is not confined to their mother, although a preference for one person is usually retained (Bowlby, 1979). It could be hypothesised that both mothers and fathers have expectations of forming attachment relationships with their child. Mothers are adversely affected by the lack of such a relationship (Hoppes and Harris,
1990), and therefore, it would follow that fathers would be too. In general the literature suggests that mothers of children with learning disabilities and autism experience greater levels of parenting stress compared to fathers. One suggestion has been that this reflects the greater responsibility and burden of child care carried by mothers. However, it is also necessary to consider possible differences in mothers’ and fathers’ responses to stressful situations. A review of relevant literature by Kwai-sang Yau and Li-Tsang (1999), suggests that mothers and fathers of children with developmental delay, do not differ in the amount of stress they experience, but in the types of stress they experience and the strategies they use to cope.

The following section will discuss the relationship between stress and coping, including comparison of coping styles in men and women. The section will begin with a description of models of stress and coping.
1.5 Stress and Coping

1.5.1 Models of Stress and Coping

Stress experienced by parents of children with special needs is an area widely addressed in the literature. Levels of stress are equated with psychological (and physical) health. Various theoretical models have been used to describe a family’s adjustment. Initially, after briefly considering two other models, the cognitive model of stress and coping will be discussed.

1.5.1.1 Stage Model of Stress

Alternative to the process model of stress and coping is the concept that an individual goes through a series of stages in an effort to cope with a stressful situation. The grief model is an example of this kind of model of stress (see Parkes, 1988). It will not be discussed in detail here, but will be referred to later with regard to individual coping styles. It should be noted that some parents and clinicians feel that use of the grief model with regard to parents of children with developmental disorders is inappropriate, as it poses an overly negative view. Folkman and Lazarus (1984) caution against the use of a stage model as it suggests a specific sequence of coping, and so may not promote a view of individual differences.

1.5.1.2 ‘Stress-Reaction’ Model

Referred to as the ‘stress-reaction model’, this describes unsuccessful family functioning as a result of being overwhelmed by stressful demands (Frey, Greenberg and Fewell, 1989). This model generated many earlier research studies. However, many families adapt well to the presence of a learning disabled child. Therefore, the model has received criticism because it fails to recognise that parents can be resilient and resourceful (Gallagher et al, 1981).

1.5.1.3 Folkman and Lazarus’ Model of Stress and Coping

The most widely accepted and researched model of stress and coping is Lazarus and Folkman’s Process model of Stress and Coping (1984) which can be described as a ‘Cognitively oriented,
process-centred theory of stress and coping’ (Folkman and Lazarus, 1985, pp.150). This model emphasises the interaction between the individual and the environment in the mediation and experience of stress (Beresford, 1994).

Stress is described as:

"A relationship between the person and the environment that is appraised by the person as relevant to his or her well-being and in which the person’s resources are taxed or exceeded"

(Folkman and Lazarus, 1985, p.152, check).

This differs from the models of stress and coping outlined above, in that the emphasis is placed on a stressful episode being viewed as a dynamic, changing process, which results in a variety of cognitive and emotional responses from the individual at different times.

With regard to the process of stress, the authors emphasise the importance of the individual’s subjective appraisal of the stressor. The model also acknowledges that this process of appraisal will constantly be influenced by changes in both interpersonal and situational factors (Lazarus and Folkman 1984). The model includes two aspects of cognitive appraisal. Primary appraisal relates to an individual’s evaluation of the degree of potential threat or opportunity proposed by the stressful event. At this point an event can be appraised as irrelevant or positive. Alternatively, if an event is appraised as stressful, it may be seen as threatening, harmful or challenging (presenting the potential for gain). Secondary appraisal refers to the subsequent process of the individual considering the resources available to them and impacts on their following course of action. Some situations may seem ambiguous to the individual, and hence produce feelings of both threat and challenge (Folkman and Lazarus, 1979). However, the individual will generally become more able to categorise the event as it progresses and they gain more information (Folkman and Lazarus, 1985).

The model recognises emotions as the product of an individual’s appraisal and evaluation of how the stressful event is affecting them. As a result, emotions are considered to be ‘of high diagnostic value’ (Folkman and Lazarus, 1985).
1.5.2 **Coping Strategies**

Folkman and Lazarus’ model defines coping as:

> 'Constantly changing cognitive and behavioural efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person'

*(Folkman and Lazarus, 1984, p. 141).*

This differs greatly from previous models of stress and coping, which tended to emphasise the ability to cope as a trait or individual quality which influenced a person’s ability to respond to a stressful situation. An important distinction between the lay concept of coping and that of this model, is that the model recognises a coping strategy regardless of the effectiveness of its use. That is, they acknowledge that a person may use a coping strategy, regardless of whether or not it is helpful (Beresford, 1994). The process model of coping is concerned with what the person actually does in the situation, and the changes in their behaviour which may be due to changes in the person-environment relationship. These changes can include a shift in the meaning the person gives to a situation, or be a result of actual changes in the environment.

Folkman and Lazarus (1985) have demonstrated that individuals will use different strategies to cope with a stressful situation as it unfolds.

The model incorporates two functions of coping, related to two different styles of coping strategy: Problem-focused (sometimes referred to as ‘practical coping’) and Emotion-focused (sometimes labelled ‘wishful thinking’). Problem-focused coping involves strategies which aim to manage or alter the situation causing stress. Emotion-focused coping aims to ease or regulate the individual’s emotional response experienced as a result of the stressor (Folkman and Lazarus, 1985; Beresford 1994). Those events appraised by the individual as changeable are more likely to result in problem focused coping than those situations viewed as unchangeable, which in turn, are more likely to result in emotion focused coping (Folkman and Lazarus, 1985). It is recognised that the different types of coping strategy impact and influence each other, and at times may also impede each other. Either coping style may be used by an
individual at different times, and it is recognised that individuals use a combination of both (Folkman and Lazarus, 1985). The use of different types of coping resources, including strategies, can be viewed as either helpful or unhelpful, depending on whether they result in the individual feeling more in control or more vulnerable in the situation (Rutter and Garmezy, 1983).

The cognitive-behavioural theory of stress and coping, suggests that individuals using 'problem-focused' coping tend to experience less stress than those using 'emotion-focused' coping (Folkman and Lazarus, 1984; Vitaliano, Maiuro, Russo and Becker, 1987). Research suggests that different coping styles relate to specific outcomes related to physical and emotional health (Folkman and Lazarus, 1984). The proportionally higher use of problem-solving strategies, in comparison to other kinds of strategy such as emotion focused strategies, is associated with good psychiatric health (Vitaliano et al, 1987).

1.5.3 Variation in Coping Style as a Possible Factor in Mothers' and Fathers' Differential Experience

Studies which have considered coping style in parents of children with learning disabilities have produced some conflicting results. Frey, Greenberg and Fewell (1989) reported that high use of problem-focused coping was associated with less stress and less psychological distress in both mothers and fathers. Similarly Sloper and Turner (1993) reported that low use of wishful thinking as a coping strategy was associated with good parental adaptation to a learning disabled child in both mothers and fathers. Essex, Seltzer and Krauss (1999) found no significant difference between mothers’ and fathers’ use of emotion-focused coping in a sample of older parents caring for adult children with learning disabilities. The study also reported that mothers employed significantly higher levels of problem-focused coping strategies than fathers. The authors concluded that mothers and fathers were affected by different sources of stress and therefore employed different coping strategies. This finding opposes that reported by Ptacek, Smith and Dogde (1994) who found that women are generally less likely to use problem-focused coping in comparison with men. Additionally, McNeil and Chabbossol (1984) suggest
that the use of problem-solving strategies is more important for fathers' successful adjustment to a child with special needs, compared to that of mothers. However, in this instance, the authors suggest that this effect was due to parents being asked specific problem-solving questions in areas of reportedly more concern to fathers (e.g. child care services).

Research studies into reactions to bereavement and loss typically refer to a stage model of grief. However, this body of research provides further suggestions about differences in male and female styles of coping by considering differences in reactions to grief. It has been suggested that the process of grief and loss involves changes in an individual’s assumptions and inner beliefs about the world, in order to accommodate the experience of loss (Parkes, 1988). Grieving has been suggested to be an ongoing feature of parenting a learning disabled child (Bruce, Schultz and Smyrnios, 1996). Not only is the initial diagnosis of the child experienced as a loss, but this experience continues throughout the child’s life as discrepancies between the child’s progress and a non-disabled child’s development become apparent (Lamb and Meyer, 1991). As the process of grief involves revision of internal constructs, different individuals react to any loss in various ways (Parkes, 1988). It would follow, therefore, that mothers and fathers react differently, since they have had different expectations of parenting. In a comparison study of parents who had experienced loss of a child through cot death and those who had experienced the loss of an ‘idealised’ baby through diagnosis of learning disability, both sets of parents were found to demonstrate an intense grief response. In both sets, mothers were found to be more depressed and anxious than fathers (Nicolas and Lewin, 1986). Studies comparing parents’ reactions to death of both adult and infant children, have consistently reported that mothers express more intense and painful reactions to the loss compared with fathers (Shanfield, Benjamin, and Swain, 1984; Dyregrov and Matthiesen, 1987).

It is more probable that gender related coping styles are influenced by both social influence and biological factors (Schilling et al 1985). Mothers and fathers may react differently because they have different expectations of parenting. Mothers carry their unborn child for nine months and then experience the physical acts of giving birth and breast feeding. The presence of different male and female physiology may give rise to different feelings, with regard to parenthood (Richards, 1982). It is acknowledged that in many mammals, males and females differentially invest time and energy in the care of their offspring.
Denial is described as the stage in the grief process, which serves to protect the individual from the emotional pain of accepting the discrepancy between reality and former construct (Parkes, 1988). Similarly emotion-focused coping strategies may allow an individual to deny the existence of a problem. Those individuals able to employ problem-focused coping are in a position of having acknowledged a problem and accepted that they can act in the situation with an aim to relieve stress.

It is possible that this process is experienced differently by mothers and fathers of children with autism. In some cases the activity of going to work may enable fathers to remain in 'denial' for longer, due to less interaction time spent with child. Fathers of autistic children may also be at greater risk of responding in this way, as their child provides them with less obvious 'evidence' of a problem. In this case, the grief process is likely to be delayed, and the individual will take longer to move through the stages to reach a stage of adaptation and acceptance. Trute (1995) reported that fathers of children with learning disabilities experienced increased levels of depression if their child was less disabled. The author hypothesised that fathers can accept situations more readily if the child's disability is obvious. If however the child's impairment is less obvious, for example in autism, fathers may cope less well.
1.6 **Overview, Conclusions and Unresolved Questions**

1.6.1 **Is Parenting a Child with Autism more Stressful than Parenting a Child with other Developmental Disabilities?**

Studies consistently point to the fact that the experience of parenting a child with autism is more stressful than parenting a child with other learning disabilities. It is suggested that this increased stress is at least partly due to the autistic child's lack of reciprocal emotion in their interactions with their caregiver, which would facilitate the attachment relationship. Although other factors such as challenging behaviour and problems in recognition of the condition doubtless also add to the stress experienced by parents of children with autism.

1.6.2 **Do Fathers of Children with Developmental Disabilities Experience Less Stress than Mothers?**

Although the findings of studies which compare the levels of stress experienced by mothers and fathers of autistic children have been somewhat inconsistent, it is generally thought that mothers experience higher levels of stress in comparison to fathers.

1.6.3 **Possible Factors Involved in Father's Lower Experience of Stress**

1.6.3.1 **Lower Practical Involvement with Child**

Despite major changes in social policy over recent decades, it would seem that in general mothers continue to be more involved in child care compared to fathers. Research suggests that higher rates of stress in mothers are due in part to increased actual burden of care, and lack of self-esteem gained through work outside of the family home. However, there is little evidence as to whether this pattern of differential parental involvement is actually found in the families of autistic children.
1.6.3.2 Lower Emotional Involvement with Child/Lower Impact of Attachment Difficulties

Theoretical models have traditionally focused on the unique importance of maternal influence on child development. Due to physiological attributes of mothers and their subsequent nurturing role mothers are generally assumed to be highly emotionally involved with their child. By comparison, fathers are attributed with less emotional involvement and so thought to experience less stress as a result of problematic parent-child relationships. Again, however, there is little evidence on the issue of whether mothers of children with autism do actually experience greater stress related to their relationship to the child compared to fathers.

1.6.3.3 Greater Use of Problem-Focused, Lower Use of Emotion-Focused, Coping Strategies than Mothers

Whilst mothers are attributed a more emotional role in child care, fathers are equated with a more instrumental role. Research into the different coping styles of men and women have generally suggested that men demonstrate greater use of problem-solving coping strategies and lower use of emotion-focused strategies in comparison to women. Since problem-solving strategies are associated with better psychological outcomes in comparison to emotion-focused strategies, such a difference in coping style could account for lower stress levels in fathers than mothers. Importantly, however, some research on families with children with disabilities has suggested that mothers may be more problem-focused, and less emotion-focused, in their coping styles than fathers. Resolution of this apparent conflict in findings concerning the general population and families of children with autism is thus particularly important to understand the dynamics of family functioning in families with an autistic child.
1.7 **Research Questions and Hypotheses**

Based on the above overview of the literature, a series of research questions and hypotheses were generated for the present study. Although the focus of this research is on differences in stress and possible contributory factors for mothers and fathers of children with autism, comparison groups of mothers and fathers of children with learning disabilities were also included. This approach enables parent gender effects specific to parents of children with autism to be separated from those general to parents of children with developmental disabilities. The research questions and hypotheses were as follows.

1.7.1 **Research Questions**

1.7.1.1 Do parents of children with autism experience different levels of stress than parents of children with learning disabilities, and is any such association different in fathers and mothers?

1.7.1.2 Do parents of children with autism experience stress in different areas of parenting compared to parents of children with learning disabilities, and are any such associations different in fathers and mothers?

1.7.1.3 Do parents of children with autism perceive their child to be less attached to them than parents of children with learning disabilities, and is any such association different in fathers and mothers?

1.7.1.4 Are fathers of children with learning disabilities and autism less involved in their care than mothers?

1.7.1.5 Do fathers of children with learning disabilities and autism use more practically-oriented coping strategies than mothers?
1.7.2 **Research Hypotheses**

1.7.2.1 Parents of children with autism will experience higher levels of psychological distress than parents of children with other learning disabilities, but this differential will be lower for fathers than for mothers.

1.7.2.2 Parents of children with autism will experience higher levels of stress in areas relating to their experience of emotional attachment with their child than parents of children with other learning disabilities, but this effect will be lower for fathers than for mothers.

1.7.2.3 Parents of children with autism will experience less emotional attachment from their child than parents of children with other learning disabilities, but this differential will be lower for fathers than for mothers.

1.7.2.4 Fathers of both learning disabled and autistic children will be less involved in the care of their child than the mothers.

1.7.2.5 Fathers of both learning disabled and autistic children will use more practically-oriented coping strategies than mothers.
METHOD
2.1 Design

This study employed a group comparison design, involving four groups: Fathers of autistic children, Mothers of autistic children, Fathers of children with learning disabilities and Mothers of children with learning disabilities.

2.2 Participants

2.2.1 Recruitment

Participants were 40 mothers and 36 fathers of children who attended special needs schools and nurseries within Leicestershire. Parents were recruited through the Leicester Child Learning Disability Team, Educational Psychology, 12 Special Needs schools, 3 Special Needs nurseries and 4 parent support groups and the Autism Outreach Service. Thirty-three (19: Autism; 14: Learning Disability) children were from families where parents lived together and both parents participated in the study; two (2: Autism) children were from parents who were separated but where both parents participated in the study, and five (1: Autism; 4: Learning Disability) children were from families in which parents lived together, but only the mother chose to participate. Six parents dropped out, and four were not included in the study due to questionnaires which were too incomplete to analyse. Figure 1 presents a flow chart of data collection procedure (figures are estimates based on the number of invitations given to head-teachers).

Families were recruited through members of the learning disability team, and by sending invitation letters (Appendix 1), participant information sheets (Appendix 2), and consent forms (Appendix 3), through the schools and nurseries involved. Letters were also distributed to parents via the support groups and the Autism Outreach Service. Interested families volunteered to take part in the study.
Initially letters were distributed via the learning disability team and educational psychology service only. Due to a very low response rate, reminder letters were sent to parents who would have received an invitation letter over the Christmas holidays, as it was recognised that this was a very busy time for families. Following this the principal investigator visited each of the 12 schools and presented details of the study to head teachers. This information was also presented to parent support groups. Following interest in the study from parents of pre-school children who attended support groups, three special needs nurseries were approached and presented with details of the study. In each case head teachers of schools and nurseries were given letters in blank envelopes to distribute to parents who would be eligible for the study. They were asked not to send invitations to any parents who were known to be going through a particularly stressful time (e.g. seeking diagnosis) for ethical reasons.

During the period in which this study was conducted two other research projects were also being conducted. For ethical and methodological reasons parents were not approached to be involved in more than one study. This reduced the availability of eligible participants. Approximately 334 letters were sent out to eligible participants (161 = Autism; 173 = Learning Disability).
**Method**

**Figure 1. Data Collection Procedure Flow Chart**

- **Parents of Autistic Children**
  - Contacted through Educational Psychology
  - Letters sent: 31
  - Replies: 8

- **Parents of Learning Disabled Children**
  - Contacted through Learning Disability Team
  - Letters sent: 13 (Autism) 24 (LD)
  - Replies: 4 (Autism) 7 (LD)

  **Research presented to head-teacher in 12 Special Schools**
  - Letters sent: 63 (Autism inc. 24 reminders) 116 (LD)
  - Replies: 4 (Autism) 6 (LD)

- **2 support groups for parents of children with autism**
  - Letters taken: 9
  - Replies: 2

- **2 support groups for parents of children with learning disabilities**
  - Letters taken: 3
  - Replies: 0

  **Research presented to autism outreach worker**
  - Letters sent: 10
  - Replies: 1

**Age range criteria dropped from 5-12 to 2-12, in order to approach nurseries.**
**Age lowered to avoid adolescence and due to questionnaire norms.**

- **Three special needs nurseries approached.**
  - Letters sent: 35 (Autism) 30 (LD)
  - Replies: 3 (Autism) 1 (LD)

- **Autism**
  - Total number of letters sent to families: 161
  - Total number of families recruited: 23

- **Learning Disability**
  - Total number of letters sent to families: 173
  - Total number of families recruited: 18
2.2.2 **Participant Group**

The participant group was made up of mothers and fathers of children with autism. Inclusion criteria were that the parents’ child was aged between 5 and 12 years old and the child had received an official diagnosis of autism from a psychiatrist or psychologist (on their statement of special educational needs\(^1\)). Parents who were separated were included if they considered themselves to have regular and frequent contact with their child.

Exclusion criteria were as follows: children with poorly controlled epilepsy were not included in the study (as their behaviour patterns were likely to be very unpredictable). Parents of children who attended mainstream school, or who were considered to be ‘high-functioning’ (i.e. those children who have Asperger Syndrome), were not included in the study.

2.2.3 **Comparison Group**

The comparison group was made up of mothers and fathers of children with other types of moderate or severe learning disabilities.

Inclusion criteria were that the child was aged between 5 and 12 years old. Parents who were separated were included if they considered themselves to have regular and frequent contact with their child.

Exclusion criteria were as follows: children who were considered to have autistic features relating to social interaction were not included in the study. Parents of children with poorly controlled epilepsy were not included in the study. Parents of children with mild learning disabilities, who attended mainstream school were not included.

The age range for both groups was increased from 5-12 years to 2-12 years in the latter stages of data collection, so that parents of children attending special needs nurseries could be approached, in an effort to raise participant numbers.

Children in the comparison group all had moderate to severe learning disabilities (based on category of school) but were heterogeneous in their diagnosis: 15 had undiagnosed developmental delay, 2 had Down Syndrome and 1 had William’s Syndrome.

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\(^1\) Statement of Special Educational Needs, Education Act 1996.
A summary of demographic information for each group is presented in Table 1. Diagnostic groups were found to be broadly comparable on demographic characteristics, with the exceptions of marital status and living arrangements.

Table 1. Summary of Family Demographic Information for each Group

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Autism Fathers</th>
<th>Autism Mothers</th>
<th>L.Disab Fathers</th>
<th>L.Disab Mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Age (Mean)</td>
<td>39.3 yrs</td>
<td>37.3 yrs</td>
<td>39.5 years</td>
<td>37.1 yrs</td>
</tr>
<tr>
<td></td>
<td>(s.d. 6.3)</td>
<td>(s.d. 4.1)</td>
<td>(s.d. 4.2)</td>
<td>(s.d. 4.1)</td>
</tr>
<tr>
<td>Parent Ethnic Origin</td>
<td>100% White</td>
<td>100% White</td>
<td>100% White</td>
<td>94% White</td>
</tr>
<tr>
<td></td>
<td>British (n = 22)</td>
<td>British (n = 22)</td>
<td>British (n = 22)</td>
<td>White British (n = 17)</td>
</tr>
<tr>
<td>Marital Status</td>
<td>82% Married</td>
<td>86% Married</td>
<td>93% Married</td>
<td>94% Married</td>
</tr>
<tr>
<td></td>
<td>(n = 18)</td>
<td>(n = 19)</td>
<td>(n = 13)</td>
<td>(n = 17)</td>
</tr>
<tr>
<td></td>
<td>9% Separated</td>
<td>5% Separated</td>
<td>7% Cohabiting</td>
<td>6% Cohabiting</td>
</tr>
<tr>
<td></td>
<td>(n = 2)</td>
<td>(n = 1)</td>
<td>(n = 1)</td>
<td>(n = 1)</td>
</tr>
<tr>
<td></td>
<td>5% Divorced</td>
<td>5% Separated</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(n = 1)</td>
<td>(n = 1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5% Cohabiting</td>
<td>5% Cohabiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(n = 1)</td>
<td>(n = 1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living Arrangements</td>
<td>9% Alone, with</td>
<td>9% Alone, with</td>
<td>100% Spouse,</td>
<td>100% Spouse,</td>
</tr>
<tr>
<td></td>
<td>no children</td>
<td>children</td>
<td>with children</td>
<td>with children</td>
</tr>
<tr>
<td></td>
<td>(n = 2)</td>
<td>(n = 2)</td>
<td>(n = 14)</td>
<td>(n = 18)</td>
</tr>
<tr>
<td></td>
<td>5% Spouse, no</td>
<td>91% Spouse,</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>children</td>
<td>with children</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(n = 1)</td>
<td>(n = 20)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>86% Spouse,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>with children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(n = 19)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Age at leaving School</td>
<td>64% Age 1-16</td>
<td>56% Age 10-16</td>
<td>57% Age 10-16</td>
<td>44% Age 10-16</td>
</tr>
<tr>
<td></td>
<td>years (n = 14)</td>
<td>years (n = 12)</td>
<td>years (n = 8)</td>
<td>years (n = 8)</td>
</tr>
<tr>
<td></td>
<td>36% Age 17+</td>
<td>45% Age 17+</td>
<td>43% Age 17+</td>
<td>56% Age 17+</td>
</tr>
<tr>
<td></td>
<td>years (n = 8)</td>
<td>years (n = 10)</td>
<td>years (n = 6)</td>
<td>years (n = 10)</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Autism Fathers</td>
<td>Autism Mothers</td>
<td>L.Disab Fathers</td>
<td>L.Disab Mothers</td>
</tr>
<tr>
<td>---------------</td>
<td>---------------</td>
<td>---------------</td>
<td>----------------</td>
<td>----------------</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>9% No Qualifications (n = 2)</td>
<td>9% No Qualifications (n = 2)</td>
<td>14% GCSE (n = 2)</td>
<td>22% No Qualifications (n = 4)</td>
</tr>
<tr>
<td></td>
<td>18% GCSE (n = 4)</td>
<td>27% GCSE (n = 6)</td>
<td>7% A level (n = 1)</td>
<td>33% GCSE (n = 6)</td>
</tr>
<tr>
<td></td>
<td>5% A level (n = 1)</td>
<td>9% A level (n = 2)</td>
<td>29% Further Qualifications (n = 4)</td>
<td>6% A level (n = 1)</td>
</tr>
<tr>
<td></td>
<td>23% Further Qualifications (n = 5)</td>
<td>27% Further Qualifications (n = 6)</td>
<td>11% Further Qualifications (n = 2)</td>
<td>11% Degree (n = 2)</td>
</tr>
<tr>
<td></td>
<td>14% Degree (n = 3)</td>
<td>9% Degree (n = 2)</td>
<td>50% Professional (n = 7)</td>
<td>17% Professional (n = 3)</td>
</tr>
<tr>
<td></td>
<td>32% Professional (n = 7)</td>
<td>18% Professional (n = 4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Socio-Economic Class (Based on employment)</strong></td>
<td>59% Professional (n = 13)</td>
<td>14% Professional (n = 3)</td>
<td>46% Professional (n = 6)</td>
<td>18% Professional (n = 3)</td>
</tr>
<tr>
<td></td>
<td>23% Skilled manual (n = 5)</td>
<td>23% Clerical (n = 5)</td>
<td>15% Clerical (n = 2)</td>
<td>12% Clerical (n = 2)</td>
</tr>
<tr>
<td></td>
<td>5% Semi-skilled (n = 1)</td>
<td>9% Semi-skilled (n = 2)</td>
<td>23% Skilled manual (n = 3)</td>
<td>35% Semi-skilled (n = 6)</td>
</tr>
<tr>
<td></td>
<td>5% Unskilled (n = 1)</td>
<td>5% Unskilled (n = 2)</td>
<td>8% Armed Forces (n = 1)</td>
<td>35% Wife (n = 6)</td>
</tr>
<tr>
<td></td>
<td>5% Armed Forces (n = 1)</td>
<td>45% Wife (n = 10)</td>
<td>8% Husband (n = 1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5% Husband (n = 1)</td>
<td>5% No occupation (n = 1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parental Employment</strong></td>
<td>82% Employed (n = 18)</td>
<td>41% Employed (n = 9)</td>
<td>71% Employed (n = 10)</td>
<td>61% Employed (n = 11)</td>
</tr>
<tr>
<td></td>
<td>9% Unemployed (n = 2)</td>
<td>56% Unemployed (n = 12)</td>
<td>14% Unemployed (n = 2)</td>
<td>33% Unemployed (n = 6)</td>
</tr>
<tr>
<td></td>
<td>9% Self-employed (n = 2)</td>
<td>5% Self-employed (n = 1)</td>
<td>14% Self-employed (n = 2)</td>
<td>6% Self-employed (n = 1)</td>
</tr>
</tbody>
</table>
Method

2.3 Procedure

The study involved each parent completing a battery of questionnaires (estimated to take 1 hour to complete), and an additional 30 minute interview concerning relationship issues with their child. Once a parent had returned their consent form regarding their wish to be included in the study, they were contacted by telephone in order to arrange an appropriate time and place for completion of the interview. Parents were offered the opportunity to either be interviewed at a pre-arranged setting (local child services) or at their own home. All participants chose to be interviewed in their own homes. The majority of interviews took place in the evening.

Parents were then sent questionnaire packs 5 days in advance of the interview. The subsequent meeting with the investigator provided an opportunity to complete the interview and to discuss any queries regarding the questionnaires. Parents were instructed to complete their questionnaires on their own without discussion with their partners. After parents had completed the questionnaires and interview, they were given the opportunity for some time to de-brief. Each participant’s General Practitioner was also informed of their participation in the study.
2.4 Measures

A summary of measures used in this study are presented in Table 2.

Table 2 Summary of Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic Questionnaire</td>
<td></td>
</tr>
<tr>
<td>General Health Questionnaire 28 (GHQ-28)</td>
<td>Goldberg and Hillier (1979)</td>
</tr>
<tr>
<td>Parenting Stress Index (PSI)</td>
<td>Abidin (1983)</td>
</tr>
<tr>
<td>Attachment Questionnaire</td>
<td>Hoppes and Harris (1990)</td>
</tr>
<tr>
<td>Parenting Burden and Difficulty Scale (PBDS)</td>
<td>Milgram and Atzil (1988)</td>
</tr>
<tr>
<td>Shortened Ways of Coping Scale (Revised) (SWC-R)</td>
<td>Hatton et al (1994)</td>
</tr>
</tbody>
</table>

2.4.1 Demographic Questionnaire

A basic demographic questionnaire (Appendix 4) was completed by each participant, providing information on parent age, ethnic origin, level of education, employment status, socio-economic class, martial status and family characteristics.

2.4.2 Developmental Behaviour Checklist

The Developmental Checklist (DBC) (Einfeld and Tonge 1992) provides an assessment of behavioural and emotional disturbance in children with learning disabilities. The DBC is published in two versions, these being the Parent/Carer Version and the Teachers Version. This study used the Parent/carer version. The questionnaire consists of 96 items, asking information about child behaviour within the last 6 months. Each item is in the form of a behavioural
description and is rated from 0 to 2, where 0 = 'not true as far as you know', 1 = 'somewhat or sometimes true' and 2 = 'very true or often true'.

The DBC can be scored in a variety of ways. The measure provides a Total Behaviour Score, relating to the overall measure of behavioural/emotional disturbance. It also provides a score for each of the six sub-scales, these being Disruptive; Self-Absorbed; Communication Disturbance; Anxiety; Autistic Relating; and Antisocial.

The measure is reported to have high inter-rater reliability between responses from parents and teachers. In this study the DBC was used to investigate the assumption that the children with autism would (at least according to parental perception) present overall higher levels of difficult behaviour than the children with learning disabilities.

2.4.3 General Health Questionnaire

The General Health Questionnaire (GHQ) is a self-administered questionnaire, originally developed as a screening tool for psychiatric disorders in general medical out-patients (Goldberg and Williams 1991). It was used in this study to evaluate whether participant groups experiencing higher levels of parenting stress would also be experiencing higher levels of overall psychological distress.

The questionnaire considers two main areas, the inability of an individual to carry out normal functioning and the presence of new and distressing phenomena. It provides an assessment of an individual’s level of psychopathology.

There are 4 versions of the General Health Questionnaire (GHQ) available. For this study the GHQ-28 was selected. This version was developed by Goldberg and Hillier (1979). This instrument is a 28 item scaled questionnaire with four sub scales: somatic symptoms; anxiety and insomnia; social dysfunction; and severe depression. Responses to the questionnaire provide a sum for each sub scale and an additional total score. There continues to be some debate with regard to the best scoring method for the GHQ-28. In the present study, simple Likert scoring (0-1-2-3) was employed as it is suggested that this is the preferable method for sub-scale scores. In this case the highest possible score would be 84 (21 for each sub-scale).
Method

Likert scoring was chosen in comparison to GHQ scoring (0-0-1-1), as it is recommended for use in order to produce less skewed distribution (Goldberg and Williams, 1991).

2.4.4 Parenting Stress Index

The Parenting Stress Index (PSI) (Abidin, 1995) was selected to measure participant’s stress, as it provides a measure of the specific stress within the parent and child relationship. It measures a variety of contextual stressors associated with parent-child characteristics. The PSI was standardised for use with parents of children aged from 1 month to 12 years. It has been used in research with parents of both disabled and non-disabled children (Beckman, 1991). Abidin (1995), has reported good content and construct validity. Alpha reliability coefficients are .89 for the Child domain and .93 for the Parent domain.

In this study the Long form of the PSI was used. It is a 120 item questionnaire, consisting of 3 domains: Child Domain, Parent Domain and General Life Stress. The Child Domain contains 6 scales: Child Adaptability; Acceptability to the parent; Demandingness; Mood; Distractibility/Hyperactivity; and Reinforcement to parent. High scores in the Child Domain indicate that the child’s characteristics are the main cause of stress, causing the parent to experience difficulty in their task of parenting. The Parent Domain consists of 7 scales: Parent Depression; Attachment to child; Restrictiveness of the parent role; Sense of Competence; Social Isolation; Relationship with Spouse; and Health. High scores in the Parent Domain indicate that stress is more likely to be related to parental characteristics and functioning. The questionnaire also includes an additional 19 optional General Life Stress items. This provides information regarding recent stressful situational circumstances experienced by the respondent. Child Domain scores are predicted to be higher than Parent Domain scores for families in which the child has a specific disability (Abidin, 1995). The PSI provides a score for the Child Domain, the Parent Domain, General Life Stress and a Total score. Parents scoring over 260 for the total PSI score are thought to be experiencing levels of stress which warrant referral to professional services (Abidin, 1995).
2.4.5 **Attachment Questionnaire**

This questionnaire was taken from a study by Hoppes and Harris (1990) (Appendix 5). The questionnaire consists of eight open-ended attachment-focused items, which are administered during an open-ended interview. The measure provides more detailed information regarding parental perception of their child’s attachment to them, and sense of gratification from their relationship with their child. Items provide information on both theoretical attachment behaviour and in addition, behaviours which can be understood to facilitate a positive relationship between parent and child.

The data gained from this questionnaire is largely qualitative. A method of scoring was employed to allow a sum total for the whole questionnaire. Questionnaire item responses were placed in one of two categories. Those responses relating to positive parent perception of child attachment were given a score of 1. Those responses relating to negative parent perception of child attachment were given a score of 0. Thus the higher the total score the more positive the parents perception of their child’s attachment to them (highest total score = 8). Additionally, it is possible to employ further analysis in order to consider each item independently. In order to establish the reliability of interview response coding, a calculation of inter-rater reliability for interview item responses were made. All Attachment interview responses were coded by two independent raters, and good reliability was established at 94%. Total score on this measure was used to investigate the hypothesis that parents of children with autism would perceive their child as less attached to them than parents of learning disabled children, but that this differential would be lower for fathers than for mothers.

2.4.6 **Parenting Burden and Difficulty Scale**

The Parenting Burden and Difficulty Scale (PBDS) (Appendix 6) used in this study was based on a scale developed by Milgram and Atzil (1988). In this study, the measure was used to assess the degree to which parents rate their involvement in 15 daily child-care tasks, and their perceived difficulty of these tasks. Parents rate each task on a 5-point Likert scale, from *no*
difficulty at all and requiring no special effort (1) to severe difficulty, requiring great effort in the part of the adult carer (5). Parents were asked to rate the difficulty of the task according to their own perception, regardless of whether they were actually involved in it or not.

In order to establish some understanding of how parenting tasks were shared between the couple, parents were asked which of the 15 tasks they carried out more often than their partner. In each case parents were asked to respond with regard to child care relating to the child who was the subject of this study. The PBDS was used in this study to investigate the hypothesis that (at least according to parents’ perceptions) mothers of children with disabilities carry higher burden of care than fathers.

2.4.7 The Shortened Ways of Coping Scale (Revised)

The Shortened Ways of Coping Scale (SWC-R) (Appendix 7) was derived by Hatton et al (1994) from the Ways of Coping Scale originally devised by Lazarus and Folkman (1985). This scale assesses the specific coping styles used by individuals, in response to a stressful situation. It consists of two sub-scales, Practical Coping (measuring problem-focused coping) and Wishful thinking (measuring emotion-focused coping), which represent different types of coping strategy. The SWC-R consists of 14 items to which participants respond using a Likert scale (0 = Not Used, 1 = Used Somewhat, 2 = Used Quite A Bit, 3 = Used A Great Deal). The version used in this study also includes a further sub-scale of 5 items concerning the use of social support. These items were found to be significant in a previous study involving parents of children with a learning disability (Knussen, Sloper, Cunningham and Turner, 1992). In this study, parents were instructed to focus on how they coped with any problems in bringing up their child, when completing the questionnaire.

2.4.8 Family Support Scale

The Family Support Scale (FSS) (Dunst, Jenkins and Trivette, 1984) evaluates the extent to which various kinds of support have been helpful to a family caring for a young child. The questionnaire was initially developed for use with parents of children with developmental delay and assesses how social support influences both the individual and the family system. The
parent rates how helpful they have found 18 different possible sources of support over the last 3-6 month period. The measure provides information about both the amount of support available and the perceived quality of that support. The measure consists of five sub-scales, Partner/spouse; Informal kinship; Formal kinship; Social organisations; and Professional services. Responses are rated on a 5-point Likert Scale, from 'not helpful at all' (1) to 'extremely helpful' (5). The form also includes space to include any additional forms of support.

Scoring the FSS provides a variety of information. Firstly it can provide information with regard to the total number of sources of support available to the family. Secondly each of the five sub-scales are scored to demonstrate their independent level of helpfulness. These sub-scales are then summed together to give a measure of total level of social support. Thirdly, since there are a different number of items in each of the five categories, each sub-scale total needs to be 'weighted' to allow for comparison of the degree to which each type of support is helpful. This is achieved by dividing the sub-scale score by the number of items within that sub-scale. Additional items added by the participant are included within the sub-scale which is considered to be the most appropriate. In this study, the FSS was used to evaluate the possibility that apparent parent gender differences in coping style might simply reflect differential availability of coping resources. It was also used to evaluate the levels of support available to parents groups according to child diagnosis.

2.5 Ethical Considerations

It is clearly recognised that parents of children with special needs represent a group of people who face additional pressures and demands in their daily lives. It was considered of paramount importance that involvement in this study should not present participants with an additional stressor. The measures were chosen (so far as was possible) to be short and easy to self-administer. Interviews were carried out in participants homes. These plans were all devised to make the experience as easy for parents as possible. Ethical approval was given by the Leicestershire Committee on the Ethics of Clinical Research. Whilst this methodology may have been less standardised than would have been the ideal, the points of compromise were deemed to be both ethically and clinically necessary. Given the relatively low response rate
achieved, it is likely that a less ‘user-friendly’ procedure for data collection would have resulted in an even lower rate.

In addition, information letters (Appendix 8) were sent to all participants’ General Practitioners (GPs). It was also stated that relevant GPs would be informed of any participant who was found to be presenting with severe psychological distress. All information received from participants was treated as confidential. Participants were also aware of their right to withdraw from the study at any time.

This study was designed in the hope that it would generate findings which would inform services about the needs of both mothers and fathers. In this way, the time and energy given by parents who participated in this study, contributed to improving the services that they received.
RESULTS
3.1 **Method of Analysis**

This study has generated five questions and five subsequent hypotheses from current literature which aim to explore the experiences of fathers and mothers of autistic children, in comparison with parents of children with other learning disabilities. Descriptive and statistical analyses were carried out with an aim to address these questions. In the following section, each question will be considered separately.

Preliminary statistical tests were carried out to establish characteristics of the data and to determine the appropriateness of parametric or non-parametric statistics. One sample Kolmogorov-Smirnov Tests were carried out on all main outcome measures for each of the four groups, to test the assumption of normal distribution of variables in the population from which samples were drawn (Kinnear and Gray, 1999); and Levene’s Test was used to test the assumption of homogeneity of variances. Neither test yielded significant results for any measure, suggesting that the data could appropriately be subjected to parametric analysis. For most measures used in this research, larger studies of comparable groups have similarly concluded that population distributions meet the assumptions of parametric analyses. For some of the measures used in this study, however, (e.g. the measures of attachment and parenting burden), less is known regarding psychometric properties of the measure.

Howell (1991) has, however, argued that it is safe to assume that parametric statistics are robust even when assumptions are dishonoured. For the purposes of this study it was felt important to employ parametric statistics to maximise power, given the relatively low sample size (see also Bryman and Cramer, 1997). For most measures, therefore, parametric analyses were selected.
3.1.1 Missing Data

Complete sets of data were obtained from the majority of participants. However, occasionally a questionnaire within a data set was found to be too incomplete to analyse. In these cases analyses were only carried out on sufficiently completed measures. Therefore the number of completed measures for each group will be shown in mean and standard deviation tables for each group.

3.2 Descriptive and Explorative Analysis

Table 3 presents demographic information regarding the characteristics of children relevant to this study. Diagnostic groups were found to be broadly comparable on demographic characteristics, with the exception of child gender. The higher ratio of boys to girls in the autistic group, represents the prevalence of males in the autistic population (Aarons and Gittens, 1999).

Table 3. Summary of Child Demographic Information for each Group

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Autism</th>
<th>Learning Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Age (Mean)</td>
<td>7.9 years (n = 22)</td>
<td>7.6 years (n = 18)</td>
</tr>
<tr>
<td>Level of Child Learning Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate Learning Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>64% (n = 14)</td>
<td>61% (n = 11)</td>
<td></td>
</tr>
<tr>
<td>Severe Learning Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36% (n = 8)</td>
<td>39% (n = 7)</td>
<td></td>
</tr>
<tr>
<td>Child Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male 77% (n =17)</td>
<td>Male 50% (n = 9)</td>
<td></td>
</tr>
<tr>
<td>Female 23% (n =5)</td>
<td>Female 50% (n = 9)</td>
<td></td>
</tr>
<tr>
<td>Position of Child in family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eldest Child 32%</td>
<td>Eldest Child 39%</td>
<td></td>
</tr>
<tr>
<td>Not Eldest Child 68%</td>
<td>Not Eldest Child 61%</td>
<td></td>
</tr>
<tr>
<td>Total Number of children in family (mean)</td>
<td>2.5</td>
<td>2.6</td>
</tr>
</tbody>
</table>
Differences in degree of behavioural disturbance as rated by parents in each group were investigated using data from the Developmental Behaviour Checklist (DBC). Table 4 presents means and standard deviations for each group for both sub-scales and total score. Since the DBC is a measure of parental *perception* of child behaviour, and not of behaviour per se, it was deemed appropriate to include all four groups in analysis.

**Table 4**

**DBC Means and Standard Deviations for Each Group**

<table>
<thead>
<tr>
<th></th>
<th>Autism Fathers (n = 22)</th>
<th>Autism Mothers (n = 22)</th>
<th>L. Disab Fathers (n = 14)</th>
<th>L. Disab Mothers (n = 17)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DBC Sub-scale</strong></td>
<td><strong>Mean (s.d)</strong></td>
<td><strong>Mean (s.d)</strong></td>
<td><strong>Mean (s.d)</strong></td>
<td><strong>Mean (s.d)</strong></td>
</tr>
<tr>
<td>Disruptive</td>
<td>13.95 (7.61)</td>
<td>13.68 (6.79)</td>
<td>11.57 (8.74)</td>
<td>14.24 (10.97)</td>
</tr>
<tr>
<td>Self-Absorbed</td>
<td>17.14 (9.00)</td>
<td>16.77 (9.00)</td>
<td>10.36 (7.00)</td>
<td>11.88 (7.55)</td>
</tr>
<tr>
<td>Communication</td>
<td>5.23 (4.42)</td>
<td>5.55 (4.42)</td>
<td>2.07 (2.87)</td>
<td>3.71 (4.22)</td>
</tr>
<tr>
<td>Disturbance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>8.73 (3.76)</td>
<td>9.18 (3.39)</td>
<td>6.50 (4.55)</td>
<td>8.12 (5.37)</td>
</tr>
<tr>
<td>Autistic</td>
<td>8.50 (4.41)</td>
<td>8.73 (3.63)</td>
<td>3.71 (3.97)</td>
<td>4.71 (3.64)</td>
</tr>
<tr>
<td>Anti-Social</td>
<td>0.86 (1.46)</td>
<td>0.68 (1.52)</td>
<td>0.79 (1.12)</td>
<td>0.82 (0.95)</td>
</tr>
<tr>
<td><strong>DBC Total</strong></td>
<td><strong>64.82 (27.44)</strong></td>
<td><strong>64.91 (28.03)</strong></td>
<td><strong>42.64 (23.88)</strong></td>
<td><strong>52.59 (30.47)</strong></td>
</tr>
</tbody>
</table>

A 2 (child diagnosis) x 2 (parent gender) Anova was used to identify any difference in child behaviour characteristics between groups. A significant effect for child diagnosis was found for DBC Total score (F (1,71) = 7.00, p = 0.010). Mean scores for each group indicate that parents of children with autism rate their child as more behaviourally challenging than the parents of children with other learning disabilities.

Mean scores for each of the DBC sub-scales are presented in figure 2. The chart indicates that the children with autism display higher scores in the three domains most closely associated with autistic presentation: Self-Absorbed; Communication Disturbance; and Autistic Features.
### Figure 2

**Means for DBC Sub-scales for Autistic Children and Learning Disabled Children**

![Bar chart showing means for DBC sub-scales](image)

Diagnosis: A - Autism; LD - Learning Disability

#### 3.2.1 Group Characteristics

It was decided that all groups should be treated as independent for the purposes of analysis. Although within each child diagnostic group (autism vs. learning disability) many mothers and fathers could be paired by reference to their shared child, they could not be regarded as matched pairs for many psychological variables relevant to the measures used in this study. Analysis was repeated on the main outcome measures (PSI, Attachment total and DBC), both excluding and including the two step-fathers in the fathers of autistic children group. Inclusion versus exclusion of step-fathers had no effect on outcomes of any analysis, and results hereafter are reported for the total sample including stepfathers.
3.3  **Research Hypotheses**

3.3.1  **Hypothesis One**

Parents of children with autism will experience higher levels of psychological distress than parents of children with other learning disabilities, but this differential will be lower for fathers than for mothers.

In order to explore this question it was first necessary to address the question of whether or not there was a difference in level of psychological distress between parents of children with autism compared to parents of children with other learning disabilities. Mean scores (and standard deviations) for mothers and fathers of children with autism and learning disabilities on the General Health Questionnaire 28 (GHQ-28) are presented in table 5.

**Table 5**

**GHQ-28 Means and Standard Deviations for each Group**

<table>
<thead>
<tr>
<th>Sub-scale</th>
<th>Autism Fathers (n = 22)</th>
<th>Autism Mothers (n = 22)</th>
<th>L. Disab Fathers (n = 14)</th>
<th>L. Disab Mothers (n = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GHQ-28 Mean (s.d)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somatic</td>
<td>5.45 (2.92)</td>
<td>5.73 (3.20)</td>
<td>6.00 (5.26)</td>
<td>6.00 (3.99)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>6.32 (4.36)</td>
<td>5.82 (3.69)</td>
<td>4.71 (4.16)</td>
<td>5.56 (3.31)</td>
</tr>
<tr>
<td>Social Dysfunction</td>
<td>7.32 (2.61)</td>
<td>7.95 (2.48)</td>
<td>7.57 (2.47)</td>
<td>7.94 (1.89)</td>
</tr>
<tr>
<td>Depression</td>
<td>.95 (2.03)</td>
<td>1.36 (1.94)</td>
<td>1.29 (2.09)</td>
<td>1.00 (2.17)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20.05 (8.16)</strong></td>
<td><strong>20.86 (8.51)</strong></td>
<td><strong>19.57 (11.30)</strong></td>
<td><strong>20.50 (9.36)</strong></td>
</tr>
</tbody>
</table>
Results

It was hypothesised that parents of children with autism would experience higher levels of psychological distress than parents of children with other learning disabilities, and that this differential would be lower for fathers than for mothers. A 2 (child diagnosis) x 2 (parent gender) Anova found no significant main effects nor any significant interaction for GHQ-28 total score, and the hypothesis was therefore not supported. Inspection of the group means shown in Table 1 shows that overall, GHQ-28 scores differed little across groups. The highest score for each group was social dysfunction and the lowest score for each group was depression.
3.3.2 Hypothesis Two

Parents of children with autism will experience higher levels of stress in areas relating to their experience of emotional attachment with their child than parents of children with other learning disabilities, but this effect will be lower for fathers than for mothers.

No significant difference was found between groups with regard to overall level of psychological distress, however the next step of analysis was taken in order to explore differences in levels of stress relating to the specific experience of parenting. Outcome measures for the Parenting Stress Index (PSI) were compared across each group. Mean scores and standard deviations for each group are presented in table 6.

Table 6
PSI Means and Standard Deviations for each Group

<table>
<thead>
<tr>
<th></th>
<th>Autism Fathers</th>
<th>Autism Mothers</th>
<th>L.Disab Fathers</th>
<th>L.Disab Mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Domain</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
</tr>
<tr>
<td></td>
<td>151.3 (27.78)</td>
<td>147.2 (25.08)</td>
<td>127.9 (21.72)</td>
<td>142.6 (29.57)</td>
</tr>
<tr>
<td></td>
<td>(n = 21)</td>
<td>(n = 21)</td>
<td>(n = 14)</td>
<td>(n = 17)</td>
</tr>
<tr>
<td>Parent Domain</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
</tr>
<tr>
<td></td>
<td>135.9 (24.29)</td>
<td>138.5 (21.54)</td>
<td>117.9 (26.78)</td>
<td>126.8 (31.44)</td>
</tr>
<tr>
<td></td>
<td>(n = 21)</td>
<td>(n = 21)</td>
<td>(n = 14)</td>
<td>(n = 18)</td>
</tr>
<tr>
<td>Life Stress</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
</tr>
<tr>
<td></td>
<td>8.7 (6.43)</td>
<td>7.8 (8.32)</td>
<td>8.5 (8.57)</td>
<td>9.4 (10.08)</td>
</tr>
<tr>
<td></td>
<td>(n = 21)</td>
<td>(n = 21)</td>
<td>(n = 14)</td>
<td>(n = 18)</td>
</tr>
<tr>
<td>PSI Total</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
</tr>
<tr>
<td></td>
<td>287.2 (45.60)</td>
<td>285.7 (37.65)</td>
<td>245.9 (45.64)</td>
<td>272.6 (55.10)</td>
</tr>
<tr>
<td></td>
<td>(n = 21)</td>
<td>(n = 21)</td>
<td>(n = 14)</td>
<td>(n = 17)</td>
</tr>
</tbody>
</table>
The data were analysed using a 2 (child diagnosis) x 2 (parent gender) Anova. Analysis was repeated using the PSI Total and the three domain scores (Child Domain, Parent Domain and General Life Stress) as dependent variables.

It was hypothesised that parents of children with autism would experience higher levels of stress in areas relating to their experience of emotional attachment with their child compared to parents of children with other learning disabilities, and that this differential would be lower for fathers than for mothers. Results of the analysis of variance confirmed a significant effect for child diagnosis for total level of parenting stress ($F(1, 69) = 6.23, p = 0.015$), but not for parent gender or the diagnosis x parent type interaction. Significant effects of child diagnosis were also found for the Child Domain ($F(1, 69) = 4.98, p = 0.029$), and Parent Domain ($F(1, 70) = 5.90, p = 0.018$), again with no significant effects for parent gender or the parent gender x child diagnosis interaction. Parents of autistic children consistently reported higher levels of stress in each of the three comparisons. No significant effects were found for General Life Stress. This finding indicates that no significant difference was found in the experience of stressful life events between groups. No significant difference was found for parent gender in either total parenting stress or the three separate domains. Therefore the hypothesis that mothers would experience higher levels of stress compared to fathers was not confirmed.

As a significant difference was found for child diagnosis in both the Parent Domain and the Child Domain, further 2 (child diagnosis) x 2 (parent gender) Anovas were used with each of the individual scales as dependent variables. Comparison of means and standard deviations for each group are given in table 7. Since a total of 13 univariate Anovas were performed, a probability of 0.01 was required in order for an effect to be viewed as significant. None of the Parent domain sub-scales yielded significant main effects of child diagnosis or parent type, nor any significant interactions.

In the Child domain, a significant effect for diagnosis was found for the individual scales of adaptability ($F(1, 70) = 12.91, p = 0.001$) and reinforcement to parent ($F(1, 70) = 7.86, p = 0.007$). No significant effects were found for parent type, nor for the child diagnosis x parent gender interaction. Parents of autistic children reported higher levels of stress in these
Results

areas compared to parents of children with other learning disabilities. No significant effects were found for the remaining scales of acceptability, demandingness, mood or distractibility.

Table 7

PSI Individual Scales Means and Standard Deviations for each Group

<table>
<thead>
<tr>
<th></th>
<th>Autism Fathers</th>
<th>Autism Mothers</th>
<th>L.Disab Fathers</th>
<th>L.Disab Mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
</tr>
</tbody>
</table>

Parent

- Depression: 21.00 (4.22) 22.43 (5.80) 18.29 (4.39) 19.67 (6.29)
- Attachment: 14.52 (3.23) 13.71 (2.65) 13.43 (3.03) 13.11 (4.21)
- Role Restrict: 20.86 (6.44) 21.33 (4.66) 17.64 (6.50) 20.33 (5.80)
- Competence: 31.67 (6.41) 32.38 (5.12) 27.43 (7.04) 30.83 (8.40)
- Social Isol: 15.81 (3.23) 15.00 (4.07) 13.14 (3.72) 13.22 (4.29)
- Spouse: 18.76 (4.63) 19.38 (2.89) 16.07 (4.76) 17.39 (6.69)
- Health: 13.29 (3.20) 14.29 (3.84) 11.93 (4.39) 12.22 (3.42)

Child

- Adaptability: 39.67 (7.55) 38.00 (7.71) 29.43 (7.34) 34.33 (9.98)
- Acceptability: 22.43 (4.25) 21.95 (3.64) 19.93 (4.60) 21.44 (4.95)
- Demanding: 29.95 (7.21) 29.62 (7.14) 25.14 (6.10) 28.39 (8.15)
- Mood: 13.05 (4.24) 12.67 (3.29) 11.57 (3.59) 13.17 (4.49)
- Distract: 31.81 (6.17) 31.10 (7.21) 31.43 (5.18) 31.65 (6.43)
- Reinforce: 14.43 (4.34) 14.38 (3.80) 10.43 (3.18) 12.94 (4.77)

3.3.2.1 Defensive Responding

The PSI includes a mechanism with which to detect possible defensive responses. Participants scoring 24 or below on the defensive responding scale may be responding in a defensive manner. Although none of the parents of autistic children were found to be responding in a defensive manner, three mothers and three fathers of learning disabled children did present with defensive responding scores which were below 24.

Since it was not practical to remove these participants for the purpose of analysis, they were included in all statistical tests. Therefore it is advised that caution should be exercised in interpreting the other scores. This matter will be addressed further in the discussion.
Results

3.3.3 Hypothesis Three

Parents of children with autism will experience less emotional attachment from their child than parents of children with other learning disabilities, but this differential will be lower for fathers than for mothers.

Total scores from the Attachment questionnaire were explored to compare parental perception of attachment across the groups. Data was analysed using a 2 (child diagnosis) x 2 (parent gender) Anova. It was hypothesised that parents of children with autism would experience less attachment from their child than parents of children with other learning disabilities. Results of the analysis of variance confirmed a significant effect for child diagnosis ($F(1, 72) = 23.09, p < 0.001$). Parents of children with autism scored significantly lower on the Attachment Questionnaire compared to parents of children with learning disabilities. This indicates that parents of autistic children perceive their child to be significantly less attached to them than parents of children with other learning disabilities.

The hypothesis that this differential would be lower for fathers than for mothers was not confirmed; no significant effect for parent gender was found, and no significant diagnosis by parent gender interaction was found.

Means and Standard Deviations for each group are presented in table 8.

Table 8
Attachment Questionnaire Means and Standard Deviations for each Group

<table>
<thead>
<tr>
<th></th>
<th>Autism Fathers</th>
<th>Autism Mothers</th>
<th>L. Disab Fathers</th>
<th>L. Disab Mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>22</td>
<td>22</td>
<td>14</td>
<td>18</td>
</tr>
<tr>
<td>Mean (s.d)</td>
<td>3.64 (2.24)</td>
<td>3.50 (1.97)</td>
<td>6.07 (1.86)</td>
<td>5.61 (1.94)</td>
</tr>
</tbody>
</table>
In order to investigate further which specific child behaviours or other factors contribute to parents’ perception of impaired attachment, categorical responses to individual items on the attachment questionnaire were analysed across diagnostic groups using chi-square.

**Attachment Question 1**

**Do you wish your child demonstrated more affection towards you?**

No significant association was found for child diagnosis and response pattern on this item.

**Attachment Question 2**

**In what ways does your child demonstrate affection towards you?**

No significant association was found for child diagnosis and response pattern on this item.

**Attachment Question 3**

**Do you feel like your child initiates contact with you?**

A significant association was found for child diagnosis and response pattern on this item ($\chi^2 = 5.321$, d.f. = 1, $p < 0.05$). Parents of children with autism are less likely to perceive that their child initiates enough contact with them, compared to parents of children with other learning disabilities.

**Attachment Question 4**

**In general, does your child worry about, or make an effort to win your approval?**

A significant association was found for child diagnosis and response pattern on this item ($\chi^2 = 6.297$, d.f. = 1, $p < 0.05$). Parents of children with autism are less likely to feel that their child worries about or makes an effort to win their approval, compared to parents of children with other learning disabilities.

**Attachment Question 5**

**In general, do you ever feel like your child views you or treats you more like an object in his/her world, than like a mother/father who is very important to your child?**

A significant association was found for child diagnosis and response pattern on this item ($\chi^2 = 25.33$, d.f. = 1, $p < 0.05$). Parents of children with autism were significantly more likely to feel
that their child viewed them as an object, compared to parents of children with learning disabilities.

**Attachment Question 6**

Does your child's disability interfere with his/her ability to be close and loving in his/her relationship with you?

A significant association was found for child diagnosis and response pattern on this item ($\chi^2 = 11.461$, d.f. = 1, $p < 0.5$). Parents of children with autism were more likely to feel that their child's disability interfered with their relationship with them, compared to parents of children with other learning disabilities.

**Attachment Question 7**

Do you feel that your child recognises you as his/her parent and differentiates you from other people?

No significant association was found for child diagnosis and response pattern on this item.

**Attachment Question 8**

Does your child convey appreciation toward you when you do something your child finds pleasurable?

A significant association was found for child diagnosis and response pattern on this item ($\chi^2 = 11.90$, d.f. = 1, $p < 0.5$). Parents of children with autism were significantly less likely to feel that their child conveyed appreciation towards them, compared to parents of children with learning disabilities.
3.3.4 **Hypothesis Four**

Fathers of both learning disabled and autistic children will be less involved in the care of their child than the mothers.

In order to answer this question, data from the Parenting Burden and Difficulty Scale (PBDS) was analysed. This measure was used to provide different ratings of parenting tasks. The first rating provides a total for the number of tasks that they felt they carried out more often than their partner. A 2 (child diagnosis) x 2 (parent gender) Anova was used to investigate difference in number of parenting tasks each participant stated that they carried out more often than their partner. A significant effect was found for parent gender (F (1, 71) = 24.08, p < 0.001). No significant effect was found for child diagnosis. No significant child diagnosis by parent type interaction was found. Mean scores and standard deviations are presented in Table 9.

**Table 9**

Number of Parenting Tasks Carried Out More Often Than Partner

Means and Standard Deviations for each Group

<table>
<thead>
<tr>
<th></th>
<th>Autism Fathers</th>
<th>Autism Mothers</th>
<th>L.Disab Fathers</th>
<th>L.Disab Mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 21</td>
<td>n = 22</td>
<td>n = 14</td>
<td>n = 18</td>
<td></td>
</tr>
<tr>
<td><strong>No. of Tasks</strong></td>
<td><strong>Mean (s.d)</strong></td>
<td><strong>Mean (s.d)</strong></td>
<td><strong>Mean (s.d)</strong></td>
<td><strong>Mean (s.d)</strong></td>
</tr>
<tr>
<td></td>
<td>3.10 (3.00)</td>
<td>7.31 (4.05)</td>
<td>2.28 (2.27)</td>
<td>6.17 (4.12)</td>
</tr>
</tbody>
</table>

The second rating gained from this measure is PBDS total score for difficulty experienced by the parent with regard to parenting tasks. A further 2 (child diagnosis) x 2 (parent gender) Anova was used to explore difference in parenting difficulty. A significant effect for parent gender was found (F (1, 72) = 6.01, p = 0.017). A significant effect for child diagnosis (F (1, 72) = 4.93, p = 0.03) was also found, but the child diagnosis by parent type interaction was not significant. The hypothesis that fathers of both learning disabled and autistic children would be less involved in care of their child than the mothers would seem to be confirmed, as fathers of both autistic children and learning disabled children seem to experience less difficulty and less
The results further indicate that both mothers and fathers of children with autism experience more difficulty in their role of being a parent compared to mothers and fathers of children with other learning disabilities. Mean scores and standard deviations for each group are presented in table 10.

Table 10

PBDS Total Score Means and Standard Deviations for each Group

<table>
<thead>
<tr>
<th></th>
<th>Autism Fathers n = 22</th>
<th>Autism Mothers n = 22</th>
<th>L.Disab Fathers n = 14</th>
<th>L.Disab Mothers n = 18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (s.d)</td>
<td>39.32 (11.26)</td>
<td>43.32 (12.17)</td>
<td>31.79 (6.53)</td>
<td>39.89 (10.07)</td>
</tr>
</tbody>
</table>

Results
3.3.5 **Hypothesis Five**

Fathers of both learning disabled and autistic children will use more practically-oriented coping strategies than mothers.

Outcome measures for each of the Shortened Ways of Coping Scale -Revised (SWCS-R) were compared for each group. Means and standard deviations for each group are presented in Table 11.

**Table 11**

**Ways of Coping Means and Standard Deviations for each Group**

<table>
<thead>
<tr>
<th></th>
<th>Autism Fathers n = 22</th>
<th>Autism Mothers n = 21</th>
<th>L.Disab Fathers n = 14</th>
<th>L.Disab Mothers n = 18</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean (s.d)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wishful Thinking</td>
<td>6.09 (4.05)</td>
<td>6.00 (4.23)</td>
<td>3.79 (2.99)</td>
<td>5.83 (4.40)</td>
</tr>
<tr>
<td>Practical Coping</td>
<td>12.09 (3.46)</td>
<td>11.10 (4.23)</td>
<td>11.86 (3.78)</td>
<td>12.39 (5.36)</td>
</tr>
<tr>
<td>Social Support</td>
<td>4.64 (2.63)</td>
<td>7.43 (2.44)</td>
<td>4.36 (2.76)</td>
<td>7.72 (2.85)</td>
</tr>
</tbody>
</table>

**3.3.5.1 Practical Coping**

It was hypothesised that fathers of both learning disabled and autistic children would use more practically-oriented coping strategies compared to mothers. Results of a 2 (child diagnosis) x 2 (parent gender) Anova found no significant main effects or interaction for practically-oriented coping strategies, and therefore, the hypothesis was not supported.

Additional analyses were carried out on the remaining coping strategies data.
3.3.5.2 **Wishful Thinking**

A 2 (child diagnosis) x 2 (parent gender) Anova was carried out and found no significant main effects or interaction for wishful thinking as a coping strategy.

3.3.5.2 **Social Support**

A 2 (child diagnosis) x 2 (parent gender) Anova found a significant effect for parent gender \((F (1, 71) = 24.41, p < 0.001)\). Mean scores indicate that mothers use more coping strategies involving social support than fathers. No significant effect for child diagnosis was found. No significant child diagnosis by parent gender interaction was found.

3.3.5.3 **Availability of Social Support**

The above analysis did not confirm the hypothesis that fathers would make more use of problem-focused strategies than mothers, but did find that mothers made more use of social support. A further analysis was calculated to investigate whether this effect might simply be a result of greater availability of social support for mothers.

Results from the Family Support Scale (FSS) were used to examine this possibility. Means and standard deviations for each group are presented in table 12.

**Table 12**

**Family Support Scale Means and Standard Deviation for each Group**

<table>
<thead>
<tr>
<th></th>
<th>Autism Fathers</th>
<th>Autism Mothers</th>
<th>L.Disab Fathers</th>
<th>L.Disab Mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Sources of Support</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
<td>Mean (s.d)</td>
</tr>
<tr>
<td></td>
<td>13.23 (3.48)</td>
<td>12.18 (3.02)</td>
<td>12.08 (2.53)</td>
<td>11.56 (3.03)</td>
</tr>
<tr>
<td></td>
<td>(n = 22)</td>
<td>(n = 22)</td>
<td>(n = 13)</td>
<td>(n = 18)</td>
</tr>
<tr>
<td>Total Support</td>
<td>35.14 (9.43)</td>
<td>33.68 (8.44)</td>
<td>38.54 (9.22)</td>
<td>37.50 (11.13)</td>
</tr>
<tr>
<td></td>
<td>(n = 22)</td>
<td>(n = 22)</td>
<td>(n = 13)</td>
<td>(n = 18)</td>
</tr>
</tbody>
</table>
3.3.5.4 Number of Sources of Support

A 2 (child diagnosis) x 2 (parent gender) Anova found no significant main effects nor significant interaction for the number of sources of support available.

3.3.5.5 Total of Support

A 2 (child diagnosis) x 2 (parent gender) Anova found no significant main effects nor significant interaction for total level of quality, of support available.

3.3.5.6 Sub-scales

Finally, the possibility was considered that groups might differ in the patterns of social support available to them. Figure 3 presents the degree of helpfulness experienced from different sources of support for each group. The graph indicates that for both parents of autistic children and parents of children with learning disabilities, partners are rated as the most helpful source of support, followed by support from social organisations. Although the third most helpful source of support is rated as being professional services, there would seem to be quite a discrepancy between the two groups, indicating that parents of autistic children experience professional services as less helpful than parents of children with other learning disabilities do. Whilst there is little difference between the degree of helpfulness from formal sources of support experienced by each group, the graph indicates that parents of autistic children experience less helpfulness from informal sources of support, compared to parents of children with other learning disabilities.
Figure 3
Means for FSS Sub-scales for Parents of Children with Autism and Parents of Children with Learning Disabilities
DISCUSSION
4.1 Overview

This study aimed to investigate differences in the nature and degree of stress experienced by mothers and fathers of children with autism, and to compare their experiences with mothers and fathers of children with other learning disabilities. The study was particularly interested in parental perception of child attachment in relation to parenting a child with autism, and specifically endeavoured to investigate the experience of fathers in this area. The following chapter will consider each of the research hypotheses derived from the literature review. The results of this study will be compared to those of previous research and new findings will be highlighted. Directions for future research will be highlighted, and limitations of the present study will be considered. Finally, clinical implications for services, in the light of present findings will be discussed.
4.2 Research Hypothesis

4.2.1 Hypothesis One

Parents of children with autism will experience higher levels of psychological distress than parents of children with other learning disabilities, but this differential will be lower for fathers than for mothers.

The hypothesis that parents of children with autism will experience higher levels of psychological distress than parents of children with other learning disabilities, was not confirmed according to total scores on the General Health Questionnaire-28 (GHQ-28) (Golderg and Williams, 1991). This result is not consistent with previous studies which have found higher levels of anxiety and depression in parents of children with autism compared to parents of children with other learning disabilities (Piven, Gray, Chase, Landa, Wzorek, Gayle, Cloud and Folstein, 1991; Sanders and Morgan, 1997). It is possible that the relatively small, self-selected sample of parents who felt able to participate in this study, might have done so because of low levels of psychological distress. It is impossible to ascertain the frequency of problems of psychological distress in the larger population of parents who were eligible for participation in this study; but it could be hypothesised that symptoms of psychological distress (e.g. depression and anxiety), may have contributed towards lack of response.

In addition the hypothesis that this differential would be lower for fathers than for mothers was also not confirmed. No significant findings were revealed for either child diagnosis or parenting gender. This result is interesting in that it is not consistent with previous studies which have found mothers of autistic children to report higher levels of psychological disturbance in comparison to fathers (Demyer, 1979; Gray and Holden, 1992; Sharpley et al, 1997). A possible explanation for this could be that the fathers participating in this study represent a fairly atypical group, who were actively involved in their child’s development. Previous discussion has suggested that fathers in general may be less affected by the stress of caring for a
child with special needs because of their ‘instrumental’ role in the family, which allows them to distance themselves from the child care issues (Lamb and Meyer, 1991).

However, significant differences were obtained on total level of parenting stress on the Parenting Stress Index (PSI) (Abidin, 1995). Parents of children with autism were found to have significantly higher levels of stress compared to parents of children with other learning disabilities. This finding is consistent with previous research studies, which have indicated that parents of autistic children experience significantly increased levels of stress with regard to the task of parenting (Bouma and Schweitzer, 1990; Dumas et al, 1991).

No significant effect was found for parent gender for total PSI score. This finding is consistent with that of Perry, Sarlo-McGarvey, and Factor (1992), who found no difference in PSI total score for mothers and fathers caring for daughters with Rett syndrome. Rett syndrome is a disorder which can present with similar features to those found in children with autism (Howlin, 1998). However, many previous studies have indicated that mothers of autistic children generally report higher levels of parenting stress than fathers (Dumas et al, 1991; Moes et al, 1992). In addition the wider literature concerning parents of children with learning disabilities also has consistently found that mothers report higher levels of stress in comparison to fathers (Beckman, 1991; Bristol, Gallagher and Schopler, 1988). Some studies, however, have reported that stress experienced by mothers and fathers of children with learning disabilities differs in the areas which are perceived to be stressful, rather than the level of stress itself (Dyson, 1997).

The results of this study suggest that whilst parents of autistic children experience significantly higher levels of stress in parenting compared to parents of children with learning disabilities, this may not be sufficient to generalise to higher levels of overall psychological distress. The fact that no significant effect for gender was detected is also interesting, as previously studies have generally concluded that mothers of both autistic children and learning disabled children report significantly higher levels of stress than fathers. Possible reasons for this finding are considered later in this discussion.
4.2.2 **Hypothesis Two**

Parents of children with autism will experience higher levels of stress in areas relating to their experience of emotional attachment with their child than parents of children with other learning disabilities, but this effect will be lower for fathers than for mothers.

The hypothesis that parents of children with autism will experience higher levels of stress in areas relating to their experience of emotional attachment with their child than parents of children with other learning disabilities was supported. The mean Child Domain score was higher than the mean Parent Domain score for both groups, and this indicates stress due to child characteristics. Parents of children with autism scored significantly higher in the Child Domain of the Parenting Stress Index (PSI) than parents of children with learning disabilities. The Child Domain measures the degree of stress experienced as a result of child characteristics and the result of this study indicates that parents of autistic children experience more stress as a consequence of their child’s characteristics, compared to parents of children with other learning disabilities. Further analysis involving PSI sub-scales, found that parents of autistic children also scored significantly higher in the areas of Child Adaptability and Child Reinforcement to parent, within the Child Domain.

A high score in the area of Child Adaptability suggests that the child demonstrates extreme distress in relation to changes in their routine or environment and are subsequently difficult to comfort. Consequently it is reported that parents are likely to feel that their efforts to build a relationship with their child are thwarted (Abidin, 1995). A high score in the area of Reinforcement to parent, reflects parent-child interactions which fail to reinforce the parent in their parenting role, and may indicate that the parent feels rejected by their child (Abidin, 1995). No significant effect was found for the remaining sub-scales which do not directly relate to reciprocal attachment (Acceptability, Demanding, Mood and Distractibility). None of these remaining sub-scales are particularly indicative of child attachment towards the parent.

Parenting Domain scores were also significantly higher for parents of autistic children. No individual sub-scales in this domain were found to indicate significant differences between
Discussion

groups. The absence of any significant effects for PSI sub-scales of Health, Social Isolation and Depression would seem to be consistent with the GHQ-28 findings, reported in the current study.

In this study, scores on the Attachment sub-scale, within the Parent Domain, were not significantly higher for fathers than for mothers. This is not consistent with previous studies (Beckman, 1991; Krauss, 1993) which have found that fathers of learning disabled children score significantly higher on this sub-scale, compared to mothers. The Attachment sub-scale measures parental sense of attachment to their child. The results from this present study indicate that neither mothers nor fathers who participated in this study, appeared to report significantly higher negative feelings in relation to feeling attached to their child. This apparently paradoxical finding of an absence of a parent gender effect on perceived attachment to a child with autism, when such an effect has been found for parents of children with learning disabilities, clearly merits further investigation. Failure to find an effect may simply reflect the limited power on the present analysis. Alternatively, the parent gender effect found for families with a learning disabled child may be absent in families with autistic children, perhaps because the father reacts to the child’s social difficulties with an enhanced perception of his own attachment to the child.

Overall PSI total scores are above the clinical cut off point for all groups (> 260), except for fathers of children with learning disabilities. The fact that parents of autistic children scored significantly higher than parents of children with learning disabilities is consistent with previous research (Bouma and Sweitzer, 1990; Dumas et al, 1991; Fisman, Wolf and Noh, 1989).
4.2.3 **Hypothesis Three**

Parents of children with autism will experience less emotional attachment from their child than parents of children with other learning disabilities, but this differential will be lower for fathers than for mothers.

In addition to the sub-scales of the PSI, a semi-structured attachment interview was used to provide additional information with regard to the parents’ perception of how attached they felt their child was to them. The original study from which the Attachment Questionnaire was taken (Hoppes and Harris, 1990) notes that differences in parental reports of perception of child attachment were borne out more obviously from the interview than from a parallel anonymous questionnaire. The same would seem to be apparent in this study. The inclusion of the Attachment Questionnaire in this study provided a rich source of information concerning parents’ perception of their child’s attachment to them. The following section will include some relevant quotes from parents to emphasise statistical findings.

As predicted by the hypothesis, parents of autistic children scored significantly lower on the questionnaire compared to parents of children with other learning disabilities. Interpretation of this result suggests that parents of autistic children experience their children to be significantly less obvious in their attachment and reciprocation of emotion, compared to parents of children with other learning disabilities. This perceived lack of attachment behaviour from the child may, therefore, be a source of the enhanced parenting stress related to the child characteristics demonstrated by parents of autistic children in the PSI Child Domain.

Given the lack of research studies which have investigated paternal perception of child attachment, the hypothesis that a significant difference would be found between mothers and fathers of children with autism on this measure in the current study, was based on previous findings which have identified fathers as being primarily concerned with the practical implications of their child’s disability (Hornby, 1995a; Rodrigue et al, 1992). However, no significant difference between mothers’ and fathers’ perceptions was found. The overall finding...
of the present study is consistent with previous research which has solely considered the maternal perception of attachment (Hoppes and Harris, 1990) and additionally suggests that fathers of autistic children also perceive their child to be less attached to them. This study was also different in that it included a more diverse comparison group. The original study conducted by Hoppes and Harris (1990) included a comparison group consisting of mothers of children with Down’s syndrome. Choice of comparison group will be discussed in more detail later in this chapter.

The results of the present study thus extend the findings of previous research in two ways. Firstly, the current study replicates the findings of Hoppes and Harris (1990), that mothers of children with autism perceive their child as less attached to them than do mothers of learning disabled children, but with a control group of children with diverse learning disabilities, rather than Down’s syndrome only. Secondly, the results of the present study show that the same effect holds for fathers.

With regard to the current study it is particularly interesting to consider which individual items of the Attachment Questionnaire were found to demonstrate a significant difference in responses between groups. Previous studies (Dissanayake and Crossley, 1996; Kasari et al, 1988; Sigman et al., 1986) have found that whilst autistic children may not differ from other children in their ability to demonstrate secure attachment relationships with their carers, they do differ in their style of interaction. Autistic children were found to engage less in interaction involving joint attention with their caregivers (Kasari et al, 1988), and in addition, considerable parent-child interaction was found to be initiated and maintained by the parent, and therefore seemed to be a result of the parents’ own orchestration (Sigman et al, 1986). Results from this study would seem to be in line with the previous research findings.

In the current study, parents in each group (autistic vs. learning disabled children) reported experiencing similar levels in amount of affection they received from their child. In addition they reported no significant difference in the ways in which their child demonstrated affection (mostly physically), and also reported no significant differences in their child’s ability to recognise them as their parent. In many ways these results suggest that parents of autistic children and learning disabled children perceived no difference in their child’s attachment
behaviour towards them. However, results from the remaining items found that parents of children with autism reported significant differences in their child’s style of interaction. In addition to the above findings, quotes given by parents of autistic children during the interview, illustrate this point further. Whilst it is stressed that this information was not analysed rigorously, the parents’ words interestingly illustrate the above findings. The following key themes were apparent:

In comparison to parents of children with other learning disabilities, parents of autistic children felt that their child did not initiate enough contact with them:

“Sometimes I make things difficult, so that she has to come to me...I anticipate (what she wants)...but I want her to come to me”

“She uses affection...because I’ve asked for a lot of affection. She’s learnt”.

It would seem that the children that many of these parents were describing would fit with the description given by Wing and Gould (1979), of children who do not initiate contact themselves, but who are passive in their style of social interaction. Additionally, the parents in this study commented that the quality of their child’s contact with them was different. The way they described their child’s contact with them, suggested that they felt that their child used affection as a learned, goal-orientated behaviour:

“She does (initiate contact) when she wants something...(it’s) not often because she wants to be with you”.

“It’s what she gets out of it...I see it through rose-tinted glasses...one hug and I’m fine for a week. The truth is...she’s not affectionate, it’s because she wants something...Dads like to feel they are special”.

“(Affection is)...partly through conditioning, through his mum...she used to ask him if he loved her”.
Parents of autistic children felt that their child made significantly less effort to gain their approval, than did parents of children with other learning disabilities, and in fact, seemed unaware of their parents’ opinion.

“*No... he’s in his own world*."

“*He’s in his own little world and he doesn’t care about anything like that*”.

Parents of autistic children were also more likely to report that their child treated them as though they were an object (or tool):

“*He’s got no idea what I’m here for...I’m general dogs body...I’m just this person who looks after him*”

“*He doesn’t recognise me, sometimes, as his Dad...he probably sees me as a way of getting a drink*”

“*We are a tool for him... he will take us to what he wants*”

“*We only ever exist as a part of his world. He’ll use us as an object...as a means to an end*”

Parents of autistic children felt that their child demonstrated less appreciation of them, compared with parents of children with learning disabilities.

“*He can’t say ‘thank you’, and he wouldn’t understand that he should...I can just tell that he’s happy*”

“*He wouldn’t say ‘thank you’. I might say ‘Give me a kiss’, and he will do it, but I have to ask*”

“I can tell she’s happy...but I don’t think she relates it back to me*.”
The comments given by these parents suggested that they felt that their child was not aware of the parent’s intention to do something that the child would find pleasurable. This would seem to fit with the child’s lack of ‘Theory of Mind’ (Baron-Cohen et al, 1985; Baron-Cohen, 1989a). The child’s behaviour did not demonstrate an awareness that their parents’ behaviour had been motivated by an intention to please them.

It would seem that as a result of these differences in the child’s style of interaction, both mothers and fathers of autistic children were more likely to feel that their child’s disability interfered in the child’s ability to form a close and loving relationship with them:

“I felt pushed aside when she was little...I wanted a hug”

“She can’t talk about how she feels...and that’s a big part of a relationship...I find that hard”

“We have not got a normal father-son relationship, we have to adjust”

“If I go to cuddle him, he’ll shrug me off or pull his hand away...it does create a bit of a barrier”

In many ways the information gained from parents through the Attachment Interview indicates that parents do experience warmth in their relationship with their child. However, parents of autistic children were able to identify areas in which they experienced a qualitative difference in their child’s behaviour towards them. It would seem that, to some extent, this contributed to a sense of sadness about their relationship with their child.
4.2.4 **Hypothesis Four**

Fathers of both learning disabled and autistic children will be less involved in the care of their child than the mothers.

The hypothesis that fathers of both learning disabled and autistic children would be less involved in care of their child than the mothers was confirmed. This study found that mothers carry significantly more of the perceived parenting burden, compared to fathers. This finding is consistent with previous research (Milgram and Atzil, 1988).

This result would seem to reflect the fact that more mothers worked as full time carers than fathers. However, it may also reflect the fact that since fathers have less time available for child care, they may feel less confident about becoming involved when they are at home. Children with special needs and particularly with autism tend to need routines to an even greater extent than children with normal development, and may have special requirements with regard to their care (e.g. feeding, medication). This may be the reason why mothers seem more likely to take the lead role in parenting at weekends as well. Fathers may feel less competent in their ability to help (McBride, 1989). It has also been suggested that mothers may want their relationship with their child (Barnett and Baruch, 1987) to be exclusive and so do not encourage their partner to be involved. This could be even more pronounced in caring for a child who is autistic. A feature of autism is an intense desire for routines and familiarity (Aarons and Gittens, 1999), therefore, it is possible that autistic children who experience their mothers as being involved in their care for the majority of time, may themselves be resistant on the occasions when their fathers attempt to become involved. Consequently, lower participation of fathers in child-centred activities may not be only a function of them working and, therefore, being less available. They may also be positively excluded through the mother's desire for a 'special’ relationship with her child, reinforced by the child’s resistance to accepting change in routine or personnel.
The result for parenting difficulty reported a significant effect for parent gender and for child
diagnosis. This suggests that for both mothers and fathers of autistic children, the parenting
role is more difficult than for mothers and fathers of children with other learning disabilities.

The increased parenting difficulty associated with parenting an autistic child, then, is a further
potential cause of the higher level of parenting stress reported by both parents compared with
those of children with learning disabilities. The parent gender effect for parenting burden and
difficulty, with mothers reporting higher levels of demand in child care than fathers is not
however reflected in a corresponding effect on PSI scores. Mothers appear to take the major
role in caring for disabled children, without experiencing higher levels of parenting stress than
the less involved fathers. A possible interpretation of these results may be that there is a
compensatory mechanism in terms of stress between the difficulty of the task, and the
perception of ‘achievement’. Mothers may have the larger task, but can achieve more through
physically caring for their child, thereby having some form of relationship with him/her.
Fathers, conversely, may have little practical responsibility for the care of their child, but may
also feel they have fewer means of relating to or communicating with them, generating more
stress through frustration.

Again, this finding warrants further investigation. Although the absence of a parent gender
effect for PSI scores may again result from limited analytic power associated with small sample
size, it may also indicate that the effect of some other factor allows mothers to carry a higher
share of parenting load than fathers without suffering higher levels of stress. The findings of
this study on coping style may be relevant to this question.
4.2.5 **Hypothesis Five**

Fathers of both learning disabled and autistic children will use more practically-oriented coping strategies than mothers.

The hypothesis that fathers of both learning disabled and autistic children would engage in more practical coping strategies than mothers was not confirmed. Although mothers and fathers both reported a higher use of practically-focused coping in comparison to emotion-focused coping (i.e. wishful thinking), this study found no significant effect for either parent gender or child diagnosis, on use of wishful thinking or practical coping as coping strategies.

This finding challenges previous research which has generally suggested that men and women employ different coping strategies. In general previous studies (e.g. Ptacek et al, 1994) have suggested that women are less likely to use problem-focused strategies compared to men. However, the current findings are consistent with previous research on parents of children with disabilities (Frey et al 1989; Sloper and Turner, 1993), and support the possibility that gender differences in coping style typically found in the general population are not found in families of disabled children. Whether this effect reflects an increased maternal use of problem-focused coping or an increased paternal use of emotion-focused coping in families of disabled children compared to the general population is clearly a fascinating question deserving of systematic study.

This study did however, find significant differences in the use of social support as a coping strategy. Consistent with previous studies (Knussen et al, 1992), mothers were found to be more likely to use social support than men. However, no differences were found in the total number of support sources available for each group, or the total ‘helpfulness’ level of support available for each group. The higher use of social support by mothers, therefore, offers to reflect a genuine gender difference in coping style rather than simply to reflect a difference in availability of social support as a coping resource. This issue does not appear to have been previously considered in research on parents with children with autism. The higher use of social support by mothers may be crucial to their ability to bear a higher level of parenting burden than fathers without experiencing corresponding higher stress levels. However, it is
Discussion

acknowledged that whilst mothers may seek support in child care issues, fathers may seek support in other areas (e.g. sport, projects). This study did not measure the use of support in these areas.
4.3 Summary of Findings and Relation to Previous Literature

The results of this study revealed both similarities and differences with regard to the possible sources of stress experienced by mothers and fathers of autistic children.

In comparison to mothers and fathers of children with other learning disabilities, mothers and fathers of autistic children did not report significantly different levels of psychological distress; nor was there any effect of parent gender on this variable. This result is in contrast with previous studies which have reported higher levels of psychological distress in parents of autistic children (Piven et al, 1991; and Sanders and Morgan, 1997); and which have also found higher levels of distress in mothers of children with learning disabilities, compared to fathers (Demeyer, 1979; Gray and Holden, 1992; Sharpley et al, 1997).

In comparison to parents of children with other learning disabilities, parents of children with autism did report higher levels of parenting stress, and this finding is consistent with previous studies (Bouma and Schweitzer, 1990; Dumas et al, 1991). However, it did not find any significant difference between level of parenting stress experienced by mothers and fathers. Although previous research has been inconsistent in its findings in this area, the current result is in contrast to the majority that have reported higher levels of stress in mothers (Moës et al, 1992).

The results from the Attachment Questionnaire suggest that a lack of emotional reciprocity from their child is a particular source of parenting stress for both mothers and fathers of autistic children. This is a new finding with regard to the experience of fathers and extends the results of previous research which has concentrated solely on mothers (Hoppes and Harris, 1990). Although this study cannot claim that all fathers are adversely affected by lack of reciprocal attachment from their autistic child, it does suggest that some are.

The results from the Parenting Burden and Difficulty Scale (Milgram and Atzil, 1988) also suggest that parenting children with autism is perceived by parents as involving higher demands than is the case for children with learning disabilities. This finding extends the results of previous work on parenting burden using the Parenting Burden and Difficulty Scale, as
Discussion

the original study did not include a comparison group in it’s design (Milgram and Atzil, 1988).
In addition, results found that mothers shoulder most of the burden, and this would seem to be
consistent with the previous study (Milgram and Atzil, 1988). That they do so without
resultant higher stress levels *may* be due to mothers greater use of social support as a coping
strategy.

Table 13 Summary of Hypotheses and Corresponding Results

<table>
<thead>
<tr>
<th>Hypothesis</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hypothesis One:</strong> Parents of children with autism will experience</td>
<td>No significant differences in levels of psychological distress was found</td>
</tr>
<tr>
<td>higher levels of psychological distress than parents of children with other</td>
<td>or either child diagnosis or parent gender.</td>
</tr>
<tr>
<td>learning disabilities, but this differential will be lower for fathers than</td>
<td></td>
</tr>
<tr>
<td>for mothers.</td>
<td></td>
</tr>
<tr>
<td><strong>Hypothesis Two:</strong> Parents of children with autism will experience</td>
<td>Parents of autistic experienced significantly higher levels of parenting</td>
</tr>
<tr>
<td>higher levels of stress in areas relating to their experience of</td>
<td>stress. No significant difference was found for parent gender.</td>
</tr>
<tr>
<td>emotional attachment with their child than parents of children with other</td>
<td></td>
</tr>
<tr>
<td>learning disabilities, but this effect will be lower for fathers than for</td>
<td></td>
</tr>
<tr>
<td>mothers.</td>
<td></td>
</tr>
<tr>
<td><strong>Hypothesis Three:</strong> Parents of children with autism will experience</td>
<td>Parents of autistic children experienced significantly less emotional</td>
</tr>
<tr>
<td>less emotional attachment from their child than parents of children with</td>
<td>attachment from their child. No significant difference was found for</td>
</tr>
<tr>
<td>other learning disabilities, but this differential will be lower for</td>
<td>parent gender.</td>
</tr>
<tr>
<td>fathers than for mothers.</td>
<td></td>
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<tr>
<td><strong>Hypothesis Four:</strong> Fathers of both learning disabled and autistic</td>
<td>Mothers carried out significantly more parenting tasks than fathers. No</td>
</tr>
<tr>
<td>children will be less involved in the care of their child than the</td>
<td>significant effect was found for child diagnosis.</td>
</tr>
<tr>
<td>mothers.</td>
<td>Mothers were found to experience significantly more parenting difficulty</td>
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<tr>
<td></td>
<td>than fathers. Parents of autistic children were also found to experience</td>
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<td></td>
<td>significantly more parenting difficulty than parents of children with</td>
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<td></td>
<td>other learning disabilities. No significant difference was found for</td>
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<td></td>
<td>parent child interaction.</td>
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<tr>
<td><strong>Hypothesis Five:</strong> Fathers of both learning disabled and autistic</td>
<td>No significant difference was found in use of practically-orientated</td>
</tr>
<tr>
<td>children will use more practically-oriented coping strategies than</td>
<td>coping strategies, for either parent gender or child diagnosis.</td>
</tr>
<tr>
<td>mothers.</td>
<td></td>
</tr>
</tbody>
</table>
4.4 **Limitations of Study**

As with all research studies, various limitations to the design of this study have been identified. Some of these may also provide possible explanations for some of the unexpected results. The following section provides a discussion of limitations of the present study.

4.4.1 **Sample**

4.4.1.1 **Sampling**

Participants in this study clearly represent a self-selected sample, and this has to be borne in mind when the results are analysed. Participants in this study may have represented parents who were successfully dealing with the stress they experienced through parenting demands. It is possible that those parents experiencing high levels of stress would have been less likely to volunteer to participate in this study, posing as it did, further demands on their time. Previous studies have used different selection procedures, such as including all parents referred to child services, and so would have possibly included a more diverse participant group.

Another possible explanation for having found no differences in level of psychological distress related to child diagnosis could again be sampling. The majority of parents who chose to take part in this study, did so as a couple. This possibly indicates that their marriage/relationship was fairly robust and supportive. Previous research has noted that supportive marital relationships act as a buffer to psychological stress as a result of caring for a child with special needs (Fisman, Wolf, and Noh, 1989). This is a possible explanation for not having found a significant difference between mothers and fathers on psychological distress and parenting stress.

Siegal (1997) has made reference to the continually changing levels of stress, experienced by parents of children with special needs. This refers to the fact that families will experience times of crisis in which they experience greater stress in comparison with intermediate times of
successful coping. Participants in the current study may have felt able to offer their time in
taking part in the study because they were experiencing a period of relative calm.

Also this study is likely to have attracted people to take part who are the kind of individuals
who feel comfortable with services. It may be that those people who felt less confident in
interacting with professionals chose not to take part. It could be hypothesised that those
parents who feel able to access services, receive sufficient help and support, and therefore
represent a less distressed group.

4.4.1.2 Sample Size

The larger sample sizes in other studies may well reflect the fact that participants were drawn
solely from families accessing services, who were likely to be less self-selecting and possibly
with less cohesive partnerships. It is recognised that the participants in this study were only a
small number of those parents who were approached, and therefore the results may not be
representative of the larger population of parents of children with autism and learning
disabilities.

Every effort was made to confirm access to a more diverse pool of participants, but events
conspired against this. As this was a time limited study, it was necessary to think creatively
about how to extend the participant group. Even in larger studies, it is likely that the majority
of participants self-select. It is noted that as the sample size in this study is relatively small,
results should be interpreted with caution, until such time as they are confirmed in studies
involving larger groups. Statistical power varied somewhat from analysis to analysis owing to
variation in participant size, but in general was below 0.6, for a medium effect size. It is
suggested that it is particularly important to interpret the results of this study in the light of
previous research.
4.4.2 Measures

In the current study the General Health Questionnaire-28 (GHQ-28) was used to provide a measure of psychological distress. Results were unable to find any significant differences between parents in each group. Previous studies have used different measures and this may have made a difference. However, the GHQ is highly correlated with other psychological health measures e.g. BDI (Goldberg and Williams, 1991).

The Parenting Stress Index was also used in this study, and is recognised as a highly reliable and valid measure. However, it is recognised that three mothers and three fathers of children with learning disabilities were found to have fallen within the range of defensive responding in the PSI. Therefore, their responses may have been more positive (less stressed) than the reality of their experience. It is possible, therefore, that their experience of parenting stress was in reality higher than their responses suggest. As it was impractical to discard these questionnaires, results from the analyses should be interpreted with caution. However, it is also recognised that low defensive responding scores can indicate a very successful parent-child relationship, within an advantaged environment (Abidin, 1995).

It is recognised that this study did not include a formal psychometric measure of level of child learning disability. However, it was felt acceptable for this study to base level of child disability on the type of school which the child attended. As a result, children were either categorised as having severe or moderate learning disabilities. This level of information is consistent with other studies (Beckman, 1991). Also, no additional measure of autistic rating was used to identify degree of autistic features in the children with autism, but rather, independent professional diagnosis was taken as adequate. The Developmental Behaviour Checklist was chosen to provide a level of behavioural problems presented by children across both groups, and did include a measure of autistic behaviour. It was felt that where possible, the number of questionnaires given to parents should be kept to a minimum.

The use of a variety of measures and subsequent analysis raises the possibility of Type 1 errors. As a consequence, the reduced probability value of 0.01 was employed for those measures.
involving repeated analysis. It was not considered practical to employ the use of this reduced value for all analysis.

It is recognised that this study used two measures which are not standardised (Attachment Questionnaire and Parenting Burden and Difficulty Scale). The fact that the results pertaining to these measures, in this study are consistent with previous findings is reassuring. However, it is recognised that caution should be exercised in interpretation of the results.

4.4.3 Methodological Limitations

Due to poor response rate, the original age-range for children associated with this study was extended. It is recognised that this design did not address the many different developmental issues regarding children of different ages; especially regarding parent-child relationships, and parental acceptance of their child’s disability. Some of the children in the learning disability group (especially the very young children) may be diagnosed with autism in the future, but may currently be presenting few behavioural problems to their parents.

The comparison group used in this study comprised parents whose children presented with a variety of learning disabilities. Previous studies have favoured the use of comparison groups comprising only of children with Down’s syndrome. However, research suggests that parenting a child with Down’s Syndrome is less stressful for parents. Kasari and Sigman (1997) suggests that Down’s Syndrome children represent a unique group of children with learning disabilities. Therefore, they suggest that using a comparison group comprising of children with a variety of learning disabilities would be present a less biased design. In addition, Down’s Syndrome represent a different group of children, in that they are typically diagnosed at birth, and have physical characteristics. This implies that their parents experience a very different process of adjustment to diagnosis compared to parents of children with autism.

The process of data collection may have also influenced parental responses. It is also possible that individuals did not trust that their responses would remain sufficiently confidential, as they recognised that they would meet the researcher at their interview. In some cases participants may have also been concerned that their spouses would also see their response. This could have
biased their responses. However during the course of interviewing, it was not felt that any participant presented as obviously distressed. Some participants expressed stress or sadness about their experiences of parenting, but were sufficiently able to cope so that this didn’t affect their psychological health.

Some of the findings of this study would appear to be inconsistent with those of previous research. This may in part be due to some of the limitations previously discussed. However, Ainge (1995), has suggested that inconsistent findings from research involving families of children with learning disabilities reflects the highly individual nature of children:

‘...Parents involved in studies should not be thought of as samples, but as unique groups who may be expected to give unique sets of responses’

(Ainge, 1995, p.177).
4.5 **Directions for Future Research**

As with all research, the findings of this study lead to new questions which remain to be answered. The following is a discussion of proposed directions for future research.

This study was unable to find an effect for child diagnosis on psychological distress. It has been acknowledged that this may be the result of lack of power owing to relatively small sample size. However, this could have also been the result of a sampling bias. Previous research has suggested a differential outcome for psychological distress of parenting a child with autism, it is recommended that future research is directed at identifying factors which may be associated with both positive and negative outcomes.

Studies are also increasingly acknowledging that many parents successfully cope (Beresford, 1994) and although parenting a child with special needs is stressful, it also provides many opportunities for joy and growth (Margalit and Ankonina, 1991). Many of the participants who took part in this study clearly experienced their child as source of both pleasure and stress. In the future, it is recommended that research involving families of children with autism include a measure of positive as well as stressful outcomes of parenting.

Results from the current study have suggested that greater use of social support in mothers, may enable them to carry greater parenting burden without experiencing higher levels of psychological distress. The majority of pervious research has focused on problem-focused and emotional coping styles. The current findings suggest that larger-scale research into the association between social coping and outcome would be helpful.

The current study suggested that perceived lack of child emotional attachment could be a stressor for parents. It is recognised that a child’s attachment behaviour changes over time, as do parental expectations of their relationship with their child. For reasons of practicality, his study included parents whose children’s’ ages ranged form 2-12 years. Many parents of autistic
Discussion

children in this study commented that their child had recently become more openly affectionate, but had been more ‘aloof’ at pre-school age. It would be interesting to record levels of perceived child attachment in mothers and fathers of autistic children of different ages, and in particular, to consider the effect of this on parent stress. In addition, few studies have considered fathers’ experiences of parenting an adult child with special needs (Lamb and Meyer, 1991). This area of research would greatly benefit from future, longitudinal studies.

This study focused on children with autism, and did not include those children who were diagnosed with Asperger syndrome. Future research is needed to explore paternal perception of attachment in this group of children. This research would be particularly timely in the light of recent research, which has suggested that fathers of children with autism and Asperger syndrome share a cognitive phenotype with their child.

The extent to which the findings of this study generalise to other populations leads to suggestions for further research. Although the majority of participants were professionals, they represented individuals from a range of economic backgrounds. However, the participants were almost entirely from a white, British population. Other cultures may have different expectations of child attachment behaviour, and fatherhood. Future studies, focusing on participants from ethnic minorities would provide valuable additional information.

This research has suggested that both mothers and fathers of children with autism experience their child as demonstrating less reciprocal attachment behaviour, compared to parents of children with other learning disabilities. Future research could endeavour to investigated the attributions parents give to their autistic child’s behaviour, and possible relationships between parental attributions and coping style. Any differences in mothers and fathers attributions could lead to both informing services and the couples themselves.

Finally, this study has suggested some implications for service delivery, in the light of its findings. If services are committed to addressing the needs of fathers, it is recommended that any changes in service provision be evaluated. The publication of information relating to successful services aimed at fathers, would be of value to other service providers.
4.6 Clinical Implications for Services

One of the focuses of this study has been to raise the awareness of needs of fathers of children with autism. The results suggest that fathers of children with autism are possibly no less stressed than mothers, and therefore, services have a responsibility to address the needs of both parents, and to recognise the significant, though understated, role played by fathers. The following section will consider implications for services in the areas of parental perception of attachment, parenting burden and provision of support.

4.6.1 Issues of Attachment

Results from the current study suggest that both fathers and mothers of autistic children perceive a lack of specific attachment behaviours from their child, concerning reciprocal emotion. (Aarons and Gitten, 1999) have referred to the importance of providing information regarding the diagnosis of autism to both mothers and fathers, and have emphasised that this should include an emphasis to both parents that the child’s presentation is not something for which either of them are to blame. Parents need to be provided with information to enable them to increase their understanding of their child’s behaviour. This may in some way help parents to experience their child’s apparent lack of reciprocal attachment as less rejecting (Happe, 1994). In a review the experiences of fathers’ of learning disabled children experiences, Lamb and Meyer (1991) concluded that professionals’ views of fathers as periphery to the family, caused increased distress:

"Fathers, it appears, experience additional stress when treated as second-class parents at the time of diagnosis”.

(Lamb and Meyer, 1991, p.161)

Services need to go beyond provision of a diagnosis, and to provide information for both parents. This may require professionals to work more creatively with families. Often, due to real commitments at work, fathers are unable to attend appointments concerning their child’s progress beyond the initial assessment. Mothers often don’t know what their partners would have wanted to ask the clinician if they’d been present. Provision of written feedback or an
Discussion

audio tape of the session, could be made immediately available for fathers who were unable to
attend. Clinicians could also arrange specific times when they would be available to discuss
current information with fathers via telephone. This would provide an opportunity for fathers
to ask their own questions following their session feedback.

Services also need to be aware that both parents may need time and space to acknowledge and
express their feelings, not only following their child’s diagnosis, but as a result of the continued
challenges they face as a parent. One father in the current study, summed this up by describing
how he felt that other people did not acknowledge any stress or sadness he himself might
experience:

‘They (other people) do tend to forget fathers...at work they’ll say “How
does your wife cope?” ninety-five percent of the time...(but) there are two of
us’.

Lastly, both parents might benefit from advice and encouragement about how best to spend
time with their child. This may be especially important for fathers. Research has suggested that
whilst mothers interactions with their child mainly involve child care activities, fathers generally
interact with their child through play (Lamb, 1981). It is, therefore, likely that fathers of autistic
children are particularly frustrated in their attempts to interact with their child, and without
support may give up trying.

“The traditional fathers roles of physical playmate and model for the male
child are largely diminished or not present at all with the moderately to
severely handicapped child”

(Gallagher, Cross and Scharkman, 1981, pp. 13).

Professionals may be effective in supporting fathers in exploring new ways of interacting with
their child. Most autistic children prefer the type of interaction offered by fathers (e.g. rough
and tumble play) in comparison to person-focused play generally favoured by mothers. Fathers
could be encouraged to explore interaction with their child in this manner.
4.6.2 **Issues of Parenting Burden**

It would seem that fathers continue to be less involved in the practical care of their child, even in families where they are clearly committed and interested in their child's progress. Mothers ultimately seem to take the majority of the burden of child care, and whilst they may employ effective coping strategies to relieve the effect of this, the situation is likely to place them at increased risk of ill-health. Clearly, mothers cannot begin to take less of the burden without fathers taking more.

However, another consequence of fathers not taking more responsibility for child care is that they are kept at a distance from both their child's needs and from services. As a result fathers may feel less informed and so, incompetent in areas of child care. It may be helpful for professionals to help both mothers and fathers to identify practical ways in which fathers can share more of the parenting burden. Additionally, services also need to consider increasing availability of good quality respite care, in order to offer families the opportunity to re-charge their energies as a whole (Factor et al, 1990).

It is acknowledged that not all fathers would be willing to accept a greater responsibility for child care. However, it seems likely that services may have a role in encouraging those who are willing, and to support them in their efforts to become more involved in the practical care of their child.

4.6.3 **Provision of Support**

Current findings would seem to support the fact that mothers continue to access social support as a coping mechanism to a greater extent than fathers. It has also been suggested that fathers receive support through their employment outside of the home (Holroyd, 1974). However, it is proposed that services need to consider ways in which to make support more accessible for fathers. Firstly, if services are to aim to encourage fathers to take more of the burden of child care, they are likely to need increased levels of support in order to cope effectively with this.
Secondly, the extra familial support accessed by mothers is generally in the form of parent support groups, and subsequent friendships with mothers in similar positions to themselves. These connections not only provide emotional support, but also provide support in the form of education and advice. If fathers miss out on support, they also miss out on knowledge and education, through both formal and informal means. This may mean that they feel less competent and also excluded from being involved in child care.

The word ‘support’ may have negative connotations for some parents, as it implies an inability to cope. Cultural and social differences suggest that men are less likely than women to admit that they need assistance (Knussen et al, 1992). It is possible that fathers are generally dissuaded from attending parent groups because of the implication that they are doing so in order to get help. The purpose of support groups is often generally associated with social contact. It is possible that changing an emphasis from support to education or information provision, with regard to parent support groups may result in them becoming more acceptable and productive for both men and women. Providing a practical focus for the group would also continue to provide an additional forum for potentially supportive contacts with other parents. Fathers seem to make less use of social support, therefore, perhaps support offered by professionals is particularly important.

Studies have found that fathers express having negative feelings towards professional services, and it is suggested that they have no opportunity to develop relationships with professionals (Hornby, 1992). Both education and health services are typically female dominated. Attending meetings and building contacts within these services may seem difficult or alien for fathers. Clinicians may need to consider the benefits of offering at least one home visit to families. Wherever possible, it would be of even greater benefit to visit the family at a time when both parents are at home. It is of the greatest importance for services to allow families to feel listened to, not only for their engagement with services and also to provide information for the clinician. During the process of this study, many parents expressed the fact that filling out questionnaires did not allow them to describe their child as an individual. Parents are experts of their own children, and fathers have huge amounts of knowledge about their child which is often lost to services through lack of contact.
4.7 Conclusions

The findings of this research are consistent with those reported by previous studies, suggesting that parenting a child with autism is likely to be more stressful than parenting a child with other special needs. The findings from the Attachment Questionnaire adds another perspective for reasons why parenting role might be experienced as more stressful.

The positive contribution of this study is its provision of new information regarding fathers. Given the numbers of fathers included in research in the past, this study achieved a relatively high response rate. It is interesting to note that whilst mothers and fathers of autistic children were not found to differ in their experience of psychological distress, parenting stress and perception of attachment, they did experience a difference in parenting burden and use of social support as a coping mechanism. It would seem from the results of this study, that mothers carry more of the burden, but use social support as an effective coping strategy to mediate possible negative psychological effects.

This research has added to the small body of knowledge concerning fathers of autistic children. It is hoped that information gained through this study would encourage services to consider the needs of both parents.
REFERENCES
References


References


References


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References


APPENDICES
Appendix 1  Participant Information Letter

Dear Parent/s,

Please find enclosed an information leaflet regarding a study I am undertaking to investigate the different pressures experienced by mothers and fathers of children who present with different kinds of difficulties. The findings of this study will inform professionals in providing more appropriate services for both mothers and fathers.

Although part of the study focuses on parents of children with autism, it will also provide important information about parents whose children have other types of special needs.

I have asked the Educational Psychology Department, schools, nursery schools and the Leicester Child Learning Disability Team, to pass on this information to any parent who might be interested in taking part in the study. Parents are also being contacted via local support groups.

Please find two copies of a consent form detailing confidentiality and freedom from obligation also enclosed.

If you feel that you are able to take part in the study, I would be very grateful if you could find the time to sign both copies of the form, retaining one for your own record and returning the other in the envelope provided, by..................

On receipt of your form, I will contact you with regard to arranging a time and location suitable to you, for meeting to complete the questionnaires and interview.

If you feel that you would like more information about the study, do not hesitate to contact me.

Thank you very much for your help.

Liz Hart
Trainee Clinical Psychologist
Supervised by Mike Hodgkinson, Consultant Clinical Psychologist and Dr. Fred Furniss, Leicester University.
Appendix 2  Participant Information Sheet

PARTICIPANT INFORMATION SHEET

An investigation into the relationship between parent gender, perception of child attachment and coping style, in relation to the experience of parenting a child with autism.

Principal Investigator: Liz Hart, Trainee Clinical Psychologist

I am currently working as a trainee clinical psychologist, with the Child Learning Disability Team, at Westcotes House.

As part of my Doctorate in Clinical Psychology, I am undertaking an investigation into the different experiences of mothers and fathers of children with autism compared to mothers and fathers of children with learning disabilities.

I am particularly interested in including fathers in this study, as currently very little is known about their experiences.

The findings of this study will lead to a greater understanding of the different pressures experienced by mothers and fathers of children who present with different kinds of difficulties. This information will inform professionals in organising and providing services for both parents, appropriate to their needs.

I plan to recruit parents through Leicester Child Learning Disability Team, and through local schools (via Educational Psychology). I am interested in contacting parents whose child is aged between 2 and 12 years old. Parents who are separated, and no longer live with their child, but who have regular contact with them, are encouraged to take part in the study.

The proposed study would involve each parent completing a battery of questionnaires about parenting stress, coping and child behaviour, and an additional brief interview concerning relationship issues with their child. It is estimated that the questionnaires will take approximately an hour to complete, with a follow up interview of about 30 minutes. Parents taking part in the study, will be offered the opportunity to either meet with myself at a pre-arranged setting (e.g. local child services) or at their own home.

Parents taking part in the study will be forwarded the questionnaires 5 days in advance, for completion. The subsequent meeting with myself will provide an opportunity to complete the interview, and to discuss any queries regarding the questionnaires. The information parents provide will remain completely confidential. Parents will be under no obligation to complete the interview or questionnaires, and their involvement with services will not be affected in any way.
This study is undertaken as part of the University of Leicester, Doctorate in Clinical Psychology Course. It is supervised by Dr. Mike. Hodgkinson, Consultant Clinical Psychologist. It also has the support of Philip Whitaker, Senior Educational Psychologist and members of the Child Learning Disability Team.

After participants have completed the questionnaires and interview, it will be possible to offer them some time if they should feel that they would like the opportunity to de-brief. It is also regarded as standard procedure for myself as the researcher, to inform each participant’s GP, of their participation in my study.

I realise that your lives are very busy and that you may have been approached for inclusion in studies in the past. I am very grateful for your consideration in participating in this research.

Please contact me if you would like any more information or clarification regarding this matter.

Liz Hart
Trainee Clinical Psychologist, Supervised by Dr. Mike Hodgkinson, Consultant Clinical Psychologist Westcotes House, and Dr. Fred Furniss, Leicester University.
Appendices

Appendix 3  Participant Consent Form

Participant Consent Form

An Investigation into the relationship between parent gender, perception of child attachment and coping style, in relation to the experience of parenting a child with autism.

Principal investigator: Liz Hart, Trainee Clinical Psychologist

This form should be read in conjunction with the Participant Information Sheet.

I agree to take part in the above study as described in the Participant Information Sheet.

I understand that I may withdraw from the study at any time without justifying my decision and without affecting my normal care and medical management.

I understand that members of the research team may, having discussed their reasons with me, wish to view relevant sections of my child’s medical records, but that all information will be treated as confidential.

I understand that my interview with the investigator will be audio recorded and that this information will be treated as confidential.

I understand medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS, i.e. compensation is only available if negligence occurs.

I have read the patient information leaflet on the above study and have had the opportunity to discuss the details with Liz Hart and ask any questions. The nature and the purpose of the tests to be undertaken have been explained to me and I understand what will be required if I take part in the study.
Please complete one or both of the following sections, as appropriate:

Signature of participant (mother) .......................................................... Date.

(Name in BLOCK LETTERS) .....................................................................

Contact Address: ...........................................................................................

......................................................................................................................

Contact Phone Number ................................................................................

......................................................................................................................

Signature of participant (father) .......................................................... Date.

(Name in BLOCK LETTERS) .....................................................................

Contact Address (if different from above): ................................................

......................................................................................................................

Contact Phone Number ................................................................................

......................................................................................................................

I confirm I have explained the nature of the investigation, as detailed in the Participant Information Sheet, in terms which in my judgement are suited to the understanding of the participant.

Signature of Investigator .......................................................... Date.

(Name in BLOCK LETTERS) .....................................................................
Appendices

Appendix 4 Demographic Questionnaire

Demographic Questionnaire

1. Participant code number:

2. Age:

3. Ethnic Origin:
   1. White British
   2. White European
   3. White (other)
   4. Black Caribbean/ West Indian
   5. Black African
   6. Black (other)
   7. Indian
   8. Pakistani
   9. Bangladeshi
   10. Asian (other)
   11. Other

4. Age at leaving school:
   1 = 0-4 years
   2 = 5-9 years
   3 = 10-16 years
   4 = 17+ years

5. Educational Achievements:
   1 = No formal Qualifications
   2 = Left with CSE/ GCSE/ O’ Levels
   3 = Left with A’ Levels, no further qualifications
   4 = Further qualifications - diplomas, certificates
   5 = Degree level qualifications
   6 = Professional qualifications

6. Employment Status:
   1. Employed
   2. Unemployed
   3. Self-employed
   4. Student
   5. Retired

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7. Socio-economic class based on employment: 1. Professional group  
2. Clerical, non-manual  
3. Skilled manual  
4. Semi-skilled  
5. Unskilled  
6. Armed forces  
7. Police  
8. Husband  
9. Wife  
10. Student  
11. No occupation  

8. Marital Status: 1. Married, living with spouse  
2. Married, separated from spouse  
3. Divorced  
4. Widowed  
5. Cohabiting  
6. Single  
7. Romantic Partner (more than 6 months)  

9. Children:  
Age of child connected to this study:.......................  
Age/s of other child/children:.............................  
Sex of child connected to this study:.......................  
Sex of other child/children:...............................  

Is the child connected to this study: 1. From current relationship  
2. From previous relationship  

Is /are your other child/children: 1. From current relationship  
2. From Previous relationship  
3. From both current and previous relationships.  

10. Living arrangements: 1. Alone, no children  
2. Alone, plus children  
3. Spouse/ Common law partner, no children  
4. Spouse/ Common law, plus children  
5. Other relative  
6. No fixed abode
Appendix 5  Attachment Questionnaire

Attachment Interview Items

N.B. These questions cover some of the areas in which autistic children are known to experience difficulties.

1. Do you wish your child demonstrated more affection towards you?

2. In what ways does your child demonstrate affection towards you?

3. Do you feel like your child initiates enough contact with you?

4. In general, does your child worry about, or make an effort to win your approval?

5. In general, do you ever feel like your child views you or treats you more like an object in his/her world, than like a mother/father who is very important to your child?
6. Does your child’s disability interfere with his/ her ability to be close and loving in his/ her relationship with you?

7. Do you feel that your child recognises you as his/ her parent and differentiates you from their people?

8. Does your child convey appreciation toward you when you do something your child find pleasurable?

(Questions taken from Hoppes and Harris, 1990).
Appendices

Appendix 6  **Parenting Burden and Difficulty Scale**

**Items used for Parenting Burden and Difficulty Scale**

We would like to know the degree of difficulty you experience with regard to the following parenting tasks. Please rate the degree of difficulty you experience for each task, by circling your response on the scale provided.

<table>
<thead>
<tr>
<th>No difficulty at all and requiring no special effort on my part</th>
<th>Severe difficulty requiring great effort on my part</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

1. Instructing or educating your child. 1 2 3 4 5

2. Protecting your child against injury. 1 2 3 4 5

3. Managing your child’s behaviour in public. 1 2 3 4 5

4. Handling difficult behaviour from your child. 1 2 3 4 5

5. Assisting your child with physical activity. 1 2 3 4 5

6. Involvement in interactive play with your child. 1 2 3 4 5

7. Assisting your child with getting dressed. 1 2 3 4 5

8. Assisting your child with communication. 1 2 3 4 5

*continued*
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<table>
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<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>9. <strong>Managing the destruction of property by your child.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 5</td>
</tr>
<tr>
<td>10. <strong>Assisting your child with getting washed.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 5</td>
</tr>
<tr>
<td>11. <strong>Assisting your child with eating.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 5</td>
</tr>
<tr>
<td>12. <strong>Assisting your child with toileting.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 5</td>
</tr>
<tr>
<td>13. <strong>Managing your child's sleep throughout the night.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 5</td>
</tr>
<tr>
<td>14. <strong>Attending to your child when they wake in the morning.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 5</td>
</tr>
<tr>
<td>15. <strong>Involvement in your child's bedtime ritual.</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 5</td>
</tr>
</tbody>
</table>
Appendices

Appendix 7  The Shortened Ways of Coping Questionnaire (Revised)

Shortened Ways of Coping Questionnaire (revised)

Please read each item below and indicate, by circling the appropriate category, to which extent you use it in coping with any problems in bringing up your child.

<table>
<thead>
<tr>
<th>Item</th>
<th>Not used</th>
<th>Used somewhat</th>
<th>Used quite a bit</th>
<th>Used a great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I daydream or imagine a better time or place than the one I am in.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. I draw on my past experience.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. I talk to someone about how I am feeling.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. I wish I could change how I feel.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. I try to come out of experiences better than when I went in.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. I wish that I could change what has happened.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. I ask relatives or friends I respect for advice.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. I talk to someone to find out more about the situation.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. I take it out on other people.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. I avoid being with people in general.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

continued
<table>
<thead>
<tr>
<th></th>
<th>Not used</th>
<th>Used somewhat</th>
<th>Used quite a bit</th>
<th>Used a great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I accept sympathy and understanding from someone.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I stand my ground and fight for what I want.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I wish that the situation would go away or somehow be over with.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I make a plan of action and follow it.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I think up a couple of different solutions to problems.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I try and analyse the situation in order to understand it better.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I usually know what has to be done, so I keep up my efforts to make things work.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I have fantasies or wishes about how things might turn out.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I let my feelings out somehow.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 8  GP Information Sheet

GP INFORMATION SHEET

An investigation into the relationship between parent gender, perception of child attachment and coping style, in relation to the experience of parenting a child with autism.

Principal Investigator: Liz Hart, Trainee Clinical Psychologist

I am currently working as a trainee clinical psychologist, with the Child Learning Disability Team, at Westcotes House.

As part of my Doctorate in Clinical Psychology, I am undertaking an investigation into the different experiences of mothers and fathers of children with autism compared to mothers and fathers of children with learning disabilities.

I am particularly interested in including fathers in this study, as currently very little is known about their experiences.

The findings of this study will lead to a greater understanding of the different pressures experienced by mothers and fathers of children who present with different kinds of difficulties. This information will inform professionals in organising and providing services for both parents, appropriate to their needs.

I plan to recruit parents through Leicester Child Learning Disability Team, and through local schools (via Educational Psychology). I am interested in contacting parents whose child is aged between 2 and 12 years old. Parents who are separated, and no longer live with their child, but who have regular contact with them, are encouraged to take part in the study.

The proposed study would involve each parent completing a battery of questionnaires about parenting stress, coping and child behaviour, and an additional brief interview concerning relationship issues with their child. It is estimated that the questionnaires will take approximately an hour to complete, with a follow up interview of about 30 minutes. Parents taking part in the study, will be offered the opportunity to either meet with myself at a pre-arranged setting (e.g. local child services) or at their own home.

Parents taking part in the study will be forwarded the questionnaires 5 days in advance, for completion. The subsequent meeting with myself will provide an opportunity to complete the interview, and to discuss any queries regarding the questionnaires. The information they provide will remain completely confidential. Parents will be under no obligation to complete the interview or questionnaires, and their involvement with services will not be affected in any way.
This study is undertaken as part of the University of Leicester, Doctorate in Clinical Psychology Course. It is supervised by Dr. Mike. Hodgkinson, Consultant Clinical Psychologist. It also has the support of Philip Whitaker, Senior Educational Psychologist and members of the Child Learning Disability Team.

After participants have completed the questionnaires and interview, it will be possible to offer them some time if they should feel that they would like the opportunity to de-brief. I will inform you of the involvement of any of your patients in this study. If during the course of my contact with participants, I come across information I feel you should be immediately made aware of, I will contact you with that information.

Please contact me if you would like any more information or clarification regarding this matter.

Liz Hart
Trainee Clinical Psychologist, Supervised by Dr. Mike Hodgkinson, Consultant Clinical Psychologist, Westcotes House and Dr. Fred Furniss, Leicester University.